Breaking the Cycle of Invisibility: A mixed methods inquiry into the disclosure behaviours and experiences of children living with epilepsy and their parents

A thesis presented to Dublin City University for the Degree of Doctor in Philosophy

By

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Declaration

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of Doctor in Philosophy is entirely my own work, that I have exercised reasonable care to ensure that the work is original, and does not to the best of my knowledge breach any law of copyright, and had not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work.

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Operational Definitions

Absence Seizures:

Seizures that may make the individual appear as if they are daydreaming. The individual "switches off" for a few seconds and experiences a temporary lapse in awareness.

Atonic Seizures:

Drop attacks; the individual experiences an abrupt loss of muscle tone (temporary paralysis), and may drop to the ground. In some individuals, only their head suddenly drops.

Clonic Seizures:

The individual experiences rhythmic jerking movements of the arms and legs.

Complex Partial Seizures:

These seizures may manifest as automatisms (such as lip smacking, picking at clothes, fumbling) or verbal/emotional outbursts. Individuals who experience these types of partial seizures experience a loss of awareness and may wander or stare blankly.

Concealable Stigmatised Identity:

A concealable stigmatised identity is an identity that is socially devalued with negative perceptions attributed to the identity, but that has the potential to be kept hidden from others due to the fact that it is not overtly or immediately physically apparent to others.

Disclosure:

"The verbal [and non-verbal] *communication that occurs between a discloser and an interaction partner regarding the discloser's possession of a concealable stigmatized identity"* Chaudoir & Fisher (2010, p. 241)

Epilepsy*:*

"Epilepsy is a disease of the brain defined by any of the following conditions:

- *At least two unprovoked (or reflex) seizures occurring >24 h apart*
- *One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years*
- *Diagnosis of an epilepsy syndrome"*
  Fisher et al. (2014. p.477)

Electrical Status Epilepticus in Sleep (ESES):

"An electroencephalographic pattern showing significant activation of epileptiform discharges in sleep." Nickels & Wirrell (2008, p.50)

Monotherapy:

A form of epilepsy treatment that involves the person with epilepsy taking one type of anti-epileptic drug (generally daily or bi-daily).

Myoclonic Seizures:

These seizure types manifest as extremely brief shock-like jerks/twitches of a muscle or group of muscles; during such seizures, the individual will usually be awake and be able to think clearly.

Nuclear Family:

In the present study, the nuclear family is defined as the child's immediately family group consisting of the child with epilepsy, his/her parent(s) and sibling(s).

Polytherapy:

A form of epilepsy treatment that involves the person with epilepsy taking two or more types of anti-epileptic drugs (generally daily or bi-daily).

Seizure:

"A period of sudden, excessive activity of cerebral neurons" Carlson (2005, p.435)

Simple Partial Seizures:

Partial seizures can manifest as motor seizures, sensory seizures, autonomic seizures or psychic seizures. Individuals who experience simple partial seizure types are fully awake, alert and able to interact throughout the seizure.

Tonic Seizures:

The individual's arms or legs make sudden stiffening movements; consciousness is usually preserved.

Tonic-Clonic Seizures:

This type of seizure involves loss of consciousness and consists of a tonic phase where the patient's muscles contract forcefully (i.e. the muscles become tightened and clenched) and a clonic phase where the patient's muscles shake or jerk rhythmically and uncontrollably, the eyes roll and the face becomes contorted. Following this type of seizure, the patient generally falls into an unresponsive, exhausted sleep that can last anywhere from a few minutes to a few hours.

Vagus Nerve Stimulation (VNS):

A technique used to treat epilepsy that involves the implantation of a device similar to a pacemaker that generates and sends regular, mild pulses of electrical energy to the brain via the vagus nerve. VNS is generally not utilised as a mono-therapy to treat epilepsy but rather acts as an adjunctive therapy (i.e. it is used to compliment drug therapy).

Abbreviation List

AEDS	Anti-epileptic Drugs
CASP	Critical Appraisal Skills Programme
CATIS	Child Attitudes Towards Illness Scale
CHEQOL-25	Health-related Quality of Life Measure for Children with Epilepsy
CoP	Community of Practice
CPM Theory	Communication Privacy Management Theory
CSI	Concealable Stigmatised Identity
CSS	Child Stigma Scale
CWE	Children/Adolescents Living With Epilepsy
DDI	Distress Disclosure Index
DPM	Disclosure Processes Model
EDS	Epilepsy Disclosure Scale
EDS-P	Epilepsy Disclosure Scale – Parent Version
EDS-Y	Epilepsy Disclosure Scale –Youth Version
EI	Epilepsy Ireland (The Irish Epilepsy Association)
ESES	Electrical Status Epilepticus in Sleep
HARCES	Hague Restrictions in Childhood Epilepsy Scale
HCPs	Healthcare Professionals
HRQoL	Health-related Quality of Life
IBE	International Bureau for Epilepsy
ILAE	International League Against Epilepsy
IPES	Impact of Pediatric Epilepsy Scale
KMO	Kaiser-Meyer-Oklin
MeSH	Medical Subject Headings
MSA	Measures of Sampling Adequacy
MSPSS	Multi-dimensional Scale of Perceived Social Support
PCA	Principle Component Analysis
PRCI Scale	Parent Response to Child Illness Scale
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PSS	Parent Stigma Scale
PWE	People Living With Epilepsy
QOL	Quality of Life
SPPC	Self-Perception Profile for Children
SSS	Seizure Severity Scale
SSSCA	Social Support Scale for Children and Adolescents
TSCUH	Temple Street Children's University Hospital
WHO	World Health Organization
VNS	Vagus Nerve Stimulation

Abstract

Breaking the Cycle of Invisibility: A mixed methods inquiry into the disclosure behaviours and experiences of children living with epilepsy and their parents

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Disclosing a child's epilepsy to others external to the nuclear family presents a salient challenge for children with epilepsy (CWE) and their parents. However, a systematic review revealed that empirical evidence regarding how such populations experience epilepsy disclosure is limited. The core contribution this study makes is the explication of CWE's and parents' epilepsy disclosure behaviours and experiences, and the elucidation of the relationships between CWE's and parents' epilepsy disclosure behaviours and demographic/clinical characteristics, psychosocial wellbeing and illness attitudes. This mixed methods study involved two phases: 1) semi-structured interviews with CWE (n=29) and their parents (n=34); and 2) a cross-sectional survey of 72 parents and 47 CWE. Findings revealed that CWE and their parents adopt varying disclosure management strategies, ranging from voluntary disclosure to concealment. CWE and their parents identified many barriers to and enablers of disclosure, including: the desire for normalcy; others' reactions; the condition's invisibility; media coverage of epilepsy; emotional responses to the diagnosis; the complexity of epilepsy; self, other and public perceptions of, and attitudes towards epilepsy; and seizure characteristics. Greater concealment amongst CWE and parents was significantly correlated with: 1) CWE reporting greater stigma, and poorer illness attitudes and health-related quality of life; and 2) parents responding negatively to the child's illness, perceiving greater stigma and reporting fewer epilepsy-related interactions with CWE. This study provides a nuanced understanding of the disclosure process engaged in by CWE and parents, enhancing our knowledge of their disclosure strategies and targets, the content and situational context of their disclosure exchanges, barriers to and enablers of disclosure, and the consequences of disclosure in doing so. Overall, the findings suggest that greater concealment is associated with more negative outcomes for CWE and parents. Interventions to assist CWE and parents to navigate epilepsy disclosure could beneficially impact on their psychosocial wellbeing.

Chapter 1: Introduction

1.0 Introduction

This thesis explores the epilepsy disclosure behaviours and experiences of children/adolescents living with epilepsy (CWE) and their parents. In this chapter, background information is provided pertaining to epilepsy as a chronic neurological disease, its impact/consequences for CWE and their parents, epilepsy-related stigma and CWE's and parents' disclosure behaviours surrounding a child's epilepsy condition. To conclude, the thesis conspectus outlines the breakdown of each chapter.

1.1 Epilepsy: Definitions, Epidemiology, Aetiology and Consequences

Epilepsy is a common, largely invisible, chronic neurological disease (Fisher et al., 2014). According to the latest definition of epilepsy, the condition is characterised by the presence of either: 1) the manifestation of at least two or more unprovoked (or reflex) seizures occurring >24 hours apart; 2) the occurrence of one unprovoked (or reflex) seizure coupled with the presence of factors that are associated with a high likelihood of an individual experiencing a persistently lowered seizure threshold (e.g. a recent stroke occurrence or structural damage), thus resulting in the individual being placed at high risk of experiencing recurrent seizures; and/or 3) the diagnosis of a specific epilepsy syndrome (Fisher et al., 2014). Epileptic seizures can result in disturbances to the motor activity, sensation, behaviour and consciousness of an individual (Solomon & McHale, 2012).

It is estimated that globally there are approximately 50 million people living with epilepsy (PWE) (World Health Organization [WHO], 2001; Leonardi & Ustun, 2002). Within an Irish context, 10 per 1,000 persons 18 years or older self-report a lifetime prevalence of epilepsy (Linehan et al., 2010). Children and adolescents are particularly susceptible, with approximately 2.9-3.3 in 1000 5-11 year olds and 4-4.5 in 1000 12-15 year olds in Ireland affected (Linehan et al., 2010). Estimated childhood prevalence rates for epilepsy range from 3.6-9.0/1,000 population internationally (Beilmann, Napa, Sööt, Talvik & Talvik, 1999; Linehan et al., 2010; Oka et al., 2006; Pandey, Singhi & Bharti, 2014; Waaler, Blom, Skeidsvoll & Mykletum, 2000). In all likelihood, the aforementioned prevalence rates of epilepsy are underestimations as epilepsy's historical association with stigma has resulted in many PWE's reluctance to publicly admit its presence (Yemadje, Houinato, Quet, Druet-Cabanac & Preux, 2011).

From a n aetiological perspective, there are three classifications of epilepsies. Approximately 25% of diagnoses arise as a result of injury to the Central Nervous System (CNS) (e.g. traumatic brain injury, stroke or brain infections) (Ottman, Annegers, Risch, Hauser & Susser,

1996). For others, epilepsy develops due to the presence of another distinct metabolic condition or disease. These epileptiforms are thus defined as epileptiforms with a structural/metabolic origin (Berg et al., 2010). A second classification of epilepsies are the genetic epilepsies (Berg et al., 2010) comprising epileptiforms with a documented genetic basis (e.g. childhood absence epilepsy and Dravet syndrome). Finally, the third classification includes the epilepsies of unknown cause (Berg et al., 2010) - these are epileptic syndromes where, as yet, there is insufficient scientific evidence to nominate a specific aetiology.

On receiving a diagnosis of epilepsy during childhood or adolescence, CWE and their parents must not only contend with the medical aspects of the condition. The condition can also impact on psychosocial wellbeing. Epilepsy encompasses consequences that extend beyond disrupted neurobiological mechanisms to considerably impact on the cognitive, psychological and emotional wellbeing of individuals (De Boer, Mula & Sander, 2008). Physicians experience considerable difficulties in delineating whether such consequences of epilepsy arise directly as a result of the chronic condition itself (i.e. due to neuropathology or epileptic discharges), whether they represent side effects of anti-epileptic drugs (AEDs) or treatments that PWE are subjected to, whether psychosocial factors play a role, or indeed whether they arise as a result of the complex interactions among such influences (Kwan & Brodie, 2001). Irrespective of their origin, these consequences can detrimentally impact on the quality of life (QOL) of PWE and therefore must be considered when discussing the condition.

Physically, aside from the obvious manifestations of epilepsy (i.e. seizures), CWE can experience significant consequences that are directly or indirectly associated with the condition including fatigue, impaired motor functioning and seizure-related injuries (Beckung & Uvebrant, 1993; Elliott, Lach & Smith, 2005; Hernandez et al., 2002; Wirrell, 2006). Such consequences can be extremely disruptive to the daily functioning of CWE. Epilepsy has also been known to negatively impact on the cognitive functioning of PWE. In fact, a study investigating the subjective experiences of adult PWE found that when patients were asked to rank a list of potential problems, cognitive impairment was ranked highest (Fisher et al., 2000). Children and the elderly have been identified as being most susceptible to adverse effects on cognition, particularly when these effects arise as a result of AEDs (Hirsch, Schmitz & Carreno, 2003). Memory, concentration/attention and speech are the aspects of cognitive functioning that are most often reported as problematic in CWE (Dunn & Kronenberger, 2005; Caplan et al., 2001; Clarke et al., 2007; Nolan et al., 2004; Oostrom, Van Teeseling, Smeets-Schouten, Peters & Jennekens-Schinkel, 2005; Sánchez-Carpintero & Neville, 2003; Sillanpää, 1992). Epilepsy in childhood and adolescence has also been documented to deleteriously affect self-concept, self-esteem and autonomy (Austin, 2007; Nordli Jr., 2001). Finally, CWE are at significantly greater risk of experiencing depression, anhedonia, internalizing behaviour problems, and social

anxiety than their healthy peers (Austin et al., 2002; Baker, Spector, McGrath & Soteriou; 2005).

Amongst parents of CWE, consequences of a child receiving a diagnosis of epilepsy evidenced in the literature include fatigue, disrupted sleep patterns, anxiety, stress, depression, overexpression of emotion, feelings of frustration, anger, guilt and hopelessness, poor QOL, parental hypervigilance and clinical levels of parenting stress (Cottrell & Khan, 2005; Duffy, 2011; Hodes, Garralda, Rose & Schwartz, 1999; Iseri, Ozten & Aker, 2006; Larson et al., 2012; Lv et al., 2009; Mu, 2008; Rodenburg, Meijer, Deković & Aldenkamp, 2007; Thomas & Bindu, 1999; Wirrell, Wood, Hamiwka & Sherman, 2008).

1.2 Epilepsy-related Stigma

One of the most significant social issues experienced by PWE is stigma. Historically, epilepsy has a notoriously poor reputation. Kale (1997) describes the history of epilepsy as consisting of "4000 years of ignorance, superstition and stigma, followed by 100 years of knowledge, superstition and stigma" (p.2). Previous to the 1800s, epilepsy was not recognised as a medical disorder; rather links were made between epilepsy and the supernatural (De Boer, 2010). In fact, in some of the developing countries, such views of epilepsy persist. For example, in sub-Saharan Africa, some individuals still believe that seizures are associated with witchcraft or breaking taboos and that angered ancestors send such ailments as a punishment for deviant social behaviours (Baskind & Birbeck, 2005). In the past, epilepsy was also seen as indicative of lunacy. The extent to which such perceptions persist in the modern era vary cross-culturally (Kim, et al. 2003).

Remnants of such antiquated negative stereotypes have filtered down through the generations and perpetuated misconceptions, poor public attitudes and stigma surrounding epilepsy. In fact, in a recent survey conducted by Amárach Research/Epilepsy Ireland (2013) assessing awareness and knowledge of epilepsy within an Irish context, when people were asked whether epilepsy was contagious, 7% of people thought that it was, whilst a further 7% were unsure.

As a result of negative attributes imputed to epilepsy, PWE have been subject to persecution. Literature reports that historically, PWE were burned at the stake akin to witches (Heller, Alberto, Forney & Schwartzman, 1996), exorcised (Kluger & Kudernatsch, 2009), stoned to death and buried alive (Radcliffe, 1955). Although the persecution of PWE is largely a thing of the past, there are some exceptions (Keusch, Wilentz & Kleinman, 2006).

The implications of epilepsy-related stigma are extensive, affecting multiple domains of the lives of PWE, from the physical to the psychosocial. In fact, according to De Boer (2010), the

most significant problems encountered by PWE in daily life are not those related to the severity of the condition, but rather are those that stem from public perceptions of the condition.

Scambler and Hopkins (1986) distinguish between two types of stigma that PWE may experience; *"enacted"* and *"felt"*. Enacted stigma refers to individuals' experiences of actual episodes of discrimination and/or exclusion solely due to the discrediting attribute (i.e. epilepsy). Comparatively, felt stigma is regarded as a process of self-stigmatisation, whereby the individual internalises feelings of shame as a result of possessing the discrediting attribute that has the potential to result in stigmatisation in society (i.e. epilepsy), and consequently fears encountering enacted stigma (Scambler & Hopkins, 1986).

PWE (adults and children) in both the developed and developing countries often experience discrimination and/or social exclusion because of epilepsy – manifestations of enacted forms of epilepsy-related stigma (Austin, MacLeod, Dunn, Shen & Perkins, 2004; Bautista, Shapovalov, Saada & Pizzi, 2014; MacLeod & Austin, 2003; Thomson, Fayed, Sedarous & Ronen, 2014). Public perceptions of epilepsy are poor; only 31% of a population of 19,441 adolescents in the U.S. reported that they would date a person with epilepsy (Austin, Shafer & Deering, 2002), while 46.2% of 1,556 Italian adults deemed the potential for marriage to be limited due to an individual receiving a diagnosis of epilepsy, and 36.5% indicated that they perceived epilepsy as a form of insanity (Mecarelli et al., 2010). Furthermore, 21% of a sample of employers in the U.K. (n=204) perceived hiring a person with epilepsy as being "a major issue" (Jacoby, Gorry & Baker, 2005). This finding was replicated within an Irish context, with 19% of survey respondents aged 15 years + (n=1001) stating that they would not employ an individual if they had a diagnosis of epilepsy (Amárach Research/Epilepsy Ireland, 2013).

In the 1990s, a large-scale study found that 51% of 5,211 adult respondents across 15 European countries reported feeling stigmatised as a result of their epilepsy (Baker, Jacoby, Buck, Stalgis & Monnet, 1997). Despite some improvements in public perceptions of epilepsy due to recent public education efforts to bring epilepsy "out of the shadows" (De Boer, 2002; De Boer, Moshe, Korey & Purpura, 2013; Price, Kobau, Buelow, Austin & Lowenberg, 2015, Reynolds, 2000; WHO, 2000), epilepsy-related stigma remains rife. In Ireland, a survey conducted by Epilepsy Ireland (2012) echoed the findings of Baker et al. (1997), whereby 52% of a sample of adult PWE (n=464) reported experiencing epilepsy-related stigma. Similarly, in Turkey, 41% of 220 CWE aged 8-17 years reported feeling stigmatised by their peers due to their epilepsy, with stigma perceptions significantly increasing with age (Hirfanoglu et al., 2009).

In summary, the history of epilepsy-related stigma is long and convoluted with various sources (religious and cultural in nature) contributing to the myths and untruths that encircle the condition. It is as a result of these myths, and their perpetuation in mainstream media, that significant misunderstanding persists amongst the general public in relation to epilepsy

(Baxendale & O'Toole, 2007; McCagh, 2010). Misconceptions about epilepsy make members of the public unnecessarily wary of PWE and can even generate active discrimination and prejudice against PWE - i.e. enacted stigma (Jacoby, Gorry, Gamble & Baker, 2004). There is a need, therefore, to debunk the myths surrounding epilepsy, in order to shatter epilepsy-related stigma. Whilst much attention has been devoted in epilepsy research to eradicating enacted forms of epilepsy-related stigma by enhancing public knowledge and perceptions of the condition, little effort has been made to address felt epilepsy-related stigma. This is despite the fact that a review of the literature reveals that felt stigma poses a greater threat to PWE in developed/Western societies (i.e. Europe and North America), whereas enacted stigma is more problematic and salient in the developing countries (i.e. countries in the southern hemisphere such as Africa) (Reis & Meinardi, 2002). Furthermore, Jacoby and Austin (2007) postulate that amongst PWE, felt stigma may cause greater personal anguish and unhappiness than enacted stigma. Felt stigma may result in an individual concealing a stigmatised attribute, quality/trait or illness from others (Reis & Meinardi, 2002) and/or limiting his/her engagement in a social context in order to avoid enacted stigma (Baskind & Birbeck, 2005). As Scambler (1989) and Jacoby and Austin (2007) contend, felt stigma can result in the perpetuation of a self-fulfilling prophecy, whereby due to fear and shame, PWE conceal their diagnosis from others but in doing so they are denied the opportunity to test whether the enacted stigma and discrimination they anticipate experiencing will indeed materialise. Lewis and Parsons (2008) further argue that there is a *cycle of invisibility* encircling epilepsy, with the unwillingness by those living with the condition to be open and honest about it with others contributing to the silence surrounding the condition, perpetuating misconceptions that encircle the condition and consequently exacerbating epilepsy-related stigma.

1.3 Disclosing Epilepsy: A Concealable Stigmatised Identity

Whilst epilepsy-related stigma remains rife and globally problematic, many PWE have the capacity to conceal the diagnosis from others (Jacoby, Snape & Baker, 2005; Tröster, 1997). Epilepsy is an example of a concealable stigmatised identity (CSI) (Quinn & Earnshaw, 2013), with visibility of the condition contingent upon either: 1) disclosure of the condition; or 2) the manifestation of symptoms (i.e. seizures) or cues that indicate the presence of the condition (i.e. medication-taking) in a public setting. Quinn and Chaudoir (2009) demonstrated that individuals with CSIs (including mental illness, epilepsy, and HIV) are at risk of experiencing poor psychosocial outcomes, particularly in instances where they anticipate experiencing stigma on disclosing their stigmatised identity to others.

Many contend that it is as a result of such anticipated stigma (i.e. felt stigma) that some PWE choose to conceal their condition from others (Jacoby, 2002; Joachim & Acorn, 2000; Scambler & Hopkins, 1986; Schneider & Conrad, 1980; Tröster, 1997), with felt stigma believed to be

more prevalent and attributable to families employing an information concealment strategy (Tröster, 1997). This equates with the *hidden distress* model proposed by Scambler (1989) which was epitomized in three propositions; 1) on hearing of a diagnosis of epilepsy the person quickly learns to regard the diagnostic label of epilepsy as a social liability because they come to define epilepsy as stigmatising in which a fear of enacted stigma prevails; 2) this fear of enacted stigma promotes selection of a non-disclosure strategy to keep the epilepsy condition hidden and to pass as 'normal'; and 3) this policy of concealment minimises the risk and rate of enacted stigma. However, as a consequent net effect, this felt stigma, and the fear of enacted stigma, is more disruptive to the lives of PWE than enacted stigma. In fact, successful passing as a member of the non-stigmatised majority by PWE has often been found to increase psychological distress in individuals that opt for this strategy (Scambler, 1989).

Beyond concealment, other disclosure management strategies adopted by PWE as evidenced in studies examining epilepsy disclosure amongst adults include: 1) preventive disclosure (i.e. telling others prior to seizure occurrences in order to avoid the inherent risk of detection and/or to forestall stigmatisation) (Tröster, 1997); 2) selective disclosure (i.e. restricting to whom and/or what information about the diagnosis is disclosed) (Aydemir et al., 2009); 3) voluntary disclosure (i.e. voluntarily disclosing epilepsy to others between seizures) (Scambler & Hopkins, 1980); and 4) social broadcasting (i.e. broadcasting the epilepsy diagnosis to educate others) (Scambler & Hopkins, 1990). In addition, epilepsy disclosure can be forced in two circumstances: 1) in the event of an unplanned revelation (i.e. others witnessing seizures/drug-taking) (Scambler, 1984); and 2) when others broadcast the diagnosis (Elafros et al., 2013).

In conclusion, because of epilepsy's largely invisible nature and historical association with stigma, disclosing an epilepsy diagnosis to others is complex. Consequently, one way in which felt stigma is implicitly expressed by PWE is through diagnosis concealment. Epilepsy concealment can be particularly problematic in the context of childhood and adolescence for two reasons. First, experiences of felt and/or enacted stigma can threaten and detrimentally affect the present and future psychosocial wellbeing of CWE because childhood and adolescence are critical periods for identity formation and self-definition (MacLeod & Austin, 2003). Second, concealing a child's epilepsy condition from others who may be responsible for the child has the potential to have significant negative ramifications for the safety of the child. Despite the importance of the topic of epilepsy disclosure in the context of childhood and adolescence, little has been documented in terms of how and why CWE and their parents select specific disclosure management strategies and what the complex disclosure process involves for them. The core contribution that this thesis presents is the explication of the disclosure behaviours and experiences of CWE and their parents, the contextual factors that inform this disclosure, the consequences of the disclosure management strategies they adopt and the

relationship between CWE's and parents' epilepsy disclosure behaviours and their demographic and clinical characteristics, psychosocial wellbeing and illness attitudes.

1.4 Thesis Conspectus

In chapter 2, a systematic review of evidence on disclosure of a child's epilepsy condition, from child and parent perspectives, is presented.

Chapter 3 discusses the philosophical foundations and methodological underpinnings of this two-phased mixed methods study.

Chapter 4 details the qualitative methods implemented during the first phase of this mixed methods inquiry. Chapter 5 presents the thematic findings to emerge on analysis of child and parent interviews. Chapter 6 critically discusses the findings from the qualitative phase.

In chapter 7, methodological details pertaining to the second quantitative phase of the mixed methods study are provided. Chapter 8 outlines the quantitative findings yielded through descriptive, correlational and group difference analyses of cross-sectional survey data from 47 CWE and 72 parents of CWE. Chapter nine comprises a critical discussion of the quantitative findings.

In chapter 10, an integrative analysis of the findings from the qualitative and quantitative phases of the study is presented, alongside a discussion of the overarching key discoveries.

Concluding this thesis, in chapter eleven, the unique contribution that this thesis offers is outlined. In addition, the strengths and limitations of this mixed-methods study are indicated, and the practical implications of the findings are highlighted.

Chapter 2: Literature Review

2.0 Introduction

In this chapter, pre-existing empirical evidence on the disclosure behaviours of CWE and parents of CWE is systematically reviewed and critically discussed. The chapter concludes by: (i) identifying gaps in paediatric epilepsy literature with regard to CWE's and parents' epilepsy disclosure behaviours/experiences; and (ii) outlining how such gaps are going to be addressed in the current programme of research.

2.1 Conducting a Systematic Review

Examining disclosure experiences in child/adolescent populations is important because, as discussed in chapter 1, epilepsy is a CSI, childhood and adolescence are critical periods for identity formation and self-definition; and experiences of felt and/or enacted stigma during these critical life periods can significantly affect CWE's psychosocial health (MacLeod & Austin, 2003). The disclosure experiences of parent populations are also worth attention because CWE often take cues from parents in terms of how they perceive their own epilepsy. If negative attitudes towards epilepsy are endorsed by parents, this may result in stigma coaching of the child (i.e. parents relaying to the child the perception that epilepsy is something to be ashamed of and should not be spoken about) (Jacoby & Austin, 2007).

In order to examine the current state of empirical evidence with regard to epilepsy disclosure by CWE and their parents, a systematic review was conducted. The specific objectives were to:

- synthesise research evidence on disclosure of a child's epilepsy condition, from child and parent perspectives (either self- or proxy-reported);
- identify enablers and/or barriers to disclosure for CWE and their parents;
- examine the consequences of various disclosure management strategies for CWE and their parents;
- investigate the relationship between demographic, clinical, and psychosocial factors and disclosure behaviours amongst CWE and their parents; and
- identify and review any pre-existing quantitative measures of epilepsy disclosure employed for use in populations of CWE and/or their parents.

2.2 Methods of the Systematic Review

This systematic review was conducted and reported in accordance with guidelines outlined by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher, Liberati, Tetzlaff & Altman, 2009).

2.2.1 Search Strategy

Eligible papers for inclusion in this review were identified through searches of the following electronic databases in March 2015: PsycINFO (1597-March 2015); Medline (1946-March 2015); PubMed (1940s-March 2015); Scopus (1966-March 2015); Web of Science (1900-March 2015); and CINAHL (1937-March 2015). Search terms using both controlled vocabulary from databases (e.g. Medical Subject Headings [MeSH]) and free text words, were used in various combinations as displayed in Table 2.1. No limiters were applied. Ancestry searching was also engaged in (i.e. a manual search of bibliographies was conducted for (i) all studies deemed eligible for inclusion and (ii) any relevant review papers identified).

Table 2.1: Systematic Review: Search Terms and Strategy

Key Search Terms	Search Strategy
Epilepsy	• Epilepsy OR epilept* OR epileps* OR epilepsies OR seizure disorder OR seizure condition AND
Family, Parent, Child	• Family OR familie* OR parent* OR father* OR mother* OR caregiver* OR stepparent* OR child* OR infant* OR adolescen* OR teen* OR young* OR young person* AND
Disclosure	• Disclosure OR disclos* OR tell* OR talk* OR letting know OR informing OR conversat* OR conversing OR self-disclosure OR truth disclosure OR information disclosure OR duty to warn OR parental notification OR health communication OR mandatory reporting OR public disclosure OR diagnosis disclosure OR conceal*

2.2.2 Study Selection Criteria

Prior to commencing the search strategy, inclusion and exclusion criteria were specified for types of studies, types of participants, and types of outcomes. All types of research designs were considered across quantitative, qualitative and mixed-method paradigms. Peer-reviewed publications of English language studies comprising original research were considered for

inclusion provided they addressed one or more objectives of the review. Editorials, books, book chapters, commentaries, dissertations, and review papers were excluded.

Studies with children/young people aged 0-18 years of any sex with epilepsy of any type (idiopathic, cryptogenic and/or symptomatic) were deemed eligible for inclusion. Manuscripts were excluded if they combined results for adults (18 years+) and children with no delineation of child-specific or adult-specific findings. Any studies examining the disclosure behaviours of parents of CWE (aged 0-18 years) were also included.

In terms of study outcomes, any studies (a) that explicitly examined disclosure of an epilepsy diagnosis from child and/or parent perspectives (self- and/or proxy-reported) as the primary focus of the study, (b) that examined disclosure of an epilepsy diagnosis from child and/or parent perspectives (self- and/or proxy-reported) as a sub-focus of a larger study, or (c) where findings pertaining to disclosure of an epilepsy diagnosis from child and/or parent perspectives (self- and/or proxy-reported) emerged as an incidental theme or sub-theme, were included.

For the purposes of this review (and indeed for the present study in its entirety) the following definition of disclosure of a CSI was employed: *"the verbal communication that occurs between a discloser and an interaction partner regarding the discloser's possession of a concealable stigmatized identity"* (Chaudoir & Fisher, 2010, p. 241). Alongside this definition, which emphasises the verbal components of a communication encounter, cognisance was also given to non-verbal communication behaviours that might have acted as the initial stimulus to CWE or parents revealing the child's epilepsy diagnosis (e.g. the potential for unplanned revelations via others witnessing seizures or medication administration). For the purposes of this review and throughout this thesis, the interaction partner refers only to individuals outside of the nuclear/immediate family context of the CWE (where the nuclear/immediate family is defined as the family group consisting of the CWE and his/her parent(s) and sibling(s)).

2.2.3 Methods of the Review

Drawing on the study selection criteria, a two-stage screening process was undertaken to identify studies eligible for inclusion in the review. Stage one involved two reviewers screening the titles and abstracts of all the retrieved evidence from the electronic searches for relevance. Stage two involved retrieval of the full-texts of studies deemed eligible for inclusion in the review. These texts were independently read in-full by two reviewers against the inclusion criteria before a final decision regarding inclusion was confirmed. The reasons for excluding studies at this stage were noted (see Figure 2.1). Bibliographies of all studies deemed eligible for inclusion and relevant review papers were also manually screened. For all stages of the screening process, discrepancies were resolved through discussion with two further reviewers.

2.2.4 Data Extraction and Data Synthesis

The following methodological information was extracted for each study: author, year, and country of origin; overall study aim/objective; study design; data collection method; sample; and details of any pre-existing instruments for quantifying disclosure (if applicable) (see Appendix A). To capture key findings pertaining to the existing evidence available on epilepsy disclosure by CWE and their parents the following data were extracted; how disclosure findings emerged (i.e. primary focus of the study, sub-focus of a larger study or incidental emergent theme/sub-theme); disclosure behaviours of CWE and their parents; enablers for disclosure; barriers to disclosure; disclosure impact and/or consequences; and any identified relationship between disclosure management and other demographic, clinical or psychosocial variables (see Appendix B). All data were extracted independently by two reviewers and cross-checked by two further reviewers for accuracy, with any discrepancies resolved through discussion.

The data were synthesised narratively. Because of the heterogeneity of the study designs and instruments employed to capture disclosure experiences of CWE and their parents, meta-analysis or meta-synthesis of the data was not possible.

2.2.5 Quality Assessment

The quality of the studies was assessed using two different quality appraisal tools in order to account for the different research designs. The manuscripts were assessed for quality using: 1) a modified version of a quality appraisal tool developed by Tsimicalis, Stinson & Stevens (2005) for quantitative and mixed methods papers; and 2) the critical appraisal skills programme (CASP) appraisal tool (1998) for qualitative papers. Tsimicalis et al.'s quality appraisal tool (2005) involves the assessment of five study parameters: 1) study design; 2) participants and recruitment; 3) comparison group; 4) number of participants; and 5) QOL instruments. For the purposes of this review, item five pertaining to instruments measuring QOL was adapted to pertain to instruments where the disclosure behaviours of CWE and/or their parents were assessed. Each parameter is assessed based on ratings from 0-3. Thus, the tool yields an overall methodological quality score ranging from 0 to 15 for each study, with higher scores indicative of more robust methodological quality. The CASP appraisal tool (1998) is a 10-item checklist that facilitates researchers in reporting on the methodological quality of a number of components of qualitative studies including methodological appropriateness, sample, data collection, data analysis, and findings. Employment of the CASP appraisal tool (1998) involves reviewers choosing one of the three following options to indicate whether items on the checklist have been addressed within a study (as highlighted by the research paper) or not: 1) Yes; 2) No; and 3) Can't Tell. Two reviewers independently conducted the quality appraisal, which was cross-checked by a third reviewer, with discussion to reach consensus on any discrepancies.

2.3 Results of the Systematic Review

An adapted PRISMA flow diagram depicting the stages of the screening and selection process is outlined in Figure 2.1. The initial search strategy yielded 2689 papers for screening. After removing duplicates and following stage one screening of titles and abstracts, 79 papers were deemed potentially eligible for inclusion in the review. A further 126 papers were added following manual screening of bibliographies of: (i) papers deemed eligible for inclusion; and (ii) relevant review papers. This resulted in a total of 205 papers for stage two screening of full-texts, following which 173 papers were removed. Reasons for exclusion at this point are summarised in Figure 2.1. A total of 32 papers were identified as eligible for inclusion in the review.

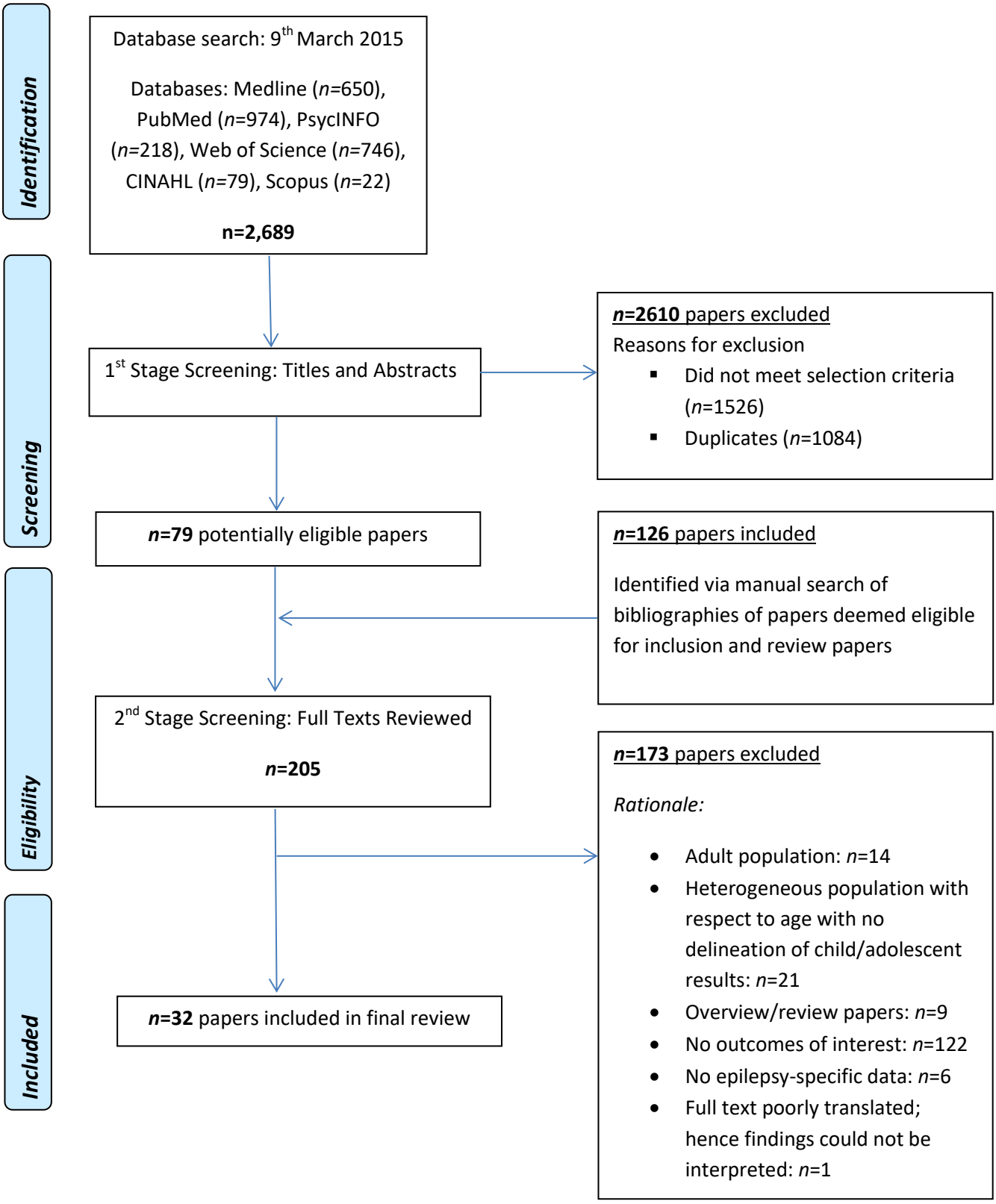

Figure 2.1: Systematic Review: PRISMA diagram representing flow of identification and selection process

2.3.1 Description of the Studies

The methodological characteristics of the 32 studies are summarised in Appendix A. These studies were published between 1968 and 2015 and comprised findings pertaining to child and/or parental disclosure of a child's epilepsy (self- and/or proxy-reported) from a combined total of 1,429 CWE and 1,838 parents of CWE. Seven studies were conducted in the United Kingdom (Bannon, Wildig & Jones, 1992; Hoare, Mann & Dunn, 2000; Hoare & Russell, 1995; Holdsworth & Whitmore, 1974; Houston, Cunningham, Metcalfe & Newton, 2000; McEwan, Espie, Metcalfe, Brodie & Wilson, 2004; Moffat, Dorris, Connor & Espie, 2009), five in the United States (Austin et al., 2004; Coulter & Koester, 1985; Hightower, Carmon & Minick; 2002; Hodgman et al., 1979; Kleck, 1986), two in Zimbabwe (Butau & Piachaud, 1993; Saburi, 2011), two in Italy (Mecarelli et al., 2011; Mecarelli et al., 2014), two in Canada (Ronen, Rosenbaum, Law & Streiner, 1999; Roberts & Whiting, 2011), two in Taiwan (Chen, Chen, Yang & Chi, 2010; Mu, 2008), and one in Iran (Zamani, Shiva, Mohammadi, Mahmoudi Gharaie & Rezaei, 2014), Chile (Lewis, Salas, Sota, Chiofalo & Leake, 1990), China (Kwong, Wong & So, 2000), Germany (Jantzen et al., 2009), Japan (Hanai, 1996), Korea (Ryu, Lee, Eom, Kim & Korean QoL in epilepsy study group, 2015), Saudia Arabia (Abulhamail et al., 2014), Serbia (Gazibara, Nikolovski, Lakic, Pekmezovic & Kisic-Tepavcevic, 2014), Nigeria (Ojinnaka, 2002), India (Pala & Vankar, 1997) and Croatia (Prpic et al., 2003). One study recruited participants from 16 countries internationally (Baker et al., 2008).

Of these 32 studies, 20 employed a quantitative design (Abulhamail et al., 2014; Austin et al., 2004; Baker et al., 2008; Bannon et al., 1992; Butau & Piachaud, 1993; Coulter & Koester, 1985; Gazibara et al., 2014; Hanai, 1996; Hoare et al., 2000; Hoare & Russell, 1995; Hodgman et al., 1979; Kwong et al., 2000; Mecarelli et al., 2011; Mecarelli et al., 2014; Ojinnaka, 2002; Pala & Vankar, 1997; Prpic et al., 2003; Ryu et al., 2015; Saburi, 2011; Zamani et al., 2014), nine a qualitative design (Chen et al., 2010; Hightower et al., 2002; Holdsworth & Whitmore, 1974; Houston et al., 2000, McEwan et al., 2004; Moffat et al., 2009; Mu, 2008; Roberts & Whiting, 2011; Ronen et al., 1999), and three a mixed methods research design (Jantzen et al., 2009; Kleck, 1968; Lewis et al., 1990).

With the exception of one study, which examined parental disclosure via retrospective proxy-reports from adult children (Kleck, 1968), no study investigated epilepsy disclosure by CWE and/or their parents as a primary focus. Most studies (n=22) examined disclosure behaviours or attitudes towards disclosure as sub-foci of larger studies (Abulhamail et al., 2014; Austin et al., 2004; Baker et al., 2008; Bannon et al., 1992; Butau & Piachaud, 1993; Gazibara et al., 2014; Hanai, 1996; Hodgman et al., 1979; Hoare et al., 2000; Hoare & Russell, 1995; Holdsworth & Whitmore, 1974; Jantzen et al., 2009; Kwong et al., 2000; Lewis et al., 1990; Mecarelli et al., 2011; Mecarelli et al., 2014; Ojinnaka, 2002; Pala & Vankar, 1997; Prpic et al., 2003; Ryu et al., 2015; Saburi, 2011; Zamani et al., 2014). In nine studies, findings pertaining to disclosure

emerged incidentally as qualitative sub-themes (Chen et al., 2010; Coulter & Koester, 1985; Hightower et al., 2002; Houston et al., 2000; McEwan et al., 2004; Moffat et al., 2009; Mu et al., 2008; Roberts & Whiting, 2011; Ronen et al., 1999).

In the 31 studies where disclosure was discussed and explored in the context of larger studies or where findings related to child or parental disclosure emerged incidentally, in 10 papers, findings regarding disclosure of epilepsy by CWE emerged through examination of the perspectives of CWE only (Austin et al., 2004; Chen et al., 2010; Hightower et al., 2002; Hodgman et al., 1979; Houston et al., 2000; Lewis et al., 1990; McEwan et al., 2004; Moffat et al., 2009; Ronen et al., 1999; Zamani et al., 2014). In nine papers, findings pertaining to parental disclosure of the child's epilepsy emerged via parental self-reports only (Butau & Piachaud, 1993; Coulter & Koester, 1985; Gazibara et al., 2014; Hoare et al., 2000; Hoare & Russell, 1995; Kwong et al., 2000; Roberts & Whiting, 2011; Ryu et al., 2015; Saburi, 2011). Furthermore, in eight papers findings pertaining to child and/or parental disclosure emerged via proxy-reports by teachers (Abulhamail et al., 2014; Bannon et al., 1992; Holdsworth & Whitmore, 1974; Mecarelli et al., 2011; Mecarelli et al., 2014; Ojinnaka, 2002; Pala & Vankar, 1997; Prpic et al., 2003). In one paper, findings pertaining to parental disclosure emerged via parental self-reports and proxy-reports by teachers (Hanai, 1996). Finally, in three papers disclosure of epilepsy to others by both CWE and their parents was examined via child and parent self- and/or proxy-reports (Baker et al., 2008; Jantzen et al., 2009; Mu, 2008).

2.3.2 Quality Appraisal of the Included Studies

Using a modified version of Tsimicalis et al.'s quality appraisal tool (2005) the quality of 20 quantitative studies (Abulhamail et al., 2014; Austin et al., 2004; Baker et al., 2008; Bannon et al., 1992; Butau & Piachaud, 1993; Coulter & Koester, 1985; Gazibara et al., 2014; Hanai et al., 1996; Hodgman et al., 1979; Hoare et al., 2000; Hoare & Russell, 1995; Kwong et al., 2000; Mecarelli et al., 2011; Mecarelli et al., 2014; Ojinnaka, 2002; Pala & Vankar, 1997; Prpic et al., 2003; Ryu et al., 2015; Saburi, 2011; Zamani et al., 2014) and three mixed methods studies (Jantzen et al., 2009; Kleck, 1968; Lewis et al., 1990) was critically appraised. From a total possible score of 15 (indicative of extremely robust methodological quality), the studies appraised obtained scores ranging from 1-11 (see Table 2.2). This range of scores is comparable to the range of scores of 3-9 reported for studies appraised using this quality appraisal tool in the original review paper in which it was employed (Tsimicalis et al., 2005).

Employing the CASP appraisal tool (1998), the methodological quality of the nine qualitative studies deemed relevant for inclusion in the review (Chen et al., 2010; Hightower et al., 2002; Holdsworth & Whitmore, 1974; Houston et al., 2000; McEwan et al., 2004; Moffat et al., 2009; Mu, 2008; Roberts & Whiting, 2011; Ronen et al., 1999) was critically appraised across ten study parameters (see Table 2.3).

Table 2.2: Systematic Review: Critical Appraisal of Quantitative and Mixed Methods Studies

Study	Parameters					Total
	Study design[1]	*Participants and recruitment*[2]	*Comparison group*[3]	*Number of participants*[4]	*Disclosure instruments*[5]	
Abulhamail et al. (2014)	0	0	0	3	0	3
Austin et al. (2004)	0	1	1	3	2	7
Baker et al. (2008)	0	1	0	3	1	5
Bannon et al. (1992)	0	1	0	3	0	4
Butau & Piachaud (1993)	0	0	0	1	0	1
Coulter & Koester (1985)	0	2	1	1	0	4
Gazibara et al. (2014)	1	3	0	3	1	8
Hanai (1996)	0	1	1	3	0	5
Hoare & Russell (1995)	0	1	0	1	2	4
Hoare et al. (2000)	0	0	1	3	3	7
Hodgman et al. (1979)	0	0	0	1	0	1
Jantzen et al. (2009)	3	3	2	3	0	11
Kleck (1968)	0	1	0	2	2	5
Kwong et al. (2000)	0	2	1	2	1	6
Lewis et al. (1990)	3	0	2	3	0	8
Mecarelli et al. (2011)	0	0	0	3	0	3
Mecarelli et al. (2014)	1	0	2	3	0	6
Ojinnaka (2002)	1	1	0	3	0	5
Pala & Vankar (1997)	0	0	0	3	1	4
Prpic (2003)	0	1	0	3	1	5
Ryu et al. (2015)	1	1	0	3	1	6
Saburi (2011)	1	1	0	1	0	3
Zamani et al. (2014)	1	0	0	3	3	7

[1] Study design: 0=Survey or do not report; 1=Cross-sectional (explicitly stated); 2=Retrospective or mixed design (explicitly stated); 3=Longitudinal prospective design (explicitly stated)

[2] Participants and recruitment: 0=More than two criteria missing; 1=Two criteria missing; 2=Minimal description of at least four criteria; 3=Description of the population (1), and eligibility criteria for participants (2), precise details of the recruitment process (3), accounted for the numbers recruited (4), and lost to follow-up (5)

[3] Comparison group: 0=No comparison group; 1=Other comparison group (i.e. Adult epilepsy population, children with other chronic illnesses, parent-report); 2=Reference sample; 3=Healthy, age-appropriate comparison

[4] Number of participants: 0=Did not report; 1=N<50; 2=N=50-100; 3=N>100

[5] Disclosure instruments: 0=Investigator constructed clinical rating of disclosure with no psychometric properties reported. Use of self-report or proxy-report; 1=Psychometric properties of disclosure instruments, or sub-scales, not reported or reported as inadequate for measuring disclosure. Use of self-report or proxy-report; 2= Some weak psychometric properties reported for generic and/or disease-specific disclosure measures or sub-components of measures. Use of self-report; 3=Report of psychometrically sound generic and/or disease-specific disclosure measures or sub-components of measures. Use of self-report.

Table 2.3: Systematic Review: Critical Appraisal of Qualitative Studies

Study	Clear Statement of Aims	Qualitative methodology appropriate	Research design appropriate to address aims	Recruitment strategy appropriate to address aims	Data collection appropriate to address aims	Consideration of the relationship between the researcher(s) and participants	Consideration of ethical issues	Rigorous data analysis	Clear statement of findings	Value of the research
Chen et al. (2010)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hightower et al. (2002)	Yes	Yes	Can't tell	Can't tell	Yes	No	Can't tell	Can't tell	Yes	Yes
Holdsworth & Whitmore (1974)	No	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Yes
Houston et al. (2000)	Yes	Yes	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell
Mc Ewan et al. (2004)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes
Moffat et al. (2009)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Mu (2008)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Roberts & Whiting (2011)	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Can't tell	Yes	Yes	Yes
Ronen et al. (1999)	Yes	Yes	Yes	Yes	Can't tell	Can't tell	Can't tell	Yes	Yes	Yes

The quality appraisal scores and assessments reported in Tables 2.2 and 2.3 do not necessarily reflect the methodological rigor of the included papers. Rather, such scores and assessments are demonstrative of methodological reporting. That is, in many of the studies (quantitative, mixed methods and qualitative), important details pertaining to methodological rigor were not explicitly reported. This made it difficult to establish whether the research was conducted in a methodologically rigorous fashion.

2.3.3 Quantitative Measures of Epilepsy Disclosure Behaviours

In 22 of the 32 papers identified for review, attitudes towards disclosure and/or the self- or proxy-reported disclosure behaviours engaged in by CWE and/or their parents were assessed quantitatively (Abulhamail et al., 2014; Austin et al., 2004; Baker et al., 2008; Bannon et al., 1992; Butau & Piachaud, 1993; Coulter & Koester, 1985; Gazibara et al., 2014; Hanai et al., 1996; Hodgman et al., 1979; Hoare et al., 2000; Hoare & Russell, 1995; Jantzen et al., 2009; Kwong et al., 2000; Lewis et al., 1990; Mecarelli et al., 2011; Mecarelli et al., 2014; Ojinnaka, 2002; Pala & Vankar, 1997; Prpic et al., 2003; Ryu et al., 2015; Saburi, 2011; Zamani et al., 2014). Eight of these studies measured parents' perspectives only (Butau & Piachaud, 1993; Coulter & Koester, 1985; Gazibara et al., 2014; Hoare et al., 2000; Hoare & Russell, 1995; Kwong et al., 2000; Ryu et al., 2015; Saburi, 2011), seven studies measured parental and/or child disclosure via proxy-reports by teachers (Abulhamail et al., 2014; Bannon et al., 1992; Mecarelli et al., 2011; Mecarelli et al., 2014; Ojinnaka, 2002; Pala & Vankar, 1997; Prpic et al., 2003), four measured the perspectives of CWE (self-reported only) (Austin et al., 2004; Hodgman et al., 1979; Lewis et al., 1990; Zamani et al., 2014), one study measured parent perspectives self- and proxy-reported by teachers (Hanai, 1996), one study measured child perspectives self- and proxy-reported by the child's parents (Jantzen et al., 2009), and one study measured the perspectives of both CWE and their parents (Baker et al., 2008).

The 22 quantitative studies were reviewed for the measures employed to capture the disclosure behaviours and attitudes of CWE and/or their parents. Ten studies provided no specific detail or information pertaining to either the actual disclosure measurement utilised or the specific items on measures that assessed disclosure behaviours and/or attitudes (Abulhamail et al., 2014; Baker et al., 2008; Bannon et al., 1992; Hanai, 1996; Hodgman et al., 1979; Kwong et al., 2000; Lewis et al., 1990; Pala & Vankar, 1997; Prpic et al., 2003; Zamani et al., 2014). In a further 11 studies, the details provided highlighted that disclosure behaviours or attitudes towards disclosure were measured via one to three items, either as a sub-component of another domain (for example, on QOL, stigma, or teacher knowledge and attitudes towards epilepsy scales) (Austin et al., 2004; Hoare et al., 2000; Hoare & Russell, 1995; Mecarelli et al., 2011; Mecarelli et al., 2014; Ojinnaka, 2002) or via investigator constructed items developed with the purpose of measuring CWE's disclosure ability, parental attitudes and/or parental concerns/stressors with

no psychometric properties reported (Butau & Piachaud, 1993; Coulter & Koester, 1985; Gazibara et al., 2014; Jantzen et al., 2009; Saburi, 2011).

Only one study employed a tool developed specifically to measure disclosure behaviours (Ryu et al., 2015). This tool was originally developed for use in an adolescent/young adult population (Westbrook, Bauman & Shinnar, 1992), but for the purpose of the Ryu et al. study (2015) it was adapted for use in mothers to assess maternal concealment behaviours. The measure comprises four items that capture the following information: frequency of the adoption of maternal concealment strategies, level of maternal peer awareness of the child's epilepsy diagnosis, how maternal disclosure of the child's epilepsy diagnosis arises, and frequency of maternal disclosure/conversation with others about the child's epilepsy diagnosis. Responses on this tool are measured on a 4-point Likert scale (ranging from 0 to 3) with higher scores indicative of higher levels of concealment. In the original paper where the measure was developed for use in adolescents/young adults aged 12-20 years, the reported psychometric properties included: inter-item correlations (moderate - averaging 0.40), internal consistency (acceptable - Cronbach's alpha 0.71) and construct validity (the authors suggested a more sensitive measure may be required) (Westbrook et al., 1992). No psychometric properties for the maternal version of the instrument are reported (Ryu et al., 2015).

2.3.4 Disclosure-Specific Findings across the Identified Studies

Findings pertaining to epilepsy disclosure by CWE and/or their parents (self- and/or proxy-reported) are synopsised for each of the individual studies in Appendix B, whilst themes that were identified on examination of the 32 studies collectively are presented in Appendix C with reference to the frequency of their occurrence. All findings pertaining to disclosure across the 32 studies are depicted narratively below, with parent and child findings presented separately.

2.3.5 Parent Disclosure Behaviours

In 17 of the 22 studies where findings pertaining to parental disclosure behaviours and attitudes were reported, there was evidence of some parents of CWE adopting concealment strategies, perceiving concealment strategies as desirable and/or promoting secrecy around their child's epilepsy (Abulhamail et al., 2014; Baker et al., 2008; Bannon et al., 1992; Butau & Piachaud, 1993; Hanai, 1996; Holdsworth & Whitmore, 1974; Jantzen et al., 2009; Kleck, 1968; Kwong et al., 2000; Mecarelli et al., 2011; Mecarelli et al., 2014; Mu, 2008; Ojinnaka, 2002; Pala & Vankar, 1997; Prpic et al., 2003; Ryu et al., 2015; Saburi, 2011). In 7 studies where the adoption of parental concealment policies surrounding a child's epilepsy were quantified, the proportion of parents opting to engage in this disclosure management strategy ranged from 7% to 77% (Baker et al., 2008; Hanai, 1996; Kleck, 1968; Kwong et al., 2000; Prpic et al., 2003; Ryu et al., 2015; Saburi, 2011). Two studies reported details of active parental concealment strategies including actions of: physically hiding the child from others, prohibiting family

members from speaking about the child's epilepsy outside of the immediate family context, passing off the seizure symptomatology as being related to something other than epilepsy (e.g. febrile seizures), avoiding bringing the child to social occasions, and/or preparing the child in advance of social situations to ensure that seizures are controlled (Kleck, 1968; Mu, 2008). Other parental disclosure strategies reported included: voluntary disclosure (Bannon et al., 1992; Hanai, 1996; Holdsworth & Whitmore, 1974; Kwong et al., 2000; Mecarelli et al., 2011; Mecarelli et al., 2014; Mu, 2008; Ojinnaka, 2002; Pala & Vankar, 1997; Roberts & Whiting, 2011; Saburi, 2011) and preventive telling (i.e. in an attempt to forestall stigmatisation, one mother disclosed the child's epilepsy to the child's peers in order to explain his behaviour and foster understanding and support) (Mu, 2008). Finally, in five of the studies, disclosure, to teachers and/or head-teachers specifically, occurred through unplanned revelations (for proportions of the population ranging from 14% to 48.3% in studies where explicit quantifications were provided), via teachers either witnessing the child: (i) having a seizure within the school context; and/or (ii) taking his/her AEDs (Abulhamail et al., 2014; Bannon et al., 1992; Holdsworth & Whitmore, 1974; Ojinnaka, 2002; Pala & Vankar, 1997).

Across 15 of the studies, parental disclosure of the child's epilepsy within the school environment was explored (Abulhamail et al., 2014; Bannon et al., 1992; Butau & Piachaud, 1993; Coulter & Koester, 1985; Hanai, 1996; Holdsworth & Whitmore, 1974; Kwong et al., 2000; Mecarelli et al., 2011; Mecarelli et al., 2014; Mu, 2008; Ojinnaka, 2002; Pala & Vankar, 1997; Prpic et al., 2003; Roberts & Whiting, 2011; Saburi, 2011). In these studies, some teachers learned of the child's epilepsy diagnosis through parental voluntary disclosure (Bannon et al., 1992; Hanai, 1996; Holdsworth & Whitmore, 1974; Kwong et al., 2000; Mecarelli et al., 2011; Mecarelli et al., 2014; Mu, 2008; Ojinnaka, 2002; Pala & Vankar, 1997; Roberts & Whiting, 2011; Saburi, 2011), whilst others learned through unplanned revelations (Abulhamail et al., 2014; Bannon et al., 1992; Holdsworth & Whitmore, 1974; Ojinnaka, 2002; Pala & Vankar, 1997), other informants (such as school nurses, doctors and/or researchers) (Bannon et al., 1992; Holdsworth & Whitmore, 1974; Prpic et al., 2003), and/or as a result of school requirements for parents to disclose medical conditions at time of registration of the child (Roberts & Whiting, 2011). Finally, some teachers were still unaware of the child's epilepsy at the time of the studies (Hanai, 1996; Holdsworth & Whitmore, 1974; Kwong et al., 2000; Mu, 2008; Saburi, 2011). Two studies identified that a higher percentage of parents with a child in a special school or class than with a child in a mainstream school were likely to disclose their child's epilepsy diagnosis to the school (Hanai, 1996; Kwong et al., 2000). Parental attitudes towards disclosure to schools were assessed in three studies (Butau & Piachaud, 1993; Coulter & Koester, 1985; Roberts & Whiting, 2011). In one study, telling the child's teacher about the epilepsy was identified as a parental source of concern (Coulter & Koester, 1985), whilst in another study parents tended to report low agreement with the statement that 'parents should

talk to the child's school teacher about the child's epilepsy (Butau & Piachaud, 1993). In the third study, some parents expressed their frustrations over the disclosure process within a school context as the multitude of forms to be filled out represented an arduous task (Roberts & Whiting, 2011). However, in this same study, all parents deemed it desirable to have all members of staff in the school aware of the child's epilepsy rather than just the child's class teacher. For one family, despite disclosing the child's diagnosis to the school at registration, the child's teacher did not become aware of the epilepsy until the mother informed the teacher personally (Roberts & Whiting, 2011).

In relation to any other disclosure targets of parents of CWE (i.e. who parents target to disclose the child's epilepsy diagnosis to), evidence emerged that at least some parents disclosed to extended family (Saburi, 2011), friends (Ryu et al., 2015; Saburi, 2011), other families (Roberts & Whiting, 2011), neighbours (Saburi, 2011), and/or the child's peers (Mu, 2008).

Three studies referred to the information content of disclosure exchanges between parents of CWE and other parties (Holdsworth & Whitmore, 1974; Mu, 2008; Roberts & Whiting, 2011). One highlighted that parents discussed seizure first aid protocols with teachers (and at times unknowingly provided them with misinformation about how to correctly handle the child's seizures) (Holdsworth & Whitmore, 1974); one referred to how parents explained the child's medication routine and seizure first aid to other families if the CWE was going to be visiting with them (Roberts & Whiting, 2011); and the other referenced the fact that the word 'epilepsy' and/or the folk culture term used to refer to epilepsy in Taiwan, 'yan-dan-fun', were rarely employed by parents during disclosure exchanges (Mu, 2008).

Finally, in studies where parental perceptions of epilepsy disclosure were examined more generally, varied findings emerged. Some considered it a source of concern (Coulter & Koester, 1985), a difficulty (Hoare et al., 2000; Hoare & Russell, 1995; Roberts & Whiting, 2011) and a stressful aspect associated with the child having epilepsy (Hoare et al., 2000). In particular, compared to parents of children with diabetes, parents of CWE more frequently reported finding it difficult to explain the child's illness to others and more frequently reported that explaining the child's condition to others was stressful (Hoare et al., 2000). However, for other parents, positive attitudes towards disclosing the CWE's condition to others were demonstrated, with parents reporting a high level of agreement with a statement that assessed their desire for friends and family to be aware of the child's epilepsy diagnosis (Gazibara et al., 2014).

2.3.6 Barriers/Enablers for Parent Disclosure

The main barriers to parental disclosure of their child's epilepsy condition to others identified were: fear of stigmatisation (Hanai, 1996; Jantzen et al., 2009; Kwong et al., 2000; Mu, 2008; Saburi, 2011), parental fear that the CWE would be treated differently and/or that unnecessary restrictions would be imposed on the child (Baker et al., 2008; Hanai, 1996; Roberts & Whiting,

2011), negative parental attitudes about epilepsy (e.g. perceiving epilepsy as unacceptable, damaging and shameful) and feelings towards epilepsy (e.g. shame, anger, guilt and despair) (Kleck, 1968; Mu, 2008), concern that the child's future would be affected (Hanai, 1996; Mu, 2008) and difficulty in explaining the condition to others (Hoare et al., 2000; Hoare & Russell, 1995). Further barriers to disclosure encountered by parents of CWE that were reported less frequently across the studies included: parental non-acceptance of the child's epilepsy diagnosis (Kleck, 1968); the perception that others would only focus on the child's epilepsy and not on his/her other attributes thereafter (Roberts & Whiting, 2011); the perception that maintaining secrecy around the condition serves to protect the child from physical and emotional harm (Saburi, 2011); parental worry that the child would suffer negative consequences (Mu, 2008); the inability of parents to control others' reactions (Mu, 2008); previous experiences of negative reactions to disclosure - e.g. rejection of the child (Jantzen et al., 2009); stress associated with explaining the condition to others (Hoare et al., 2000); cultural attitudes towards epilepsy (in Taiwan) (Mu, 2008); parental hope that the child would grow out of the condition before disclosure to others becomes necessary (Mu, 2008); the perception that confidentiality is inadequate and concerns regarding violations to privacy (particular to the school context) (Hanai, 1996); and the perception that disclosure is unhelpful (Kwong et al., 2000).

Four of the studies where parental disclosure was examined identified factors that enabled parental disclosure (Hoare et al., 2000; Mu, 2008; Roberts & Whiting, 2011; Saburi, 2011). Key factors that seemed to encourage parents to disclose the CWE's diagnosis to those external to the nuclear family included: 1) the perception that disclosure results in enhancing the child's safety (Mu, 2008; Roberts & Whiting, 2011) and others' understanding of the child (Mu, 2008); 2) previous positive reactions to disclosure - i.e. others conveying an openness to engage with and learn about the condition (Roberts & Whiting, 2011); 3) the perception that explaining the condition to others is not difficult and/or stressful (Hoare et al., 2000); 4) the perception that disclosure is necessary in order to assist the child's successful entry into society (Mu, 2008); 5) the perception that disclosure helps to reduce anxiety and stigma (Roberts & Whiting, 2011); 6) the perception that disclosure prepares others in the event of a seizure occurring in their presence (Saburi, 2011); and 7) the perception that disclosure can serve to prevent others from saying hurtful things (Saburi, 2011).

2.3.7 Consequences of the Disclosure Management Strategies Adopted by Parents of CWE

Four studies discussed the actual and/or potential consequences of parental disclosure behaviours (Kleck, 1968; Mu, 2008; Roberts & Whiting, 2011; Ryu et al., 2015). In one study, adult participants retrospectively reflected on how their parents' attitudes towards disclosure during childhood had influenced their own attitudes towards disclosure (Kleck, 1968). For instance, some participants reported feeling pressured as a result of their parents' concealment

strategies to not discuss their epilepsy with others, with parental tendencies towards concealment conveying that epilepsy was something shameful (Kleck, 1968). In another study, one parent acknowledged that due to his/her adoption of concealment strategies, if his/her child were to have a seizure within the school environment, the teachers would be ill-prepared (Mu, 2008). In a third study, maternal concealment behaviours were found to significantly predict greater stigma perceptions amongst adolescents with epilepsy (Ryu et al., 2015). Finally, in the fourth study, teachers' positive responses to disclosure resulted in parental relief for some families, whilst for other families disclosure resulted in: 1) teachers feeling anxious and becoming overprotective; and/or 2) other families reacting in a fearful manner due to the possibility of the child having a seizure in their care (Roberts & Whiting, 2011).

2.3.8 Relationship between Parental Disclosure Management and Demographic, Clinical and Psychosocial Factors

In one study, the relationship between parental disclosure management and other demographic, clinical and psychosocial variables was quantitatively explored (Ryu et al., 2015). In this study, maternal concealment behaviours were significantly correlated with the mother's age (r=0.132, p=.044) and stigma perceptions (r=0.335, p<0.001), but not with maternal level of education, the type of school the child was attending or the child's gender (Ryu et al., 2015).

2.3.9 CWE Disclosure Behaviours

In 13 of the 15 studies that examined the disclosure behaviours of CWE via self- and/or proxy-reports, epilepsy concealment was deemed desirable (Moffat et al., 2009) or adopted by at least one child participant at some time (Austin et al., 2004; Baker et al., 2008; Chen et al., 2010; Holdsworth & Whitmore, 1974; Houston et al., 2000; Jantzen et al., 2009; Lewis et al., 1990; McEwan et al., 2004; Mu, 2008; Ojinnaka, 2002; Ronen et al., 1999; Zamani et al. 2014). In two studies, the behaviours engaged in by some children in order to maintain secrecy around their epilepsy were reported - i.e. taking medication in the toilet to avoid discovery (Holdsworth & Whitmore, 1974; McEwan et al., 2004). Other disclosure management strategies adopted by CWE included: voluntary disclosure (Hightower et al., 2002; Ojinnaka, 2002); and selective disclosure in terms of disclosure targets (who the CWE told), and content (what aspects the CWE disclosed) (Chen et al., 2010; Lewis et al., 1990; McEwan et al., 2004). Finally, disclosure also occurred for some CWE as a result of unplanned revelations (i.e. others witnessing seizures or medication-taking) (Holdsworth & Whitmore, 1974; Ojinnaka, 1974) and/or due to someone other than the CWE (i.e. the CWE's parents, teachers, school nurse or paediatric epilepsy nurse) informing others about the CWE's epilepsy (Hightower et al., 2002; Mu, 2008).

One study highlighted information content that CWE were reluctant to disclose - i.e. information about hospital appointments (Moffat et al., 2009). A number of studies also reported findings in relation to disclosure targets of CWE (i.e. who the child targeted to disclose

his/her epilepsy diagnosis to). In one study, two CWE had not disclosed their epilepsy to any of their peers (McEwan et al., 2004). In four studies, CWE had disclosed their diagnosis to some of their close and/or other friends (Houston et al., 2000; Lewis et al., 1990; McEwan et al., 2004; Moffat et al., 2009). In three studies, evidence of selective disclosure in terms of the disclosure target was provided, with at least some participants only having told one or two friends (Lewis et al., 1990; McEwan et al., 2004) or reporting that they specifically would not want to tell their good friends about the epilepsy (Chen et al., 2010).

One study reported statistical findings regarding how frequently CWE talked to others about their epilepsy, revealing that a large proportion (65.8%) of CWE never talked to their friends or teachers about their condition (Zamani et al., 2014).

Children's attitudes towards epilepsy disclosure varied, with some reporting an unwillingness or reluctance to disclose their epilepsy to others (Lewis et al., 1990; Moffat et al., 2009), and others fearing discovery via peers witnessing seizures (Chen et al., 2010; Jantzen et al., 2009). The decision to disclose was seen as a particularly complex and significant factor in the lives of adolescents (McEwan et al., 2004). In comparison to the disclosure behaviours of children living with other chronic illnesses (e.g. diabetes and asthma), CWE were significantly less likely to disclose their condition to others including peers and teachers (Houston et al., 2000).

2.3.10 Barriers/Enablers for CWE Disclosure

Barriers to epilepsy disclosure for CWE were identified in 11 studies (Baker et al., 2008; Chen et al., 2010; Hightower et al., 2002; Hodgman et al., 1979; Houston et al., 2000; Jantzen et al., 2009; Lewis et al., 1990; McEwan et al., 2004; Moffat et al., 2009; Mu, 2008; Ronen et al., 1999). The main barriers to disclosure for CWE included: CWE fearing that disclosure would result in peer rejection, social exclusion, and/or teasing/bullying (Chen et al., 2010; Houston et al., 2000; Jantzen et al., 2009; Lewis et al., 1990; McEwan et al., 2004; Ronen et al., 1999); previous experiences of being bullied, teased or laughed at due to epilepsy (Houston et al., 2000; Moffat et al., 2009; Chen et al., 2010); negative perceptions of epilepsy by others - anticipated and experienced negative perceptions (Houston et al., 2000; McEwan et al., 2004; Moffat et al., 2009); experience of previous negative reactions by others to seizures (Hightower et al., 2002; Lewis et al., 1990; Moffat et al., 2009); negative reactions from others in the past to disclosure such as fear of infection, doubt, shock, worry, overprotectiveness, rejection, and alarm (Chen et al., 2010; Lewis et al., 1990; McEwan et al., 2004); the fear of how others would react (Houston et al. 2000; Jantzen et al., 2009; Ronen et al., 1999); fear of being treated differently - particularly by classmates (Baker et al., 2008; Houston et al., 2000); and fear and/or experience of others broadcasting the condition against their will (McEwan et al., 2004; Moffat et al., 2009). Further barriers to CWE's epilepsy disclosure that were reported less frequently across the studies included: the perception that disclosure would result in peers being

scared (Chen et al., 2010); peer responses (e.g. others asking specific questions about AEDs or seizures) (Moffat et al., 2009); epilepsy being a condition associated with the brain (McEwan et al., 2004); CWE experiencing difficulty in explaining epilepsy to others (Jantzen et al., 2009); CWE's belief that others should not know (Baker et al., 2008); lack of public knowledge about epilepsy (McEwan et al., 2004); feelings of embarrassment (Lewis et al., 1990); better seizure control and thus a perceived lack of need to explain the epilepsy to others (Hodgman et al., 1979); parental desire for secrecy around the child's epilepsy and/or the invisibility of epilepsy at home due to lack of epilepsy-related discussion within the context of the family home (Mu, 2008); and negative portrayals of epilepsy in the media (Houston et al., 2000).

Factors that were posited as enabling CWE's epilepsy disclosure were reported in four studies (Houston et al., 2000; Jantzen et al., 2009; McEwan et al., 2004; Moffat et al., 2009). The enabling factors for disclosure amongst CWE that emerged on review of these studies were: the receipt of help and support from others as a result of disclosure in the past (McEwan et al., 2004; Moffat et al., 2009); positive past reactions from others - i.e. people being understanding, supportive, and taking an interest in learning more about the epilepsy (McEwan et al., 2004); enhanced feelings of safety as a consequence (Moffat et al., 2009); knowing others with epilepsy (Houston et al., 2000); and participation in a psycho-educational programme resulting in improvements in the CWE's ability to explain the condition to others (Jantzen et al., 2009).

2.3.11 Consequences of the Disclosure Management Strategies Adopted by CWE

Two studies discussed the consequences of the adoption of specific disclosure management strategies by CWE (Hightower et al., 2002; Holdsworth & Whitmore, 1974). Voluntary disclosure resulted in greater feelings of acceptance, peers advocating on their behalf, and fewer people bullying or teasing the CWE (Hightower et al., 2002). For one child, epilepsy concealment resulted in embarrassment and misunderstandings (Holdsworth & Whitmore, 1974).

2.3.12 Relationship between CWE's Disclosure Management and Demographic, Clinical and Psychosocial Factors

The relationship between CWE's disclosure management and other demographic, clinical and psychosocial variables was explored quantitatively in two studies (Hodgman et al., 1979; Lewis et al., 1990) and qualitatively in two studies (Houston et al., 2000; McEwan et al., 2004). Across the quantitative studies, participation in a psychoeducational program did not seem to significantly impact on CWE's disclosure to friends and others (Lewis et al., 1990), but better seizure control was identified as being significantly correlated with adolescents communicating less openly with friends about their epilepsy (r=-0.50) (Hodgman et al., 1979). In the qualitative studies, disclosure was associated with knowing someone with epilepsy for some but not all

CWE (Houston et al., 2000), and contingent upon factors such as seizure frequency, time spent with friends, and safety (McEwan et al., 2004).

2.4 Discussion of the Systematic Review Findings

This systematic review is the first to examine and synthesise evidence pertaining to the disclosure behaviours of CWE and their parents. Only one of the 32 studies identified had disclosure of epilepsy as the primary research aim; a study that is almost 50 years old (Kleck, 1968). This suggests that disclosure has not been prioritised in recent epilepsy research. However, although limited, evidence to date suggests that disclosure is a significant issue and poses a substantial challenge to both CWE and their parents, with CWE and/or parent populations identifying disclosure as: (i) a factor that impacts on their lives (Baker et al., 2008; Chen et al., 2010; Houston et al., 2000); (ii) a QOL issue (Hoare & Russell, 1985; Hoare et al., 2000; Jantzen et al., 2009; McEwan et al., 2004; Moffat et al., 2009; Ronen et al., 1999; Zamani et al., 2014), and (iii) a source of concern (Coulter & Koester, 1985; Roberts & Whiting, 2011; Saburi, 2011). Disclosure decisions are evidently difficult amongst these populations, with many contextual factors emerging as influencing the process either positively (i.e. enablers) or negatively (i.e. barriers). Outcomes pertaining to the adoption of specific disclosure management strategies denoted largely negative consequences related to epilepsy concealment and largely positive consequences following disclosure of the diagnosis to others. While it may be anecdotally assumed that openness and honesty in disclosing one's epilepsy condition to others might result in positive outcomes, limited empirical evidence exists to support such propositions. Therefore, at this time, there is insufficient evidence to make a definitive conclusion regarding which disclosure management strategies are optimal.

2.4.1 Disclosure Behaviours and their Situational Context

Overall, the evidence identified that the disclosure strategies of CWE and their parents are highly variable, with some families reporting openly discussing the child's diagnosis with others and other families expressing discomfort with disclosing the condition to those external to the nuclear family, and actively working to maintain secrecy around the condition.

In 25 of the 32 papers reviewed, self- and/or proxy-reports indicated that at least some CWE and/or their parents engaged in concealment or selective disclosure management strategies (Abulhamail et al., 2014; Austin et al., 2004; Baker et al., 2008; Bannon et al., 1992; Chen et al., 2010; Hanai, 1996; Hodgman et al., 1979; Holdsworth & Whitmore, 1974; Houston et al., 2000; Jantzen et al., 2009; Kleck, 1968; Kwong et al., 2000; Lewis et al., 1990; McEwan et al., 2004; Mecarelli et al., 2011; Mecarelli et al., 2014; Moffat et al., 2009; Mu, 2008; Ojinnaka, 2002; Pala & Vankar, 1997; Prpic et al., 2003; Ronen et al., 1999; Ryu et al., 2015; Saburi; 2011; Zamani et al., 2014). This finding suggests that diagnosis disclosure can be problematic

for CWE and parent populations. Concealment and selective disclosure management strategies not only can place CWE at risk of physical harm as a result of the lack of awareness of others about their propensity towards seizures, but also such silence can reinforce misconceptions about epilepsy and exacerbate epilepsy-related stigma. As Lewis and Parsons (2008) contend, there is a cycle of invisibility surrounding epilepsy, with stigma surrounding the condition perpetuated not only by lack of public knowledge, but also by a limited willingness by those living with epilepsy to be open and honest about it with others. In contrast to those CWE and parents of CWE who adopted concealment disclosure strategies, voluntary disclosure of the child's epilepsy diagnosis to others was also reported (Bannon et al., 1992; Hanai et al., 1996; Hightower et al., 2002; Holdsworth & Whitmore, 1974; Kwong et al., 2000; Mecarelli et al., 2011; Mecarelli et al., 2014; Mu, 2008; Ojinnaka, 2002; Pala & Vankar, 1997; Roberts & Whiting, 2011; Saburi; 2011), indicating that not all CWE and their parents feel the need to maintain secrecy around the condition.

The dichotomy between parents and CWE who prefer to keep the child's epilepsy hidden and parents and CWE who openly disclose the diagnosis to others raises the question of the situational context surrounding disclosure decisions amongst CWE and parent populations. Both barriers and enablers to disclosure were evidenced in this review. Largely, these findings emerged as incidental findings in qualitative studies. In particular, many factors emerged as posing challenges for CWE and their parents when disclosing the child's epilepsy to others (such as fear of stigmatisation, exclusion, rejection and being treated differently), indicating that disclosure to those external to the nuclear family is problematic. Further research is required to elucidate whether this is in fact the case. Relatively, fewer enabling factors to disclosure were reported suggesting that this is an area that warrants further investigation. There is a need to explore avenues with respect to how best to assist families and enable disclosure; it may be that families do not know how to navigate the disclosure process and they may require input from healthcare professionals (HCPs).

Whilst a number of enabling factors and barriers were evidenced in the 32 papers reviewed that may account for some of the variance in the disclosure management strategies adopted by CWE and/or their parents, existing research fails to provide a comprehensive theoretical framework or model that explains the situational differences between families living with epilepsy who do disclose the child's epilepsy to others versus families who conceal or selectively disclose the child's epilepsy. Future studies should focus on quantitatively examining the contextual factors that inform CWE and parents' decisions to disclose (or not) a child's epilepsy to others. The identification of the variables that are most likely to influence disclosure decisions could prove beneficial in providing insight so that interventions can be tailored to assist CWE and their parents to navigate the epilepsy disclosure process.

All but two (Lewis et al., 1990; Jantzen et al., 2009) of the studies identified for the purposes of this review were cross-sectional in nature and therefore, did not involve the collection of data that would facilitate the identification of factors associated with changes in the disclosure behaviours of CWE and their parents over time. Studies employing a longitudinal design could be beneficial in terms of clarifying whether the disclosure behaviours of CWE and their parents remain static over time or whether there is a continuum along which the disclosure management strategies adopted by CWE and their parents progress, with disclosure behaviours evolving as they adjust to the diagnosis.

2.4.2 The Consequences of Specific Disclosure Management Strategies

Consequences pertaining to various disclosure management strategies were only referred to in six studies (Holdsworth & Whitmore, 1974; Hightower et al., 2002; Kleck, 1968; Roberts & Whiting, 2011; Mu, 2008; Ryu et al., 2015) and were largely qualitative, incidental findings (with the exception of the Ryu et al. study, 2015) that emerged from cross-sectional studies with small sample sizes (N=85 [Holdsworth & Whitmore, 1974]; N=8 [Hightower et al., 2002], ; N=50 [Kleck, 1968]; N=18 [Mu, 2008]; N=7 [Roberts & Whiting, 2011]). Thus, at this time, no cause/effect relationships can be determined as the findings are not transferable and warrant further investigation. The existing evidence is lacking with regard to its ability to definitively state whether it is appropriate to promote disclosure amongst CWE and parent populations, as a closed approach and the adoption of concealment disclosure management strategies may in fact be optimal and serve as protective. Therefore, there is a need for studies to engage in systematic explorations of the consequences of specific disclosure management strategies on the psychosocial wellbeing of CWE and their parents.

2.4.3 Quantitative Measures of Disclosure

On review of the evidence, there appears to be no uniform, standardised, and psychometrically robust way to measure disclosure. The evidence from this review supports the need for the development of rigorous and psychometrically sound measures to specifically capture the complexity of disclosure experiences of CWE and their parents. Such measures could prove extremely beneficial in terms of systematically elucidating (a) a profile of the disclosure behaviours engaged in by CWE and their parents, (b) the contextual factors surrounding disclosure decisions, and (c) the consequences of adopting specific disclosure management strategies on the psychosocial and physical wellbeing of families living with epilepsy.

2.4.4 Contextualising the Evidence

Contextualising the evidence yielded in this review is important. One of the studies dates back to the 1960s (Kleck, 1968), two to the 1970s (Hodgman et al., 1979; Holdsworth & Whitmore, 1974), one to the 1980s (Coulter & Koester, 1985), and seven to the 1990s (Bannon et al., 1992; Butau & Piachaud, 1993; Hanai, 1996; Hoare & Russell, 1995; Lewis et al., 1990; Pala &

Vankar, 1997; Ronen et al., 1999). In some of these studies, concealment strategies were adopted by CWE (Holdsworth & Whitmore, 1974; Hodgman et al., 1979; Lewis et al., 1990; Ronen et al., 1999) and parents of CWE (Bannon et al., 1992; Butau & Piachaud, 1993; Hanai, 1996; Holdsworth & Whitmore, 1974; Kleck, 1968; Pala & Vankar, 1997). Caution must be exercised in interpreting the evidence from these studies. For example, the employment of concealment strategies to the extreme that is outlined in the Kleck study (1968) (i.e. physically hiding the child from others) is likely reflective of how epilepsy was perceived during this period rather than being representative of the practices of parents of CWE in modern-day society. To provide perspective, in the U.K., marriage was only legalised for those with epilepsy in 1970, while in Sweden PWE were the victims of eugenic sterilisation programs up until 1975 (Valeta & De Boer, 2010). Whilst it is unlikely that such extreme concealment behaviours are enforced by parents of CWE today, based on regional and global campaigns that aim to bring epilepsy 'Out of the Shadows' (De Boer, 2002; Jallon, 1997; Meinardi, Scott, Reis, Sander & ILAE Commission on the Developing World, 2001; Reynolds, 2000; WHO, 1997; WHO, 2000), one could surmise that remnants of epilepsy-related stigma persist. This coupled with the evidence highlighting that many CWE and parents reported barriers to disclosure that involved either fearing or having experienced epilepsy-related stigma in some form (felt and/or enacted stigma), suggests that some of these issues may still be salient.

Cognisance should also be taken of the fact that the included studies were extremely heterogeneous in terms of the cultural context in which they were undertaken. Despite the fact that epilepsy-related stigma is a global problem (De Boer et al., 2008), some contend that enacted-stigma, in particular, is a more salient issue in Eastern cultures than in Western cultures and in the developing countries than in the developed countries (Baker, 2002; Jacoby et al., 2005). Therefore, the evidence presented pertaining to the disclosure behaviours of CWE and parents from some studies included in this review may reflect culturally-specific findings.

2.4.5 Strengths and Limitations of the Review

Recommended practice for the conduct and reporting of systematic reviews was followed, but nonetheless there are a number of limitations inherent in this review. First, although multiple databases were searched and a deliberately inclusive search strategy was employed, the possibility cannot be entirely excluded that relevant papers might have been missed. Second, the exclusion of non-English language studies may have resulted in publication bias. Third, because of the limited number of quantitative studies and the heterogeneity in the measures employed in such studies to capture the disclosure behaviours of CWE and their parents, it was not feasible to formally pool results across studies and perform meta-analyses/meta-syntheses. Finally, only one study included in the review had disclosure as the primary research aim. Consequently, caution must be exercised in terms of how much weight can be placed on the findings presented in this review, particularly for studies where findings emerged incidentally.

Despite a number of limitations, this review provides the first synthesis of evidence pertaining to the important topic of epilepsy disclosure amongst a CWE and parent of CWE population. Self-stigmatisation and diagnosis concealment amongst PWE are fundamental issues that need to be tackled in order to break down barriers and make epilepsy more recognisable and acceptable to the general population. As it stands, the high proportion of CWE and/or their parents adopting epilepsy concealment strategies only serves to perpetuate the *cycle of invisibility* encircling the condition, reinforcing epilepsy-related stigma. Gaining a clear understanding from the perspective of CWE and their parents of the situational context that informs their disclosure process is critical. It will facilitate the development of interventions to promote disclosure amongst epilepsy populations, and there are no better advocates than PWE themselves to promote positive perceptions and dispel myths and misconceptions about epilepsy.

2.5 Conclusions of the Systematic Review

The decision to disclose an epilepsy diagnosis is evidently complex and multi-faceted for CWE and their parents; and contingent upon numerous factors. The evidence from this systematic review highlights that while some preliminary work has been conducted in a limited number of studies to explore disclosure in CWE and their parents, epilepsy disclosure is a topic that has been largely neglected in research conducted with these populations. This is despite the fact that the limited evidence available suggests that disclosure can be a challenge and a source of stress for families living with epilepsy. There is a need for more rigorous research to systematically identify: (a) patterns of disclosure among CWE and their parents; (b) reasons for CWE's and parents' employment of specific disclosure management strategies; and (c) the consequences of the adoption of specific disclosure management strategies for CWE and their parents.

The present study will thus endeavour to address such gaps in epilepsy literature by comprehensively exploring the disclosure behaviours of CWE and their parents, employing a sequential exploratory mixed methods design that will comprise a qualitative component (involving semi-structured interviews with CWE and their parents) and a quantitative component (involving surveys of CWE and parents of CWE). In undertaking such an exploration and addressing the aforementioned research questions, it is anticipated that key insights will be gained into: (i) the complex epilepsy disclosure process engaged in by CWE and their parents; and (ii) the influential factors involved in CWE's and parents' epilepsy disclosure decisions. Furthermore, it is anticipated that the personal, dyadic and interpersonal implications of CWE and parents adopting specific disclosure management strategies surrounding a child's epilepsy condition will be elucidated, and that associations between CWE's and parents'

epilepsy disclosure behaviours and their psychosocial wellbeing and illness attitudes will be determined for the first time.

Chapter 3: Methodology

3.0 Introduction

This chapter outlines the methodology of the present study. The study aims and the research questions will be outlined. Subsequently, mixed methods research and the philosophical paradigm underpinning the design of the study will be discussed. Additionally, the diverse strengths and challenges associated with employing mixed methods research designs will be considered. Finally, the specific design to be utilised in the present study will be highlighted, and the rationale underpinning the selection of this study design will be discussed.

3.1 Study Aims

The purpose of this study is twofold:

(a) to explore the disclosure behaviours and experiences of CWE and their parents, as well as the situational context of CWE's and parents' disclosure exchanges with others external to the nuclear family, from both child and parent perspectives (phase 1); and

(b) to quantitatively assess CWE's and parents' epilepsy disclosure behaviours and experiences; and to investigate the relationships between CWE's and parents' epilepsy disclosure behaviours and demographic and clinical characteristics, and psychosocial and illness attitude attitudes variables (phase 2).

3.2 Research Questions

Specific research questions that are to be addressed include:

- What disclosure behaviours do CWE and parents of CWE engage in surrounding a child's epilepsy?
- To whom and how do CWE and their parents disclose the child's epilepsy?
- Are there perceived personal characteristics of disclosure targets that influence CWE's and parents' disclosure to such individuals?
- What aspects of the child's epilepsy do CWE and their parents disclose and/or discuss during their disclosure exchanges with others?
- In which situational contexts do CWE and parents of CWE disclose the child's epilepsy to others external to the nuclear family?
- What informs CWE's and parents' decisions to disclose or not the child's epilepsy to others?

- What are the factors that facilitate and/or hinder CWE's and parents' disclosure of the child's epilepsy to others?
- What are the consequences of disclosing the child's epilepsy to others for CWE and parents of CWE and how does this make them feel?
- What is the relationship between CWE's epilepsy disclosure behaviours and their self-reported demographic and clinical characteristics?
- What is the relationship between parents' disclosure behaviours surrounding a child's epilepsy and parent-reported demographic characteristics and parent-reported demographic and clinical characteristics of the child?
- What is the relationship between CWE's epilepsy disclosure behaviours and their perceived stigmatisation, illness attitudes, self-perception, health-related quality of life (HRQoL), social support, level of epilepsy-related communication with their parents, need for epilepsy-related information and support, and satisfaction with level of epilepsy-related information received during their engagements with HCPs?
- What is the relationship between parents' disclosure behaviours surrounding their child's epilepsy and their stigma perceptions, responses to their child's illness, general tendency to disclose distress to others, perceived social support, level of epilepsy-related communication with the child, perceptions regarding the level of disability and activity restrictions experienced by their child due to epilepsy, perceptions regarding the impact of the epilepsy on the child and the family, need for epilepsy-related information and support, and satisfaction with level of epilepsy-related information received during their interactions with HCPs?
- What is the relationship between CWE's epilepsy disclosure behaviours and parents' epilepsy disclosure behaviours?
- What is the relationship between CWE's epilepsy disclosure behaviours and parent-reported psychosocial and illness attitude variables?
- What is the relationship between parents' epilepsy disclosure behaviours and child-reported psychosocial and illness attitude variables?

3.3 Mixed Methods Research

In the present study, a mixed methods research design is implemented in order to address the research aims and the specific research questions posited. Varying definitions of mixed methods research have been proffered (O'Cathain and Thomas, 2006). However, according to Creswell & Plano Clark (2007), mixed methods research can be defined as a research design (or methodology) that: "focuses on collecting, analysing and mixing both quantitative and qualitative data in a single study or series of studies." (p. 5)

Qualitative research involves the collection of open-ended information that is typically analysed by aggregating words or images that display some elements of commonality into categories or themes. In contrast, quantitative research involves the collection of closed-ended information that can be statistically analysed to test hypotheses or to answer research questions (Creswell & Plano Clark, 2007).

Proponents of mixed methods research advocate for the combination of both qualitative and quantitative approaches (i.e. the collection, analysis and integration of qualitative and quantitative data), proposing that such a design facilitates the research problem being more comprehensively addressed than either approach could offer alone.

3.3.1 Pragmatism

Pragmatic epistemology is the philosophical perspective that informs and underpins the mixed methods approach that is employed in the present study. Counter to the incompatibility thesis i.e. the assertion that combining qualitative and quantitative methods is epistemologically problematic (Howe, 1988), under the philosophical paradigm of pragmatism, it is argued that qualitative and quantitative research designs can be mixed (Robson, 2002). Pragmatists maintain that primary importance should be placed on the research question(s) rather than on the method or the paradigm underlying the method (Creswell & Plano Clark, 2007). In fact, pragmatism is not bound to any particular system of philosophy or reality (Cherryholmes, 1992; Murphy & Rorty, 1990). Instead, the basic tenet underpinning the pragmatic philosophy is that the techniques, methods and procedures that best address the needs of the researcher in attending to the research objectives are those that are most appropriate to employ (Robson, 2002). Thus, multiple methods of data collection can be utilised if such an approach is deemed likely to best answer the research question (Robson, 2002).

Tashakkori & Teddlie (2003) highlight that pragmatism has been embraced by many researchers; many view it as the paradigm that offers the best foundation for mixed methods research as it facilitates the simultaneous use of qualitative and quantitative methods (Howe, 1988). Thus, pragmatists are proponents of mixed methods research and advocate for: 1) the combination of methodological approaches; 2) the utilisation of the most practical data collection approach that is available to address the research question(s); and 3) the integration of findings from the multiple data collection approaches adopted (Creswell and Plano Clark, 2007). Johnson & Onwuegebuzie (2004) argue that according to the pragmatic perspective, mixed methods research should involve mixing research approaches in ways that enable the best opportunities to integrate the insights yielded from both qualitative and quantitative research into a workable solution.

A pragmatic approach to research aims to address the anomalies inherent in paradigms suited only to quantitative or qualitative approaches. In terms of the usefulness of a pragmatic

approach in connecting theory and data, pragmatists argue for abductive reasoning which involves alternating back and forth between using inductive (data-driven) reasoning and deductive (theory-driven) reasoning inherent in qualitative and quantitative approaches to research respectively. Morgan (2007) postulates that such an approach facilitates researchers in first translating observations into theories and then examining those theories through action. In the present study, the researcher engages in such an abductive process, with the inductive results from the qualitative phase informing the deductive objectives of the quantitative phase.

3.3.2 The Advantages and Disadvantages of Mixed Methods Research

There a number of advantages to using mixed methods research. Adopting a mixed methods approach allows the researcher to capitalise on the strengths and offset the weaknesses of both quantitative and qualitative research (Creswell & Plano Clark 2007; Doyle, Brady & Byrne, 2009; Johnson & Onwuegbuzie, 2004). Quantitative research is frequently criticised for not taking into account the subjective voice of the participants (Creswell & Plano Clark, 2007; Cherryholmes, 1992). Many would also argue that quantitative research fails to convey information regarding the contextual factors surrounding people's opinions (Doyle et al., 2009; Johnson & Unwuegbuzie, 2004). In contrast, qualitative research comes under criticism due to the fact that analysis of the data is subject to interpretation by the researcher and thus is open to bias (Doyle et al., 2009; Johnson & Onwuegbuzie, 2004). Additionally, due to its time-consuming nature, qualitative research generally involves the utilisation of small sample sizes. This limits the generalisability of findings (Johnson & Onwuegbuzie, 2004). Proponents of mixed methods research suggest that such weaknesses inherent in using either of the approaches alone can be compensated for by using both approaches in combination (Creswell & Plano Clark, 2007; Doyle et al., 2009; Johnson & Unwuegbuzie, 2004). Furthermore, addressing a research question via two methodological approaches can offer a more complete answer than could addressing the research question using one approach alone by ensuring that a more holistic representation of experiences or associations is attained (Barbour, 1999; Doyle et al., 2009; Farquhar, Ewing & Booth, 2011; Tashakkorri & Teddlie, 2003).

Other advantages of mixed methods research include the following: it can facilitate the researcher in addressing research questions that cannot be answered by qualitative or quantitative approaches alone (Creswell & Plano Clark., 2007); it encourages multi-disciplinary collaboration (O'Cathain, Murphy & Nicholl, 2008); it is ideal in exploring topics where there is a dearth of empirical evidence (O'Cathain & Thomas, 2006); and it is a practical approach which facilitates the researcher in using any and all methods necessary to address the research problem under investigation (Johnson & Onwuegbuzie, 2004). Furthermore, evidence can be strengthened through convergence and corroboration of findings across the various phases of the study, enhancing the generalisability and transferability of the findings (Johnson & Onwuegbuzie, 2004).

The challenges of using mixed methods research are that it is a time-consuming and resource intensive process. This is particularly salient when the mixed methods research design involves the conduct of sequential studies with distinct phases (Ivankova, Creswell & Stick, 2006). Additionally, mixed methods research is a complex process and requires the researcher to be familiar with both qualitative and quantitative data collection whereas generally most investigators are only trained in one form of inquiry (Doyle et al., 2009). Finally, conflicting findings across methods can be difficult to contend with and many researchers fail to consider the integrative element (Creswell & Plano Clark, 2007). With adequate planning, resources and training, the challenges associated with mixed methods research can be overcome.

3.4 Present Study Design

This study will implement a mixed methods sequential exploratory design consisting of two distinct phases: a qualitative phase (Phase 1) followed by a quantitative phase (Phase 2). The qualitative phase involves the researcher conducting semi-structured interviews with CWE and their parents. The interviews will be audiotaped, transcribed verbatim, and thematically analysed. Phase two comprises a cross sectional survey of CWE and their parents; the development of which will be informed by the findings of the qualitative phase. Quantitative data will be statistically analysed, whereby descriptive statistics, correlations and group comparisons will be performed. The two phases of this mixed methods study are first reported separately. Subsequently, the findings are considered integratively.

3.4.1 Rationale for Using a Sequential Exploratory Design

Several factors informed the decision to employ a sequential exploratory design in the present study inclusive of consideration of: 1) various types of mixed method designs; 2) the timing of phases; 3) the weighting of phases; 4) the data integration approach; and 5) advantages and disadvantages of a sequential exploratory design. Each factor is discussed below.

3.4.1.1 Type of Design

According to Creswell & Plano Clark (2007), there are four major types of mixed methods research designs, with decisions regarding which type of design to utilise contingent on the purpose of the mixed methods research. First, a mixed methods approach can facilitate complementarity via a triangulation design, whereby different but supplementary data on the same topic is collected and analysed. Second, the embedded design is a mixed methods design that involves each component of the project addressing different aspects of the research question under investigation. Third, mixed methods research can act as explanatory, whereby the intention is to use qualitative methods and data to explain the results from the first quantitative phase of a study. This type of mixed methods research design is appropriate when the quantitative results are insufficient in explaining the outcomes and therefore qualitative

data is required to supplement and explain the quantitative findings. Fourth, mixed methods research can serve as exploratory, whereby qualitative data from the first method can be utilised to assist in developing or informing the second method which is quantitative in nature. In the present study, the mixed methods research will serve as exploratory with the qualitative findings from phase one informing the development of a quantitative measure to capture the epilepsy disclosure behaviours of CWE and their parents, as well as the constructs to be examined in phase two of the study.

3.4.1.2 Timing of Phases

Mixed methods research designs can involve exploring a phenomenon via concurrent phases or sequential phases (i.e. first examining quantitative data and then qualitative data or vice versa). In the present study, the decision was made to first explore CWE's and parents' disclosure behaviours and experiences qualitatively, and subsequently to conduct a quantitative investigation. This decision was primarily based on the dearth of empirical evidence pertaining to the epilepsy disclosure behaviours and experiences of CWE and/or parents of CWE as identified in the systematic review (see chapter 2). The previously limited empirical evidence was insufficient in establishing which aspects of CWE's and parent's epilepsy disclosure behaviours and experiences warranted quantitative investigation. The absence of psychometrically sound, reliable and valid instruments with which the disclosure behaviours of CWE and their parents could be measured further informed this decision (see section 2.3.3). In addition, there was a lack of evidence of guiding theory or frameworks that could be utilised in order to select the quantitative variables to be examined in relation to the epilepsy disclosure behaviours adopted by CWE and their parents. Therefore, the qualitative data from the first phase of this sequential exploratory mixed methods study will serve four purposes:

- it will act as a rich source of qualitative information pertaining to the disclosure behaviours and experiences of CWE and their parents;
- it will enable the identification of the aspects of CWE's and parents' epilepsy disclosure behaviours and experiences to be examined in phase two of the study;
- it will inform the development of instruments that measure the disclosure behaviours of: (i) CWE and (ii) their parents, as no such measures previously exist; and
- it will allow for the identification of constructs that may be related to disclosure and thus warrant further investigation in the second phase of the study.

The utility of conducting a quantitative phase subsequent to the qualitative phase was based upon three factors. First, it will allow the researcher to test the results of the first qualitative phase with regard to aspects of CWE's and parents' epilepsy disclosure behaviours and experiences which will determine the generalisability and salience of specific findings. Second, the quantitative phase will facilitate psychometric testing of newly developed scales

that measure CWE's and parents' epilepsy disclosure behaviours. Third, prior to the conduct of this study there was a scarcity of guiding theory available pertaining to the impact of specific epilepsy disclosure behaviours engaged in by CWE and parents of CWE. Thus, the new scales will not only enable the quantitative assessment of CWE's and parents' epilepsy disclosure behaviours, but also the assessment of the relationships between CWE's and parents' epilepsy disclosure behaviours and demographic, clinical, psychosocial and illness attitude variables. This in turn, will facilitate the development of preliminary theory pertaining to the relationships between CWE's and parents' epilepsy disclosure behaviours and other variables.

3.4.1.3 Weighting of Phases

In considering the weighting of phases, phases can be equally weighted or unequally weighted, with the findings from one phase deemed more important than the findings of another (Creswell & Plano Clark, 2007). In the present study, equal priority is given to the qualitative and quantitative data as it was anticipated that both data sources would address specific (but distinct) research questions and yield rich findings, thus meriting "stand alone" status.

3.4.1.4 Data Integration Approach

Integration is critical in the context of mixed methods research (Johnson, Unwuegbuzie & Turner, 2007). However, as previously mentioned, it is often overlooked (Creswell & Plano Clark, 2007). In the present study, the findings will be integrated in two ways. First, the qualitative findings will be utilised to inform the design of the survey to be implemented in phase two; thus, data across the phases will be connected in this way. Second, subsequent to analysing the data from each phase separately, the data across both phases will be integratively discussed. In doing so, the findings will be triangulated, adopting an approach in accordance with the recommendations of O'Cathain, Murphy & Nicholl (2010) and Farmer, Robinson, Elliott & Eyles (2006). The integrative discussion will involve considering the findings across both phases of the study and elucidating whether specific findings are convergent (i.e. consistent), dissonant (i.e. discrepant) or complementary (i.e. they further elaborate, enhance, illustrate and/or clarify knowledge and/or understanding of the phenomenon under investigation). Silences in findings across study phases (i.e. instances where no data on a specific theme are collected using a specific method) will also be identified and discussed.

3.4.1.5 The Advantages and Disadvantages of a Sequential Exploratory Design

According to Hanson, Creswell, Plano Clark, Petska & Creswell (2005), there are a number of advantages to using a sequential exploratory design. Firstly, the design is useful when developing a new psychometric instrument as the data from the first qualitative phase of the study can be utilised to inform the design of the measure to be employed and psychometrically evaluated in the second quantitative phase of the study. Second, the design facilitates theory

development in the absence of pre-existing theories or conceptualisations of the topic under investigation. Both aforementioned advantages were particularly salient in considering the appropriate research design for the present study. However, there are also a number of disadvantages related to employing a sequential exploratory design. For instance, such an approach to research is extremely time-consuming as a consequence of the sequential nature of the phases and the time required for integration (Creswell & Plano Clark, 2007). A second disadvantage relates to the issue of obtaining ethical approval (Creswell & Plano Clark). As the procedure and research questions to be addressed in the quantitative phase of such studies are largely contingent upon the findings from the qualitative phase, researchers adopting such a design will often have to apply for ethical approval for each phase separately. This only adds to the time consuming nature of using a sequential exploratory research design. Therefore, in order to utilise this research design effectively, the researcher is required to ensure to incorporate an adequate amount of time into the research schedule for each phase, the preparation of ethics applications and the integration and discussion of findings (Creswell & Plano Clark, 2007).

3.4.1.6 Summary

Taking into consideration the various types of designs, the timing and weighting of study phases, integration approaches and the advantages and disadvantages of utilising a sequential exploratory design, a sequential exploratory design was deemed the most appropriate research design to adopt for the present study. Collectively, the qualitative and quantitative data from both phases of this study will enable an enriched understanding of the complex phenomenon of disclosure of a CSI (i.e. epilepsy) by CWE and parents of CWE; a topic that previously was underexplored and under-researched in epilepsy literature.

3.5 Conclusions

To conclude, in the present study, in order to address the research aims and to answer the specific research questions posited, a two-phased mixed methods sequential exploratory design, underpinned by the philosophical paradigm of pragmatism, is implemented. Figure 3.1 provides a visual representation of the study design (format based on Aldridge, Fraser & Huang, 1999).

In subsequent chapters, the specific methods employed in the qualitative and quantitative phases of the study are outlined; beginning first with the qualitative method in chapter four.

Figure 3.1: Visual Diagram of the Study Design

Chapter 4: Phase One: Qualitative Method

4.0 Introduction

This chapter outlines the methodological details of the first, qualitative phase of the study, including: 1) study design; 2) aims and specific objectives; 3) participants; 4) study procedure; 5) key ethical considerations; and 6) data analysis.

4.1 Design

In phase one, a qualitative exploratory design was implemented, whereby semi-structured interviews were held to unearth CWE's and parents' (mother, father or both mother and father) perspectives on disclosing the child's epilepsy condition to others external to the nuclear family.

4.2 Aims and Objectives for Phase One

4.2.1 Aim of Phase One

The aim of this first phase was to gather rich qualitative information pertaining to the disclosure behaviours and experiences of CWE and their parents and to explore the situational context surrounding how CWE and their parents adopt specific disclosure management strategies, from both child and parent perspectives.

4.2.2 Objectives for Phase One

The objectives for phase one were to:

- Explore CWE's and parents' disclosure behaviours surrounding epilepsy, from both child and parent perspectives.
- Ascertain to whom and when CWE and their parents disclose (or not) the child's condition to others outside the immediate family unit, from both child and parent perspectives.
- Determine the content of CWE's and parents' disclosure exchanges with others external to the nuclear family, from both child and parent perspectives.
- Identify the factors that challenge and/or enable CWE and their parents when planning or engaging in disclosure exchanges with others external to the nuclear family, from both child and parent perspectives.

In addition, two secondary objectives of the first phase of the study were to:

- Utilise the rich qualitative data to inform the development of:
  (i) two psychometrically sound and reliable quantitative instruments to measure epilepsy disclosure behaviours in: (1) CWE; and (2) their parents.

(ii) survey items to quantitatively assess other important elements of CWE's and parents' epilepsy disclosure (i.e. their disclosure targets, the content and situational context of their disclosure exchanges, and perceived barriers to and enablers of epilepsy disclosure).

- Identify constructs that may be related to CWE's and parents' epilepsy disclosure behaviours and thus warrant further statistical investigation in phase two.

4.3 Participants

The sample for phase one comprised 29 families living with epilepsy. In total, 29 CWE (aged 6-16 years) and 34 parents of CWE were interviewed (see section 5.1.1 in chapter five for more detailed information on the participants' characteristics).

4.3.1 Inclusion and Exclusion Criteria

The inclusion and exclusion criteria specified for recruitment are outlined below.

Inclusion criteria:

- Children aged between 6 and 16 years who had a diagnosis of any type of epilepsy (inclusive of genetic epilepsies, structural/metabolic epilepsies and epilepsies of no known cause) and a prescription for anti-epileptic drugs (AEDs) were eligible to participate.
- Parent participants were required to be the parent(s)/guardian(s) of the recruited children.

The age range (6-16 years) was selected following consultation with clinical personnel and a review of the research evidence. It includes those considered to be most at risk of engaging in more restrictive disclosure behaviours, in particular those at the upper end of the age range i.e. adolescents (Westbrook et al., 1992; Baker et al., 2008). It also considers the age at which CWE start to become aware of potential negativity about epilepsy and its perception by peers i.e. 5 years + (Houston et al., 2000). Furthermore, it responds to the literature in that persons with childhood onset epilepsy have been identified as being placed at a high risk of experiencing poor psychosocial outcomes (Sillanpää, Haataja & Shinnar, 2004; Camfield & Camfield, 2007; Camfield & Camfield, 2008). The limited empirical evidence identified on review of epilepsy literature indicated that disclosure is an issue for CWE of various ages. Whilst one might assume that as CWE move from middle to later childhood, the issue of disclosure might become more salient due to increased independence, a burgeoning desire for autonomy and greater awareness of identity; this might not always be the case. It may equally be an issue for younger aged CWE. Therefore, due to the fact that little was known about CWE's epilepsy disclosure experiences and about the age-groups most at risk of engaging in more restrictive disclosure behaviours, the aim was to recruit CWE across a wide age span during this first phase of the study to build a profile of disclosure issues amongst CWE.

It is important to note that for this first phase of the study, the upper end of the age range (16 years) was selected based on the fact that within an Irish context, in theory children are supposed to transition to adult services aged 16 years. Thus, given that one of the routes via which participants were recruited for this first phase of the study was contingent on CWE attending a paediatric neurology clinic, 16 years was selected as the upper age limit for participants.

Exclusion criteria:

Children presenting with any of the following were ineligible to participate:

- Intellectual disability or developmental delay
- Additional significant medical conditions (other than epilepsy)

These children were excluded in an attempt to eliminate any confounding findings due to the fact that such issues may present their own unique challenges in terms of: 1) communicating with others; and/or 2) disclosing such conditions to others outside the immediate family unit.

4.4 Procedure

4.4.1 Ethical Approval

Prior to commencing recruitment for the first phase, ethical approval was obtained from research ethics committees in Dublin City University (DCU) and Temple Street Children's University Hospital (TSCUH) (see Appendices D.1 and D.2).

4.4.2 Interview Schedule Development

The semi-structured interviews with CWE and parents were directed by interview schedules (see Appendices E.1 and E.2), which were developed following engagement with research literature pertaining to the psychosocial impact of childhood epilepsy on CWE and their parents and disclosure of epilepsy and/or other CSIs. These interview schedules were developed collaboratively with clinical personnel, advocates and researchers with expertise in interviewing children/young people and their parents. All attempts were made to ensure that the interview schedules were not inhibiting or rigid but rather allowed diverse and rich data to emerge to capture the complexity of disclosure. Discussions centred upon issues related to the interpersonal processes and context surrounding the disclosure behaviours engaged in by CWE and their parents, including their perceived barriers to and enablers of epilepsy disclosure.

Additionally, demographic information was collected for each of the participants via structured forms that were administered during parent interviews. Information captured by these forms pertained to the child's age, gender, urban versus rural living, type of epilepsy, length of time since diagnosis, seizure type, severity and frequency, and AEDs (see Appendix F).

Subsequent to the completion of four interviews with CWE and parents, the researcher reflected on the interview schedule and interview process, and engaged in discussions with the research supervisors about any issues that arose during these interviews, following which minor amendments were made.

4.4.3 Recruitment

CWE and their parents were recruited via one of the two following recruitment routes;

Route 1: Purposive recruitment through a Paediatric Neurology Clinic in TSCUH

Potential participants (families) who met the inclusion criteria (see section 4.3.1) were identified and informed about the study by nominated gatekeepers in the Neurology Department of TSCUH during epilepsy clinic hours. If families expressed an interest in the study they were referred to the researcher who provided them with further information (verbally and in writing) about the study and sought their consent to take part.

Route 2: Volunteer recruitment through Epilepsy Ireland (the Irish Epilepsy Association)

CWE and their parents were voluntarily recruited via advertisements displayed on the Epilepsy Ireland (EI) website and in the monthly EI members' print newsletter (see Appendix G). Contact details for the researcher were included so that interested parents and children could contact her directly.

For both routes of recruitment, if parents and children expressed an interest and willingness to be involved, the researcher arranged to meet with the consenting child and parent at a time and location convenient to them. Parents and CWE were sent out written information about the study in the form of plain language statements (see Appendices H.1, H.2 and H.3) prior to the interview. Bearing in mind the varying levels of comprehension and reading ability of the child participants, two information sheets were devised for CWE - one for younger CWE aged 6-10 years (Appendix H.2) and one for older CWE aged 11-16 years (Appendix H.3). This information further informed their decision to participate in the study. Forty-eight hours prior to the interview the researcher telephoned the family as a reminder and to ensure that the child and parents were still satisfied with their decision to participate.

4.4.3.1 Rationale for using two recruitment routes

The rationale for combining volunteer and purposive sampling was an attempt to: 1) capture a diverse group of CWE who were not merely linked to one neurology clinic or service provider (i.e. CWE cared for in rural communities by primary care providers); 2) reduce any bias in sampling that may have arisen if only volunteer recruitment were to be undertaken due to the self-selection of participants who were actively engaging with an epilepsy association; and 3) ensure that a maximum variation sample was obtained to ensure that the situational context

and variations of CWE's and parents' perspectives on disclosure were captured. This facilitated an enriched understanding of the concept of disclosure.

4.4.4 Conducting the Interviews

Semi-structured interviews, guided by interview schedules (as previously discussed), were conducted with CWE and their parents in order to directly explore their experiences of disclosing (or not) the child's epilepsy condition to others external to the nuclear family. According to Longhurst (2003, p. 103), semi-structured interviews involve:

"a verbal interchange where one person, the interviewer, attempts to elicit information from another person by asking questions. Although the interviewer prepares a list of pre-determined questions, semi-structured interviews unfold in a conversational manner offering participants the chance to explore issues they feel are important".

Semi-structured interviews were deemed appropriate for use in the present study because they are particularly useful in circumstances where a complex phenomenon is under investigation (e.g. disclosure of a CSI) or sensitive issues (e.g. stigma experiences) are being explored as they facilitate the researcher in probing for further information and clarifying the answers of participants when unexpected findings emerge (Barriball & While, 1994).

Interviews took place at a location and time convenient for CWE and their parents. Prior to commencing with the interview process, the researcher engaged in general conversation with the CWE and parent participants to develop rapport. Furthermore, CWE and their parents were invited to raise any queries about partaking in the study and the interview process. Interviews only commenced when CWE and their parents were entirely satisfied and comfortable to do so.

During child interviews, the researcher remained cognisant of the varying developmental stages of the CWE participants and thus their varying needs. In considering how to optimise the interview experience for CWE and best serve the child's needs, different rapport-building techniques and interviewing styles were employed by the researcher in accordance with CWE's varying ages and interests.

Across all ages, as the interview context can have a profound impact on children's ability to communicate, during child interviews a rigid question/answer format was avoided. Furthermore, interviews were interspersed with creative methods which primarily functioned as a rapport-building mechanism. This served as a particularly useful tool in capturing the interest and attention of younger-aged children, and putting them at ease about the research process. CWE aged 6-8 years were invited to create a drawing to illustrate their experiences of living with epilepsy and/or of telling others about their epilepsy. As older CWE (9-16 years) may have viewed drawings as childish and worried about artistic ability, they were invited to create a collage to visually illustrate their experiences of living with epilepsy and/or of talking about

their epilepsy with others. Once finished, CWE were asked to write or tell a story about the meaning of their drawing and/or collage. In addition, CWE (of all ages) were invited to tell stories about a number of different situations in which they disclosed and/or did not disclose their epilepsy. This enabled an exploration of the meaning(s) CWE ascribed to each situation encountered, how they felt about the situation/s, what others did that was helpful or unhelpful, and any suggestions they had about what could have been done to improve the situation. The use of creative methods in data collection with children/young people has proven particularly successful in stimulating interactive dialogue between child participants and researchers (Driessnack, 2005; Lambert, Glacken & McCarron, 2013).

Interviews were recorded by a digital recording device (with CWE and parents' consent/assent) for later transcription and analysis. The length of interviews was entirely dependent on the amount of information CWE and their parents wished to relay about their experiences with disclosure, as well as their level of engagement with the interview process.

In order to capture valuable information about the interview context, the researcher wrote up detailed field notes immediately subsequent to the completion of interviews with families.

4.5 Ethical Considerations

This study was guided by the principles of beneficence, non-maleficence and autonomy, and informed by the report on Ethical Review and Children's Research in Ireland (Department of Health & Children and Office of the Minister for Children and Youth Affairs, 2010). Furthermore, it was underpinned by article 3.1 of the United Nations Convention on the Rights of the Child (1989) which states the following:

"In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration."

The aforementioned principles, as well as issues of child protection and anonymity (all of which were considered prior to undertaking this qualitative phase) are discussed below.

4.5.1 Beneficence

The welfare of CWE and their parents was always the primary consideration and outweighed any commitment to the study. As this study was non-therapeutic in nature, there may have been no direct benefits to participating CWE and/or parents. However, other CWE and parents may benefit from the findings of this study in the future. This was fully explained to all prospective participants in order to ensure that they knew clearly what they could and could not expect.

4.5.2 Non-maleficence

In order to ensure that CWE and their parents were protected from harm at all times, the researcher was Garda vetted prior to commencement of recruitment. Furthermore, during interviews with CWE, parents were invited to remain in the vicinity by leaving an adjoining door open, or in view of the child via a glass door if this was possible. If CWE desired to have their parent(s) present with them during the interview, this wish was facilitated. Finally, bearing in mind the sensitivity of the topic to be discussed and the clinical population under investigation, protocols were devised to outline the actions the researcher should take if: 1) any child and/or parent showed signs of upset/anxiety or tiredness; 2) any child disclosed abusive behaviour; and/or 3) a child had a seizure or became unwell. These protocols are outlined in Appendix I. With particular reference to the risk of CWE participants becoming unwell or having seizures during child interviews, it is important to note that the researcher had first aid training and thus was knowledgeable about appropriate seizure first aid protocols. Furthermore, the researcher sat in on clinical consultations in a paediatric neurology unit for the six months prior to commencing recruitment. During this period, the researcher witnessed a number of CWE experiencing seizures. Thus, the researcher was well-versed in terms of coping with and handling seizures.

4.5.3 Autonomy/Self-determination

In keeping with the ethical principles of autonomy and self-determination, all participants were fully informed about the nature of the study and given the opportunity to make their own decisions about whether they would like to participate. It was appreciated that young children may not have been able to articulate 'informed consent'. Thus, whilst recognising children's ability and right to participate in their own decision-making process by seeking their assent to participate, parental consent was also obtained. If CWE refused to take part or wished to withdraw at any time, interviews were stopped, even if there was continuing parental consent.

As previously mentioned, participants were fully informed about the study verbally and in writing through the distribution of age-appropriate plain language statements (see Appendices H.1, H.2 and H.3). Prior to the commencement of data collection, written (see Appendix J.1) and verbal informed consent was obtained from the parents of child participants for their own, as well as their CWE's participation. In addition, written (see Appendices J.2 and J.3) and verbal assent was acquired from CWE participants. To ensure that the younger aged CWE (particularly those aged 6-8 years) fully understood the nature of the study prior to assenting to participate, parents were advised to read the information sheet with their CWE. Additionally, prior to obtaining assent from CWE at the beginning of interviews, the researcher clarified that they were fully informed about the study details and what their involvement would entail by doing a verbal check with them and answering any further questions that they may have had.

4.5.4 Anonymity

In order to protect participants' right to anonymity, all participants were assured that neither their identity nor their involvement in the study would be disclosed to anyone other than the researcher. In the case of child and parent participants recruited via TSCUH, the nominated gatekeepers were aware of which families they informed about the study but not about which families ultimately chose to participate. Participants' anonymity was safeguarded through the removal of any identifiable data from transcripts or artwork. Finally, pseudonyms self-selected by CWE participants were utilised in place of their names in order to protect their identity.

4.6 Data Analysis

Qualitative findings were thematically analysed - a process that involves identifying repeated patterns of meanings by searching across a data set - utilising Braun and Clarke's (2006) six-phase framework for purposeful, systematic and rigorous thematic analysis. First, the researcher became familiar with the data through transcription of audiotaped materials and reading/re-reading the transcripts (phase one). Phase two comprised the generation of initial codes, whereby the researcher systematically manually coded the data line-by-line in each transcript across the entire data set whilst collating data pertinent to each created code. At this stage, a coding framework was generated. Appendix K provides examples of coded data extracts. Subsequently, all findings were entered into NVivo 10 computer software (QSR International Pty Ltd, 2012), organisational software that facilitates the storage, retrieval and manipulation of large quantities of qualitative data. Third, all codes were collated and then synthesised into themes and sub-themes. At this stage, the data were also examined to determine whether any developmental differences existed between younger and older CWE participants. No stark differences in CWE's disclosure behaviours and experiences emerged according to their developmental stages. However, a number of minor developmental differences with regard to CWE's perspectives on epilepsy disclosure were revealed and these are specified in the subsequent sections of the thesis. Fourth, all codes, themes, and sub-themes were reviewed by members of the research team with interpretations validated and substantiated through discussion and repeated referral to the coded extracts and original dataset. Fifth, definitions and names for the themes and sub-themes were developed. The entire process culminated in the production of a written report of the analysis (phase six), whereby the researcher selected pertinent and compelling extract examples to present in order to address the research questions, relating findings back to pre-existing literature (see chapters five and six).

Chapter 5: Phase One: Qualitative Findings

5.0 Introduction

In this chapter, findings from phase one will be presented related to each of the following aspects of CWE's and parents' epilepsy disclosure: 1) disclosure management strategies; 2) disclosure targets; 3) disclosure content; 4) situational context of disclosure; 5) perceived barriers to disclosure; and 6) perceived enablers of disclosure.

5.1 Overview of Participants, Recruitment & Interview Setting

In total, 29 families comprising CWE and one and/or both of their parents were interviewed. In order to protect participants' anonymity, pseudonyms self-selected by the CWE are used throughout this chapter to refer to individual participants.

5.1.1 Sample Description: Demographics and Clinical Characteristics

A total of 29 CWE (12 male, 17 female) aged 6-16 years (mean age=11.17 years; *SD*=2.85) participated. All of the child/young person participants were attending school and ranged from having completed senior infants in primary school (*n*=2) to fourth year in secondary school (*n*=1). At the time of their diagnosis, CWE ranged in age from 2 years to 14.5 years (mean=7.35 years; *SD*=3.2). In terms of the amount of time that had lapsed between the child's diagnosis and the time of the child being interviewed for the present study, this ranged from 2 months to 10 years (mean=3.87 years; *SD*=2.87).

In relation to the types of therapies being utilised to control CWE's seizures, 41.4% were being treated with monotherapy (i.e. they were taking just one type of AED daily/bi-daily), whilst 55.2% were being treated with polytherapy (i.e. they were on a medication regime that involved taking two or more types of AED daily/bi-daily). Other epilepsy therapies reported included surgery (*n*=1) and vagus nerve stimulation (*n*=1). One further participant was under consideration for surgery and was thus undergoing testing to assess his/her suitability for this type of therapy. Finally, one child (3.4%) was taking no medications because he/she had been attempting to come off medications to assess whether his/her epilepsy had resolved itself. However, at the time of interviews he/she had been re-prescribed AEDs because of a return of seizures and was due to refill the prescription and recommence medication therapy in the near future.

The majority (58.6%) of parents reported that their child had experienced seizures in the 4 weeks prior to their interviews, whilst only 6.9% of parents reported that their child had experienced 13-15 months of seizure freedom. Moreover, 65.5% of the CWE's parents

reported that their child had experienced multiple types of seizures. The demographic and seizure characteristics of the child participants are presented in Table 5.1.

Furthermore, 34 parents of 29 CWE were interviewed. In the majority of families, the child's mother chose to participate (*n*=22), in two families the child's father (*n=2)* participated and in five families both parents participated (*n*=10).

Detail pertaining to each CWE participant, including their: 1) self-selected pseudonyms; 2) gender; 3) age; 4) class in school; 5) age at diagnosis; 6) seizure type(s); 7) period of seizure freedom; 8) treatment regime (current and previous); 9) family history of epilepsy; and 10) language employed around epilepsy, is provided in Appendix L.

Table 5.1: Phase One: Demographic and Seizure Characteristics of the Child Participants (N=29)

Demographic and Seizure Characteristics	
Gender	***N (%)***
Male	12 (41.4%)
Female	17 (58.6%)
Age	***(years)***
Mean	11.17 (*S.D.*=2.85)
Range	6-16
Age at Diagnosis	***(years)***
Mean	7.35 (*S.D.*=3.20)
Range	2-14.5
Time Since Diagnosis	***(years)***
Mean	3.87 (*S.D.*=2.87)
Range	0.17-10
Seizure Type(s)/Epileptic Activity	***N (%)***
One Type Only	10 (34.5%)
Multiple Types	19 (65.5%)
Complex Partial	10 (34.5%)
Simple Partial	4 (13.8%)
Tonic-Clonic	19 (65.5%)
Tonic	5 (17.2%)
Absence	14 (48.3%)
Atonic	4 (13.8%)
Myoclonic	6 (20.7%)
Electrical Status Epilepticus in Sleep (ESES)	1 (3.4%)
Period of Seizure Freedom at Time of Interview	***N (%)***
Seizures Occurring During Interviews	2 (6.9%)
Hours	8 (27.6%)
Days	2 (6.9%)
Weeks	5 (17.2%)
1-6 months	7 (24.1%)
7-12 months	3 (10.3%)
13-15 months	2 (6.9%)

Demographic and Seizure Characteristics	
Treatment Type	***N (%)***
Monotherapy	12 (41.4%)
Polytherapy	16 (55.2%)
Vagus Nerve Stimulation	1 (3.4%)
Surgery	1 (3.4%)
Under consideration for surgery	1 (3.4%)
No treatment at time of interview	1 (3.4%)
Family History of Epilepsy	***N (%)***
Yes	9 (31%)
No	19 (65.5%)
Parent unsure	1 (3.4%)

5.1.2 Recruitment Source

The majority of the families who participated (65.5%) were purposively recruited through the neurology clinic in TSCUH (*n*=19), whilst 10 families were recruited through EI (34.5%). In terms of the uptake rates for this qualitative phase, within the clinical setting in TSCUH, out of the 33 families approached, three families (9.1%) were not eligible to participate as the child did not meet the inclusion/exclusion criteria, 11 families (33.3%) were eligible and opted not to participate and 19 families (57.6%) were eligible to participate and were interviewed. Recruitment through EI resulted in 20 people contacting the researcher. Of these, five individuals (25%) were not eligible to participate as they were adults living with epilepsy, three families (15%) were not eligible to participate as the child did not meet the inclusion/exclusion criteria, two families (10%) were eligible to participate but opted not to after receiving further information on the study and 10 families (50%) were eligible to participate and were interviewed.

With regard to where the child was receiving care for his/her epilepsy amongst those families recruited via EI, two further children received care from TSCUH, four children received care in other paediatric neurology units, three children received care from paediatric neurologists in general hospitals and one child received care from a paediatrician in a local hospital.

Participants were recruited from 14 counties across Ireland (see Figure 5.1) including Dublin, Sligo, Cork, Kildare, Wexford, Galway, Waterford, Mayo, Monaghan, Kilkenny, Tipperary, Meath, Louth and Cavan.

Figure 5.1: Geographic Profile of the Participants from Phase One

5.1.3 Interview Setting

The majority of the interviews (CWE and parent) were conducted in the homes of the interviewee families (*n*=27 families). For one family, child and parent interviews were conducted in a hotel lobby and for another family interviews were conducted in a private room on the university campus.

For child interviews, the option of the child's parent being present during the interview process was left to the discretion of the child because research has indicated that parental presence during interviews can act as inhibiting or as comforting depending on the child (Spratling, Coke & Minick, 2012). Most CWE (n=24; 83%) opted to be interviewed separate from their parents, with only five CWE (17%) opting to be interviewed with their parents present. For parent interviews, if both parents wished to participate, they were given the option of being interviewed separately or together. In all instances of both parents participating, they opted to be interviewed together.

The option to engage with creative methods as a rapport-building mechanism was offered to all but four CWE participants (in such circumstances, the interview setting was not deemed suitable for engaging in artwork). Ten CWE (41.67%) chose to avail of this option and

provided drawings related to their epilepsy (see Appendix M for sample artwork accompanied by descriptions as verbalised by CWE).

Parent interviews lasted between 14-67 minutes (average length=37 minutes), whilst child interviews lasted between 6-59 minutes (average length=24 minutes). As a general rule, interviews were shorter for younger aged children.

5.2 Child Findings

In this section of the chapter, findings are outlined related to the disclosure management strategies endorsed by CWE, their disclosure targets, the content and situational context of their disclosure exchanges, and the factors they perceived as challenging or enabling their disclosure to others external to the nuclear family (see Figure 5.2 for a visual representation of the emergent themes according to CWE's perspectives). Selected illustrative quotes representative of the emergent themes will be embedded in the text to enhance the credibility of the findings. The perspectives of CWE themselves in relation to epilepsy disclosure are presented as self-reported data. Furthermore, proxy-reported data offering the perspectives of parents on their children's disclosure behaviours and/or attitudes towards disclosure-related issues are also incorporated where appropriate. Such data were included because during parent interviews, parents were specifically asked about their CWE's disclosure behaviours, attitudes and/or experiences. However, in accordance with the perspectives of Deatrick & Faux, the researcher recognised and valued CWE as "competent interpreters of their world" (1991; cited by Sartain et al., 2000, p.919) and experts of their own experiences. Thus, all attempts were made to keep proxy-reported data to a minimum, with such data only reported in the subsequent sections if: 1) parent perspectives on their CWE's epilepsy disclosure offered perspectives unreported by their CWE that seemed to hold resonance in the context of research in the area of childhood epilepsy or other CSIs; or 2) parents verbalised or reiterated a perspective that their CWE also verbalised during child interviews but in a way that was more accessible to the reader (this was particularly salient in considering the data from younger aged children in situations where they struggled to verbalise certain elements of their disclosure behaviours or experiences)..

Figure 5.2: Phase One: Emergent Themes pertaining to CWE's Experiences of Disclosing an Epilepsy Condition to Others

5.2.1 Children's Disclosure Management Strategies

CWE engaged in diverse disclosure management strategies ranging from total concealment to open and voluntary disclosure. The ways in which these disclosure management strategies specifically manifested themselves in CWE are outlined below.

5.2.1.1 Concealment

Attempts to keep the epilepsy condition hidden from others comprised of concealment strategies that could be described as either active or passive in nature. Active concealment strategies involved CWE actively working to maintain secrecy around their epilepsy by either concealing all physical evidence of the condition (e.g. medication and seizures) from others or by engaging in passing (i.e. attributing symptoms or cues of the epilepsy to something other than epilepsy or to someone other than themselves).

- *"…So when I'd be at my friend's house and I had to take it [referring to medication], I would go into the bathroom and take it so she wouldn't know I was taking it."*
  Aoife (female, aged 16 years)
- *"If they saw me taking the tablets and asked, 'why do you take the tablets?' …Then they came back another time, and say I said, 'I just have a cough.'"*
  Robyn (female, aged 10 years)

In contrast, more passive concealment strategies involved CWE concealing the condition from others through non-disclosure of the condition to others verbally.

- *"Well, I wouldn't like to just talk…I wouldn't like to tell it to my friends or anyone..."*
  Jack (male, aged 9 years)

5.2.1.2 Open and Voluntary Disclosure

A number of CWE were on the other end of the disclosure spectrum to concealment endorsing either open (i.e. reporting having no issues with disclosing the condition to others) or voluntary (i.e. telling those external to the nuclear family about the condition without any prompting) disclosure management strategies.

- *"I…I don't mind talking about any of it."*
  Hermione (female, aged 13 years)
- *"Well I suppose I didn't really want to hide it, I didn't really care, I just told my friends and my friends talked about it to other people and then other people talked about it to them and eventually after six months the whole school knew."*
  Jessie (female, aged 11 years)

5.2.1.3 Preventive Disclosure

Several CWE reported engaging in preventive telling, which involved telling others to forewarn and prepare them so that they knew what to do in the event of a seizure occurring in their presence.

- *"My mother. She'll be like 'make sure you warn them now that, eh, you could take a fit' or whatever, so…I do be like eh…'I have epilepsy so if I take a seizure don't be freaked out or anything and don't call an ambulance' [laughs]"*
  Nikki (female, aged 15 years)

5.2.1.4 Selective Disclosure

Some CWE recounted times when they were selective in terms of disclosure targets (i.e. who they told) and disclosure content (i.e. what aspects of their epilepsy they discussed with others). A number of CWE highlighted the importance of their having control over who learned about their epilepsy condition. Amongst such CWE, decisions regarding disclosure targets were carefully thought out.

- *Interviewer: "Is it important that you get to decide who you want to tell?"*
  Interviewee: "Yes."
  Interviewer: "Why do you think it is better that you get to decide?"
  Interviewee: "Because if I told the wrong person then it could turn out bad."
  Robyn (female, aged 10 years)

Additionally, some CWE expressed an unwillingness to disclose particular information relating to the epilepsy diagnosis to others. For instance, a number of CWE avoided discussing: (i) specific aspects of their seizure manifestations that they perceived to be embarrassing, and (ii) AEDs.

- *Interviewer: "Is there any aspects about the epilepsy that would bother you to have to talk about?"*
  Interviewee: "I think taking the medication because usually when you hear of someone, especially of my age, oh they are taking medication, there must be something wrong with them. That people would go, oh my God she takes medication, what is up with her? Is it doing anything to her? And sometimes it has side effects and stuff like that."
  Aoife (female, aged 16 years)

5.2.1.5 Unplanned Revelations

For some CWE, they did not consciously choose to disclose the condition to others external to the nuclear family, rather the condition became apparent to others as a result of unplanned revelations whereby seizures occurred in the presence of others and/or others witnessed drug-taking. Such circumstances either stimulated or forced CWE to converse with others about the epilepsy condition.

- *"…and I stay in one guy's house a lot and he always sees me take it so and he asks eh…"why do you have to take the medicine" and I, I told him……no but now I take it, like, in a bathroom…eh or something."*
  Dave (male, aged 12 years)

5.2.1.6 Indirect Telling (via others)

Finally, several CWE reported that others outside the family unit learned about their epilepsy not through their own self-disclosure but instead through indirect telling via parents and peers.

- *"…a few of my friends know that I have it but I haven't actually told them in person. Like, my Mum's told their Mum."*
  Dave (male, aged 12 years)

A number of CWE (particularly those of a younger age [6-10 years]) felt that it was their parents' responsibility (rather than their own) to disclose their epilepsy condition to others (especially if the disclosure targets were adults).

- *Interviewee: "I don't know who I told about it… Well my…people in school know. Well, my teacher definitely knows because if I have a thing in school…"*
  Interviewer: "So [teacher name removed] knows? So, what did you tell [teacher name removed] about your epilepsy?"
  Interviewee: "Well, my Mum usually does all that sort of talking."
  Claw (male, aged 7 years)

Furthermore, some CWE discussed how their peers played a role in disclosing the condition to others. This form of indirect telling arose as a result of CWE's peers either: (i) spontaneously disseminating information about the CWE's epilepsy to others (beyond the CWE's immediate social circle), or (ii) explaining symptoms to others when they visibly manifest.

- *"...usually if I am with my friends or they get somebody new…a person that I wouldn't know or I am acquaintances with, if I go into a stare they would kind of explain and I wouldn't really have to. They explain how it is and if you don't like it, get out."*
  Rebecca (female, aged 15 years)

5.2.2 Disclosure Targets for Children

Disclosure targets for CWE (i.e. the individuals to whom CWE chose to disclose their epilepsy diagnosis) included their extended family, peers, school personnel (e.g. principals, teachers and special needs assistants), healthcare professionals (including doctors and nurses), and sports coaches and/or instructors of extra-curricular activities. How perceived personal characteristics of these disclosure targets encouraged or discouraged CWE disclosure is outlined below.

5.2.2.1 Extended Family

A number of CWE made reference to disclosing their epilepsy condition to members of their extended family, i.e. their grandparents, aunts/uncles, cousins etc. Extended family members who CWE perceived to be understanding, supportive and who were less inclined to 'freak out' about seizure symptomatology were those to whom CWE reported that they were most likely to disclose their epilepsy and discuss aspects of their condition with.

- *Interviewee: "Well I talk to my mummy's mummy because she is the only one [referring to grandparents] that is kind of alive…I tell her it is hard because I keep falling and I can't really keep my balance."*
  Interviewer: "And is she good to talk to about it?"
  Interviewee: "Yes."
  Interviewer: "What makes her a good person to talk to?"
  Interviewee: "Because she is really nice and she doesn't freak out about things."
  Lucy (female, aged 7 years)

Some CWE mentioned that at times, it was easier for them to discuss certain aspects of their epilepsy or epilepsy-related issues with members of their extended family rather than members of their nuclear family. For instance, several CWE reported confiding in extended family members for support in situations when conflict arose within the nuclear family due to the child's epilepsy and the child needed to discuss this with somebody.

- *Interviewee: "Yes my Aunty [name removed], she is really nice and sometimes I would say more to her than I would to my mother."*
  Interviewer: "What do you think it is about her that makes it easier?"
  Interviewee: "Just because it might be something about my mother that I just feel, why did she do that? And then she would say, maybe this."
  Interviewer: "Can you give me an example?"
  Interviewee: "Well [brother's name removed] helps out a lot in the house because he is always there and she is always giving him the credit. And then I would tell [aunt's name removed] and she would say, 'well maybe because she gives more attention to you in the hospital'."
  Ruth (female, aged 13 years)

Extended family members who were very involved in the lives of the CWE and/or had a large presence in their lives due to their frequently being around were also common disclosure targets for CWE, according to parents.

- *Interviewer: "Who are the kinds of people he would end up telling about his epilepsy or talking about his epilepsy?"*
  Mother Interviewee: "A lot of the time he would talk to my Mum. If he has a thing the first thing he wants to do the next morning is get on the phone and tell my Mum, 'oh I had another fit Nana'…I suppose because he is with her an awful lot, he is very close to her…We are down there most days and he would always sit up on the couch and have a cuddle with his Nana because he was the first grandchild..."
  Mother of Ryan (male, aged 9 years)

CWE and their parents verbalised that if members of the extended family appeared reticent to engage in conversation with CWE about their epilepsy, this played a role in dictating CWE's disclosure decisions and their level of communication with specific disclosure targets in the extended family.

- *Interviewer: "And, what about…do you talk to, like…maybe your aunties or your uncles or your Granny or your Granddad and stuff about your epilepsy or…?"*
  Interviewee: "Eh…no."
  Interviewer: "No? Do you not like to talk....about it to them?"
  Interviewee: "Well, I don't think that…I think they know but they just don't ask anything or…"
  Carl (male, aged 11 years)

5.2.2.2 Peers

Several CWE reported that they disclosed their epilepsy to their peers including, but not limited to, friends, classmates and sports team members. Many CWE endorsed selective disclosure policies, only disclosing their condition to best friends, close friends and/or those in their

immediate social circle. For many CWE, the perceived strength, durability, resilience, and closeness of their friendships with peers encouraged disclosure.

- *Interviewer: "And, how did it make you feel to tell her?"*
  Interviewee: "Well…I knew it was gonna be fine 'cause I know her really well and we never get in fights so…it was working that we never get in fights, so she wouldn't tell."
  Tom (male, aged 11 years)

Furthermore, peers who were deemed to be reliable, protective of them and/or trustworthy were those who CWE reported that they were most likely to tell.

- *Interviewer: "So you would tell him a bit about it, would you?"*
  Interviewee: "Yes, he is always there. If I ever got hurt or if anybody was ever trying to do mean things to me he would chase them, he would even chase them all day until he got them. He is the fastest in our class. He is like a little Ferrari."
  Ryan (male, aged 9 years)

CWE avoided telling those who they perceived would bully and/or tease them about it.

- *"I really wouldn't tell this guy that I don't like at all, he is like my enemy. He is a 13 year old and he used to bully me."*
  Ryan (male, aged 9 years)

Some CWE reported opting to disclose their epilepsy to peers that were 'smart' and capable of understanding the condition.

- *"Interviewee: "…Some boys are stupid, but my best friend was in that class, he was in it and he is smart enough, smarter than me. Kind of all his friends are really kind of interested in it."*
  Interviewer: "And do you think that smarter people are easier to talk to about it?"
  Interviewee: "They are definitely."
  Rebecca (female, aged 15 years)

Many CWE (particularly females and/or those in the younger age category [6-10 years]) were more likely to disclose to peers of their own gender than peers of the opposite gender. For some CWE, this was due to 'sameness' being viewed as a desirable factor for disclosure targets.

- *Interviewer: "So, is there anyone in your class that you really wouldn't like to tell about it?"*
  Interviewee: "Boys."
  Interviewer: "Why do you think boys would be hard to tell about it?"
  Interviewee: "Because they aren't the same, not nice. Except my daddy…Well they are nice but they are not the same."
  Robyn (female, aged 10 years)

For other CWE, this was due to the perception that those of the opposite gender communicate less effectively than those of the same gender.

- *Interviewer: "And have you ever told any boys about your epilepsy?"*
  Interviewee: "No because I don't play with boys."
  Interviewer: "Do you think it would be easier or harder to tell them?"
  Interviewee: "Harder."
  Interviewer: "Why?"

Interviewee: "Because I only had one boy best friend and that was when I was small and then when we went into junior infants we kind of slipped away. So I am used to girls now. Girls communicate better."
Interviewer: "So, you think boys would be difficult to communicate with?"
Interviewee: "Boys can be rough and like, 'yo dude'."
Selena (female, aged 11 years)

However, one adolescent reported finding it easier to disclose to members of the opposite sex, highlighting that her male peers were less judgemental and more interested in learning about her epilepsy than their female counterparts.

- *Interviewee:* "*Actually a lot of boys are interested in it more than girls. The girls around here are very stuck up or something. I get on with boys more than I would with girls…my friends know that I am having an interview or whatever and the guys were like, oh my God I would love to be there because it is so cool..."*
Interviewer: "And the girls; were they just less interested?"
Interviewee: "The girls were kind of like, they are more stuck up, it is so weird."
Rebecca (female, aged 15 years)

A common thread to emerge from data analysis was that CWE often reported finding it easier to disclose their epilepsy to peers who had a medical condition, physical or intellectual disability or behavioural condition. They felt that they could relate to them in terms of what it is like to live with a chronic condition.

- *Interviewee: "Other people have disabilities, I tell them, 'I know how you feel.'"*
Interviewer: "Do you think it makes it easier to talk to people who have other disabilities?"
Interviewee: "It is yes."
Interviewer: "Why is that do you think…?"
Interviewee: "They know how it feels not to be as average as the average person."
Tony (male, aged 13 years)

In particular, CWE who had experienced conversing with other CWE reported that such experiences were positive and made them feel less alone and different. The element of 'sameness' conferred upon CWE by knowing other CWE was viewed positively by CWE.

- *Interviewer: "And is it good to talk to other people with epilepsy then?"*
Interviewee: "Yes like it kind of feels they know more about it. It just feels better because whenever I tell people I have epilepsy they would just be like, the main question would be, how does it feel when you get a seizure. But when I meet [friend with epilepsy's name removed] or [friend's name removed]'s brothers that they know what it feels like so I wouldn't really have to…"
Interviewer: "…And what are the things that you like talking to them about in relation to your epilepsy?"
Interviewee: "Well [friend with epilepsy's name removed] has to go to bed early too so I just like talking to her going, 'oh my God I can't believe I have to go to bed so early.' And she'd be like, 'I know, isn't it so annoying."
Jessie (female, aged 11 years)

Finally, some children selected disclosure targets who possessed characteristics or traits that children perceived as making them 'different' in the eyes of others (i.e. peers who were adopted

or peers who had unusual phobias), reporting that they felt that they would be better able to identify with them as a result of this.

- *Interviewee: "Actually once when we were in the park on the way back and this guy went on this dizzy thing and he got sick all over the place in the park. [Friend's name removed] gets a bit nervous when he is looking at it. He thought everyone was looking at him. And this guy [name removed], from [teacher's name removed]'s class, came over and said, 'why are you so afraid?' I just told him to f' off. And he went away. He said, 'everyone is going to make fun of me now because of my problem.' And I told him about what it is like having mine."*
  Interviewer: "So you told him to kind of help him out…Did it make you feel good that you could help him out?"
  Interviewee: "Yes…"
  Interviewer: "So you kind of understood him. And do you think that made it easier to talk to him, that he felt scared about people slagging him?"
  Interviewee: "Yes."
  Ryan (male, aged 9 years)

5.2.2.3 School Personnel

A number of CWE made reference to disclosing their epilepsy to adults within the school context (i.e. their teachers, principals and special needs assistants). Some CWE reported that when school personnel were aware of their epilepsy condition (whether as a consequence of their own disclosure or of their parents' disclosure to such individuals), this made them feel reassured and comforted.

- *Interviewer: "What about your teachers in school?"*
  Interviewee: "They know, well not all of them, just the ones..."
  Interviewer: "Who have you kind of or…?"
  Interviewee: "Yes…and my principal."
  Interviewer: "Is that a good thing?"
  Interviewee: "Yes because if it happens they will know what it is."
  Robyn (female, aged 10 years)

One child in particular spoke about how her year head teacher and other school personnel going above and beyond to ensure her wellbeing and comfort with her epilepsy encouraged her to adopt an open epilepsy disclosure policy with others.

- *Interviewer: "...And has your school been good about it and everything or…?"*
  Interviewee: "Yeah actually, my old year head, she still calls [laughs]…she's really, really nice and she's like 'oh', you know, like she won't be my year head for the next three years but she's like 'if you ever need to talk to us, come and, you know, talk to me' so...they're really, really supportive, so…"
  Interviewer: "Yeah, that's brilliant. So, do you think, kind of, the fact that you have had good experiences and support like, I suppose, has helped with you being quite open with it and stuff or…?"
  Interviewee: "Definitely, yes. Yeah."
  Audrey (female, aged 15 years)

Several CWE reported less favourable experiences of epilepsy disclosure to school personnel. In particular, situations in which unnecessary restrictions were imposed on them and/or where they

felt that they were being treated differently than their peers or unfairly due to their epilepsy condition deterred CWE from future disclosure exchanges with school personnel.

- *"Most of the time I wouldn't want to tell my teacher because he would make a big fuss and stuff…I don't like that."*
  Jessie (female, aged 11 years)

5.2.2.4 Healthcare Professionals

Another group of disclosure targets for CWE included healthcare professionals (i.e. doctors and nurses). In this context, disclosure obviously does not specifically relate to disclosing the epilepsy diagnosis to such individuals because HCPS are inherently likely to be aware of the child's epilepsy condition. Instead, it refers to how CWE talk to HCPs about various aspects of their condition or seizures during clinical engagements and what they reveal to HCPs in terms of what has unfolded relating to their epilepsy in the period of time since their last hospital appointment. For several CWE, their doctors' and nurses' easy-going and sunny temperaments, interest in them, sense of humour and understanding manner facilitated their disclosure of details pertaining to their condition that they may not disclose to other individuals.

- *"…I mean the neurology department, they're lovely like, they really understand and they…they answer all your questions and, you know, so it's been a really nice experience actually."*
  Audrey (female, aged 15 years)

Some CWE, however, reported that engagements with HCPs (particularly consultations) were tedious and bothersome due to the fact that HCPs did not seem to value their input, instead speaking primarily to their parents and in effect ignoring their perspectives. Amongst CWE who felt this way, disclosing details about their epilepsy to HCPs was deemed undesirable and CWE opted to disengage during appointments and let their parents handle disclosure in this regard.

- *Interviewer: "And obviously your doctor, you have to tell them what happened and stuff."*
  Interviewee: "My mum does that, I just...it is a bit boring. The last time I was just sitting there like this for ages."
  Ryan (male, aged 9 years)

5.2.2.5 Sports Team Coaches and/or Instructors of Extra-Curricular Activities

Some CWE spoke about sports team coaches and/or instructors of extra-curricular activities as disclosure targets. A number of CWE reported a desire for these individuals to be aware of their condition but relied on their parents to inform them about their epilepsy.

- *"My dad tells the coaches. One day I heard my dad talking about my thing…and [coach name removed] was saying it was amazing how Ryan is our best player and him having the epilepsy as well."*
  Ryan (male, aged 9 years)

5.2.2.6 Adults vs. Children

A number of CWE spoke about differences they perceived to exist between disclosing their epilepsy to adult versus children disclosure targets. Some CWE preferred disclosing their epilepsy to adults because they perceived that adults would have a greater understanding of the condition and therefore, would respond more positively.

- *Interviewer: "Do you think it is easier for you then to talk to adults or children about your epilepsy?"*
  Interviewee: "Adults."
  Interviewer: "Why is that?"
  Interviewee: "Because they know more about it, most of them."
  Robyn (female, aged 10 years)

However, other CWE reported a greater affinity towards openly discussing their epilepsy with other children due to their open-mindedness, receptiveness to change, and acceptance of their explanations.

- *Interviewer: "Who do you think is easier to talk to about epilepsy and who understands it more- adult or children?"*
  Interviewee: "Children because they're still learning and they have more space for it…if you're telling them about something…they might em…you know take it in better than adults might…because adults might…if you're a child...they might just think you're talking gibberish…or something because some adults don't really understand children."
  Hermione (female, aged 13 years)

Finally, some parents reported that their CWE were more prone to selecting children as disclosure targets than adults because children are more direct and frank about such conversation topics than their adult counterparts.

- *"I suppose if people were more matter of fact with him about it…I think he'd, that would make it a lot easier for him then…I think kids probably are better, like, in terms of just asking out straight, where I think a lot of adults, kind of, are too…pussy foot around it…and so, he kind of takes the lead then from them…"*
  Mother of Carl (male, aged 11 years)

5.2.3 Content of Child Disclosure Exchanges

The content of disclosure exchanges between CWE and others outside the immediate family unit included four core topics: 1) epilepsy and seizure descriptions; 2) the impact of epilepsy on the child; 3) hospital appointments; and 4) medication and/or other epilepsy treatments.

5.2.3.1 Descriptions of Epilepsy and Seizures

The main content of CWE disclosure exchanges with others external to the nuclear family comprised descriptions of epilepsy and seizures.

- *"I just said, 'guess what, I have epilepsy.' And they were like, 'what is that?' And I was like, 'when I have these fit things.'"*
  Jessie (female, aged 11 years)

CWE who had less visible forms of epilepsy and/or experienced mild seizure symptomatology emphasised this point during their disclosure exchanges with others.

- *"…when people think of epilepsy they think of…like, lights flashing, convulsing on the floor, foaming at the mouth kind of epilepsy, you know?…that's actually what kind of shocks, like 'oh my God, do you...?', like 'if you see flashing lights, is this what happens to you?' and I had to explain to them 'no, no, they're just little black outs', you know?"*
  Audrey (female, aged 15 years)

In contrast, other CWE referenced not bothering to explain their specific epilepsy type to others during disclosure exchanges due to their perception that others do not understand the various types of epilepsy.

- *"To be honest I never really went into what type of epilepsy I have because I don't think they would really understand, the words would mean nothing to them so I just kind of went, 'yes I have epilepsy.' I never go into what type it is or anything..."*
  Anna (female, aged 15 years)

Many CWE (specifically those in the younger age category [6-10 years]) utilised personalised language to describe their particular seizure symptomatology, so that the information was simple, accessible and easy for others to understand.

- *Interviewee: "I told a couple of people but I said it different ways really…I said my head takes a short break."*
  Interviewer: "That is a good way of explaining it. And do people understand it better when you say it that way than saying, I have epilepsy?"
  Interviewee: "Yes because some people don't understand."
  Robyn (female, aged 10 years)
- *"I would say in a lot of cases she won't even use the term epilepsy, she would just say her leg is getting a bit funny or it is jerking or whatever. She might explain to them, 'I am not clumsy, I just fall because my legs get too much electricity from my brain.' I think she kind of talks about it like that".*
  Father of Lucy (female, aged 7 years)

Several CWE explained to others how seizures made them feel physically and/or how they responded to seizures.

- *Interviewer: "…what are the kinds of things you'd tell them?"*
  Interviewee: "Eh like…if I panic…I kind of feel dizzy and then I have to get me Ma."
  Rooney (male, aged 10 years)
- *"...when it first happened they would like ask me what it feels like...It is sort of like...all the senses go dull and eventually you are sort of like put to sleep or something."*
  Tadhg (Male, aged 12 years)

A number of younger CWE spoke of how they attempted to explain epilepsy to others but that they struggled in doing so because they experienced difficulties in understanding the complex neurological condition.

- *"Well, I just usually say this: 'I have epilepsy…it helps me from having seizures or it…cause me to having seizures.' I don't know which one it is. I don't really know much about it but…"*
  Claw (male, aged 7 years)

Finally, one child who experienced enduring feelings that a presence was in the room with him subsequent to seizures reported specifically avoiding divulging this information regarding his seizure manifestations to others external to the nuclear family out of fear of being teased.

- *Interviewee: "I don't explain how I am feeling…About the person behind me."*
  Interviewer: "You don't explain that. And why would you prefer not to explain that?"
  Interviewee: "Because I am afraid it would be a bit silly."
  Interviewer: "So you think that people wouldn't understand, is that it?"
  Interviewee: "They would laugh at me."
  Colm (male, aged 12 years)

5.2.3.2 Impact of Epilepsy on the Child

CWE discussed disclosing information regarding the impact and effect that the condition had on their lives to others outside the immediate family unit. This included the emotions epilepsy and/or their seizures elicited in them.

- *"I tell them that I do get…em kind of sensations and em…they'd be sort of annoying and…yeah."*
  Marie (female, aged 13 years)

One adolescent relayed how she confided in her best friend about a period of emotional struggle she experienced subsequent to learning that she would not grow out of her epilepsy.

- *"Well up until last year I was fine and then I went for an EEG and it came back that I wasn't getting any better…And I had always grown up thinking once I became a teenager…I would grow out of it and I will be fine because there were all these people on TV who had grown out of epilepsy…and then I realised I wasn't getting any better so I got a bit depressed for a while because all I could think of was I am not getting any better and then it started going downhill. So only my best friend knows that…and I told her all of it and she knows everything."*
  Anna (female, aged 15 years)

During disclosure exchanges with others, some CWE highlighted how they described the difficulties they experienced and/or the restrictions imposed on them due to their epilepsy.

- *"I told her [referring to best friend] that it is hard running so if we are running don't go too fast."*
  Lucy (female, aged 7 years)

One adolescent appeared frustrated because she perceived that her peers failed to understand the gravity of her situation and the impact epilepsy had on her life.

- *"…like the driving thing, I have tried explaining to them but I don't think they get the whole, I won't be able to do it. I think it is just, 'oh none of us can drive at the moment so you will be fine.' I don't think they quite understand the seriousness of it because it is not like they have ever been affected by it...I don't think they kind of get how far it goes. I think they think it is something in the background that doesn't really matter."*
  Anna (female, aged 15 years)

For other CWE, during disclosure exchanges they made specific efforts to avoid complaining about any aspects of the epilepsy.

- *"Yes I will tell my friends, I would have a full conversation about it. But I don't like to complain about it…there is nothing I can really do about it and there is nothing they can do about it either so I just don't like to complain."*
  Rebecca (female, aged 15 years)

5.2.3.3 Hospital Appointments

CWE referred to informing others (such as peers and/or neighbours) about upcoming or previous hospital appointments, as well as the reasons for and outcomes of such appointments.

- *"…so I was telling her [referring to a neighbour] about when I came back from the hospital…and telling her about what the doctors were saying…you're just telling her not to worry and making her understand…"*
  Nikki (female, aged 15 years)

5.2.3.4 Medication and/or Other Epilepsy Treatments

CWE varied in terms of their attitudes towards discussing information specific to medication and/or other epilepsy treatments during their disclosure exchanges with others external to the nuclear family. For some CWE, medication was a sensitive topic and one that they would rather avoid when conversing with others about their epilepsy.

- *Interviewer: "And what are the questions that you don't like to answer?"*
  Interviewee: "…I forget now, but it was a really push the buttons type question."
  Interviewer: "Do you know what kind of thing…?"
  Interviewee: "It was something about the medication or something."
  Ruth (female, aged 13 years)

Other CWE, however, reported having no issues with describing their medication regime and/or epilepsy treatments to others external to the nuclear family.

- *Interviewer: "And em…what are the kinds of things about your epilepsy that you don't mind telling people?"*
  Interviewee: "Em…about my medication…like when I have to take it…or what times roughly in the mornings and…eh…what happens like when I take it…"
  Nikki (female, aged 15 years)

Finally, a number of CWE reported employing humour when speaking about their medication during disclosure exchanges with others. Such tactics were utilised in an attempt to normalise the condition for others, thus making others feel more comfortable with their epilepsy.

- *"I would make jokes about it every now and then. I'd be like, 'oh you know me, popping pills, I'd get a gold for it in the Olympics if it was a sport.'"*
  Anna (female, aged 15 years)

5.2.4 Situational Context of Disclosure for the Child

Data analysis revealed a number of situational contexts in which CWE disclose their epilepsy to others external to the nuclear family inclusive of situations when: (1) they are in secure relationships with others; 2) cues make their invisible condition visible to others; 3) others

express curiosity about epilepsy; 4) in an environment where disability and the topic of epilepsy is salient; and 5) the mood of the disclosure target is deemed appropriate for disclosure.

5.2.4.1 In Secure Relationships with Disclosure Targets

A number of CWE highlighted how they ensured to establish a relationship and/or friendship with the disclosure target prior to disclosing their epilepsy. For CWE, this strategy offered them security and reassurance that others were not solely interested in forming a friendship with them out of what CWE perceived as pity or sympathy due to their epilepsy.

- *"And I don't want them to be friends with me because they pity me or I don't want them to look at me and think of my illness, I just want them to look at me and see me."*
  Anna (female, aged 15 years)

Furthermore, several CWE reported perceiving that waiting to reveal their epilepsy until they were comfortable and secure in their relationship with the disclosure targets served to protect them from what they viewed as potentially negative reactions from others.

- *Interviewee: "That was probably my only secret because if anything went on at home she'd be like 'oh what's going on?'…I'd tell her…'"*
  Interviewer: "So you would tell her everything else. And why did you keep it from her for a while?"
  Interviewee: "I don't know, I just waited a while in case anything happened between us but she is great…we never disagree on anything."
  Selena (female, aged 11 years)

5.2.4.2 Cues Make the Invisible Condition Visible

For many CWE, disclosure exchanges with others outside the immediate family unit occurred as a result of the invisible condition becoming visible to others due to cues of the condition making the epilepsy apparent. These cues included physical cues (e.g. safety items and medication) and contextual cues (e.g. absences from school). With regard to physical cues, for one child with frequent atonic seizures, wearing a safety helmet as a method of protection to guard against injury provoked questioning from others within a school context, resulting in her disclosing her epilepsy to inquiring peers.

- *Interviewee's Mother: "What do your friends in school say when you are wearing your helmet?"*
  Interviewee: "The big boys? …They think my helmet is a boxing helmet."
  Interviewee's Mother: "What do you tell them?"
  Interviewee: "It is an epilepsy helmet."
  Hannah (female, aged 7 years)

Wearing medical I.D. bracelets and/or epilepsy alert wristbands for safety reasons also served to arouse others' curiosity and resulted in CWE engaging in disclosure exchanges with others.

- *"Em…she wears her…her bracelet…every day. And…just say…somebody says: 'Oh, I like your bracelet', she'll say: 'Oh, that's my epilepsy bracelet. I take it because I get seizures or I have seizures."*
  Mother of Mandz (female, aged 6 years)

For other CWE, disclosure exchanges occurred as a result of others witnessing them with or taking medication and posing questions about why they needed such medication.

- *"…or do you know sometimes I have to take tablets in front of people and they're asking me what it is and I'm like 'oh epilepsy tablets' and they're like 'for what?', like 'why do you have to take them?', 'what's that?'…"*
  Nikki (female, aged 15 years)

One adolescent revealed that the majority of her epilepsy disclosure exchanges with others occurred as a result of an alarm going off on her phone to remind her to take her medication.

- *"…I mean…most of the time it comes up if my alarm goes off, that's what starts it off…conversation about it but em…that…that's it really. Yeah."*
  Audrey (female, aged 15 years)

For some CWE, their invisible condition was made visible to others because their absences from school as a result of seizures or hospital appointments, or their having to cancel pre-planned social outings with peers at the eleventh hour when seizures occurred, were noted by others and raised questions. In many instances, CWE disclosed their epilepsy to others enquiring about these contextual cues

- *"Well, I would avoid talking to people about it but…if they asked why I wasn't in school…yeah, I would have to."*
  Carl (male, aged 11 years)

5.2.4.3 Others are Curious about Epilepsy

Many CWE referred to disclosing their epilepsy diagnosis when others external to the nuclear family expressed curiosity and asked questions about epilepsy.

- *Interviewer: "So, who would you tell about your epilepsy?"*
  Interviewee: "Anyone who asked."
  Interviewer: "…And what would you tell them about it?"
  Interviewee: "Em…whatever they asked really."
  Interviewer: "And em…when would you tell them about your epilepsy?"
  Interviewee: "Whenever they asked really."
  Paul (male, aged 13 years)
- *Interviewer: "And do you not like talking about your epilepsy or is it ok?"*
  *Interviewee: "I…I would prefer not to but…*sighs* if people ask me I do it."*
  Mandz (female, aged 6 years)

5.2.4.4 In an Environment where the Topic of Disability and/or Epilepsy is Salient

Some CWE highlighted that being in environments where either the topic of disability and/or epilepsy arose or bore relevance were key contexts under which they revealed their epilepsy to others outside the immediate family unit. For one child, a disclosure exchange with a peer unfolded as a result of his attendance at a camp for children with chronic illness.

- *Interviewee: "I made a friend in Barretstown and I told him...well I asked him first what was wrong with him."*
  Interviewer: "So you knew he had got something as well, an illness or something…How did it make you feel when you told him about your epilepsy?...Did it make you feel a good feeling or a bad feeling?"
  Interviewee: "Good."
  Colm (male, aged 12 years)

Other CWE spoke of divulging information related to their condition to others external to the nuclear family when conversations arose about disability and/or epilepsy specifically, as they deemed such instances to be the appropriate time to disclose their epilepsy to others.

- *"I would bring it up if they were explaining something to do with epilepsy or another type of disability, if they were talking about disability or...epilepsy, yes."*
  Tony (male, aged 13 years)

5.2.4.5 The Mood of the Disclosure Target is Deemed Appropriate

Finally, several CWE reported evaluating the mood of prospective disclosure targets when deciding the appropriate context in which to disclose their epilepsy to such individuals. A number of CWE alluded to only disclosing their epilepsy to disclosure targets outside the immediate family unit when the disclosure targets were in a good mood.

- *"It was fine because at the time…we were, like, really happy...with each other and...there was no fights or anything…so, I just...I found out that was the perfect time."*
  Tom (male, aged 11 years)

Conversely, CWE relayed that they avoided disclosure in situations where potential disclosure targets were in a bad mood for fear of suffering negative consequences.

- *Interviewer: "Is there anything that would stop you from telling people...?"*
  Interviewee: "If they were in a bad mood or something…Because they might be very cross and they might take it in a different way."
  Robyn (female, aged 10 years)

5.2.5 CWE's Perceived Barriers to Disclosure

Thematic analysis of the transcribed interview data resulted in the emergence of five core themes (and a number of relevant sub-themes) related to the barriers faced by CWE when disclosing their epilepsy to others external to the nuclear family (see Figure 5.3 for a visual representation of the themes and sub-themes). These themes were: 1) desire for normalcy; 2) out of sight but in the mind; 3) contending with negative responses to disclosure; 4) the complexity of epilepsy; and 5) self and others' perceptions of epilepsy. Some of these barriers resulted in CWE adopting concealment and/or selective disclosure management strategies.

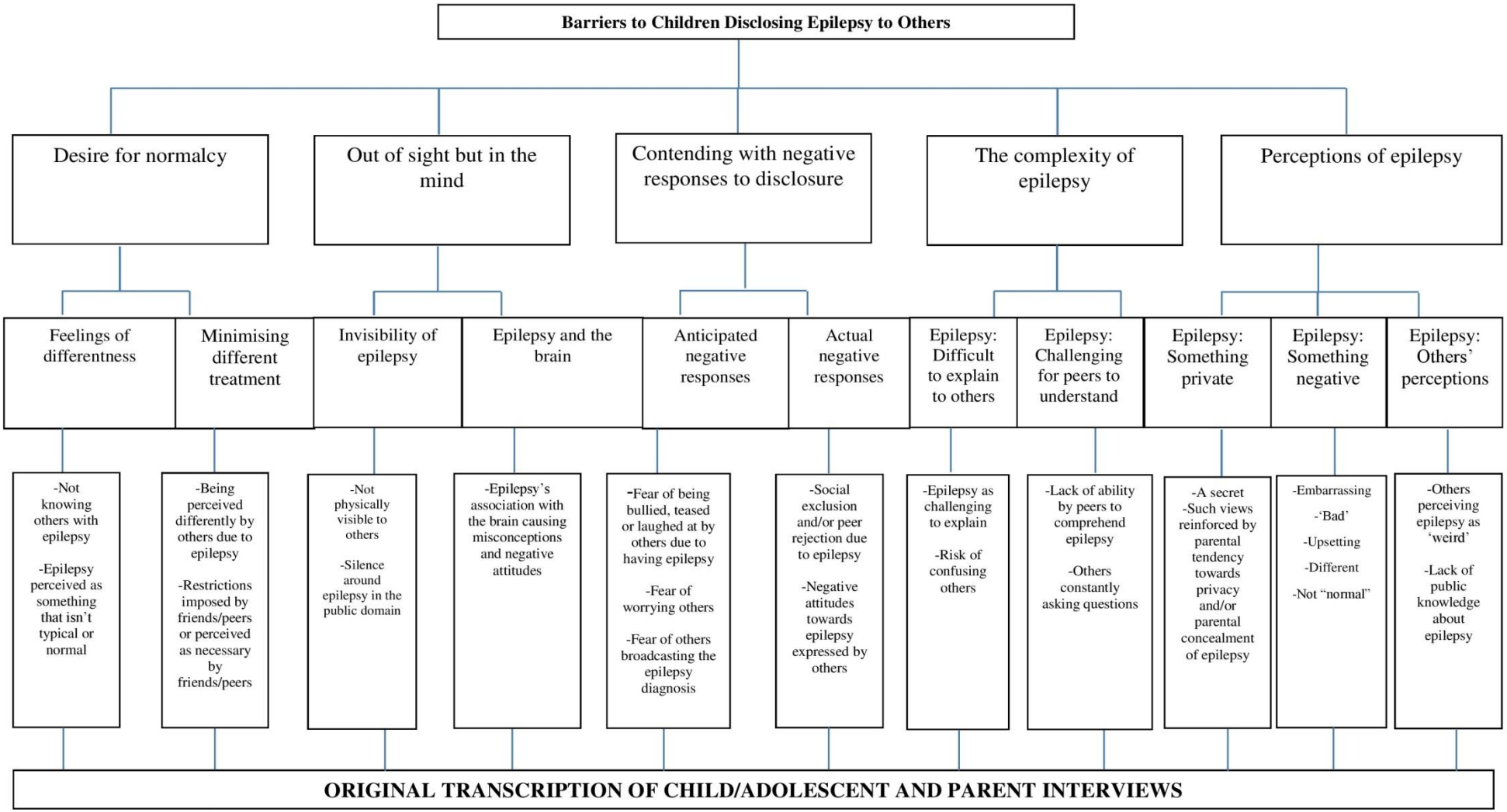

Figure 5.3: Barriers to Children's Disclosure Main Themes and related Sub-Themes: Pathway of Organisation as Identified through Analysis of Transcribed Interviews (*n=29)*.

5.2.5.1 CWE's Desire for Normalcy

Following the receipt of a diagnosis of epilepsy, maintaining a sense of normality (i.e. by keeping life post-epilepsy as consistent and congruent as possible with life as it either: (a) was pre-epilepsy; or (b) is for their siblings and/or peers) was identified as a priority by many of the CWE in this study. In particular, CWE were reluctant to feel singled out from their peers and/or siblings as a result of their epilepsy and to be perceived and/or treated differently by others post-diagnosis than they had been pre-diagnosis. A number of participants reported that disclosing the epilepsy diagnosis to those external to the nuclear family hindered this quest for normalcy and therefore they adopted concealment and/or selective disclosure management strategies.

5.2.5.1.1 Feelings of Differentness

For some CWE, disclosing the diagnosis to others elicited feelings of differentness.

- *Interviewer: "Do you not really like talking to people about your epilepsy in general?"*
  Interviewee: "No."
  Interviewer: "Why do you think that is?"
  Interviewee: "I don't know, probably because they are all normal and I am not."
  Colm (male, aged 12 years)

Feelings of differentness were exacerbated by the fact that very few of the participants had any contact with other people who also had epilepsy. Thus, there were reports by participants of isolation and feeling that they had nobody to identify with because within their social circles there were no individuals in the same position as them.

- *"It's hard to talk about it…I don't know, it's just…well not much people I know have epilepsy so it's hard to talk about it...that like no one else has it."*
  Tom (male, aged 11 years)

A number of participants also expressed feeling a sense of injustice that they suffered with epilepsy whilst their peers and siblings did not have to endure living with the condition.

- *"Because I have an illness and everyone else is perfectly fine."*
  Colm (male, aged 12 years)

The adoption of concealment and/or selective disclosure management strategies was deemed protective by CWE as these strategies facilitated the avoidance of such feelings.

5.2.5.1.2 Minimising Different Treatment

For other CWE, disclosure of their epilepsy to others was viewed as heightening the risk of others treating and perceiving them differently. CWE appeared to be highly sensitive and attuned to recognising disparities in their treatment by others.

- *"…I didn't really want my teachers to know in case they treated me differently… I don't want them to think the minute I put up my hand and say, 'I just a have a wee bit of a headache, can I go?' …I don't want them to freak out...they wouldn't with anyone else."*
  Aoife (female, aged 16 years)

Many participants conveyed that they did not want epilepsy to be a defining characteristic in their lives. They did not perceive it as an intrinsic element of their identity and many reported that they did not want to be pitied or to receive special treatment as a result of their epilepsy.

- *"You know the way if someone tells you something that is sad or something bad has happened to them you immediately start to feel sorry for them… I don't want people I know feeling sorry for me. It is not like I am having seizures every ten minutes, I am fine, I just don't want people feeling sorry for me, so that is why I don't tell people."*
  Anna (female, aged 15 years)

A number of adolescent participants in particular worried about how their autonomy would be affected, whilst some feared that unnecessary restrictions would be imposed on them if they were to disclose their epilepsy to others.

- *"Yes and I don't want them to think of me differently either [referring to peers]…We have great craic staying up all night and I think if they thought, oh I can't stay up that late because something might happen, they might start doing it differently or going to bed earlier or sleepovers might even stop..."*
  Aoife (female, aged 16 years)

Participants reported engaging in concealment and/or selective disclosure management strategies in an attempt to minimise the potential for others to treat them differently due to their epilepsy.

5.2.5.2 Out of Sight but in the Mind

The fact that it is not always physically apparent to others that an individual has epilepsy, coupled with the silence that encircles the condition within a public forum (due to a lack of public dialogue about epilepsy, its lack of presence in the media and the absence of public figures who openly speak about their experiences with epilepsy) also seemed to act as a deterrent to disclosure of the condition for CWE. In addition, the association epilepsy has with the brain emerged as an obstacle to disclosure for CWE, playing a significant role in terms of informing decisions to disclose (or not) the condition to those external to the nuclear family.

5.2.5.2.1 The Invisibility of Epilepsy

As previously mentioned, epilepsy is only overtly visible when symptoms of the condition physically manifest (i.e. during times of seizures) or if cues of the condition arise within a public context (e.g. when the person with the condition is taking medication). Several CWE reported that the invisible nature of epilepsy acted as a barrier to disclosure because both they and their peers struggled to reconcile their own perceptions of what an individual with an illness or disability should appear like with the seemingly "normal" physical appearance of the CWE.

- *"I told her and she was just like, 'oh.' You know if you see people and you can tell that they have something wrong with them…she thought, 'but you don't look it.' And I said, 'you don't have to look it, you could just have it on the inside and be normal on the outside.' And she was like, 'oh ok, how?' And I was like, 'I don't know.' And she was like, 'how do you not know?'. And I was like, 'it is hard.' '"*
  Selena (female, aged 11 years)

Some CWE reported that they would only disclose their epilepsy if others actually witnessed them having a seizure as this increased their credibility.

- *Interviewee: "Sometimes I feel the need to but…I don't know until it happens, that is why I am kind of like until it happens I will say it but I don't really want to say it if it doesn't happen and then they just have that."*
  Interviewer: "So you will kind of say it only if it happens really?"
  Interviewee: "Yes."
  Interviewer: "So only if it is visible and something that makes you..."
  Interviewee: "It is like that they have the proof that she actually does have epilepsy."
  Rebecca (female, aged 15 years)

Another way in which CWE reported that epilepsy is invisible and therefore challenging to disclose is through the silence that encircles the condition within a public domain. Many children identified that epilepsy is not something that receives the same magnitude of media coverage that other medical conditions receive.

- *"None of my friends knew what it was…I don't think anyone has a clue what it is. Because they had never come into contact with it, they had never heard of it...It is not something that gets a lot of media attention, it is not something that gets a lot of attention at all. So they would have no idea what it was, like I had to explain to them a lot of times in lots of different ways to try and get them to understand what it was."*
  Anna (female, aged 15 years)

Finally, a number of CWE highlighted how the invisible nature of epilepsy presents difficulties for them in disclosing the condition to others, as others are less likely to be aware of its existence than they may be about other medical conditions and/or to have pre-existing fundamental knowledge about it.

- *"Like do you know…if you told someone that you had cancer they wouldn't ask you as many questions because they'd know so much about it already."*
  Nikki (female, aged 15 years)

5.2.5.2.2 Epilepsy and the Brain

Several CWE reported experiencing obstacles in terms of disclosing their epilepsy to others because of its association with the brain, with one child misinterpreting this association to mean that he had something fundamentally wrong with his brain.

- *"I think maybe that might be what Jack thinks, is that there's something wrong with his brain and it's…I think he might have th-…said something like that to me at the beginning…and I think that's where he would probably…it's one of the main reasons that he wouldn't tell anyone because people might be inclined to turn around and say that."*
  Mother of Jack (male aged 9 years)

Other children expressed the view that members of the public are reluctant to engage with conditions or diseases associated with the brain. For some CWE, this association resulted in a reluctance to disclose their epilepsy to others.

- *"It is like people wouldn't want to hear about somebody who has something wrong with their brain; nobody wants to hear about that. And especially the ones that are the more severe cases...Nobody wants to hear that type of story because they are so sad*."
  Anna (female, aged 15 years)

5.2.5.3 Contending with Negative Responses to Disclosure

Both the fear of how others might respond and actual negative responses CWE had experienced subsequent to disclosure in the past acted as a barrier to epilepsy disclosure and promoted the adoption of concealment and/or selective disclosure management strategies by CWE.

5.2.5.3.1 Anticipated Negative Responses to Disclosure

Some CWE reported an unwillingness to disclose their epilepsy to others as they feared it would evoke worry and fear in others.

- *Interviewee: "Because they would be really worried and they might be afraid that I might keep getting hurt."*
  Interviewer: "So you don't want people to worry, you just want them to be..."
  Interviewee: "Be happy."
  Lucy (female, aged 7 years)

For other participants, disclosure was avoided due to apprehension that it would result in bullying/teasing.

- *"They might bully me."*
  Robyn (female, aged 10 years)

Finally, many CWE cited that they appreciated having a degree of control over who knew about their epilepsy. Consequently, a number of participants reported adopting selective and/or concealment disclosure management strategies because they were concerned that disclosure would lead to others broadcasting their condition.

- *Interviewee: "I j-just don't like, like, everyone knowing."*
  Interviewer: "Mhmm. And what is it that makes you not want them to know?"
  Interviewer: "'Cause they…would probably tell other people."
  Taylor (female, aged 10 years)

5.2.5.3.2 Actual Negative Responses to Disclosure

A number of CWE recounted how disclosing their epilepsy to others had yielded less than favourable outcomes for them in the past. CWE provided accounts of how disclosure resulted in judgemental behaviour, social exclusion and prejudice.

- *"…like some people don't really like to sit beside me….In case I… in case I would get a seizure or something like that."*
  Marie (female, aged 13 years)

Some had witnessed others imitating their seizures, whilst others had experienced teasing and bullying.

- *"Yeah, it is just that they can use that against me. People will take every chance to use it against me...They would pretend to go into a fit...Yes and they will say, 'you can't go to [name removed - a disco for teenagers]' or 'you can't go to…"*
  Rebecca (female, aged 15 years)

Previous reactions to disclosure seemed to influence CWE's attitudes towards disclosing their epilepsy to others in the future, with CWE who reported negative consequences accordingly adjusting their disclosure management strategies for future purposes.

5.2.5.4 The Complexity of Epilepsy

Many CWE referred to how the complexity of the condition impeded their disclosure of their epilepsy to others. They contended that it was neither straightforward for (a) them to provide their peers with a clear explanation of epilepsy, nor (b) their peers to comprehend epilepsy. As a result, some CWE opted to avoid engaging in conversations with others about their condition.

5.2.5.4.1 Epilepsy: Difficult to Explain to Others

For some CWE, particularly those of a younger age, they had yet to establish how to appropriately describe their condition to others, and as a result they found it challenging to disclose their epilepsy to others.

- *"It is just kind of hard to explain…Well maybe when I am older I might be able to explain it a bit better."*
  Colm (male, aged 12 years)

To some extent, CWE's capacity to describe their condition to others was dictated by their own comprehension of the condition in addition to how informed they felt themselves about their epilepsy.

- *Interviewer: "…is there anything that is difficult about talking about your epilepsy?"*
  Interviewee: "Confusing someone."
  Interviewer: "So is it hard to explain to other people?"
  Interviewee: "Yes."
  Interviewer: "Because you said it took ages for you to even..."
  Interviewee: "I wouldn't be able to explain it to anybody…I think it is really complicated."
  Ryan (male, aged 9 years)

In particular, some CWE experienced difficulties answering specific questions that others would ask them during disclosure exchanges, reporting that they were inadequately prepared to respond to such questions.

- *Interviewer: "And are some of the questions they ask hard to answer?"*
  Interviewee: "Yes because even though I am the one with epilepsy I wouldn't know anything about it…I just think it is a difficult thing to know about."
  Selena (female, aged 11 years)

5.2.5.4.2 Epilepsy: Challenging for Peers to Understand

Several CWE reported that their reluctance to disclose their epilepsy to others stemmed from an inability by their peers to grasp the meaning of what it was for the CWE to have epilepsy.

- *"Because I don't think they will understand me…I tried it once and they wouldn't understand. They keep asking me questions, like 'what's epilepsy?' and stuff like that."*
  Cee Lo (female, aged 8 years)

In particular, CWE reported experiencing a dilemma whereby their peers grappled with the medical jargon they used to describe epilepsy. Nevertheless, CWE felt they had no option but to employ such language in explaining epilepsy to their peers because they found it challenging to simplify their explanations.

- *"It is actually really hard to because there is actually no other word that I could describe it. But it would be very hard for them to understand…and then if I tried to explain it more they would ask more questions and more questions. And then I would get really frustrated and I'd be like, just forget about it."*
  Ruth (female, aged 13 years)

CWE described how this lack of comprehension of the condition was conveyed by their peers through persistent and repeated questioning. At times, frustrations arose amongst CWE as a result and this influenced their future engagements with others about their epilepsy.

5.2.5.5 Self and Others' Perceptions of Epilepsy

CWE's own perceptions of epilepsy, as well as their views on how others (including their parents) perceived the condition, also seemed to impact on their motivations to disclose (or not) their epilepsy to others and informed the disclosure management strategies they adopted.

5.2.5.5.1 Epilepsy: Something Private

For some CWE, their epilepsy was perceived as a private matter for family members only.

- *"Eh, well…I don't really talk about it…'cause it's…I just…it's kind of private to me so I don't tell anybody… well it's just I like to keep it private"*
  Jack (male, aged 9 years)

In some instances this was informed by the child's own negative attitudes towards his/her epilepsy, whilst in other instances this was informed by parental attitudes toward the child's epilepsy. For example, where concealment and/or selective disclosure management strategies were adopted by the parents of CWE an element of stigma-coaching seemed to occur where CWE came to view the epilepsy diagnosis as an undesirable characteristic and therefore were reluctant to be open with those external to the nuclear family about their condition.

- *"I just think my dad…even when I didn't have epilepsy he was like, 'don't tell anyone anything.'…There are just so many things that he keeps to himself because he doesn't trust anybody really. I don't know if that is the way to be, because it is really hard to be like that, so he always said that to me since I was small. So with epilepsy, I don't know...Yes because he is always at the back of my mind."*
  Rebecca (female, aged 15 years)

5.2.5.5.2 Epilepsy: Something Negative

Several CWE possessed negative perceptions of their epilepsy themselves and inherently perceived their epilepsy as a discrediting attribute. In particular, CWE reported that their

epilepsy was embarrassing, upsetting, unpleasant, and something that they would rather not have.

- *"Yes and I try to keep it private…Because it sort of makes me sad…Because I don't want to have it…I don't really like it…I would feel embarrassed, I would feel upset; I would feel all the bad things."*
  Robyn (female, aged 10 years)

Therefore, for some CWE their epilepsy was viewed as something that should not be spoken about within a public domain because such discussions evoked negative emotions.

- *"I just don't like talking about it mostly…it's just a kind of…eh…not a very nice thing to talk about, you know?"*
  Carl (male, aged 11 years)

5.2.5.5.3 Epilepsy: Others' Perceptions

The perceptions held by others regarding epilepsy also seemed to play a role in informing CWE's disclosure practices. CWE relayed how, in their opinions, other people viewed epilepsy as 'different', 'weird', and even potentially 'contagious'.

- *"Because like a lot of people think it is weird, some people don't even know what it is…Everyone looks at you weird…The odd person would find it really weird and would be like, 'what the hell, get away from me.'…You would swear it is contagious."*
  Rebecca (female, aged 15 years)

In addition, a number of CWE discussed how their peers lacked knowledge and understanding of the condition. Many of the adolescents in particular highlighted that their peers heavily relied on stereotypes of epilepsy to inform the extent of their knowledge on the condition. Such stereotypes only further reinforced misconceptions about the condition, exacerbating epilepsy-related stigma and causing reluctance in CWE to be open and honest with others.

- *"I think the only thing they really know is the shaking part of it and something to do with the brain but I don't think they really know anything apart from the stereotypical going crazy….I think a bit negative. It wouldn't be the minute you hear someone has epilepsy it would be, oh they are evil or whatever. It is just they think that is weird."*
  Aoife (female, aged 16 years)

Several CWE reported basing disclosure decisions on how they predicted that others would perceive epilepsy, with some expressing a particular desire to conceal the diagnosis from those who they perceived would hold negative perceptions of epilepsy.

- *Interviewer: "And do you think people think good things or bad things about epilepsy?"*
  Interviewee: "Well, sometimes I think bad things, sometimes I think good things."
  Interviewer: "And what about the people who think bad things about epilepsy? Who are they?"
  Interviewee: "Then I wouldn't tell them."
  Cee Lo (female, aged 8 years)

5.2.6 Children's Perceived Enablers of Disclosure

Five core enabling factors for epilepsy disclosure amongst CWE were identified. These factors, outlined below, which encouraged CWE to adopt open and/or voluntary disclosure management strategies included: 1) CWE's positive perceptions of and attitudes towards epilepsy; 2) open and positive family communication about epilepsy; 3) others' positive reactions to disclosure; 4) the child's seizure characteristics; and 5) getting help with disclosure.

5.2.6.1 CWE's Positive Perceptions of and Attitudes toward Epilepsy

For a number of CWE, their positive perceptions of, and attitudes towards, epilepsy enabled their epilepsy disclosure to others. Amongst CWE in the younger age bracket (6-10 years), positive perceptions included epilepsy conferring a 'special' status or 'special powers' on them. Parents reported that these types of perceptions facilitated CWE's open disclosure policies.

- *"It doesn't seem to faze him…he, he would go in to school the day after he has been into the hospital and say, I've seen the neurologist yesterday and this is what happened…Like it's nearly like an adventure, he's going in to tell everybody, you know that way? He's more proud of the fact that he gets to go in and tell different things …."*
  Mother of Claw (male, aged 7 years)

Amongst older CWE (11-16 years), disclosure was enabled by the adoption of pragmatic attitudes towards epilepsy, acceptance of the diagnosis and/or through the use of humour in an attempt to normalise the epilepsy.

- *"But I don't mind talking to people about my epilepsy because it is part of who I am, it is not a part I want to have but it is part of who I am."*
  Anna (female, aged 15 years)
- *"…she is the one who is constantly putting people at their ease and she talks about pill popping, so she is very active I think in normalising it."*
  Mother of Anna (female, aged 15 years)

5.2.6.2 Open and Positive Family Communication about Epilepsy

The adoption of open and positive family communication strategies surrounding epilepsy by CWE's parents within and external to the context of the family home reportedly facilitated CWE to engage in open and voluntary disclosure management strategies surrounding their epilepsy. In particular, parents viewed this as a key factor in enabling their children to openly and honestly discuss their epilepsy condition with others external to the nuclear family.

- *Interviewer: "What do you think are the kinds of things that have enabled her to be so open about her epilepsy?"*
  Interviewee: "I think because we are so open about it at home. And when she was first diagnosed with it we went to all the relation's houses that she would stay in and they were obviously very nervous about it and it was just sitting down and educating them about it and the medication."
  Mother of Jessie (female, aged 11 years)

A number of parents also reported that whilst they aimed to facilitate a home environment in which open discussion about their child's epilepsy condition was encouraged, they also ensured

to keep dialogue about the child's epilepsy within the home positive for CWE by not allowing their CWE to witness any stress and/or upset that they may be experiencing due to the diagnosis. Parents relayed perceiving that their normalisation of epilepsy within a family context and framing epilepsy positively served to enable their CWE's epilepsy disclosure.

- *Interviewer: …Em…so, is there anything that you think that gives her that good positive attitude towards [telling]…anything that enables that?*
  Interviewee: "Em… I suppose in some ways we've always treated it very natural. And as I said, when we bring her to the hospital, we'll always ask did she understand what was going on, we'll always explain it to her. And any…like…and trust me myself and my husband, we've had such stresses over it but we wouldn't have that in front of her. So, I think from that point of view, it's made it more natural for her."
  Mother of Mandz (female, aged 6 years)

5.2.6.3 Others Reacting Positively to Disclosure

Others' positive reactions to disclosure enabled CWE to disclose their epilepsy to others outside the immediate family unit. Some CWE reported past occasions where they had disclosed their epilepsy to peers and teachers relaying how others had reacted in a supportive and understanding manner. Other CWE highlighted that positive reactions for them comprised not only others being understanding about it, but also keeping an eye on them, not questioning them too much about the diagnosis and not broadcasting the condition against their will.

- *Interviewer: "What do you think is good about talking to other people about your epilepsy?"*
  Interviewee: "That they do look out for me… like I would tell them about it, some girls and guys in my class and I have noticed that they look out for me and it is nice."
  Rebecca (female, aged 15 years)

5.2.6.4 The Child's Seizure Characteristics

For a number of CWE, their type of epilepsy, seizure symptomatology and the context of their seizures occurrences enabled their epilepsy disclosure. For instance, one child perceived that others would be less likely to judge her about her epilepsy due to the fact that she only suffered from mild complex partial seizures.

- *"...well mostly because it is only a mild type, so it's not like, you know, people would judge you over it and…"*
  Audrey (female, aged 15 years)

Another child reported that her epilepsy being less severe in nature than the type of epilepsy other individuals suffer from (due to the infrequency of her seizures) enabled her to openly speak with others outside the immediate family unit about her epilepsy.

- *Interviewer: "What are the things that you think helps you to talk quite openly about your epilepsy?"*
  Interviewee: "Well since it is not that bad…I only get it a few times, it is not every day."
  Macklemore (female, aged 14 years)

5.2.6.5 Getting Help with Disclosure

A final factor that enabled CWE to disclose their epilepsy to individuals external to the nuclear family was others (e.g. peers and parents) offering assistance during disclosure exchanges. Some CWE highlighted how when peers who already knew about the epilepsy were present during disclosure exchanges, this made the process easier for them as they could contribute to the conversation if CWE struggled and/or forgot to disclose certain relevant aspects.

- *Interviewer: "And what are the kinds of things then that help you to talk about your epilepsy to others?"*
  Interviewee: "Em…if someone that already knows about it is there…and then they can help prompt me…if I forget something…it's nice to know that there's someone there that knows…and that they can help."
  Hermione (female, aged 13 years)

Other CWE relied on their parents to assist them in disclosing to peers as a number of CWE found it too challenging to comprehensively explain their epilepsy to peers themselves.

- *Interviewee: "…she [referring to best friend] was confused at the start so I had to go home and tell my Mum and Dad that I told her and then I had to ask her what is epilepsy and then when she was over we explained to her what it was about..."*
  Interviewer: "Brilliant so both you and your mum explained it together...And did that work well to be able to have each other to…?"
  Interviewee: "Yes."
  Selena (female, aged 11 years)

5.3 Parent Findings

In this section, findings are presented pertaining to parents' self-reported disclosure management strategies, their disclosure targets, the content and situational context of their disclosure exchanges, and the factors they perceived as challenging or enabling their disclosure of their child's epilepsy condition to others outside the immediate family unit. Figure 5.4 below visually represents the emergent themes from parents' perspectives. Throughout this section, selected illustrative quotes representative of the emergent themes will be embedded in the text to enhance the credibility of the findings.

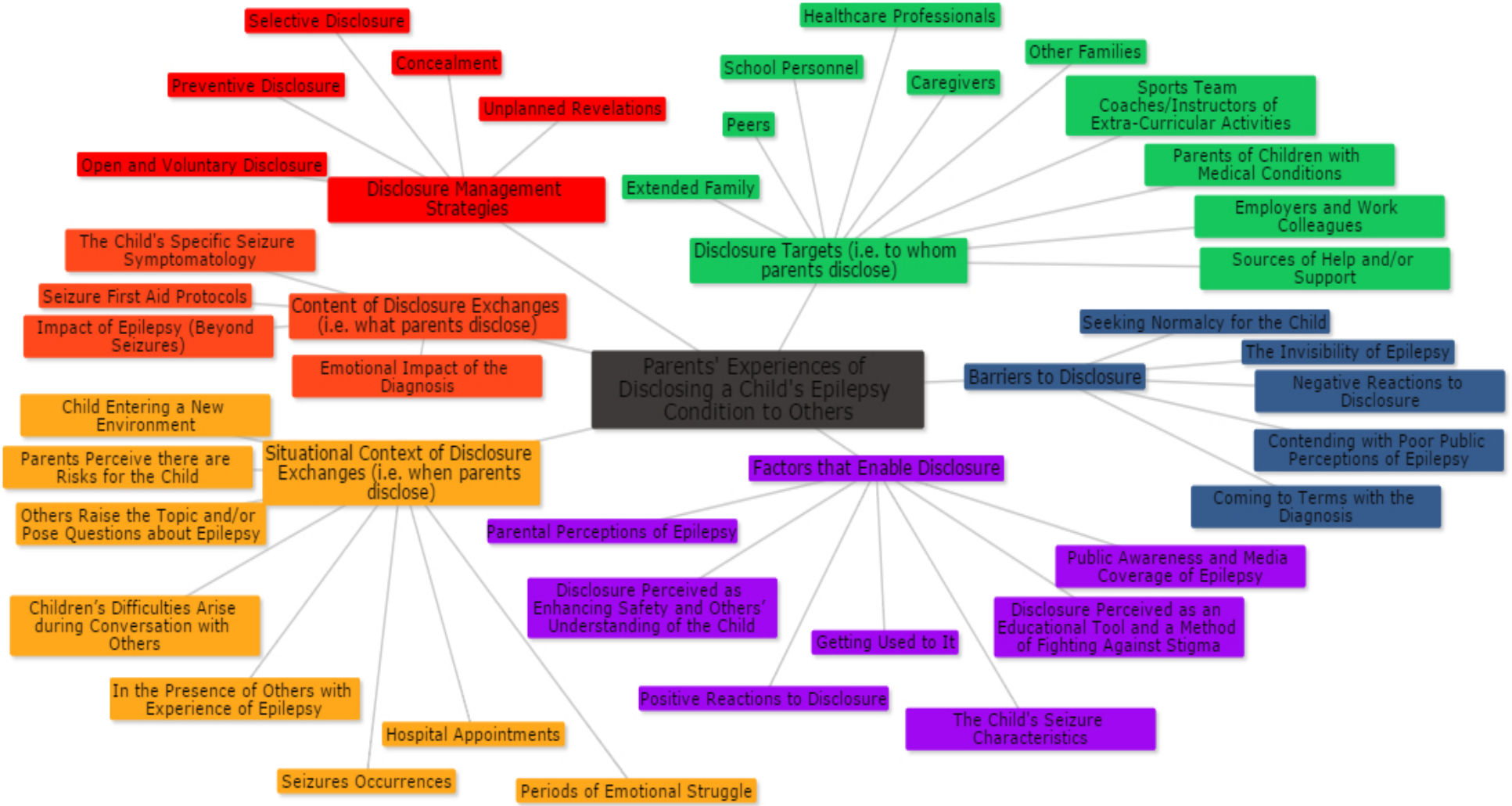

Figure 5.4: Phase One: Emergent Themes pertaining to Parents' Experiences of Disclosing a Child's Epilepsy Condition to Others

5.3.1 Parental Disclosure Management Strategies

Parents of CWE adopt a variety of strategies when communicating with others outside the immediate family unit about their child's epilepsy condition. These strategies, outlined below, span the entire spectrum of disclosure - from total concealment (i.e. working to maintain secrecy around the child's epilepsy) to full and open disclosure (i.e. disclosing to anyone and everyone).

5.3.1.1 Concealment

For some parents of CWE, concealing the child's epilepsy condition from others external to the nuclear family was reported as the preferred disclosure management strategy. A number of parents concealed their child's epilepsy by not verbally informing others about the condition (passive concealment).

- *"To date we don't discuss it as in we don't tell people, her Dad knows, you know?"*
  Mother of Taylor (female, aged 10 years)

Other parents did so by keeping physical evidence of the condition hidden from others (active concealment).

- *"…her dad finds it very hard. Men I think do, he needs to hide her helmet and stuff…"*
  Mother of Hannah (female, aged 7 years)

5.3.1.2 Open and Voluntary Disclosure

In contrast, other parents of CWE reported being more open to epilepsy disclosure. Some of these parents reported being willing and open to disclosing the child's epilepsy diagnosis and discussing the child's condition with others outside the immediately family unit if prompted.

- *"Well once we got over the initial shock of it we have always been very open about it...And we were very open that any parents or anything, if it cropped up, now we didn't go around saying, 'and of course Anna has epilepsy.' But if it cropped up we were very open about it."*
  Mother of Anna (female, aged 15 years)

Others opted to voluntarily disclose the child's epilepsy to others (by verbally instigating conversations with others about the child's condition between seizures)

- *"I mean, I talk to everybody about it, like, I talk to absolutely…like I say, I talk to strangers about it…."*
  Mother of Carl (male aged 11 years)

5.3.1.3 Preventive Disclosure

Some parents chose to disclose the child's epilepsy to others for preventative reasons (i.e. telling others in the hope of either minimising epilepsy-related stigma and/or avoiding any anticipatory risk of detection).

- *"...it was just talking to everyone about it and being open about it and not being secretive...we know about the stigma and the not talking about it and the hushing it up*

and we didn't want that. I didn't want her to be embarrassed about it or to be excluded in school, which was a major thing. So from the get go we were very open about it."
Mother of Jessie (female aged 11 years)

- *"…just in case she had a seizure in front of them…to tell them what to expect."*
Mother of Mandz (female aged 6 years)

5.3.1.4 Selective Disclosure

A number of parents spoke about being selective about: (i) who they told about their child's epilepsy condition (disclosure targets), and (ii) what information pertaining to the diagnosis they divulged to others outside the immediate family unit (disclosure content). Many parents made reference to disclosing to others on what they referred to as a need-to-know basis. This involved parents selectively disclosing the child's epilepsy only to those individuals who they deemed that it was necessary to inform, e.g. caregivers and/or any individuals who would be responsible for the child.

- *"…it's being very careful about…em…how other...people perceive him…so, I…absolutely I…I'll just make that decision myself that we don't tell anyone unless it's on a need-to-know basis and it's…yeah in sporting or, as I say, if he's to go away with, like, if he goes away on day trips with somebody or…stays overnight in somebody's house then, you know, I will be obliged to say it to them as well."*
Mother of Jack (male, aged 9 years)

Selective disclosure in terms of disclosure target was also endorsed by several parents who placed particular emphasis on withholding information about the child's epilepsy from individuals with certain perceived characteristics, e.g. those deemed to be gossipmongers.

- *"…who would I not…em…people who'd…shout from the rooftops, I definitely wouldn't tell some of the gossips, you know, who love to know other people's business, no, definitely wouldn't tell them…eh…or…em…yeah, that's who I wouldn't tell…anybody over-dramatic or love…love the bit of drama- I wouldn't tell them."*
Mother of Tom (male aged 11 years)

Furthermore, some parents highlighted the fact that they took care and were selective when choosing which aspects related to their child's epilepsy condition to reveal to others external to the nuclear family. For instance, several parents reported that during disclosure exchanges with others they stressed the child's level of seizure control. This finding was particularly salient for families where seizures occurred infrequently.

- *"Oh…I super emphasise that she very rarely gets them [laughs]. I feel sorry for those who mightn't be quite in that situation. But I would say she is highly unlikely to get anything but you have to know that she could get a seizure, she does have epilepsy. We don't make a big deal about it…and what to do if it happens. That really is it."*
Mother of Aoife (female aged 16 years)

5.3.1.5 Unplanned Revelations

Finally, several parents of CWE reported that others outside the family unit became aware of the child's epilepsy condition via unplanned revelations, whereby others physically witnessed, or

heard from others about, the child having a seizure which forced or instigated parental disclosure exchanges.

- *"…like I suppose in that way, everyone at the school…because he had such a public…em…seizure and everybody in his class saw it and everybody in his class saw the ambulance and everybody saw him…spark out on the floor…em…once that was all…like…you'd all the Mams that week asking what'd happened, if he was ok and what was going on. But once you kind of got past that…it has never really come up again."*
  Mother of Claw (male, aged 7 years)

5.3.2 Disclosure Targets for Parents

With reference to individuals outside the immediate family unit, the main groups to whom parents of CWE reported disclosing information relating to their child's epilepsy condition included extended family members, peers, school personnel (e.g. principals, teachers and special needs assistants), healthcare professionals (including doctors, nurses and psychologists), caregivers, other families, sports coaches and/or instructors of extra-curricular activities, parents of children with medical conditions, employers and work colleagues, and sources of help and/or support. Findings pertaining to the disclosure targets of parents of CWE, alongside information pertaining to defining characteristics that promote and/or discourage parental disclosure to individuals in each of these groups, are presented below.

5.3.2.1 Extended Family

Amongst parents of CWE, members of their extended family, e.g. their parents, siblings and in-laws etc., were commonly reported as disclosure targets.

- *"…I told all my sisters and my mum. Just in their own interest we just told one of your sisters and one of your brothers because we don't feel that anybody else needs to know."*
  Mother of Robyn (female, aged 10 years)

Some parents opted against disclosing their child's epilepsy to the older generations of family members (i.e. their parents and aunts/uncles) or conversations about the child's epilepsy with such individuals were limited. Such decisions were made due to the perception that epilepsy disclosure would cause elderly family members to experience undue stress and worry and/or because such individuals were deemed to possess less favourable attitudes towards epilepsy than members of the younger generation.

- *"…when I think about my family, like…they don't even use the word 'epilepsy' I know with me…I don't know, like, I kind of get the message, like, they don't really want to know because of what's happening [laughs], you know…well, I mean it must be going back, like, my Dad not telling me about his Aunt, like, and…I mean, he never mentioned it when we were growing up, like, never mentioned and she lived near us, we knew her well, like…and I never knew this about her…so there must…it's…I suppose, like, there's obviously, like, a stigma around it, like, in that generation, you know?"*
  Mother of Carl (male, aged 11 years)

5.3.2.2 Peers

Many parents reported disclosing their child's epilepsy to their own peers, in particular, friends in their immediate social circle.

- *"…I only talk to my…very close friends, my close friends about it, my buddies and…people I would trust em…"*
  Mother of Tom (male, aged 11 years)

Furthermore, some parents specified that they would only discuss certain elements of their child's epilepsy condition with their close friends.

- *"…last weekend, as I say, because we were anxious about him being so exhausted and tired - these are very good friends of ours…they know he has epilepsy…but we actually just said 'listen, if he did take a seizure in the morning, will you use a syringe, it's in the bag. Pop it into his cheek' and they didn't have a problem with that but you don't like asking people to do that, you know, they need to be pretty close to you."*
  Mother of Dave (male, aged 12 years)

Parents were more inclined to disclose to peers who adopted practical attitudes and/or were caring, kind, open-minded, understanding and good listeners. In contrast, parents were reluctant to disclose to peers who they perceived to be bigoted, ignorant, narrow-minded, gossipers, dramatic and/or overly worried types of individuals.

- *"…I just feel if somebody is going to make more of it than it is or have preconceived notions that if we felt that that may be their reaction we wouldn't be bothered with saying it."*
  Mother of Robyn (female, aged 10 years)

5.3.2.3 School Personnel

Several parents of CWE reported feeling obliged to disclose their child's epilepsy to their child's teachers, principal and other members of staff within a school context (e.g. special needs assistants) due to the duty of care conferred on such individuals during school hours.

- *"Obviously school would have to know because obviously if something happened and they didn't know that she was on a certain treatment or that."*
  Father of Lucy (female, aged 7 years)

Characteristics of school personnel that promoted parental epilepsy disclosure included their caring personalities, perceived level of involvement and personal investment in the child's condition, perceived ability to cope with the information, their practicality and/or their level of experience (this was particularly salient in reference to teachers).

- *"…I've told this teacher because…I felt she could deal with it, she didn't…she's not as soft and I felt she could, kind of, deal with it-she's teaching years and em…"*
  Mother of Tom (male, aged 11 years)

Specific factors that discouraged parents of CWE from disclosing their child's epilepsy and/or information about their child's condition to certain school personnel included their

inexperience, tendency to worry and over-react, being judgmental, defensiveness, and perceived lack of desire to engage with the topic of epilepsy.

- *"We had trouble because she* [*referring to the child's school principal] wouldn't let Ruth take part in P.E. and…it was terrible, she would leave her in 3rd and 4th class doing her work She wanted a letter from the doctor…And it wasn't just that she was free to play...Everything had to be listed, she could skip, she could jump, she could play football, she could do this. It was a nightmare. Then Ruth took another seizure later on and Ruth begged me not to tell the teacher, and I didn't. For the simple reason that it was torture for the child. So I didn't."*
  Mother of Ruth (female, aged 13 years)

5.3.2.4 Healthcare Professionals

Amongst parents, HCPs including doctors and/or consultants and nurses were frequently referred to as disclosure targets regarding their child's epilepsy. As with CWE, in the context of engaging with HCPs, for the most part, parental disclosure of the child's epilepsy does not refer to their disclosure of the child's diagnosis to such individuals due to the fact that HCPs are likely to be informed about the child's epilepsy condition prior to engaging with parents. Instead, it relates to how parents of CWE communicate with HCPs about specific elements of their child's condition, seizures and/or its consequences during clinical engagements and what they divulge to HCPs in terms of what has occurred in relation to their child's epilepsy in the period of time since their last appointment. Many parents spoke of their conversations with doctors and consultants about their child's epilepsy, with varying opinions expressed in terms of how receptive such individuals were to engaging in dialogue with them and offering help and support. For some parents, the child's doctor and/or consultant served as their primary source of information and support. Amongst such parents, several felt that they could speak with their child's doctor and/or consultant about any aspects of the child's epilepsy and that no conversation topics were off limits.

- *"And since we've started seeing Dr. [name removed], he's just so…easy to talk to. You just literally ask and he doesn't make you feel stupid. Whereas with one or two of the other consultants…you nearly felt like you were being an inconvenience calling into them…But, like, he's real easy to talk to, it's just you know, he doesn't think you're just neurotic. He doesn't think anyone's crazy…"*
  Mother of Claw (male, aged 7 years)

Furthermore, a number of parents valued HCPs who they perceived to be direct and honest with them. This encouraged open and honest parental disclosure exchanges regarding their child's epilepsy with HCPs.

- *"There are two things I look for in medical people and that would be belief in their competence and then empathy and communication…They have got the right blend of listening to you but also telling you when you need to listen and hear something. I think [neurologist name removed] is good at that, he answers questions, he invites questions but at the same time he is willing to put his opinion forward and give an opinion."*
  Father of Lucy (female, aged 7 years)

In contrast, for other parents of CWE, less favourable experiences with doctors and/or consultants caused them to be reluctant to engage in dialogue with such individuals about their child's epilepsy condition. Some doctors and/or consultants were reportedly dismissive of parents' concerns, queries and opinions.

- *"The first one [referring to neurologist] wasn't a good experience at all. I will say it straight out, he was arrogant and he didn't listen to what the mother said. Nothing personal or anything else but it was totally, what do you know, I am a doctor."*
  Mother of Hermione (female, aged 13 years)

Finally, a number of parents reported their disclosure experiences with nurses, highlighting the importance of such individuals during the immediate period following their child's diagnosis. Several parents specifically referred to clinical nurse specialists as being their 'saviour' and 'angel' during this period, with some parents reporting that these nurses were the individuals whom they confided most in about their child's epilepsy and relied heavily on.

- *"[CNS name removed] is this nurse's name, and she…I just call her my angel, she was just fantastic because I was asking all kinds of questions, one of them being 'what do we tell people?'…but she was excellent. I can't sing her praises enough…she sat with me…I said 'how did he get this? How did this happen? It's not in my family - where does it come from?'…I can't sing her praises enough...great support, yeah."*
  Mother of Tom (male, aged 11 years)

5.3.2.5 Caregivers

Many parents reported feeling compelled to disclose their child's epilepsy condition to the child's caregivers inclusive of their babysitters, nannies and childminders.

- *"…people she is staying with or who are looking after her probably need to know that it has happened…it is absolutely life as normal but the people in her life who are minding her or taking care of her would need to know. "*
  Mother of Robyn (female, aged 10 years)

5.3.2.6 Other Families

Several parents of CWE disclosed their child's epilepsy to other families inclusive of their child's friends, their child's friends' parents and their neighbours.

- *Interviewer: "Em, so who would you tell…about Luke's epilepsy?"*
  Interviewee: "Well, I have to tell…especially because it's new…we're only in [place name removed] a year now so anyone he starts playing with…I have to tell the mothers because if he's down with them…Yeah, just in case."
  Mother of Luke (male, aged 7 years)

A number of parents expressed that they found it easier to disclose the child's epilepsy to their CWE's friends than to their CWE's friends' parents, reporting that children were more receptive to epilepsy disclosure than adults.

- *Interviewer: "So do you think in a way the children are more receptive to..."*
  Interviewee: "Absolutely, than the parents...kids always come around, they are always easy with new...There is no fear with kids, they are fearless and they have seen Jessie having seizures whereas the parents wouldn't have."
  Mother of Jessie (female, aged 11 years)

5.3.2.7 Sports Coaches and/or Instructors of Extra-Curricular Activities

Sports coaches and/or instructors or facilitators of extra-curricular activities were commonly referred to as disclosure targets by parents of CWE. The fact that sports coaches, instructors and/or facilitators would be responsible for their child (albeit temporarily) was the key factor underlying parents' motivation to inform such individuals about their child's epilepsy diagnosis.

- *"Like I told...I coach the under 9s hurling and football...and I said to all the lads...all the other mentors at that age group, you know, explained what to do if he has a fit…"*
  Father of Ryan (male, aged 9 years)

Disclosure to these targets was enabled for parents where these individuals had prior experience with epilepsy and/or other medical conditions.

- *"I would make the trainers aware of it [referring to camogie trainers], they are both nurses, as it happens. So I think next week when we do go back, because she is medical in some way, I am not sure what type of nursing she does, but I might just say it to her that this might explain what you may have seen in June."*
  Mother of Robyn (female, aged 10 years)

5.3.2.8 Parents of Children with Medical Conditions

Several parents highlighted how they were particularly inclined to disclose their child's epilepsy to other parents of CWE and/or parents of children with other medical conditions.

- *"…and as I said the woman across the road as well whose son was diagnosed [also with epilepsy]…it's been amazing, like, having her…like, I've become really, kind of, quite close to her and it's been great for the two of us…"*
  Mother of Carl (male, aged 11 years)

Parents reported that their ability to identify with such individuals facilitated disclosure of their child's epilepsy to this group.

- *"We would have met another family in the hospital…myself and the mother really hit it off and she was going through the same pain as me and we were able to share a lot."*
  Mother of Ruth (female, aged 13 years)

5.3.2.9 Employers and Work Colleagues

Employers and work colleagues were a group to whom some parents reported having disclosed their child's diagnosis. For a number of parents, disclosure to such individuals occurred not out of personal preference but rather out of need; for instance, in circumstances where they required time off work due to the child's hospital appointments and/or stays, or leave due to their child's health status (dependent on their child's level of seizure control).

- *"And we need to let people know at work, my work certainly has been very flexible and helpful…All my work colleagues needed to know."*
  Mother of Tony (male, aged 13 years)

5.3.2.10 Sources of Help and/or Support

Parents also spoke about other disclosure targets who they perceived could potentially act as a source of help and/or support for them, for example, support group facilitators, adults with epilepsy, drug representatives, medical professionals, and members, liaison officers and/or employees in the national epilepsy association. For parents, disclosure of their child's epilepsy to these individuals was deemed desirable due to the potential benefits reaped through the receipt of help, assistance, guidance and/or support.

- *"…Epilepsy Ireland were brilliant. I know we went to one of their meetings…it was shortly after he'd had his diagnosis…I think I cried all the way through it…the important thing…it's like everyone says, is talking about it and being able to find a forum that you can express…your own viewpoints on it and to be able to without feeling embarrassed or anything about it, you know? So…yeah that made a big difference."*
  Mother of Jack (male, aged 9 years)

5.3.3 Content of Parental Disclosure Exchanges

Four topics relating to the content of parents' disclosure exchanges with others outside the immediate family context were identified: 1) the child's specific seizure symptomatology; 2) seizure first aid protocols; 3) the impact of epilepsy on the child and parent beyond seizures; and 4) the emotional impact of the child's diagnosis on parents.

5.3.3.1 The Child's Specific Seizure Symptomatology

Many parents spoke with others about how their child's seizures physically manifest and how such manifestations of the condition impact on the child. In particular, a number of parents specified their child's seizure type(s) and described their child's seizure symptomatology during their disclosure exchanges with others external to the nuclear family.

- *"I explain he just diverts the eyes and just kind of disappears off…it's like he just zones out…leaves the conversation, he can't hear, can't see…while it's happening em…and that's it but I always, always explain that little bit."*
  Mother of Tom (male, aged 11 years)

One of the reasons parents reported doing so was to ensure others' recognition of seizure symptomatology.

- *"…literally just that she has em…absence seizures…I normally describe it as a staring spell...she'll just stare off, normally towards the ceiling, it will last for about ten to fifteen seconds. During that time she won't be aware of what's happening around her…that's probably…the area that I'll stress...So she may be confused when she comes out of it. She will not know what's happened but she may be confused because the world has continued turning around her."*
  Mother of Mandz (female, aged 6 years)

Some parents of CWE discussed their child's seizure frequency during their disclosure

exchanges with others outside the immediate family unit.

- *"Like they know…how many did she have today and is she going mad."*
  Mother of Marie (female, aged 13 years)

Amongst parents of children with less chronic epilepsy, many cited that when conversing with others about their child's epilepsy they placed emphasis on their child's seizure freedom and the success of his/her AEDs in achieving a high level of seizure control. Downplaying and minimising seizure symptomatology during disclosure interactions was also commonly reported by parents of CWE, with parents adopting such an approach in an attempt to reassure others.

- *"…I downplay it…'listen, it's totally under control- it's nothing….just wanted you to know' because I…I say the word 'epilepsy' and people go 'oh, really? Oh right' em'…they get a bit shocked…I feel…I believe they do."*
  Mother of Tom (male, aged 11 years)

However, whilst many parents reported that their child's symptomatology was a key topic around which their disclosure interactions with others centred, some parents did not appreciate having to discuss such elements of their child's epilepsy with others.

- *"…I find it weird if people, the first thing people ask is, you know, like, what's it…what is it like and they want to, kind of, know, like, you know, they want it described, you know, the seizures, like, and I'd, kind of, find that a bit weird [laughs]…I think the hardest…I think it's when people are being really, kind of, prying about, you know, the details…the medical kind of details, I'd find a bit strange, you know?"*
  Mother of Carl (male, aged 11 years)

5.3.3.2 Seizure First Aid Protocols

Parents were extremely conscious of ensuring that others would be prepared to react in an appropriate manner to their child's seizures should seizures occur while in their presence. For this reason, several parents reported discussing seizure first aid protocols and outlining to others exactly how they should respond if they were to witness the child having a seizure.

- *"I said to all the lads...all the other mentors at that age group…in the event that I am not there and he has one, just to lie him in the recovery position and to make sure his air way is open. And obviously if it lasts longer than two or three minutes you need to ring somebody and escalate it."*
  Father of Ryan (male, aged 9 years)

In fact, one father highlighted how during his conversations with others he purposefully aimed to dispel common misconceptions about the correct protocol to adopt when responding to seizures as he himself had held preconceived notions about seizure first aid protocols prior to his child's epilepsy diagnosis.

- *"There is a big misconception, and I had it as well the first time he had the fit on the plane. I had this thing in my head that everybody said that they swallow their tongue and I started trying to stick my hands in his mouth. I nearly got my finger bitten off. I mean I thought that was what you did, genuinely, a 37 year old adult trying to stick my fingers down his throat. I specifically say that to people and I said it to all the lads in*

the GAA club, 'whatever you do, don't stick your fingers in his mouth because it is actually the completely wrong thing to do.'"
Father of Ryan (male, aged 9 years)

Finally, whilst parents were mindful to enlighten others outside the immediate family unit about seizure first aid protocols during their disclosure exchanges, some parents reported also ensuring that others did not mistake AED side-effects for indicators of seizures and/or that others did not overreact to what would be perceived as normal symptoms in other children out of fear of the child having a seizure. This was particularly salient within a school context where parents alluded to having conversations with class teachers about not sending the child home from school unless it was absolutely necessary.

- *"…I have to understand, these are young…young teachers…And it's strange. So em…I had to tell them and be persistent: 'Look she doesn't need to come home. We're not in the habit of ringing to send her home. There's no need for that'."*
  Mother of Marie (female, aged 13 years)

5.3.3.3. Impact of Epilepsy (Beyond Seizures)

When discussing the content of disclosure exchanges, parents frequently referred to the impact of the condition on the family in terms of consequences that extend beyond seizure symptomatology. Such consequences encompassed, but were not limited to, detrimental impacts on the child's behaviour, sociability and cognitive ability and on parents' sociability. Some parents highlighted discussing the diagnosis experience, as well as their child's specific diagnosis, to others external to the nuclear family during disclosure interactions. This was particularly salient amongst parents for whom the diagnosis process had been problematic.

"I just say that she has a tricky diagnosis, she has two different types. I always thought there was just one but she has two and it is a little bit of a challenge but we are getting over it and we are getting there…Our situation is getting better, it was very challenging there for a while but that is because she has two different types and it was difficult to diagnose"
Mother of Hermione (female, aged 13 years)

A number of parents discussed their child's post-ictal symptoms with others outside the immediate family unit (e.g. tiredness, heightened emotions and/or the child being non-verbal). One mother referred to the challenges of explaining the behavioural ramifications of her child's seizures to others.

- *Interviewer: "…and is there anything about the epilepsy that you do mind telling other people about or…?"*
  Interviewee: "Eh…no it's more kind of I suppose, like Claw would be non-verbal for quite a while afterwards and it would…when he was having seizures…his behaviour…the difficulties, any progress he'd made with managements…every seizure he had he went back to square one again, so you're kind of, you nearly have to retrain his brain and it's back to square one again and that would be the most frustrating thing, because you're kind of battling that as well as the epilepsy. So…"
  Mother of Claw (male, aged 7 years)

Other parents disclosed the behavioural issues associated with the child's AEDs during their interactions with others.

- *"…I remember going down and telling his [referring to the child's friend] Mum because…he was causing a bit of trouble then…in the house… I said to her, you know 'just letting you know that Jack has epilepsy and he's having some particular behavioural issues with the medication he was on'…"*
  Mother of Jack (male, aged 9 years)

With reference to the child's cognitive ability, several parents spoke of conversing with others about educational difficulties the child was experiencing due to his/her epilepsy condition.

- *"Well at the minute she is going through, like her grades in school wouldn't be that good, with all the operations her concentration is not great so at the minute I would be talking to people about that."*
  Mother of Ruth (female, aged 13 years)

Furthermore, some parents relayed that during exchanges with others about their child's condition they spoke of how epilepsy detrimentally affected their child's memory and the impact of this on their child.

- *"…She's crying out to speak to a child her age…that has epilepsy…to sit and go through things with her. She walks around in a bubble every day. She has no…conception of nothing. And do you know what? I do say to my Mam because I live next door, maybe she's better off…'Cause she's terrible memory loss…it breaks your heart…it is sad. And…it upsets me and annoys me that four years of her life is wasted. Because she can't remember four years. She cannot remember anything. They're gone. They're wiped."*
  Mother of Marie (female, aged 13 years)

Another topic that parents discussed with others external to the nuclear family was that of the social restrictions imposed on them and/or their child, as well as the adjustments that were required to be made in their lives, as a result of the child's epilepsy diagnosis.

- *Interviewer: "What are the kinds of things that you talk to people about in relation to Hannah's epilepsy?"*
  Interviewee: "…Sometimes she can't go to things or birthday parties, she can't get too excited. Or I mightn't be able to do something in the evening time because I could have to stay with Hannah, you know, that kind of way."
  Mother of Hannah (female, aged 7 years)

In addition, a number of parents highlighted that during discussions with others they relayed the risk assessments they had conducted and the adjustments that they had made to their homes with a view to minimising safety risks for their child during seizures.

- *Interviewer: "What are the kinds of things that you don't mind telling people about in relation to her epilepsy?"*
  Interviewee: "…what safety measures we have in place to avoid danger to Macklemore. For example, at night time her bed is moved into the wall, so that avoids her head dropping down between the wall and the bed. There was more furniture in that room, we took it out…What risks? It is like doing a risk assessment to reduce the risks to her."
  Mother or Macklemore (female, aged 14 years)

Though some parents reported actively discussing restrictions imposed on their child due to the epilepsy with others, other parents cited being reluctant to draw attention to such limitations. Instead, such parents spoke of placing emphasis on ensuring that others understand that epilepsy should not have consequences or repercussions for other aspects of the child's life. For instance, several parents expressed how they relayed to others that their child's development, potential and/or ability to participate in sporting activities should not be affected by their epilepsy.

- *"I suppose what I tell…that it is a challenge that she has but I don't mind telling them that it is not restricting her and it shouldn't stop her from developing normally. It shouldn't stop her from achieving her normal potential and that there is no reason for anybody with the condition to be treated differently."*
  Father of Lucy (female, aged 7 years)

Finally, some parents highlighted discussing medication and other epilepsy treatment types with others external to the nuclear family. However, for other parents they avoided this conversation topic because of either: (i) the complexity of explaining to others the process of medication withdrawal and weaning; or (ii) others' lack of comprehension about the efficacy of what they would perceive as non-traditional treatments (for example, dietary treatments).

- *Father Interviewee: "One thing I don't bother explaining to people, when you'd have to explain all about the medication and you can't come off it in one go, you have to go into big elaborate explanations so I don't bother telling people about that."*
  Mother Interviewee: "And the modified Atkin's diet was interesting because when we were on that people thought we were crazy and we used to say 'well, actually the doctor recommended it.' And at that point people were thinking we were just doing something daft and we had gone off and done this ourselves. So, I suppose that was quite a difficult process."
  Parents of Tony (male, aged 13 years)

5.3.3.4 Emotional Impact of the Diagnosis

Several parents reported that their disclosure exchanges with others outside the immediate family unit comprised discussion of the impact of their child's epilepsy diagnosis on their emotional wellbeing. For instance, parents highlighted speaking with others about their upset and struggles with the diagnosis, and also about challenging periods they had encountered as a result of the diagnosis.

- *Interviewer: "What are the kinds of things that you would talk to people about in relation to Ruth's epilepsy?"*
  Interviewee: "Em…probably the tough time we had, more so, yeah."
  Mother of Ruth (female, aged 13 years)

A number of parents reported that some of the emotionally difficult times they had experienced due to their child's epilepsy diagnosis stemmed from others' lack of understanding about their need to normalise life for the child. For instance, one mother spoke about interactions she had with her own mother surrounding sending the child to school despite the child experiencing clusters of seizures. The grandmother grappled with this choice due to the perception that she should keep the child at home; but practically the child's mother understood that if she were to

do so every time the child experienced clusters of seizures, the child would fall behind and suffer, both in terms of her schooling and her social life. Such engagements elicited feelings of frustration for this mother and she spoke of this with others to alleviate these feelings.

- *"There is times that you're upset if she's had a bad week of fits…and she's in school, and you're going…my mother's giving out to me: 'why are you putting her to school today' and I'm like 'because she has to'. You know? So, like, I talk to anybody and everybody about it."*
  Mother of Marie (female, aged 13 years)

Whilst the emotional impact of the diagnosis was a key conversation topic for parents during their interactions with others about their child's epilepsy diagnosis, a number of parents cited that discussing some of the emotional aspects of the diagnosis with others only evoked further upset and fear. One mother mentioned experiencing upset over her perceptions of the dangers of seizures, even expressing fear of death for her child. For this mother, speaking about this element of her child's epilepsy with others was evidently challenging.

- *Interviewer: "Is there any part of the epilepsy or the whole experience that you would prefer not to talk to people about?"*
  Mother Interviewee: "I suppose I don't mind speaking about any of the experiences but the one thing I do get, at times, I can get upset about it is that I feel some morning she might have a seizure and her airway is disrupted and I can't get to her in time and she might pass away. That is the one thing…The fear of her dying and not being able to get to her."
  Mother of Macklemore (female, aged 14 years)

5.3.4 Situational Context of Parental Disclosure

Thematic analysis of the data revealed eight key situational contexts under which parental disclosure of their child's epilepsy to others external to the nuclear family unfolded. These included situations when: 1) the child was entering a new environment; 2) parents perceived there being any risks for the child; 3) others raised the topic of and/or posed questions about epilepsy; 4) discussion of children's difficulties arose during conversation with others; 5) seizures occurred; 6) hospital appointments were imminent and/or had just occurred; 7) in the presence of others with experience of epilepsy; and 8) parents experienced periods of emotional struggle due to the child's epilepsy diagnosis. These situational contexts are outlined below.

5.3.4.1 Child Entering a New Environment

Many parents cited that the child entering a new environment acted as a stimulus to epilepsy disclosure. In particular, parents viewed themselves as having the onus to inform others about the child's epilepsy in circumstances where individuals outside the immediate family were going to be responsible for the child, e.g. within a school context, at extra-curricular activities or at peer playdates or parties. Sleepovers or overnight stays with others were particularly salient instances of parental disclosure exchanges with others in cases where others would have been previously unaware of the child's epilepsy diagnosis. In such situations, many parents reported

feeling obliged to tell the responsible adult about their child's epilepsy due to the duty of care temporarily conferred upon such individuals.

- *"…for example, he went on a sleepover a while ago…to a house I don't know the Mum that well, she wouldn't be a pal of mine, now, I know her and I would trust her and all that…but I felt I had to ring her and tell her just in case because he was staying the night and just in case there was anything…"*
  Mother of Tom (male, aged 11 years)

In some circumstances of CWE entering new environments, or re-registering at the start of new school years or sporting seasons, parental disclosure was necessary due to registration forms requiring them to reveal any medical conditions that the child may have for insurance purposes.

- *"…the only time recently where…I remember…he's in a badminton club…and em…we were renewing his…yeah it was in the September, we had to renew and all of that so, we went down to sign the forms and everything else and on the form…one of the things is obviously if your child has any m-, medical condition to inform us…"*
  Mother of Jack (male, aged 9 years)

5.3.4.2 Parents Perceive there are Risks for the Child

The child being in an environment in which parents perceived that risks were present for the safety of the child was a second key context under which parents disclosed the child's epilepsy diagnosis to others external to the nuclear family. Swimming pools or rivers were particular examples of such environments. Parents frequently reported that they disclosed their child's epilepsy to lifeguards and/or responsible adults in such contexts due to the risk of their child drowning during seizures if others were unaware of the child's condition.

- *"I have this automatic habit when we go swimming…'She has epilepsy', I tell the lifeguard. They need to know."*
  Mother of Marie (female, aged 13 years)

Other environments that parents perceived as presenting threats to the safety of the child and thus meriting disclosure of their child's epilepsy to others included extreme sporting activity environments (e.g. skiing) and environments where the child's specific seizure triggers may be present (for instance, one child had the potential to suffer from seizures if she became overheated; therefore, heated environments were problematic).

- *"She went down to help in the summer camp last year and of course we were told not to have her out in searing heat. Last year we had one week of searing heat…I just said to the woman would you mind making sure she has her hat on, or keep her in..."*
  Mother of Hermione (female, aged 13 years)

5.3.4.3 Others Raise the Topic of and/or Pose Questions about Epilepsy

Epilepsy coming up in conversation or others posing questions, was a further context under which incidences of parental disclosure of their child's epilepsy to others external to the nuclear family commonly arose. A number of parents made reference to disclosing their child's epilepsy to others when the topic of epilepsy was explicitly raised by others.

- *"If I am in a situation where we are chatting and epilepsy comes up, I will always say, 'I have a daughter with epilepsy.' And then discuss it like that."*
  Mother of Anna (female, aged 15 years)

However, some parents relayed that they experienced difficulties in identifying the appropriate time in a conversation to raise the topic of their child's epilepsy.

- *"…we usually tell people if it comes up. We did at the beginning go out of our way to tell people that we felt needed to know. Now it is if it comes up in conversation. Certainly it is a little bit awkward in terms of at what point you drop it into a conversation if somebody needs to know."*
  Mother of Tony (male, aged 13 years)

For other parents disclosure interactions unfolded due to others posing questions related to their child's epilepsy. Many parents indicated that it was only in such circumstances that they would disclose their child's epilepsy to others; that is, they were unlikely to raise the topic themselves.

- *"…if someone asks me about it, I'd talk to them…but I wouldn't…just come out and just tell anybody…unless I had to tell them, then I would, like…if they talk to me about it then I…I'd talk about it no problem…I don't hold it back, like, if someone asked to talk about it, I talk about it."*
  Mother of Rooney (male, aged 10 years)

Finally, for some parents, disclosure occurred not as a result of others questioning parents about the epilepsy specifically, but instead because general queries about the child indirectly resulted in the child's restrictions becoming apparent to others. In such circumstances, parents were required to explain why such restrictions existed for the child.

- *"If em…if we're talking about her in general and…or…if people are asking 'how's she getting on?' or 'does she go here?' or 'does she go there?' or 'does she babysit much?' and I can't let her babysit on her own. She used to but I can't let her now. Em…just things like that it would come up then, you know, and you'd have to explain yourself"*
  Mother of Nikki (female, aged 15 years)

5.3.4.4 Children's Difficulties Arise during Conversation with Others

Discussion of children's difficulties arising during conversation with others was a further key context under which parental disclosure exchanges with others outside the immediate family unit unfolded. Several parents relayed that they divulged information pertaining to their child's epilepsy to others (at times, in situations when they usually would not) when others were also revealing what was perceived to be difficult information about their children, such as in circumstances where parents shared information about their own children's medical conditions.

- *"And I remember, again, when I was at a badminton match…all the same women go and we all sit together and it was one of them I'd gotten to know particularly well because…Jack was partnered with her son and we were sitting down talking and she was saying her son had problems with…medical problems…and then, I don't know, it was funny, then I turned around and I said it. Normally, I wouldn't just say it…and I said...'gosh, you know, Jack' and 'he was diagnosed with epilepsy there a year ago'…"*
  Mother of Jack (male, aged 9 years)

5.3.4.5 Seizure Occurrences

Seizures occurrences denoted a further stimulus for parental disclosure to others external to the nuclear family. Parents reported that they were more prone to informing others about the child's epilepsy in instances where seizures had just occurred than in periods of seizure freedom.

- *"In terms of just every day conversation, if she has had a seizure I will say it, I will discuss it with my friends. Look Anna has just had a seizure."*
  Mother of Anna (female, aged 15 years)

Furthermore, parents reported that disclosure interactions with others surrounding incidences of seizures predominantly occurred either due to resultant infringements on the parent's life that required explaining (e.g. the parent having to take time off work) or because parents perceived that telling others would result in the receipt of support and help.

- *"... I told the teacher that she had taken the seizure because I felt...Ruth had an SNA for a year and then she was fine so she lost it after the year. Then I thought when she took this seizure I had better tell the school and for reassurance for me, her going to school, I would love if she could get the SNA back for a few days just for the extra comfort…You don't really need to know unless there are very recent ones. If it is recent I feel I have to."*
  Mother of Ruth (female, aged 13 years)

5.3.4.6 Hospital Appointments

The period of time before and after hospital appointments was a further key context under which parental disclosure of their child's condition to others arose. Parental disclosure in such a context frequently occurred due to the topicality of the child's epilepsy during these periods.

- *Interviewee: "I don't really mind talking about it. I would say, 'we are going to [hospital name removed] next week.'...if they didn't know I would tell them..."*
  Interviewer: "So you would just bring it up if there was an appointment coming up…?"
  Interviewee: "Yes I have never really made it a big issue."
  Mother of Rebecca (female, aged 15 years)

5.3.4.7 In the Presence of Others with Experience of Epilepsy

Several parents cited that disclosure exchanges with others external to the nuclear family occurred in contexts where they learned that these individuals had either personal experiences of epilepsy or a medical background and thus knowledge or occupational experience of epilepsy.

- *"I told somebody recently, I was with...we were talking about something else, and it just came up in the conversation and…it turned out then this woman, her brothers, two of her brothers have epilepsy, I learned notes from her then…"*
  Mother of Carl (male, aged 11 years)

Other parents of CWE relayed that they raised the topic of their child's epilepsy when in the presence of people with a medical background, anticipating that such individuals would have insights into the condition that lay-people may not have.

- *"…if I hear of anyone staying in [place name removed] and they are a doctor I bring it around because everyone has a nugget of information. It was actually the doctors that we had last year that said, 'everyone in America that has epilepsy, they are all doing yoga.' That is what he said…So I thought she can do yoga as well."*
  Mother of Hermione (female, aged 13 years)

5.3.4.8 Periods of Emotional Struggle due to the Child's Diagnosis

A number of parents alluded to the fact that disclosure exchanges with others unfolded in the context of periods of emotional struggle as they grappled with the child's epilepsy, for example, after a tough day and/or when seizures occurred that were particularly distressing to witness.

- *"…sometimes I need to just kind of, like, for the emotional support and just if we've had a bit of a tough day and I'm feeling like it's all a bit hopeless…I don't really feel like that very often…but every now and then I'd be like, 'oh, ok, I need to have a chat'…"*
  Mother of Cee Lo (female, aged 8 years)

5.3.5 Parents' Perceived Barriers to Disclosure

Five themes (and a number of sub-themes) representative of the barriers to disclosure parents experienced emerged, many of which promoted concealment and/or selective disclosure management strategies. These included: 1) seeking normalcy for the child; 2) the invisibility of epilepsy; 3) negative reactions to disclosure; 4) contending with poor public perceptions of epilepsy; and 5) coming to terms with the diagnosis. Further elements to each of the themes and subthemes are presented below and in Figure 5.5.

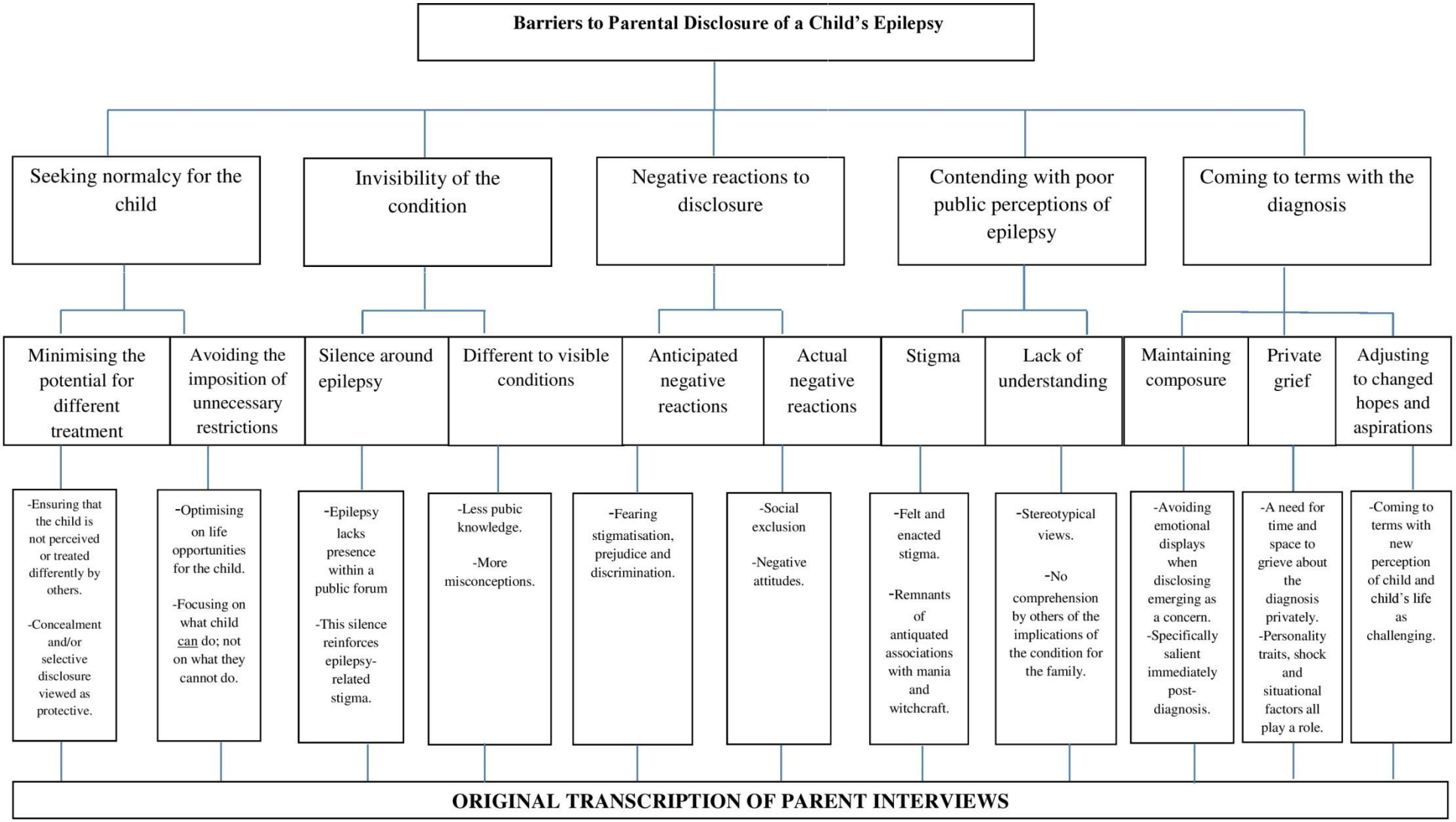

Figure 5.5: Barriers to Parental Disclosure Main Themes and related Sub-Themes: Pathway of Organisation as Identified through Analysis of Transcribed Interviews

5.3.5.1 Seeking Normalcy for the Child

For many parents, seeking normalcy for their child was a priority. Numerous parents felt they had a duty of care to protect their child from any threats to normalcy. Some parents referred to disclosure as challenging because they perceived others knowing about their child's epilepsy as placing the child at risk of receiving different treatment and experiencing unnecessary restrictions. Consequently, parents viewed concealment and/or selective disclosure management strategies as beneficial in facilitating the pursuit of normalcy for their child and protecting their child's psychosocial wellbeing. This was a particular concern for parents of younger children.

5.3.5.1.1 Minimising the Potential for Different Treatment

A number of parents described striving to foster a sense of normality for their CWE by ensuring where possible that others did not treat or perceive the CWE differently because of epilepsy.

- *Mother Interviewee: "I wouldn't like it to impact on anything that is done with her or about her. I would prefer if she continued on absolutely as normal…"*
  Father Interviewee: "I think we discussed the event in terms of that we want her to lead as normal a life as possible and we don't want it to be a crutch for her to hold her back."
  Mother Interviewee: "Or an excuse to inhibit her doing anything or making choices… I just wouldn't want anybody thinking any more or less of her because of it or treating her any differently."
  Parents of Robyn (female, aged 10 years)

Some parents reported considering the perceived risk of disclosure resulting in consequences that would compromise this sense of normality e.g., 'drama' arising, the CWE being 'labelled' or thought 'less of', or others viewing the diagnosis as infringing on the CWE's ability to reach his/her 'potential' and thus changing their treatment of the child.

- *"…She said 'no, you should tell people', she said 'because of…they're aware' and I said 'well, yes…I see what you're saying…but he's young and I…I need to protect him' and I said 'if there's any chance that anyone out there is going to treat him any differently because of it…I am not going to tell them that…you can understand that when it's your child…it's a different thing than me as an adult having it and making that decision' but I said 'I have to look out for him'."*
  Mother of Jack (male, aged 9 years)

Amongst parents who perceived such risks existed, concealment and/or selective disclosure strategies were viewed as protective mechanisms to guard against such consequences.

- *Interviewer: "And is there anything that would prevent either of you from talking about it ever?"*
  Mother Interviewee: "Not if it needed to be talked about. As I say maybe we won't now because it can be a bit tiresome or it might define him. It might be nice for people to think about Tony just as Tony and not the little boy with the epilepsy."
  Mother of Tony (male, aged 13 years)

5.3.5.1.2 Avoiding the Imposition of Unnecessary Restrictions

Many parents emphasised the importance of their child availing of the same opportunities and partaking in the same activities as their peers, and/or continuing to pursue activities (e.g. competitive sports) they had engaged in prior to the epilepsy diagnosis.

- *"…like… sport-wise, you know, he wants to get on the top team…if you say too much …if you say he's very poorly…they're not going to put him on the team. You know, he did the wakeboarding nationals and he was going for gold….we said 'do we say anything?' and we didn't this year. Now, this would have been to the drivers of the boats and the judges but we actually said nothing, we just said 'we'll keep checks, we'll know when he's not right'…we don't need to tell anybody because…it could be, you know, they could go very gently on him then…and I just felt no, just say nothing, let him do what he wants to do and we'll handle it if…if needs be…"*
  Mother of Dave (male, aged 12 years)

Concealment and/or selective disclosure strategies were deemed desirable in instances where parents were concerned that life opportunities or participation in activities would be compromised due to the imposition of unnecessary restrictions on their child by others, if they were to learn of the diagnosis.

- *"I mean the challenges, the risk of the potential of her being treated differently or to be looked on as someone who has got restrictions or stuff like that. So, someone you would view as I don't want to tell that person because I don't believe that they would make the effort or they are open-minded enough. And the worry about your life is what restrictions are going to be put in place…Whereas I just want to make sure there aren't any restrictions for her…it is just the natural fear of the stigma…."*
  Father of Lucy (female, aged 7 years)

5.3.5.2 The Invisibility of Epilepsy

The invisible nature of epilepsy both in terms of how the condition is often not immediately physically apparent to others and the silence that surrounds the condition within the public arena acted as a deterrent to disclosure for many parents. Parents also highlighted the reluctance of members of the public to broach and/or engage with the topic. Additionally, parents made reference to dissimilarities between epilepsy and other 'more visible' conditions, commenting on how these conditions are viewed more favourably than epilepsy. The invisibility of epilepsy encouraged some parents to conceal and/or selectively disclose their child's epilepsy diagnosis.

5.3.5.2.1 Silence around Epilepsy

Parents felt epilepsy was invisible within the public domain. They believed there was a lack of dialogue about epilepsy, it received limited media attention and few public figures advocated for it. Parents thought this silent message, reflective of how epilepsy is perceived by society, was not a positive one. It suggested to them that others were uncomfortable with and fearful of epilepsy.

- *"Well because I think that is something that is not in the public domain. I think it is not something that is talked about. I think people have very little awareness of it. People*

are very uncomfortable around it. I think it is a very complex one because there are very few people with a public profile who are open about having epilepsy. There are very few positive role models. And it is not something that comes up very often. I think in general it is something that people tend to cover up a lot."
Mother of Anna (female, aged 15 years)

This caused reluctance amongst several parents to disclose their child's epilepsy to others.

5.3.5.2.2 Different to Visible Conditions

A number of parents made comparisons between epilepsy and other chronic conditions (e.g. cancer, cystic fibrosis, eczema) they perceived to be more visible due to their physical manifestations, reporting that such conditions are less 'hidden', have fewer negative connotations, and receive more attention within a public forum.

- *"…it's a funny thing because, like, you know, kids that have, say, Cystic Fybrosis and other em…things…people seem to be able to talk about them more…I don't know what it is with the epilepsy…it seems to be more hidden and…I don't think people understand it…you know? I don't know…or maybe because they haven't got a physical…deformity to the…you know what I mean?"*
  Mother of Luke (male, aged 7 years)

This heightened the feeling amongst parents that epilepsy is a stigmatised condition, thus promoting parental silence surrounding the condition. Some parents also referred to how in comparison to the seemingly innocuous physical manifestations of many other more visible, chronic conditions, when the symptoms of epilepsy do physically manifest, they can be intrusive, startling, fear-evoking, and distressing to witness.

- *"…'cause it's in the mind that it's kind of invisible…I mean…if you've a broken leg or if you have, god forbid, cancer or something like that, I guess it's more visible in terms of either they'd have a cast on or if you're going to chemotherapy you'll start to lose your hair…With something like epilepsy…you look absolutely perfect from the outside…it's what goes on in the head and it's how it's manifested is so frightening…"*
  Mother of Jack (male, aged 9 years)

Amongst these parents, if the child's epilepsy was well-controlled or if seizures occurred only within the confines of their home (e.g. nocturnal seizures), some chose concealment and/or selective disclosure strategies to avoid experiencing negative reactions from others.

5.3.5.3 Negative Reactions to Disclosure

Fear of negative responses, as well as actual experiences of negative reactions by others to past parental disclosures of the CWE's diagnosis, presented challenges for some parents. In instances where parents perceived there was a risk that others would respond negatively, or indeed when they and/or their child had suffered negative ramifications as a result of previous epilepsy disclosure exchanges, parents tended to either maintain secrecy around the child's diagnosis or be selective in terms of disclosure targets (i.e. to whom they would disclose) and content (i.e. what aspects of the diagnosis they would discuss with others).

5.3.5.3.1 Anticipated Negative Reactions

Some parents relayed fearing that subsequent to disclosure of the CWE's diagnosis they and/or their child would be subjected to stigmatisation, prejudiced attitudes, discrimination, and/or exclusion from social, recreational and/or sporting activities.

- *"…and we were chatting about it [referring to the child's epilepsy]…and I came home and I was so worried about it that I rang her [referring to another child's mother] the following day and I said 'I hope you don't mind me saying…asking you would it…would you mind not telling anyone about that?' and...she said em 'my mother has epilepsy', she said 'don't worry about it', she said 'I understand how you feel' and she said 'but don't…don't feel you can't say it to people' and I went 'oh no, I…I would feel that I can't say it to certain people because of their reaction'."*
  Mother of Jack (male, aged 9 years)

In particular, several parents alluded to being apprehensive about how parents of their child's peers would respond and whether this would limit future invitations to playdates, parties and sleepovers, and consequently negatively impact on their child's friendships and socialisation.

- *"…I have found…last year he got invited to a class party and I had to tell the woman… and I was actually dreading telling her…because I was afraid she wouldn't want him to go then. And then I said to myself, well, she's not going to say he can't go because of it but…I knew by the look on her face …she didn't really want to bring him…probably in case he had one…but she still brought him…but em…he wasn't asked the next year."*
  Mother of Luke (male, aged 7 years)

5.3.5.3.2 Actual Negative Reactions

A number of parents reported how prior disclosure exchanges had resulted in negative consequences for them and/or their child. For some families, parental disclosure had resulted in the CWE receiving fewer invitations to social occasions, being excluded from participating in physical education in school or being denied enrolment in recreational activities.

- *"People are less inclined to bring you to their house because they are afraid, what if they have a seizure, what am I supposed to do? And it doesn't work like that, so there is a lot of ignorance out there...and it has been said to me, 'I would invite him over only I am afraid he will have a seizure'."*
  Mother of Colm (male, aged 12 years)

Detrimental impacts for parents included: offensive reactions (e.g. others mimicking seizures), difficulties in finding someone to care for their CWE in their absence, and others creating drama around the condition and/or demanding that the parents provided extra supervision (which was perceived as unnecessary) for their CWE during activities.

- *"…the Scouts would have to be the worst case where we tried to enrol him in the local Scout troop…the first crowd we went to were bordering on the insulting in that, God he has got epilepsy. And one of them was in the background doing this [mimicking a seizure] to the other fellow as if to say, this is what we are signing ourselves up to with this guy. It shocked me. It is a national organisation, they probably get national money and they are excluding somebody for a medical reason."*
  Father of Tadhg (male, aged 12 years)

Furthermore, a number of parents reported receiving the impression from others external to the nuclear family that they were uncomfortable with the topic of epilepsy and/or would rather not engage in dialogue about it.

- *"…her reaction was I don't know…I could just feel her backing away actually…you know, you have an instinct about things like that anyway…she didn't really say very much at all…and then I thought 'oh yeah there's the person now who doesn't want to know about it'…"*
  Mother of Jack (male, aged 9 years)

These experiences elicited negative emotions amongst parents (e.g. anger, concern, sadness, disappointment) and played a role in promoting parental disclosure decisions of concealment or selective disclosure.

5.3.5.4 Contending with Poor Public Perceptions of Epilepsy

Several parents believed public perceptions of epilepsy were poor. Some parents felt that epilepsy as a condition is stigmatised and others made reference to the dearth of knowledge and understanding about epilepsy amongst the general population. Parents asserted that negative perceptions of epilepsy were difficult to contend with and contributed to their reluctance to disclose their CWE's diagnosis to others.

5.3.5.4.1 Stigma

Some parents alluded to the stigma surrounding epilepsy, likening it to the stigma that encircles mental illness. Many parents discussed how, to their dismay, they felt that antiquated misconceptions of epilepsy persisted in modern day society, e.g. the notion of epilepsy as contagious and associated with mania and witchcraft.

- *"…it's like a hidden thing or something…like, I even find adults that have it don't like telling…you know…talking about it…I don't know whether it's the stigma attached from years ago because they thought people were…manic, you know, when they had it, so...I think it's there's a lot of stigma attached to it."*
  Mother of Luke (male, aged 7 years)

Parents highlighted how epilepsy-related stigma manifests itself in others as fear and/or discomfort.

- *"…for some people, you know…it's a throwback to that…people like that would have been burned at the stake, considered a witch, you know…because it's around the mind, as I said, like a form of a depression, em…people just would've been unsure about somebody who has depression maybe years ago…I think there's probably a little bit of a…a hangover that way with some people that they just…when it comes to the mind, it's not something they're sure about, it's not something they're comfortable around…and that maybe they'd prefer not to know about it or that they hope it won't impact on their life in anyway, so, yeah…"*
  Mother of Jack (male, aged 9 years)

For one family, this stigma seemed to be more profoundly felt due to culture dictating that epilepsy is not something that is acceptable (parents of Nigerian origin/descent).

- *"Um…well, where I come from…you know sometimes if you want to marry…they do a research into your family…and if you have something like that…it's a no-no...so…um…I'm not sure my kind of people are really aware of it…or know what…you know? They just see it as…You know, sometimes they even think it's contagious…"*
  Mother of Taylor (female, aged 10 years)

Concealment and/or selective disclosure management strategies were preferred by families who perceived epilepsy-related stigma as problematic.

5.3.5.4.2 Lack of Understanding

Lack of public understanding and knowledge regarding what epilepsy is, the various presentation of seizures, and what epileptic syndromes encompass (i.e. the physical, cognitive, emotional and psychosocial consequences of epilepsy that have ramifications for CWE and their parents) inhibited parental openness about their child's epilepsy.

- *"Interviewer: Is there anything that you would find challenging about talking to other people about Hannah's epilepsy?*
  Interviewee: That they don't understand it. And then I don't know if I am explaining it properly although I know a good lot so far."
  Mother of Hannah (female, aged 7 years)

Stereotypes, common misconceptions, and the complexity and heterogeneity of the condition exacerbated this lack of understanding by others.

- *"People have fairly simplistic views, I don't think people have any understanding of the breadth of the number of different types of seizures. They don't have any idea of how the side effects, the medication can impact or how tiring it can be."*
  Mother of Tony (male, aged 13 years)

Additionally, several parents reported that a perceived lack of desire from others to engage in discussion and learn about the child's epilepsy fostered their unwillingness to disclose.

- *"...her reaction was…I could just feel her backing away actually…she wasn't making much eye contact and…she wasn't really speaking much about it, she wasn't, kind of, em…empathising. You know the way some people go 'oh gosh, that's awful, that must have been very scary for you'...she didn't really say very much at all…and then I thought 'oh yeah there's the person now who doesn't want to know about it'…"*
  Mother of Jack (male, aged 9 years)

5.3.5.5 Coming to Terms with the Diagnosis

For many parents on receiving the diagnosis of their child's epilepsy, a period of grief ensued as parents grappled with the loss of their 'healthy child'. Many parents verbalised that the diagnosis had a profound emotional impact, evoking 'devastation', 'upset', 'concern', 'worry', and 'shock'. Parents reported struggling to maintain composure when speaking with others about their child's diagnosis. Parents also spoke about the need for time and space to privately grieve the loss of their 'healthy child'. Furthermore, parents expressed difficulties with adjusting their hopes and expectations for their child due to the epilepsy diagnosis. During this period of parental struggle (which varied considerably in length across families), many parents

expressed that disclosure was problematic. They consequently adopted concealment and/or selective disclosure management strategies.

5.3.5.5.1 Maintaining Composure

A number of parents relayed how speaking with others about their child's epilepsy diagnosis elicited tangible evidence of upset (i.e. 'tears', a 'wobble in [their] voice' and 'crying'). Several parents verbalised their discomfort with others witnessing them in this emotionally vulnerable state and their felt need to 'hold it together' when disclosing their child's diagnosis to others.

- *"Em…in the beginning I suppose I might have been slightly…no, I wasn't even nervous…I was probably more so…em concerned about my reaction, that I'd hold it together when I was telling other people about it. Because it's n-...in the very early days but at this stage it doesn't bother me…"*
  Mother of Mandz (female, aged 6 years)

Notwithstanding this, maintaining composure when speaking to others about their child's diagnosis was difficult for many parents, particularly in the time-period immediately post-diagnosis.

- "*In the beginning I…I must admit I found it very hard. I mean, I used to get very upset talking about it."*
  Mother of Audrey (female, aged 15 years)

Consequently, several parents adopted concealment or selective disclosure strategies to avoid public emotional displays.

5.3.5.5.2 Private Grief

Many parents relayed that following receipt of their child's epilepsy diagnosis, they embarked on a period of mourning for the loss of their 'healthy child'. A number of parents spoke of how they needed time and space to grieve privately, and to process and come to terms with the diagnosis before they were capable of speaking about it with others.

- *"Once she had the second one I just felt absolutely sick to the core and I actually couldn't use the word, we didn't tell anybody because I couldn't articulate it for months. It was in November and we had the grandparents here for about a month at Christmas and at that stage she was having seizures left, right and centre. We never told them so we had this farcical situation where this child was on the floor in the hall having a seizure and we were kind of standing saying, 'another cup of tea?' It was utterly crazy really. But devastated, absolutely devastated…"*
  Mother of Anna (female, aged 15 years)

How families processed this grief varied significantly across families, dependent on a number of situational factors. Some parents felt they possessed personality traits that heightened their reluctance to disclose their child's diagnosis. For instance, parents who perceived themselves as 'private' by disposition, or parents who expressed their preference to 'suffer in silence' rather than seek help and support from others, were less likely to disclose their child's diagnosis to others during this grieving period.

- *"...I wouldn't be a very good person at going away and getting help, I would probably suffer in silence. Like I never contacted that epilepsy group, never, even though I got literature. Many is the time people were trying to tell me to do it but I never…thought about it and I thought, no I don't want to. It is just me, I am not very outgoing, I am a more private kind of person."*
  Mother of Ruth (female, aged 13 years)

Some parents reported that coming to terms with their child's epilepsy diagnosis was a difficult and lengthy process because it had come as a complete shock to them ('how did this happen?', 'when I was pregnant with her I did everything right') or because they had negative perceptions of epilepsy themselves ('because I believe people might be afraid of the full seizures, because I was'). A number of parents engaged in denial as a coping mechanism in the initial period following their child's epilepsy diagnosis. In this context, disclosure was extremely challenging.

- *"I didn't want Tadhg to have epilepsy so I would have said Tadhg had encephalitis, it was having post-encephalitis seizures. I didn't use, and for a long, long time I couldn't spell the word epilepsy, I just had a mental block, I just couldn't spell it. There was definitely a mental block there...it is just not something I want my child to have."*
  Mother of Tadhg (male, aged 12 years)

Finally, in one family, situational factors surrounding the origin of the child's epilepsy (i.e. the child sustained a head injury while in his father's care) only exacerbated negative feelings surrounding the child's diagnosis. For this father, manifestations of the child's epilepsy served as a constant reminder of the role he perceived he had played in the development of his child's epilepsy, placing a heavy emotional burden on him and evoking feelings of guilt. Disclosure was particularly challenging for this father because telling others only served to evoke negative memories and caused him to relive feelings of grief, self-blame and guilt.

- *"Yeah…um…he actually fell out of my hands when he was 6 months of age…em…at the top of the steps…and he had a two inch fracture…em a tear to the brain and em…a blood clot…they did say that he more than likely was gonna have seizures…if I'm being truthful I…I think it was guilt. And…and I'll tell you for why…is because there isn't a day goes by that I've-…that I don't think about what happened…and so…it's just…I wouldn't…the reason I don't talk about it is 'cause it brings up so many bad memories…and that's why I don't talk about it."*
  Father of Paul (male, aged 13 years)

5.3.5.5.3 Adjusting to Changed Hopes and Expectations

Several parents recounted how their child's epilepsy diagnosis had dashed and/or altered pre-conceived hopes and expectations they had held (at times unwittingly) for the future of their child.

- *"…at the beginning, like…when we found out…you just think you're losing your mind…your whole world is just totally different…and I think it's just your expectations for your child are totally different and…em…you don't even know that you have an idea what their future is going to be like but…obviously I did have an idea because now I've a totally different idea what his future's going to be like or might be like…"*
  Mother of Carl (male, aged 11 years)

Particularly in the initial stages post-diagnosis, parents perceived that their child's academic, occupational, romantic and/or social potential would be limited due to his/her epilepsy.

- *"Oh sure listen at 6 years of age Anna has epilepsy and I am thinking, oh my God she will never have a child, oh my God she will never get married, oh my God she will never go to college…sure, my other three children might never get married, they may never meet someone, they may never have a child. It never dawned on me for one second. But it was just this whole…everything came tumbling in together."*
  Mother of Anna (female, aged 15 years)

During this initial period of adjustment, parents relayed that the prospect of disclosing their child's epilepsy to others was difficult as it elicited emotions of concern, worry and upset.

- *Interviewer: "…can you tell me a little bit about what it's like for you to talk to other people about Jack's epilepsy?"*
  *Interviewee: "…it's got easier. It's definitely got easier. It would have been…it would have been very upsetting at the beginning…the other day…I was talking to an old friend of mine and I could feel the tears coming on again…and I thought 'oh my God, I'm still…'…the wobble in my voice…em *gets upset*"*
  Interviewer: "We can take a break."
  Break taken until parent felt comfortable to resume the interview
  Interviewee: "I think it's more for…em…I think it's just for Jack really…it's…you don't want him to have any obstacles, you know, when he gets older…"
  Mother of Jack (male, aged 9 years)

5.3.6 Parents' Perceived Enablers of Disclosure

A number of enabling factors were identified that encouraged parents of CWE to openly disclose their child's epilepsy condition to others external to the nuclear family including: 1) parental perceptions of epilepsy; 2) the perception that disclosure enhances the safety and others' understanding of the child; 3) positive reactions to disclosure; 4) the child's seizure characteristics; 5) the perception that disclosure is an educational tool and a method of fighting against epilepsy-related stigma; 6) getting used to it; and 7) public awareness and media coverage of epilepsy. Each of these enabling factors will be discussed below.

5.3.6.1 Parental Perceptions of Epilepsy

For a number of parents, their perceptions of epilepsy played a role in enabling them to openly discuss their child's epilepsy with others.

- *Interviewer: "What is it that you think enables you to talk quite openly about his epilepsy to other people?"*
  Mother Interviewee: "I don't think we have our own, like we don't have any..."
  Father Interviewee: "Hang ups, it has just happened."
  Mother Interviewee: "There is nothing to be ashamed of, we don't have any superstitions about it, we don't have any old fashioned views about it and if anybody does then that is their problem and not ours."
  Parents of Tony (male, aged 13 years)

In addition, several parents reported adopting pragmatic attitudes towards the child's epilepsy diagnosis, viewing it as just part of the child's life and accepting that the condition is something that the family has to get on with. The adoption of practical attitudes enabled disclosure.

- *Interviewee:" Em…and so what do you think are the things that enable you to tell other people about her epilepsy so openly?"*
  Interviewee: "Em…I suppose it doesn't bother us. It's just something that…she has. It's part of her. Em…it's something that we have to deal with one way or the other… Em…so…it doesn't particularly bother us if…yeah, look she can't help having it…one way or the other. So…"
  Mother of Mandz (female, aged 6 years)

Some parents spoke of how they perceived that epilepsy being a medical condition, rather than a behavioural, psychological and/or psychiatric condition, encouraged them to be open about it with others external to the nuclear family. This was due to their perception that others view medical conditions in a more positive light and demonstrate greater understanding towards individuals with medical conditions than they do towards individuals with behavioural, psychological and/or psychiatric conditions.

- *Interviewer: "...what's it like for you yourself to tell other people about his epilepsy?"*
  Interviewee: "Em… it doesn't…like it's a medical condition so it doesn't really bother me. It's more, all…like I say…it's all his other stuff [referring to behavioural issues]… it's harder. Because people can kind of say, "Right you have a medical condition". But, the…it's the other issues that are far more harder to explain..."
  Mother of Claw (male, aged 7 years)

Furthermore, some parents rationalised the child's epilepsy diagnosis through use of downward comparison (i.e. by drawing comparisons between the impact of their child's epilepsy diagnosis on their and their child's life and the impact of more chronic and/or severe types of epilepsy or other medical conditions on other parents' and children's lives). This type of strategy, employed by numerous parents in their attempt to come to terms with the child's diagnosis, was reported as an enabling factor for disclosure of their child's epilepsy condition to others.

- *Interviewer: "And what are the things that you think enable you to talk quite openly about Audrey's epilepsy?"*
  Father Interviewee: "Well…it's nothing to be ashamed of so...it's just a fact you know."
  Mother Interviewee: Exactly, it's a fact of life now.
  Father Interviewee: "And like I said, we're just glad that we found out what it was…I think it would be much worse if we were thinking in the dark 'cause even brain tumours and all the other stuff…"
  Mother Interviewee: "Because that's what we were thinking…brain tumours or…with the headaches and everything."
  Interviewer: "Yeah exactly, so in comparison it was like…"
  Father Interviewee: "Yeah it was like a huge relief, for me at least."
  Parents of Audrey (female, aged 15 years)

5.3.6.2 Disclosure Perceived as Enhancing Safety and Others' Understanding of the Child

Amongst parents of CWE, a key enabling factor for disclosure of their child's epilepsy diagnosis to others outside the immediate family unit was the perception that disclosure enhanced the child's safety and/or others' understanding of the child.

- *"I would say for safety reasons. If I thought she was going to be amongst strangers…even thought there was an extremely slight risk of her getting a seizure I would say it. Because I think that if they know then they are not going to over react and make too big of an issue of it for her."*
  Mother of Aoife (female, aged 16 years)

This was particularly pertinent where the child was going to be in the care of someone other than an immediate family member.

- *"…disclosure is important for the people that are around him. He is in a very supportive environment wherever he is…in school and any clubs he is in...I think from that point of view we have always had full disclosure to anybody and everybody who is in charge because it is important that they need to know in case anything happens."*
  Mother of Tony (male, aged 13 years)

Additionally, for some parents, disclosure to others external to the nuclear family was enabled by their perception that this would enhance others' understanding of the child's behaviour. This was particularly salient amongst families where CWE experienced significant behavioural changes as a result of their epilepsy.

- *"…I told her [referring to the child's teacher]…they usually have a one-on-one in school…so we were talking about Taylor's behaviour, she said…'sometimes she's really quiet and other times she's really loud'…and 'sometimes she's just a bit lost' [laughs]...So, I had to explain to her that…if she…had a seizure she's…and she said 'oh, ok'…So, she kind of relates that to some of the things...going on…you know?"*
  Mother of Taylor (female, aged 10 years)

5.3.6.3 Positive Reactions to Disclosure

Many parents highlighted how positive responses to disclosure in the past had encouraged them to speak openly about their child's epilepsy. Positive reactions from others included expressions of interest, curiosity in the child's epilepsy and accepting the child's diagnosis for what it was without any judgement.

- *"Yes they would be interested and trying to ask me questions and people who are my friends would want to know more."*
  Mother of Hannah (female, aged 7 years)

Additionally, experiences where disclosure of the child's epilepsy had resulted in the receipt of support and help from others encouraged further parental disclosure exchanges with others.

- *"...yeah I do probably, particularly when he's not well, I actually do probably talk about it…em…and people are very sympathetic and very supportive…"*
  Mother of Dave (male, aged 12 years)

5.3.6.4 The Child's Seizure Characteristics

Several parents reported that factors related to their child's epilepsy symptomatology (e.g. their type(s) of seizure and level of seizure control) influenced their disclosure of their child's epilepsy to others external to the nuclear family. For instance, amongst parents of CWE with absence seizures, disclosure to others was enabled by the perception that the mildness and lack of intrusiveness of these seizures would result in a more positive response than if their child experienced other seizure types. Furthermore, disclosure was enabled for parents of CWE who had a high level of seizure control as it allowed parents to emphasise this point during disclosure exchanges with others. According to parents, this ensured that the risk of their child experiencing negative consequences as a result of their epilepsy disclosure was minimised.

- *Interviewee: "…we haven't encountered any negative perceptions, but we have always explained it away until it is nothing. We have told you, now forget about it kind of thing."*
  Interviewer: "So, her mildness, kind of…you can kind of explain it like that."
  Interviewee: "Exactly."
  Mother of Robyn (female, aged 10 years)

Additionally, a number of parents reported that the context of their child's seizure occurrences encouraged them to disclose their child's epilepsy to others. For example, in families where the child had nocturnal epilepsy, parental disclosure was enabled by the fact that they could provide the disclosure targets with reassurance that seizures were unlikely to occur in their presence.

- *"His close friends, their mums would...And from the start I said to them, 'he has epilepsy, do you mind taking him'…that he has it and he has had his medication and we are lucky, he doesn't usually have them during the day. So I think people feel a lot more comfortable taking him with that. They are just assuming he won't, the same as we kind of do. Whereas I think if he had more frequent seizures and he was inclined to have them during the day, I think that would bring up other issues with regards to people…"*
  Mother of Ryan (male, aged 9 years)

5.3.6.5 Disclosure Perceived as an Educational Tool and a Method of Fighting Against Epilepsy-related Stigma

A key enabling factor for disclosure amongst several parents of CWE was their perception that disclosure of their child's epilepsy to others external to the nuclear family served as an educational tool. Some parents highlighted that disclosure enabled them to increase awareness and educate others about epilepsy.

- *"It has obviously got easier. In the early stages I definitely didn't like the whole notion…it was very much 'he had encephalitis' or whatever, but now we have probably gone to the other extreme where I want people to know he is a normal child. Because I do feel, and I would have had myself, hands up, an ignorance of epilepsy and seizures and all the rest…so you do feel you have to inform and educate."*
  Mother of Tadhg (male, aged 12 years)

For other parents, open and voluntary disclosure strategies were endorsed as they perceived that this would enhance their own understanding of the condition. Several parents highlighted how

talking with others about their child's epilepsy resulted in others who had their own experiences with epilepsy sharing further educational information with them about the condition.

- *"…like I say, I talk to strangers about it…I just decided on that's what I'm doing…that's my kind of agenda because I kind of find I learn from them rather than…it's not really so much as in me trying to raise awareness, I actually learn…if I talk to people…"*
  Mother of Carl (male, aged 11 years)

Finally, for a number of parents of CWE, disclosure of their child's epilepsy to others outside the immediate family unit facilitated an active stance against epilepsy-related stigma and was perceived to play a role in breaking the *cycle of invisibility* surrounding the condition.

- *Interviewer: "And is that one of the reasons you would talk to people about it, to help with her independence? "*
  Interviewee: "And so there is no stigma. There is a bit of stigma attached but we don't see that now. But I do find if she now goes for sleepovers, to specific houses only, a lot of the mothers would find it very difficult to deal with. But it is just down to education at the end of the day. Whereas when we speak to her friends about it when they are around I suppose they can bring their parents around too because they can deal with it. It is just about education."
  Mother of Jessie (female, aged 11 years)

5.3.6.6 Getting Used to It

Several parents verbalised that whilst disclosure may have been a challenge to them in the initial period following the child's diagnosis, as time had progressed and they came to terms with the condition, disclosure became less problematic.

- *"Once the initial shock was over and I could actually say the word it has been fine. I couldn't say the words. I couldn't say it out loud. I actually couldn't physically say 'Anna has epilepsy' because I was so shattered. Now I look back and think, oh for God's sake, so she has epilepsy."*
  Mother of Anna (female, aged 15 years)

5.3.6.7 Public Awareness and Media Coverage of Epilepsy

Several parents discussed how greater public understanding of epilepsy, greater visibility of epilepsy in the public domain and increased media coverage of epilepsy would enable them to speak more freely and openly with others about their child's condition.

- *Interviewer: "…I know you've kind of mentioned awareness, so, is that the main thing that you think would help to talk more about it in general or…?"*
  Interviewee: "Yeah…because the awareness would take away maybe the fear…it's just a fear, isn't that all it is? It's just a fear and a lack of knowledge…I mean, people aren't going to understand what it is, they haven't witnessed it em…and what can you do, I mean, it is…I suppose, relatively speaking, it's a very small percent of the population that suffers from it but…it all boils down to awareness, that's all it is…yeah."
  Mother of Jack (male, aged 9 years)

Many parents verbalised that in their opinion poor public perceptions of epilepsy and the associated barrier to disclosure such perceptions present could be addressed by increasing public awareness and media coverage of epilepsy.

- *"I think it is more helpful obviously the more high profile people out there in society who speak about it, the likes of Rick O' Shea and people like that, I think that is important, sports people etc. And I think better education in schools. Because there are general conditions that kids have...and I think there should be education in the schools about that. So I think things like that would be important and being able to say, 'this is blah, blah, Lucy has it, who is a bright kid, who participates in sport and gets on with things.' Things to take the stigma away from it."*
  Father of Lucy (female, aged 7 years)

In fact, for a number of parents, disclosure of their child's epilepsy was enabled because they felt that public perceptions of epilepsy had improved, that the public were more informed about epilepsy and that epilepsy was now seen in a more positive light than in the past.

5.4 Summary of Child and Parent Perspectives

In summary, analysis of the qualitative data revealed that the disclosure management strategies adopted by CWE and parents in the present study were highly variable, ranging from total concealment on one end of the spectrum to open and voluntary disclosure on the other end. In particular, there was evidence of the endorsement of the following disclosure management strategies by both CWE and parents of CWE: 1) active and passive forms of concealment; 2) selective disclosure whereby CWE and parents were selective about who they revealed the child's epilepsy to (i.e. disclosure targets) and what aspects relating to the child's epilepsy they informed others about (i.e. disclosure content); 3) preventive disclosure; and 4) open and voluntary disclosure. Furthermore, for several CWE and parents of CWE, the child's epilepsy became apparent to others external to the nuclear family due to unplanned revelations which forced or stimulated disclosure exchanges with others. Finally, some CWE endorsed a policy of indirect telling, whereby they relied on parents or peers to inform others about the condition.

In relation to disclosure targets, data from phase one indicated that for both CWE and parents the following categories of individuals were potential disclosure targets: 1) extended family; 2) peers; 3) school personnel; 4) HCPs; and 5) sports team coaches or instructors of extra-curricular activities. Additional disclosure targets identified by parents only included caregivers, other families, parents of children with medical conditions, employers/work colleagues and perceived sources of help and support. Furthermore, when discussing to whom they revealed their epilepsy, several CWE distinguished between disclosing to adults versus children.

With reference to the content of disclosure exchanges, CWE and parents of CWE reported explaining the child's specific seizure symptomatology and discussing the impact of epilepsy (beyond seizures) with others external to the nuclear family. Further content of CWE's

disclosure exchanges included descriptions of epilepsy and discussion of hospital appointments, AEDs and/or other epilepsy treatments. For parents, additional topics reportedly discussed with others included seizure first aid protocols and the emotional impact of the diagnosis.

The situational context of CWE's and parents' disclosure exchanges with others outside the immediately family unit varied substantially. CWE reported mainly revealing their epilepsy condition to others in the following circumstances: 1) when in secure relationships with disclosure targets; 2) when cues made the invisible condition visible to others; 3) when others were curious about epilepsy; 4) when in an environment where the topic of disability and/or epilepsy was salient; and 5) when the mood of the disclosure target was deemed appropriate. In contrast, for parents, disclosure exchanges with others mainly unfolded in situations when: 1) the child was entering a new environment; 2) they perceived that there were risks for the child; 3) others raised the topic and/or posed questions about epilepsy; 4) children's difficulties arose during conversation with others; 5) seizures occurred; 6) hospital appointments had recently happened or were impending; 7) in the presence of others with experience of epilepsy; and 8) they were experiencing periods of emotional struggle as a consequence of the child's epilepsy.

Finally, data from phase one revealed that the adoption of specific disclosure management strategies surrounding the child's epilepsy by CWE and their parents was contingent upon an array of factors inclusive of: 1) the child's clinical characteristics (e.g. seizure-related variables); 2) perceived personal characteristics of potential disclosure targets (e.g. their age, gender, perceived trustworthiness and perceived open-mindedness); 3) CWE's and parents' perceived barriers to disclosure (i.e. threats to normalcy, anticipated and actual negative reactions to disclosure, the invisibility of epilepsy, public perceptions of epilepsy, child and parental negative perceptions of epilepsy, the complexity of epilepsy and the emotional impact of the diagnosis) and/or enablers for disclosure (i.e. positive and pragmatic child and parental attitudes towards epilepsy, others' positive responses to prior disclosures, open/positive familial communication about the condition, getting help with disclosure, getting used to it, public awareness and media coverage of epilepsy, and perceptions that disclosure enhances the child's safety, serves as an educational tool and is a method of fighting against epilepsy-related stigma). In chapter six, child and parent perspectives on disclosure and the contextual and situational factors that inform disclosure, as presented in this chapter, will be critically discussed.

Chapter 6: Phase One: Discussion of the Qualitative Findings

6.0 Introduction

The aim of the qualitative phase was to directly unearth CWE's and parents' experiences of disclosing (or not) a child's epilepsy condition to others external to the nuclear family. This chapter will discuss the qualitative findings in terms of child and parent perspectives on disclosure management strategies, disclosure targets, the content of disclosure exchanges, the situational context of disclosure exchanges, barriers to disclosure and enablers of disclosure. Similarities and differences between CWE's and parents' perspectives will be considered. Furthermore, the strengths and limitations of this phase will be highlighted. Finally, how the findings from phase one informed decisions regarding what elements of epilepsy disclosure and which psychosocial and illness attitude constructs to examine in phase two will be outlined.

6.1 Disclosure Management Strategies

The disclosure management strategies adopted by both CWE and parents who participated in phase one were varied, and replicated disclosure management strategies identified in previous research pertaining to disclosure of epilepsy in adulthood (Aydemir et al., 2009; Scambler, 1984; Scambler, 1989; Scambler & Hopkins, 1980; Scambler & Hopkins, 1986; Schneider & Conrad, 1980; Tröster, 1997). However, to the author's knowledge this is the first study that explicitly explores: 1) which disclosure management strategies CWE and parents of CWE endorse; 2) how specific disclosure management strategies manifest in the context of childhood epilepsy; and 3) the numerous contextual and situational factors implicated in CWE's and parents' selection of specific disclosure management strategies.

6.1.1 Child and Parent Perspectives: Disclosure Management Strategies

Some CWE and parents of CWE endorsed open disclosure management strategies, including open and voluntary disclosure and preventive disclosure. Others engaged in more restrictive disclosure management strategies such as selective disclosure (e.g. choosing what to tell and to whom), and total concealment. Furthermore, restrictive disclosure behaviours were evidenced for a number of CWE and parents through references to experiences of unplanned revelations.

For both CWE and parents, two key manifestations of epilepsy concealment emerged, namely active and passive manifestations of concealment. The distinction between these two types of concealment has previously been referenced in research conducted with populations with other socially devalued CSIs such as polyamorist or homosexual populations (Button, 2004; Griffin, 1991; Young, 2014). Additionally, incidental qualitative findings suggestive of both types of

concealment have been reported in research with CWE (Holdsworth &Whitmore, 1974; McEwan et al., 2004) and parents of CWE (Holdsworth & Whitmore, 1974; Kleck, 1968; Mu, 2008). However, prior to this study the distinction between these forms of concealment had not been explicitly elucidated and/or considered in the context of childhood epilepsy. This is an important consideration because we know from previous research that there can be detrimental effects (e.g. reduced feelings of belonging and heightened feelings of inauthenticity) associated with hiding one's CSI from others during social interactions (Newheiser & Barreto, 2014). However, whether there are differences in the intrapersonal and interpersonal outcomes associated with both of these conceptually distinct forms of concealment is unknown.

Selective disclosure was commonly reported by both CWE and their parents. For some CWE and parents, this involved carefully choosing confidants to whom they were comfortable disclosing the epilepsy. In particular, CWE and parents of CWE reported an affinity towards disclosing the child's epilepsy condition to individuals deemed likely to respond positively and provide them with support, whilst avoiding disclosing to those who were perceived as likely to react negatively and subject the child to differential treatment. Chaudoir & Fisher posited the Disclosure Processes Model (DPM; 2010) as a framework to explain in what context and for what reasons interpersonal disclosure of a CSI may be beneficial. As part of this model, they contended that the outcomes of disclosure are mediated by three distinct processes; one being social support. The findings from this first phase, which indicate that CWE and/or their parents are selective about disclosure targets, offer some support to this proposition. They indicate that CWE and parents are intuitively aware that disclosure renders them vulnerable to social evaluation that has either the potential to result in greater social support or greater stigmatisation. Thus, they base their decisions regarding suitable disclosure targets on the perceived likelihood of experiencing a given outcome. For other CWE and parents, a selective disclosure management strategy provided them with the opportunity to exert control over the amount of information that they wished to share with others and how they wished to share such information. Interestingly, amongst both CWE and parents of CWE, content that was avoided during disclosure exchanges included any information that was viewed as having the potential to heighten others' perceptions of the child's differentness (e.g. unusual seizure manifestations). On the contrary, where possible, many CWE and parents reported ensuring to share specific information with others that served to downplay, minimise and normalise the child's epilepsy (e.g. information about the mildness or infrequency of the child's seizures). Chaudoir & Fisher's DPM (2010) postulates that the changes in social information mechanism further mediates the consequences of interpersonal disclosure, whereby the information one shares with a confidant regarding one's CSI shapes the future actions of both the confidant and the discloser, and may fundamentally alter the nature of interactions between the confidant, the discloser and their broader social context. In being selective about the content of their disclosure

exchanges with others, CWE and parents of CWE seem to be cognisant of this fact and ensuring that changes in social information results in minimal detrimental consequences. Furthermore, often, where a selective/partial disclosure strategy was adopted, the decision to disclose was situation specific. For instance, many parents, in particular, identified that disclosure occurred for them on what they referred to as a 'need-to-know basis', which mainly comprised situations when others would be responsible for the child either temporarily or on a prolonged basis (e.g. when the child started a new sporting activity or was attending a sleepover). There is some empirical evidence that suggests that selective disclosure may be the most optimal disclosure management strategy. Such an approach has been identified as both enhancing social support and minimising stigmatisation in mental health consumers (Bos, Kanner, Muris, Janssen & Mayer, 2009). However, others contend that this strategy still involves an element of secrecy, which could: 1) represent the internalisation of negative attitudes and feelings towards the illness (e.g. shame); and 2) pose some of the same issues inherent in the adoption of concealment strategies (Corrigan & Matthews, 2003).

Whilst more restrictive epilepsy disclosure behaviours were generally adopted due to the perception that they served as protective, the adoption of such strategies by CWE and parents of CWE may be problematic for a number of reasons. First, there is some evidence to suggest that the emotional turmoil associated with maintaining secrecy surrounding a CSI has the potential to be more costly than actual negative social conditions that arise as a consequence of disclosure (Newheiser & Barreto, 2014; Smart & Wegner, 1999). This is particularly salient in the context of CWE and their parents considering the unpredictable nature of epilepsy and consequently the inherent risk of detection. Indeed, the burdensome impact of concealment was referenced by both CWE ("*I kept it in for seven years and I just couldn't hold it in any longer…"*) and parents ("*I can't put myself through the mental torture of trying to hide it*…") in this first study phase. Second, it is commonly posited that when others learn about an individual's CSI through unplanned revelations, this creates a context for more profound felt and enacted stigma experiences (Eklund & Sivberg, 2003; Lewis & Parsons, 2008; Wilde & Haslam, 1996). Based on the aforementioned evidence, one could infer that the potential risks associated with restrictive disclosure management strategies may outweigh any potential benefits.

Open disclosure management strategies that CWE and parents of CWE cited adopting included voluntary (i.e. telling others without prompting) and open (i.e. telling others when prompted) disclosure, and preventive disclosure. Phase one findings suggest that being more open about a child's epilepsy condition with others could be beneficial both in terms of: (i) ensuring the child's safety; and (ii) taking an active stance in combatting epilepsy-related stigma. However, this more indiscriminate form of disclosure poses its own risks due to the potential for others to respond in a prejudicial or discriminative manner (Chaudoir & Fisher, 2010). Some contend that more restrictive disclosure management strategies enable individuals to exert greater control

over stigma management. Indeed, a number of CWE and parents in the present study reported that past experiences of disclosure had resulted in negative outcomes (e.g. exclusion, prejudice or teasing/bullying of the child).

6.1.2 Child and Parent Perspectives on Disclosure Management Strategies: Similarities and Differences

In phase one, there was evidence of both CWE and parents of CWE endorsing the following disclosure management strategies: 1) active and passive forms of concealment; 2) selective disclosure; 3) preventive disclosure to prepare others and avoid the anticipatory risk of detection; and 4) open and voluntary disclosure. Furthermore, across both groups, there were reports that others became aware of the child's epilepsy as a consequence of unplanned revelations. However, whilst the disclosure management strategies adopted by CWE and their parents were largely similar, a number of notable differences were also revealed.

For instance, whilst both CWE and parents referenced preventively telling others about the child's epilepsy in an attempt to forewarn and prepare others, some parents reported engaging in preventive telling with a view to actively confronting epilepsy-related stigma – a rationale unreported by CWE. Indeed, the perception that disclosure served to tackle epilepsy-related stigma emerged as an enabler of disclosure for parents of CWE (see section 6.6.2). Furthermore, a number of CWE reported engaging in indirect telling (i.e. telling via parents or peers) – a strategy unreported by parents. It is likely that CWE who endorsed this strategy did so due to their inability to verbally represent the condition to others – this child-reported barrier to disclosure is discussed in greater detail in section 6.5.1.

In conclusion, the findings from phase one provide key insights into how various disclosure management strategies (ranging from total concealment to open and voluntary disclosure) manifest in CWE and parents of CWE. However, there is a dearth of empirical evidence regarding the consequences of the adoption of specific disclosure management strategies by CWE and their parents. Consequently, there is no consensus over which strategies are optimal. In the second phase of the present study, the consequences of disclosing a child's epilepsy condition to others in terms of confidants' reactions to prior disclosure exchanges will be evaluated to shed some light on this issue. However, future longitudinal research is required to tease out the long-term consequences of specific disclosure management strategies for CWE and parents of CWE.

6.2 Disclosure Targets

During interviews, both CWE and parents spoke about disclosure targets (i.e. the individuals to whom they disclosed the child's condition), as well as sociodemographic characteristics and

perceived personal characteristics of potential disclosure targets that encouraged or discouraged their disclosure to such individuals. These are discussed below.

6.2.1 Child Perspectives: Disclosure Targets

The main categories of individuals to whom CWE reported revealing their epilepsy were extended family members, peers, school personnel, HCPs, sports team coaches and instructors of extra-curricular activities. Furthermore, several CWE specifically spoke about differences in disclosing their epilepsy to children versus adult disclosure targets.

Prior to this study, the limited empirical evidence pertaining to CWE's disclosure targets largely comprised qualitative incidental findings or descriptive quantitative findings, with only school personnel (Bannon et al., 1992; Holdsworth & Whitmore, 1974; Ojinnaka, 2002; Zamani et al., 2014) or peers (Baker et al., 2008; Chen et al., 2010; Hightower et al. 2002; Hodgman et al., 1979; Houston et al., 2000; Lewis et al., 1990; McEwan et al., 2004; Moffat et al., 2009; Ronen et al., 1999; Zamani et al., 2014) identified as potential disclosure targets. Therefore, this is the first study to identify extended family members and sports team coaches/instructors of extra-curricular activities as potential disclosure targets for CWE.

Within their peer groups, CWE appeared to have a particular affinity towards disclosing their epilepsy to others with experience of chronic illness and/or epilepsy specifically. This is unsurprising given that group identification has been identified in prior research comprising samples with CSIs (e.g. populations with mental illness or disordered eating behaviours, populations of low socio-economic status or homosexual populations) as providing access to stress-buffering mechanisms inclusive of increased social support, stereotype rejection, and stigma resistance, which consequently predict enhanced psychosocial wellbeing (Crabtree, Haslam, Postmes & Haslam; 2010; Frable, Platt & Hoey, 1998). However, for some CWE, despite conveying a strong desire to speak with similar others about their experiences of living with epilepsy, difficulties in accessing and identifying similar others with whom they could share their experiences were reported. Currently, within an Irish context, there is an absence of face-to-face epilepsy-specific support groups of which CWE can avail. The support groups provided by EI only facilitate adults with epilepsy and/or parents of CWE. Identifying opportunities for CWE to interact with similar others should take priority. The use of epilepsy internet forums could represent one such avenue, particularly for CWE who live in more sparsely populated, geographically rural locations. In the context of chronic illness in childhood, children's engagement with computer networks which facilitate online contact with other chronically ill children (such as STARBRIGHT World) have been indicated to positively enhance children's perceived peer support and social connection with peers (Hazzard, Celano, Collins & Markov, 2002; Nicholas et al., 2007). Furthermore, McKenna & Bargh (1998) observed that, for individuals with CSIs, virtual group participation encompassed many of the

same benefits that face-to-face group identification forums provide, leading to greater self-acceptance, as well as increased face-to-face disclosure exchanges with family and friends. Along these lines, an international online open forum for adolescents with epilepsy entitled the TEA (Teenage Epilepsy Agenda) Room (http://www.thetea-room.com/) has recently been launched, whereby young people with epilepsy aged 13-19 years can register to an online community to talk about their epilepsy with similar others. Directing adolescents living with epilepsy to this forum could prove beneficial in enabling group identification.

Notwithstanding the associated benefits of group identification, there is some evidence to suggest that group identification can also result in negative consequences for psychosocial wellbeing amongst individuals with CSIs (Crabtree et al., 2010). This likely arises because, at the outset (i.e. upon joining a support group or on initially identifying with a similar other with a CSI), group identification can serve as a reminder of one's membership to a group that one, in all likelihood, would rather not be part of. Thus, Crabtree et al. (2010) contend that in order for group identification to yield positive rather than negative consequences, support groups (or other platforms for group identification) need to ensure that members gain more than mere confirmation that they are a member of a problematic/stigmatised group, which has the potential to result in evoking further feelings of disenfranchisement in relation to their CSI. Rather, such platforms should ensure to serve as empowering and self-enhancing for group members. Thus, in considering the potential benefits and disadvantages of group identification in the context of paediatric epilepsy, such insights need to be considered.

In addition to pinpointing salient disclosure targets, CWE identified characteristics of potential disclosure targets that informed their decisions regarding whether to divulge information (or not) about their epilepsy to others. Perceived personal characteristics that encouraged CWE's disclosure to specific targets included close and established relationships and others' practical attitudes, supportiveness, trustworthiness, high level of presence in the lives of CWE and intelligence. In contrast, factors identified as dissuading CWE from disclosing their epilepsy included others being uncaring and others' untrustworthiness, unreliability and perceived tendency to bully and tease others. The closeness of friendships was previously identified as a salient influential factor in informing CWE's decisions regarding suitable disclosure targets (Moffat et al., 2009). With the exception of this characteristic, the present study offers the first insight into the perceived personal characteristics of potential disclosure targets that play a role in impacting on CWE's disclosure decisions.

The finding that the perceived trustworthiness and reliability of disclosure targets influences CWE's disclosure to specific individuals is particularly illuminating. It provides some support for the theoretical perspective on disclosure offered by Petronio's Communication Privacy Management (CPM) Theory (2002), which posits that individuals perceive themselves as

owning their private information and expect that co-owners (or shareholders) of this information will abide by the privacy management rules they employ to determine their privacy boundaries. That is, if CWE anticipate that privacy boundaries will be violated by specific disclosure targets, with others broadcasting the epilepsy condition against their will, they will opt against sharing the private information with such individuals. Conversely, if CWE deem that disclosure targets are trustworthy and reliable enough to respect the privacy management rules and boundaries they have determined surrounding their epilepsy, CWE will accept such individuals as co-owners of their private information.

Finally, this is the first study to: 1) indicate that CWE perceive discernible differences between disclosing their epilepsy to adult versus children disclosure targets; and 2) elucidate how the sociodemographic characteristics (i.e. gender and age) of disclosure targets might encourage or discourage CWE's epilepsy disclosure to such individuals. Amongst CWE, there was no consensus on whether the gender or age of disclosure targets deterred or encouraged CWE's epilepsy disclosure to such individuals. For instance, some CWE preferred disclosing to peers of the same gender because they perceived that such individuals endorsed a similar communication style to their own. Other CWE indicated that perceived characteristics of the opposite gender (e.g. their interest and willingness to engage with the topic and lack of judgement) made such individuals more appropriate disclosure targets. Furthermore, several CWE highlighted that disclosing to adults was easier than disclosing to children due to the likelihood of adults having higher levels of pre-existing knowledge about epilepsy. Conversely other CWE reported perceiving that adults were less receptive to their epilepsy disclosure than children and questioned their credibility. These novel findings from phase one require further exploration.

6.2.2 Parent Perspectives: Disclosure Targets

For parents, key categories of disclosure targets in relation to their child's epilepsy included extended family members, peers, school personnel, HCPs, caregivers, other families, sports coaches/instructors of extra-curricular activities, parents of children with medical conditions, employers and work colleagues, and sources of help and support.

In prior studies, specific findings in relation to parents' disclosure targets surrounding a child's epilepsy seemed to emerge either as incidental findings in qualitative studies or because parents' attitudes towards disclosing to specific disclosure targets were assessed, or others' awareness of the child's epilepsy was examined (particular to the school context). Previously, the following categories of individuals were identified or referenced as potential disclosure targets for parents: 1) school personnel (Abulhamail et al., 2014; Baker et al., 2008; Bannon et al., 1992; Butau & Piachaud, 1993; Coulter & Koester, 1985; Hanai et al., 1996; Holdsworth & Whitmore, 1974; Kwong et al., 2000; Mecarelli et al., 2011; Mecarelli et al., 2014; Mu, 2008; Ojinnaka, 2002; Pala & Vankar, 1997; Prpic et al., 2003; Roberts & Whiting, 2011; Saburi, 2011); 2) extended

family members (Baker et al., 2008; Gazibara et al. 2014; Mu, 2008; Saburi, 2011); 3) peers (Gazibara et al., 2014; Mu, 2008; Ryu et al., 2015; Saburi, 2011); 4) other families (Roberts & Whiting, 2011); and 5) neighbours (Saburi, 2011). Thus, to the author's knowledge the identification of sports team coaches/instructors of extra-curricular activities, caregivers, employers and work colleagues, and sources of help and support as potential disclosure targets for parents of CWE is a novel finding of the present study.

In collectively considering the categories of disclosure targets identified by parents, it is evident that the key individuals to whom parents disclose the child's epilepsy are those upon whom a duty of care may be temporarily conferred in terms of being responsible for the child's wellbeing in parents' absence (i.e. school personnel, caregivers, other parents and sports team coaches/instructors of extra-curricular activities). This finding suggests that parents' disclosure behaviours are largely influenced by parental responsibility and duty, and safety factors. The issue of CWE's safety has previously been indicated as a factor that is implicated in parents' epilepsy disclosure behaviours (Mu, 2008; Roberts & Whiting, 2011).

Sources of help and support (e.g. support group facilitators, drug representatives and adults with epilepsy) were a further category of disclosure targets identified by parents of CWE. This finding is noteworthy for two reasons. First, it indicates that harnessing social support from others is a key reason for epilepsy disclosure amongst parents; a finding that provides support for the proposition of Chaudoir & Fisher's (2010) DPM which posits that social support is one of three distinct processes that mediate the outcomes of interpersonal disclosure. Second, it suggests that parents of CWE may feel unsupported and under-informed surrounding their child's epilepsy and thus may have to rely on non-traditional routes (i.e. routes other than clinical appointments with HCPs) in seeking epilepsy-related help and support. Parents' need for support and help surrounding a child's epilepsy condition warrants further investigation.

The findings also identified sociodemographic and personal characteristics of potential disclosure targets that parents perceive to influence their disclosure to such individuals. Key factors that reportedly facilitated parents' epilepsy disclosure to specific individuals external to the nuclear family included close friendships, and others' perceived kindness, pragmatism, caring natures, open-mindedness and listening skills. Conversely, factors that deterred parents from disclosing their child's epilepsy to specific others were inclusive of others being bigoted, ignorant, narrow-minded, gossips, dramatic or worriers. The CPM theory (Petronio, 2002) posits that one of the key decision criteria considered by individuals in developing privacy management rules and boundaries is the risk-benefit ratio analysis criterion. Consistent with this proposition, collectively, the aforementioned findings indicate that parents of CWE perform internal risk-benefit ratio analyses when selecting specific disclosure targets and choose to either: 1) approach individuals deemed likely to respond positively and offer social support; or

2) avoid individuals deemed likely to respond negatively (i.e. by over-dramatizing or trivialising the child's epilepsy, or acting in a prejudicial manner towards the child).

The influential role that the age of disclosure targets played in informing parents' decisions regarding disclosure targets is noteworthy. For some parents, their likelihood of disclosing to extended family members reportedly decreased with the increasing age of such individuals due to parents' perception that a generational stigma exists surrounding epilepsy. There is some empirical evidence to support parents' perspectives in this regard, with previous research identifying that the elderly are less knowledgeable about epilepsy (Demirci, Dönmez, Gündoğar & Baydar, 2007; Fong & Hung, 2002; Nicholaos, Joseph, Meropi & Charilaos, 2006) and endorse more negative attitudes towards epilepsy (Fong & Hung, 2002; Nicholaos et al., 2006; Njamnshi, Angwafor, Tabah, Jallon & Muna, 2009). Indeed, there is some evidence to indicate that a U-shaped distribution exists, whereby the highest proportions of misinformation about epilepsy and negative attitudes towards epilepsy are possessed by those at the extremes of age (i.e. the youngest and oldest subjects) (Jacoby et al., 2004; Spatt et al., 2005).

6.2.3 Child and Parent Perspectives on Disclosure Targets: Similarities and Differences

In terms of similarities in CWE's and parents' perspectives on disclosure targets, in phase one, both CWE and parents reported revealing the child's epilepsy condition to extended family members, peers, school personnel, HCPs and sports team coaches/instructors of extra-curricular activities. Additionally, both CWE and parents made distinctions between disclosing to adults versus children, with no consensus arrived at over which disclosure targets were more receptive in this regard. In relation to personal characteristics of disclosure targets that played an influential role in determining the selection of disclosure targets, CWE and parents of CWE highlighted that close and established friendships with others, as well as others' perceived supportiveness, caring natures and pragmatism encouraged disclosure.

With regard to differences in CWE's and parents' perspectives on disclosure targets, only parents of CWE identified caregivers, other families, parents of children with medical conditions, employers and work colleagues, and sources of help and support as categories of potential disclosure targets. Gender was a sociodemographic characteristic that only CWE identified as influencing their decisions regarding disclosure targets. However, the overrepresentation of mothers in the parent sample may have obscured gender perspective differences in this regard. In relation to perceived personal characteristics of disclosure targets, only CWE highlighted that the perceived intelligence of disclosure targets informed their disclosure decisions. It is likely that this was a particularly salient factor for CWE due to the difficulties they reported experiencing in appropriately verbalising and representing their complex condition to others (particularly in the context of disclosing to peers); this is discussed

in greater detail in sections 6.3.1 and 6.5.1. Furthermore, others' perceived trustworthiness and reliability, level of presence in the lives of CWE, and tendency to bully or tease others played an influential role in CWE's selection of specific disclosure targets – findings unreported by parents. Finally, the perceived warmth and kindness, listening skills, bigoted nature, open-mindedness and ignorance of others were all factors only reported by parents of CWE as informing their decisions regarding disclosure targets.

In conclusion, valuable insights were gained with regard to CWE's and parents' disclosure targets, particularly in terms of to whom CWE and parents disclose the child's epilepsy condition. Novel information has been revealed that could prove useful in assisting those working with CWE and parents of CWE to tailor disclosure-oriented advice in accordance with their likely disclosure targets. The identification of likely disclosure targets for CWE and their parents is also important in terms of considering the target audiences of educational campaigns surrounding epilepsy. For instance, based on the evidence of the present study it would seem important to enhance knowledge and understanding of epilepsy amongst school personnel, youths and the elderly.

6.3 The Content of Disclosure Exchanges

Often CWE and parents spoke about the content of their disclosure exchanges with others external to the nuclear family, with some participants also referencing content that was avoided. CWE's and parents' perspectives on this element of epilepsy disclosure are discussed below.

6.3.1 Child Perspectives: The Content of Disclosure Exchanges

The content of CWE's disclosure exchanges largely comprised the following: descriptions of epilepsy and seizures; discussion of the impact of the condition including its emotional impact, restrictions experienced and difficulties the child must contend with; reference to hospital appointments; and explanations about medication or other epilepsy treatments. Furthermore, several CWE reported content they avoided during disclosure exchanges with others, including specific information about seizures or medication.

Prior to this study, little was known about the content of CWE's epilepsy disclosure exchanges with others. The limited evidence available suggested that the key topic that CWE spoke about with others in relation to their epilepsy was the condition and seizures (Hightower et al., 2002). Therefore, the identification of the impact of the condition (beyond seizures), hospital appointments and medication or other epilepsy treatments as key topics raised by CWE during disclosure exchanges with others represent novel findings of the present study.

A notable finding was that whilst CWE reported that disclosure targets (particularly peers) often required explanations of epilepsy due to their lack of knowledge about epilepsy, many CWE in

the present study struggled with verbally articulating the complex neurological disease to others – a finding that supports the findings of Jantzen et al. (2009). This finding has significant implications because an inability to verbally represent the condition to others also denoted a barrier to epilepsy disclosure for CWE.

A number of CWE who reported speaking about seizure symptomatology during disclosure exchanges with others highlighted how others' lack of familiarity with varying seizure types and manifestations necessitated their explanation of what members of the public (such as peers) might perceive as "atypical seizures", e.g. absence or complex partial seizure types. This finding is consistent with the findings outlined in a study conducted by Fong & Hung (2002) assessing public knowledge and attitudes towards epilepsy, where the majority of subjects (61.9%) surveyed only cited being familiar with tonic-clonic seizure manifestations. Considered together, the evidence would indicate that there is a need to educate members of the public about the various ways in which epilepsy can manifest in PWE.

Several CWE avoided discussing with others specific elements of seizure manifestations that elicited feelings of shame (e.g. manifestations that involved a behavioural element). This was likely in an attempt to control changes in social information - a key mediating process that influences the outcomes of interpersonal disclosure in accordance with Chaudoir & Fisher's DPM (2010). That is, CWE may have perceived limiting information about potentially embarrassing elements of seizure manifestations as serving to protect them from what they viewed as more profound, deleterious ramifications as a consequence of others likely reacting in a negative manner to such information.

6.3.2 Parent Perspectives: The Content of Disclosure Exchanges

Amongst parents, key topics of conversation during disclosure exchanges with others included: the child's specific seizure symptomatology; seizure first aid protocols; the impact of epilepsy beyond seizures (inclusive of negative impacts on the child's behaviour, sociability and cognitive ability and on parents' sociability, AED side effects, post-ictal symptoms, risk assessments and restrictions); and the emotional impact of the diagnosis. The latter two findings denote unique findings of the present study. Furthermore, varying attitudes were demonstrated by parents in terms of which aspects of the child's condition they were comfortable revealing to others. For instance, some parents reported being forthcoming with information related to the child's seizure symptomatology, whilst others found discussing such details with others uncomfortable or unnecessary.

Explaining seizure first aid protocols to others was a key priority for parents of CWE; a finding that corresponds with limited evidence from prior research in childhood epilepsy (Holdsworth & Whitmore, 1974; Roberts & Whiting, 2011). Unsurprisingly, a number of parents stressed the need to dispel the misconceptions held by others with regard to appropriate responses to

seizures. There is an abundance of empirical evidence indicative of the fact that members of the public are unfamiliar with the correct protocols to undertake on witnessing an individual having a seizure (Thacker, Verma, Ji, Thacker and Mishra, 2008; Dantas, Cariri, Cariri and Ribeiro Filho, 2001; Fong & Hung, 2002). This supports the importance of parents outlining correct seizure first aid protocols during disclosure exchanges with others.

The identification of: 1) the impact of the condition (beyond seizures); and 2) parents' emotional responses to the diagnosis, as key topics raised by parents during disclosure exchanges with others is important. In doing so, parents are educating others about the broad ranging psychosocial and behavioural impacts of epilepsy beyond disrupted neurobiological mechanisms and seizure symptomatology. Furthermore, these findings suggest that parents require support in overcoming emotional issues surrounding epilepsy and that such support may be sought from individuals outside the immediate family unit. The DPM (Chaudoir & Fisher, 2010) contends that interpersonal disclosure of a CSI can yield beneficial outcomes when it results in harnessing social support from confidants. The need for ongoing emotional support has been noted as a difficult aspect of parenting a child with epilepsy (McNelis, Buelow, Myers & Johnson, 2007; Shore et al., 1998); thus, disclosing to others external to the nuclear family to garner social support when and where emotional support is needed may represent an avenue to alleviate the emotional challenges associated with parenting a child with epilepsy.

6.3.3 Child and Parent Perspectives on the Content of Disclosure Exchanges: Similarities and Differences

Both CWE and parents of CWE highlighted describing the child's specific seizure symptomatology to others. Indeed, both CWE and parents reported that if the child's seizures were mild, emphasis was placed on reinforcing this point during disclosure exchanges with others, likely in an attempt to minimise the potential of others reacting negatively. There is some evidence to support this from research with other CSIs (such as HIV) where, in an effort to empower these individuals, providing information to disclosure targets that likely reduces their risk of responding negatively has been emphasised (Stutterheim et al., 2011). Furthermore, both CWE and parents reported specifically educating others about the child's specific seizure manifestations if his/her seizure types included those that might be deemed "atypical" in the public arena (i.e. any seizure types that are not tonic-clonic seizures). The findings of the present study thus further reinforce the need for widespread dissemination of information about numerous seizure types in order to: 1) enhance public awareness that epileptic seizures manifest in many different ways; and 2) ensure others' recognition of seizure symptomatology in PWE. This is particularly salient in the context of the school environment where it was commonly reported by CWE and parents that teachers mistook manifestations of "atypical seizures" for behavioural issues, which, at times, unnecessarily prolonged the diagnosis process. Both CWE and parents of CWE also alluded to discussing the impact of

epilepsy beyond seizures, the emotional impact of the condition and information pertaining to hospital appointments, medications and/or other epilepsy treatments during disclosure exchanges with others external to the nuclear family. Seizure first aid protocols were only outlined by parents of CWE during their disclosure exchanges with others; the only notable difference in CWE's and parents' perspectives on the content of their disclosure exchanges.

In summary, the qualitative data from the present study offer unique insights into the content of child and parental disclosure exchanges. Arming families living with epilepsy with appropriate and accessible information based on conversation topics likely to arise during CWE's and parents' epilepsy disclosure exchanges with others could enable CWE and parents to disclose the child's condition to others.

6.4 The Situational Context of Disclosure Exchanges

Amongst CWE and parents of CWE, numerous situational contexts in which epilepsy disclosure exchanges unfolded with others external to the nuclear family were revealed during interviews. These are discussed below.

6.4.1 Child Perspectives: The Situational Context of Disclosure Exchanges

To the author's knowledge, this is the first study to explore the situational context of CWE's epilepsy disclosure exchanges with others outside the immediate family unit. Key situational contexts in which CWE reportedly disclosed their epilepsy condition to others included circumstances when CWE were in secure relationships with disclosure targets, cues made the invisible condition visible to others, others expressed their curiosity about epilepsy, in an environment where the topic of disability and/or epilepsy was salient and the mood of the disclosure target was deemed appropriate; novel findings of the present study.

Research with other CSIs (e.g. homosexual populations) has identified that people wait until it feels safe to tell others about their difference (Dindia, 1998). The findings of this study are similar in that a number of CWE engaged in epilepsy disclosure exchanges with others only when: 1) in secure relationships with potential disclosure targets, and 2) the mood of the disclosure targets was deemed appropriate (i.e. they were perceived as being in a receptive mood). These findings collectively indicate that CWE are intuitively aware that disclosure has potential consequences for their future interactions with others in line with the changes in social information mechanism posited as part of the DPM (Chaudoir & Fisher, 2010).

For some CWE, physical (e.g. safety helmets or AEDs) or contextual cues (e.g. school absences as a consequence of seizures or hospital appointments) made the invisible condition visible to others and provided the situational context of their disclosure exchanges. This finding has important implications. It indicates that there is an array of sources via which others can

hypothetically discover the child's epilepsy. Thus, it is not just seizures that put the child at risk of being "outed" if they opt for epilepsy concealment strategies. Notably, whilst some CWE viewed physical or contextual cues of the condition as a source of irritation, several CWE reportedly relied on these cues to make their invisible condition visible to others. In considering this finding, an interesting paradox emerges. Some CWE seem to appreciate the invisible nature of their epilepsy as it enables their concealment and consequently their successful passing for "normal" (Joachim & Acorn, 2000) which is perceived as a form of stigma management. Other CWE actively utilised cues (e.g. epilepsy alert wristband) to make their invisible condition visible in order to stimulate conversation with others about their epilepsy.

6.4.2 Parent Perspectives: The Situational Context of Disclosure Exchanges

Prior to the present study, the only empirical evidence available with regard to the situational context of parents' disclosure exchanges with others external to the nuclear family pointed towards the child entering a new environment (e.g. at school registration or when the child was visiting with new friends for the first time) as a key context under which parental disclosure exchanges occurred (Roberts & Whiting, 2011); a finding replicated in the present study. Thus, this is the first study to reveal an array of key situational contexts in which parental epilepsy disclosure exchanges with others occur, including circumstances when: parents perceive there are risks for the child; others raise the topic of epilepsy and/or pose questions about epilepsy; children's difficulties arise during conversations with others; seizures occur; hospital appointments have recently occurred or are upcoming; in the presence of others with experience of epilepsy; and parents experience periods of emotional struggle due to the child's epilepsy.

For parents of CWE, disclosure exchanges with others surrounding their child's epilepsy condition largely unfolded in safety-oriented contexts i.e. when the child was entering a new environment, in environments where parents perceived that their child may have been at risk and/or subsequent to seizure occurrences. This is unsurprising given that concern over CWE's safety represents a significant stressor in the lives of parents of CWE (Mu, 2008; Roberts & Whiting, 2011; Saburi, 2011). This finding reinforces the salient role of safety issues in determining parental disclosure behaviours.

6.4.3 Child and Parent Perspectives on the Situational Context of Disclosure Exchanges: Similarities and Differences

Both CWE and parents of CWE identified that they disclosed to others when others asked questions, when cues of the invisible condition made the condition visible to others and when they were in environments where the topic of epilepsy was salient and/or where mutual sharing of personally private/distressing, or epilepsy-specific information, was occurring. The context of CWE and parental disclosure in: 1) environments where the topic of epilepsy and/or disability is salient (child perspective); 2) the presence of others with experience of epilepsy (child and

parent perspective); and 3) situations in which children's difficulties arise during conversations with others (parent perspective), is noteworthy. In such situational contexts of learning of others' difficulties, illnesses or disabilities, CWE or parents of CWE often reported engaging in a mutual process of sharing distressing or personally private information with others outside the immediate family unit. Reciprocity has consistently been identified as an influential factor in determining disclosure decisions (Clair, Beatty & MacLean, 2005; Derlega & Berg, 1987; Ehrlich & Graeven, 1971; Jourard, 1971; Posey, Lowry, Roberts & Ellis, 2010; Sprecher, Treger, Wondra, Hilaire & Wallpe, 2013); with Barak & Gluck-Ofri (2007) coining the process of mutual self-disclosures as the "dyadic effect" or the "mutual effect". However, to the author's knowledge, this is the first study to identify this 'dyadic effect' and the reciprocal nature of CWE's and parents' disclosure exchanges in the context of childhood epilepsy.

Whilst there were a number of similarities in terms of the situational context of CWE's and parents' disclosure exchanges with others, a number of notable differences were also evident. In particular, only CWE specified that the context of their disclosure exchanges with others was contingent upon the secureness of their relationships with, and the mood of, potential disclosure targets. In contrast, only parents identified that key situational contexts in which they disclosed the child's epilepsy to others included circumstances when the child was entering a new environment or they perceived there being risks for the child. Furthermore, only parents reported that periods of emotional struggle denoted a key situational context in which they revealed the child's epilepsy condition to others. Considered together, the findings from phase one of the present study with regard to the situational context of CWE's and parents' disclosure exchanges with others provide preliminary evidence to suggest that CWE's and parents' motivations for disclosing the child's epilepsy to others differ quite considerably. That is, CWE perhaps view more selective disclosure behaviours as a means to guard against potentially negative and stigmatising outcomes, whilst for parents it would seem that ensuring the safety of the child takes precedent above all other issues in considering when and in which situations they disclose the child's epilepsy condition to others.

In summary, the present study identified unique and varying situational contexts in which CWE and parents of CWE reveal a child's epilepsy condition to others outside the immediate family unit. Knowing the situational context in which disclosure exchanges are likely to occur for CWE and parents of CWE is important in terms of: 1) preparing CWE and parents to navigate disclosure exchanges with others in specific situational contexts; and 2) understanding the situational contexts in which interpersonal disclosure of the child's CSI are going to yield beneficial outcomes for CWE and parents of CWE.

6.5 Barriers to Disclosure

Many CWE and parents reported experiencing considerable challenges in disclosing the child's epilepsy to others external to the nuclear family. Barriers to disclosure are discussed below.

6.5.1 Child Perspectives: Barriers to Disclosure

To the author's knowledge, this is the first study to be conducted with one of the primary objectives being to explore the difficulties CWE face surrounding epilepsy disclosure, from the perspectives of CWE themselves. Findings from phase one demonstrate that CWE as young as 6 years old face challenges when disclosing their epilepsy condition to others. Disclosure decisions present a range of concerns for CWE as they grapple with issues such as normalcy, the reactions of others, their own perceptions as well as others' perceptions of epilepsy, and the unique challenge that the invisibility of their condition denotes. CWE also encounter difficulties in terms of understanding and explaining their complex neurological condition. Concurrently, their peers contend with similar challenges surrounding comprehension of the condition. These components serve as barriers to disclosure for some CWE and promote the adoption of concealment or selective disclosure management strategies.

Childhood and adolescence are critical periods for identity formation, self-definition and the development of enduring peer relationships (as previously discussed in chapters one and two). Consequently, during these periods, more than during any other life-stages, children and adolescents pursue normalcy as an utmost priority and strive to gain peer acceptance (Elliott et al., 2005; Taylor, Gibson & Franck, 2008). Consistent with an abundance of previous research examining how chronic health conditions impact on children and adolescents (Elliott et al., 2005; Lambert & Keogh, 2015; MacLeod & Austin, 2003; Shaw & Davis, 2011; Taylor, Franck, Dhawan & Gibson, 2010; Wise, 2002), CWE in the present study grappled with the role that epilepsy plays in this regard. Many CWE rejected the notion that epilepsy was a defining characteristic and sought to compartmentalise this aspect of their lives because of the perception that epilepsy compromised their normalcy and threatened the successful formation of peer-relations. Concealment or selective disclosure was viewed as facilitating this compartmentalisation and the pursuit of normalcy for some CWE by reducing feelings of differentness and minimising the restrictions imposed on them by those external to the nuclear family. Similar findings have been revealed in the context of other invisible conditions such as mental illness and in the context of chronic illnesses in childhood (McKeague, Hennessy, O'Driscoll & Heary, 2015; Kaushansky et al., 2016). However, as previously discussed, epilepsy is unique as the unpredictable nature of seizures can lead to an inherent risk of discovery should a seizure occur publicly, thereby making the invisible condition suddenly visible. This can have embarrassing consequences and creates a context for more profound felt and enacted stigma, which might result in permanent negative changes to social identity and

relationships (Eklund & Sivberg, 2003; Lewis & Parsons, 2008; Wilde & Haslam, 1996). Future research should focus on elucidating whether the adoption of concealment and/or selective disclosure management strategies by CWE do indeed serve as protective or whether they result in negative long-term outcomes for CWE. The cross-sectional design of the present study did not facilitate the researcher in addressing such questions.

The child perspectives identified in this first phase of the study also lend further support to the notion of parents as potential stigma coaches who can inadvertently or purposely relay the message to CWE that epilepsy is something to be ashamed of and should not be spoken about (Jacoby & Austin, 2007; Kleck, 1968; Ryu et al., 2015). Parents can act as key informants in determining the development of self-perceptions in CWE. Some CWE in this study reported that they had come to view their epilepsy as something private that should only be discussed within the confines of their home because their parents had communicated to them (verbally and/or non-verbally through their actions) that this was the desired approach. When investigating parent perspectives on disclosure, it emerged that a number of parents perceived maintaining secrecy around the child's epilepsy as a protective mechanism to guard against the child experiencing differential treatment and negative reactions from others. Future studies should attempt to fully explicate this relationship between parental perceptions of epilepsy, and parental disclosure behaviours, and the disclosure behaviours of CWE. If parents are in fact having the undesired effect of stigma coaching their CWE rather than protecting them from threats to normalcy, psychoeducational programmes with parents of CWE could be developed to tackle this issue. To obtain a complete understanding of the process of stigma-coaching and the implications it has for CWE, it is imperative not only to explore how CWE and their parents communicate with those outside the nuclear family about the diagnosis, but also to examine parent-child dialogue surrounding epilepsy within the context of the family home. A recent systematic review identified a dearth of empirical evidence in this area (O'Toole et al., 2015).

A factor that seemed to both enable the adoption of concealment and/or selective disclosure management strategies amongst CWE, and present significant difficulties surrounding epilepsy disclosure, was the invisibility of the condition. Interestingly, CWE perceived that the condition was not only invisible because it is not always overtly visible to others. Rather, they also spoke of how this invisibility was perpetuated by the silence encircling the condition within a public domain, making reference to how it is rarely spoken about and receives scant media attention. The fact that epilepsy is physically 'out of sight' presented a struggle for CWE in disclosing the condition to others due to issues with credibility. This corresponds with the findings of Moore (2013) who, in an auto-ethnographic study about her experiences of living with ulcerative colitis, highlighted that people living with invisible illnesses are often required to legitimise, and in some instances, defend and validate their status as ill individuals. Furthermore, epilepsy's lack of presence in the public arena seemed to relay the message to CWE that epilepsy is

something that should not be spoken about and will not be received positively by others. To the author's knowledge, the unique challenge that the invisible nature of epilepsy denotes for CWE in terms of epilepsy disclosure was a novel finding of this first phase of the study.

Interestingly, there seemed to be a paradox inherent in the views of CWE in the present study, whereby they seemed to dislike the silence that encircles the condition, with such silence representing a self-reported challenge; yet, they actively worked to maintain such silence by keeping the condition hidden from others. This corresponds with the previously discussed *cycle of invisibility* posited by Lewis & Parsons (2008), with the unwillingness by PWE (and more specifically CWE) to be open and honest about their epilepsy with others only serving to contribute to the lack of public knowledge about epilepsy, perpetuating misconceptions about the condition and exacerbating epilepsy-related stigma. Tackling this *cycle of invisibility* is undoubtedly a difficult task as multiple factors and parties are involved. Future research in this field should aim to, and consider comprehensively how to, tackle this *cycle of invisibility* in order to eliminate epilepsy-related misconceptions and stigma. A multi-systems approach should be adopted in doing so, with emphasis placed on the involvement of various stakeholders (i.e. patients, patient families, patient organisations, HCPs and epilepsy associations) to account for the multiple influential factors that are involved in the perpetuation of misconceptions and epilepsy-related stigma at an individual, a familial, a community and a societal level.

Finally, evidence from phase one also suggested that CWE: 1) felt ill-informed about their epilepsy, and 2) were not equipped with age-appropriate information about their condition. The overreliance on medical jargon by HCPs during encounters with CWE only seemed to exacerbate these issues. CWE grappled with explaining the condition in a manner that made the information accessible to their peers as they themselves became reliant on this medical jargon. In support of these findings, other studies have reported a failure by clinicians to talk at the child's level (McNelis et al., 2007). Furthermore, research has indicated that CWE struggle to describe their condition to others to a greater degree than peers of a similar age with other chronic medical conditions such as diabetes and asthma (Houston et al., 2000). Therefore, collectively, the evidence suggests that clinicians and service providers should take cognisance of the need to tailor the delivery of information about this complex neurological condition so that it meets the specific needs of each individual child. Particular emphasis should be placed on providing the child with sufficient child-friendly information in order to foster confidence amongst CWE in their ability to disclose their epilepsy to others should they wish to do so.

It is important to note that work has also been undertaken in chronic illness research to explore the disclosure challenges faced by individuals with other chronic illnesses. Some of the emergent challenges from such studies aligned with the challenges pertaining to disclosure that were identified by CWE participants in the present study. For instance, others' negative

reactions (anticipated and actual), others' lack of understanding of chronic illnesses and the desire to minimise the role that the chronic illness plays in the lives of individuals with such conditions also presented barriers to disclosure for individuals with sickle cell disorder, diabetes, spina bifida, renal disease, cystic fibrosis, rheumatologic disorders, chronic heart conditions, inflammatory bowel disease and cancer (Barned, Stinzi, Mack & O'Doherty, 2016; Dyson et al., 2010; Hilton, Emslie, Hunt, Chapple & Ziebland, 2009; Kaushansky et al., 2016; Rasmussen, O'Connell, Dunning & Cox, 2007). However, poor public perceptions and the invisibility of epilepsy within the public domain appeared to be issues that presented unique challenges for disclosure amongst populations living with epilepsy.

6.5.2 Parent Perspectives: Barriers to Disclosure

Disclosure of their child's epilepsy condition to others has been posited as an important QOL issue, and source of stress and concern for parents (Coulter & Koester, 1985; Hoare & Russell, 1995; Roberts & Whiting, 2011; Saburi, 2011). However, prior to this study, limited evidence was available on parents' perspectives of navigating the disclosure process. The findings from phase one offer unique insights into the challenges parents experience when deciding to disclose the child's epilepsy to others outside the immediate family unit. Findings revealed that the main challenges confronting parents ranged from seeking normalcy for their child, contending with the invisibility of epilepsy, grappling with negative public perceptions of epilepsy and others' anticipated and/or actual negative reactions to disclosure, to the grief associated with mourning the loss of a 'healthy child' and having to negotiate and come to terms with the diagnosis. Many of these factors acted as barriers to disclosure by dissuading parents from disclosing their child's condition to others external to the nuclear family; and encouraging secrecy around the child's epilepsy.

One of the greatest challenges for parental disclosure was parents' view of themselves as 'protector' of their child, with responsibility for sheltering their child from harm and maintaining their child's sense of normality. A number of parents perceived non-disclosure as a protective mechanism to guard against their child experiencing what they viewed as unnecessary feelings of differentness, different treatment, restrictions, stigma, and others' negative reactions. Whilst parents' protective intentions for their child has been reported in prior research where parental epilepsy disclosure has been examined (Baker et al., 2008; Hanai, 1996; Jantzen et al., 2009; Kwong et al., 2000; Mu, 2008; Roberts & Whiting, 2011; Saburi, 2011), the consequences of parents concealing a child's epilepsy condition has not been evaluated to any great extent.

The limited evidence available from previous research alongside CWE's perspectives from phase one of this study, suggest that parental endorsement of concealment and/or selective disclosure management strategies can result in stigma-coaching, whereby, through parental

cues, CWE come to perceive their condition as deservedly stigmatised, shameful, and something that should not be spoken about (Jacoby & Austin, 2007; Kleck, 1968; Ryu et al., 2015). As previously highlighted, in such instances, concealment, rather than serving as protective and facilitating parents' pursuit of normalcy for their CWE, may instead actually enhance feelings of differentness. Furthermore, it is also known from previous research that the burden of keeping a chronic condition hidden from others, coupled with fear of discovery, can evoke feelings of anxiety, guilt, and isolation, and detrimentally impact on the psychosocial wellbeing of those living with CSIs (Flett, 2012; McNamara, Stevenson & Muldoon, 2013; Merin & Pachankis, 2011). Based on the aforementioned evidence, it would seem imperative to investigate the actual consequences of the adoption of more restrictive disclosure management strategies by parents of CWE.

Qualitative findings from this study also highlighted that the period immediately following the child's epilepsy diagnosis was emotionally challenging for parents. At this time-point, concealment and/or selective disclosure served to protect parents from emotional turmoil. The emotional implications of receiving a diagnosis of paediatric epilepsy for parents are well-documented in the literature, with reports of parents experiencing chronic sorrow, pain, grief, uncertainty, depression, and anxiety (Hobdell et al., 2007; Lewis, Hatton, Salas, Leake & Chiofalo, 1991; Lv et al., 2009; Mu, 2005; Yong, Cheng-Ye, Jiong & Zhang, 2008). However, the role such emotional consequences play in informing the disclosure decisions of parents of CWE are a novel finding of this study. The issues surrounding how parents understand, adjust and operationalise their child's epilepsy diagnosis continue to be poorly researched. Furthermore, inadequate attention is devoted to this topic of conversation during clinical appointments. The provision of assistance to parents in the form of counselling and/or support groups during this stressful time in their lives could benefit this population.

In spite of regional and global campaigns/initiatives to move epilepsy 'out of the shadows' (Cross, 2011; De Boer, 2002; De Boer et al., 2013; Reynolds, 2001; WHO, 2000), findings from the first phase of this study suggest that stigmatising feelings remain among some parents of CWE. In particular, felt stigma implicitly expressed through diagnosis concealment was commonly reported. Interestingly, parental perceptions of the way epilepsy is publicly perceived, as well as anticipated or actual experiences of stigmatisation due to disclosure, encouraged the adoption of a strategy of parental concealment surrounding the child's epilepsy. Yet, such a strategy could serve to foster the *cycle of invisibility* around epilepsy (Lewis & Parsons, 2008). Future research is required to investigate this bidirectional relationship between stigma and disclosure, whereby disclosure decisions are informed by perceptions of stigma, but internalised feelings of stigma amongst those living with epilepsy are implicitly expressed and relayed to others through diagnosis concealment. In summary, parents' perspectives on barriers to disclosure suggest that further educational campaigns are required to promote public learning

about epilepsy and to break down barriers and misconceptions that currently encircle the condition so that epilepsy is viewed in a more positive light. Furthermore, a facilitative environment needs to be created in which it is the norm rather than the exception for parents to openly discuss their child's epilepsy with others. Future studies should focus on explicating how epilepsy-related stigma (and specifically felt stigma) can best be eradicated.

In conclusion, the findings from phase one of this study, through qualitative exploration of the perspectives of parents of CWE, provide unique insights into the factors that impede parental disclosure of their child's epilepsy condition to others external to the nuclear family. Additionally, they identify situational factors that promote parental adoption of concealment or selective disclosure management strategies.

6.5.3 Child and Parent Perspectives on Barriers to Disclosure: Similarities and Differences

It is important to highlight that some similarities existed between the self-reported barriers to disclosure for CWE and parents of CWE. Both CWE and parents grappled with issues such as threats to normalcy, the invisible nature of epilepsy and others' negative reactions to disclosure. However, although some of the disclosure challenges CWE and their parents experienced bore resemblances, these challenges generally manifested themselves in different ways across the populations, e.g. the challenge that the invisible nature of epilepsy posed to both CWE and their parents. For some CWE, this issue arose due to difficulties with credibility and the struggle for CWE's peers to reconcile their perceptions of how a 'sick' person should appear with the physical appearance of CWE. For parents of CWE, the issue of invisibility was problematic due to perceptions that epilepsy is viewed less favourably than other visible conditions, both in terms of physical manifestations and because such conditions receive more media attention. Furthermore, the types of negative responses to disclosure from others that parents of CWE anticipated experiencing included acts of stigmatisation, prejudice, discrimination and exclusion. In contrast, CWE reported experiencing this challenge as fear of worrying or upsetting others, of bullying and teasing, and of others broadcasting the condition against their will. A number of unique challenges to disclosure specific to each population also emerged. Namely, parents experienced difficulties with disclosure due to their emotional responses to the child's diagnosis, whilst CWE struggled with the complex nature of the neurological condition, with some reporting an inability to appropriately verbalise and represent their epilepsy to others. Considered together, these findings would suggest that in considering how best to mitigate the difficulties faced by CWE and parents of CWE surrounding epilepsy disclosure, it is important to tailor efforts and take into account: 1) the unique ways in which barriers to disclosure manifest amongst CWE and parents of CWE; and 2) the salience of specific barriers to disclosure for CWE and their parents.

6.6 Enablers of Disclosure

Amongst CWE and parents of CWE, numerous factors that enabled their epilepsy disclosure to others outside the immediate family unit, and/or promoted the adoption of more open disclosure management strategies surrounding the child's epilepsy, emerged. These are discussed below.

6.6.1 Child Perspectives: Factors that Enable Disclosure

Amongst CWE, positive perceptions and attitudes towards epilepsy, open and positive family communication about epilepsy, others' positive responses to past disclosures, specific seizure characteristics and getting assistance with disclosure were key factors that encouraged their epilepsy disclosure to others external to the nuclear family. This is the first study to explicitly explore what enables CWE to disclose their epilepsy.

Of particular note, some CWE discussed how specific seizure characteristics (e.g. their seizure type, the perceived mildness of their seizures and the infrequency of their seizures) enabled their epilepsy disclosure. This finding likely relates to the changes in social information mediating mechanism posited in the DPM (Chaudoir & Fisher, 2010). That is, amongst CWE who viewed themselves as having less problematic epilepsy relative to others, the endorsement of more open disclosure management strategies may have been encouraged by the fact that such CWE were capable of minimising, downplaying and normalising the epilepsy when revealing their epilepsy condition to others. This, in turn, led them to perceive that the interpersonal consequences of their epilepsy disclosure exchanges with others would be positive rather than negative.

6.6.2 Parent Perspectives: Factors that Enable Disclosure

Factors that parents reported as enabling their disclosure of their child's epilepsy to others and promoting open disclosure management strategies included: positive perceptions of and pragmatic attitudes towards the child's epilepsy; the perception of disclosure as enhancing the child's safety and/or others' understanding of the child; others' positive reactions to prior disclosures; the child's seizure characteristics; the perception that disclosure serves as an educational tool and a method of fighting against epilepsy-related stigma; getting used to it; and public awareness and media coverage of epilepsy.

The finding that parents viewed disclosure as a mechanism via which they could ensure their CWE's safety and/or enhance others' understanding of the child was consistent with the findings of the Mu (2008) and Roberts & Whiting (2011) studies. These findings support the centrality of the issue of safety in informing parental disclosure behaviours surrounding a child's epilepsy. Furthermore, they reinforce the fact that epilepsy remains poorly understood within the public domain, particularly in considering its consequences.

A notable finding with regard to enablers of epilepsy disclosure was the belief held by some parents that disclosure provided a mechanism via which they could actively fight against

epilepsy-related stigma and educate themselves and others about epilepsy. For some parents, their desire to protect their CWE from negative consequences involved the adoption of aversive strategies, such as the employment of concealment as a stigma management technique. Amongst other parents, directly confronting the stigma associated with epilepsy and endeavouring to address public misconceptions about epilepsy was the preferred approach. As such, the findings indicate that a number of parents of CWE are actively working towards breaking the *cycle of invisibility* that encircles epilepsy. Similar proactive approaches to fighting back against stigma (e.g. open and voluntary disclosure and positive framing of the illness) surrounding other CSIs have been identified in the literature (e.g. Siegel, Lune & Meyer, 1998). The efficacy of such advocacy efforts by parents of CWE in terms of educating others about epilepsy and tackling epilepsy-related stigma requires exploration.

Finally, a number of parents posited that increased public awareness and media coverage of epilepsy would serve to enable their disclosure of their child's epilepsy to others outside the immediate family unit. According to Price et al. (2015) who reviewed epilepsy public awareness campaigns in the U.S. from 2001 through 2013, channels via which the Epilepsy Foundation have attempted to disseminate information in order to improve understanding, promote social inclusion and foster epilepsy-related empowerment have included traditional media and social media channels. Additionally, endorsements by community opinion leaders and celebrity spokespersons were noted. Price et al. (2015) contend that substantial achievements have been made in increasing the visibility of epilepsy-related issues and generating discussion utilising such channels. However, it remains to be seen whether public knowledge of and attitudes towards epilepsy have substantially improved. The qualitative findings of the present study preliminarily suggest that increasing media coverage of epilepsy via such channels within an Irish or European context could increase the likelihood of parents' engaging in disclosure exchanges with others external to the nuclear family, which could, in turn, contribute towards tackling the *cycle of invisibility* that surrounds the condition (Lewis & Parsons, 2008). Future research should investigate the potentially influential role of various media channels in improving public perceptions of epilepsy and empowering PWE and their family members to disclose the PWE's epilepsy condition to others.

6.6.3 Child and Parent Perspectives on Enablers of Disclosure: Similarities and Differences

Both CWE and parents highlighted that the child's specific seizure characteristics (in particular mild or infrequent seizures) and the internalisation of positive, accepting and/or pragmatic attitudes towards epilepsy enabled their disclosure of the child's epilepsy. The latter finding is somewhat intuitive given that such individuals likely did not perceive the child's illness as something to hide as they did not consider it as shameful or a stigmatising attribute. However, to the author's knowledge, this is the first study to identify this factor as enabling CWE's or

parents' epilepsy disclosure to others external to the nuclear family. Furthermore, consistent with prior empirical evidence pertaining to the disclosure behaviours of CWE (McEwan et al., 2004; Moffat et al., 2009) and parents of CWE (Roberts & Whiting, 2011), others' positive reactions to prior disclosures encouraged both CWE and parents in the present study to engage in future disclosure exchanges with others external to the nuclear family. This finding lends further support to the concept of a feedback loop playing a deterministic role in shaping subsequent disclosure likelihood amongst populations with CSIs (Chaudoir & Fisher, 2010; Clair et al., 2005; Greene, Derlega & Mathews, 2006). Many researchers posit that the outcomes of any single disclosure event affect and inform subsequent disclosure decisions via this feedback loop (Chaudoir & Fisher, 2010; Chaudoir, Fisher & Simoni, 2011; Ragins, 2008). That is, when people's anticipated fears of rejection and stigmatisation are not realised subsequent to disclosing the CSI to others, such feelings are alleviated and consequently they become increasingly open towards engaging in future disclosure exchanges with others, whereas the converse occurs if such fears are realised. This feedback loop warrants further investigation in the context of paediatric epilepsy, particularly given the fact that both positive and negative reactions from others were identified as being implicated in influencing the disclosure behaviours of CWE and parents of CWE in this first phase of the study.

Although some enablers to epilepsy disclosure were reported across both child and parent populations, other enablers to disclosure were unique to either CWE or parents of CWE. For example, whilst parents proxy-reported that open and positive family communication about epilepsy within the home served to enable their CWE to disclose their epilepsy condition to others external to the nuclear family, they did not report that this factor enabled their own epilepsy disclosure. Furthermore, only parents indicated that increased public awareness and media coverage of epilepsy might encourage their disclosure of their child's epilepsy. Additionally, only parents reported that disclosure was enabled by their perceptions that disclosure: 1) enhanced the child's safety and others' understanding of the child; 2) was an educational tool and served to tackle epilepsy-related stigma; and 3) got easier over time. The finding that CWE in the present study did not specifically perceive disclosure as enhancing their safety is particularly interesting because this has been identified as an enabler of disclosure by CWE in a previous study (Moffat et al., 2009). Indeed, safety was a topic that was seldom raised by CWE during child interviews in the present study.

Overall, whilst many CWE and parents discussed the challenges associated with disclosure during child and parent interviews, some CWE and parents identified potential avenues via which such disclosure challenges could be overcome. Collectively, the findings related to enablers of disclosure provide further support for the notion that the motivations for child and parental epilepsy disclosure vary quite substantially. Thus, in considering how best to assist

CWE and parents to navigate the epilepsy disclosure process, approaches need to be tailored according to the unique motivation systems that underpin their disclosure behaviours.

6.7 Strengths and Limitations of Phase One

A number of strengths were inherent in the first phase of this two-phased mixed methods study. First, the findings from this phase make a significant contribution towards our knowledge of the disclosure experiences of CWE and their parents through direct exploration of the perspectives of CWE and parents of CWE. Sartain, Clarke & Heyman (2000) contend that children's perspectives are often overlooked when conducting research pertaining to childhood chronic illness despite the fact that they are "competent interpreters of their world" (Deatrick & Faux, 1991; cited by Sartain et al., 2000, p.919). Thus, they argue that it is valuable and salient to capture the self-reported experiences of children living with chronic illnesses. Consequently, one of the key strengths of the first phase of the study was the inclusion of CWE's perspectives. Furthermore, the qualitative exploratory methodology employed facilitated the exploration of the complex topic of epilepsy disclosure. To date, disclosure has been under-researched and under-prioritised in epilepsy literature. This is in spite of the fact that the limited empirical evidence available suggests that epilepsy disclosure is a QOL issue for CWE and a stressor and source of concern for parents of CWE (Coulter & Koester, 1985; Hoare et al., 2000; Hoare & Russell, 1995; McEwan et al., 2004; Moffat et al., 2009; Roberts & Whiting, 2011; Ronen et al., 1999; Saburi, 2011). The findings from this first phase offer valuable insights into: 1) the disclosure management strategies adopted by CWE and their parents; 2) the individuals to whom CWE and their parents disclose the child's epilepsy condition; 3) the content and situational context of CWE's and parents' disclosure exchanges with others external to the nuclear family; and 4) the factors that act as barriers and enablers to disclosure for CWE and their parents. Such information is beneficial for HCPs and support organisations who aid families in navigating the epilepsy disclosure process. In particular, providing those working with families living with epilepsy with insight into the challenges associated with epilepsy disclosure will assist them in recognising and meeting the support needs of CWE and parents, and working alongside families to confront such difficulties. Tackling the challenges CWE and parents face surrounding epilepsy disclosure could ultimately assist in eliminating some of the disclosure-related issues that detrimentally impact on QOL and serve as either a source of concern or stressor, thus improving the psychosocial wellbeing of these vulnerable populations.

Although the findings from the first phase of this study provide important insights, some limitations are noteworthy. Despite implementation of a sampling strategy to capture a CWE population across the entire spectrum of epilepsy (i.e. from those with epilepsy in remission to those with refractory epilepsy), the CWE population in phase one comprised a large proportion of patients with poorly controlled epilepsy. This was evidenced by the short periods of seizure

freedom reported by the majority of parents. Thus, the child and parent perspectives on disclosure presented in chapter five may denote experiences that are unique to a more refractory population, and may not apply to populations with well-controlled epilepsy that is consequently easier to conceal. Future qualitative research using a more diverse population of CWE should aim to elucidate whether there is variance amongst the disclosure management strategies adopted by CWE, and parents of CWE, with well-controlled epilepsy versus those with intractable epilepsy; and whether barriers and enablers to disclosure across such populations are consistent or whether they differ.

A further limitation relates to the cultural homogeneity of the participating CWE and parents of CWE (i.e. with the exception of one family of Nigerian origin/descent, all other families were of Irish, American or British origin/descent). Research has documented some culturally specific differences in public perceptions of epilepsy. For instance, some contend that enacted stigma, in particular, is a more salient issue in Eastern cultures than in Western cultures and in the developing countries than in the developed countries (Baker, 2002; Jacoby et al., 2005). Therefore, cultural factors may affect CWE's and parents' disclosure decisions. Future qualitative research should assess the role of cultural factors as they relate to child and parental disclosure of a child's epilepsy condition.

6.8 Implications for Phase Two

In this sequential exploratory mixed methods study, an important consideration was how the qualitative phase could meaningfully inform the second phase of the study. To this end, the rich interview data played an instrumental role, not only in identifying important elements of CWE's and parents' disclosure behaviours and experiences that warranted further examination, but also in terms of developing survey items to meaningfully assess these constructs. In the absence of an existing measure of epilepsy disclosure behaviours for CWE and their parents, data from this phase has been used in the development of the youth and parent versions of the Epilepsy Disclosure Scale (see section 7.5.3 and Appendix U); two psychometrically sound quantitative scales that measure the extent to which CWE and their parents talk to and tell others external to the nuclear family about the child's condition. The interview data was also used to inform the design of detailed survey items to quantitatively assess other aspects of CWE's and parents' epilepsy disclosure experiences that warranted further investigation (e.g. disclosure targets, content, situational context, barriers, enablers, and consequences).

A final objective of phase one of the present study was to identify constructs that warranted quantitative investigation in phase two in terms of how they relate to CWE's and parents' epilepsy disclosure behaviours. Based on the cumulative evidence from the systematic review and this first qualitative phase of the study, it was decided that amongst CWE the relationships

between CWE's epilepsy disclosure behaviours and the following child-reported variables would be assessed: the child's seizure characteristics (type, frequency, visibility etc.), time since diagnosis, stigma perceptions, illness attitudes, self-perceptions, HRQoL, social support, level of epilepsy-related communication with parents, need for epilepsy-related information and support, and satisfaction with information received from HCPs during clinical engagements. Furthermore, the decision was made to investigate the relationships between parents' epilepsy disclosure behaviours and the following parent-reported variables: the child's seizure characteristics (type, frequency, visibility and perceived severity etc.), time since diagnosis, stigma perceptions, response to child illness, general distress disclosure, social support, level of epilepsy-related communication with the child with epilepsy, activity restrictions, perceived impact of epilepsy, need for epilepsy-related information and support, and satisfaction with information received from HCPs during clinical engagements. Finally, taking cognisance of evidence from this first phase of the study that suggests that parents are potential stigma coaches in the lives of their CWE and have the potential to influence their CWE's epilepsy disclosure behaviours, dyadic relationships between CWE's and parents' epilepsy disclosure behaviours and parent- and child-reported variables, respectively, will also be examined.

6.9 Conclusions

In summary, the qualitative phase of the present study presents unique insights into a number of aspects of CWE's and parents' epilepsy disclosure behaviours and experiences, inclusive of their disclosure management strategies, their disclosure targets, the content and situational context of their disclosure exchanges, and factors that challenge or impede versus enable or promote their disclosure. Previously, empirical evidence in this regard was extremely limited.

Amongst CWE and parents of CWE, disclosure behaviours are diverse, with both restrictive disclosure management strategies and open and voluntary disclosure management strategies endorsed by child and parent participants. However, in holistically considering the evidence from this first phase, it would seem that the motivation systems underpinning the selection of specific disclosure management strategies by CWE and parents of CWE fundamentally differ. This was particularly evidenced in terms of differences in: 1) the specific categories of disclosure targets identified by CWE and parents of CWE; 2) the content and situational context of CWE's and parents' epilepsy disclosure exchanges with others; and 3) perceived enabling factors for epilepsy disclosure identified by CWE and parents of CWE. In particular, findings point towards epilepsy disclosure being most salient and important for parents of CWE in the context of ensuring the safety of the child and garnering social support to overcome the difficulties associated with parenting a child with epilepsy. In contrast, for CWE disclosure behaviours seem to be more contingent upon CWE's perceptions of how to normalise epilepsy and minimise its impact on their lives.

Findings from phase one also suggest that disclosure represents a significant challenge in the lives of CWE and their parents; and offer support for the important role disclosure plays in the lives of families living with epilepsy by substantiating prior limited evidence that indicated disclosure was a QOL issue for CWE (McEwan et al., 2004; Moffat et al., 2009; Ronen et al., 1999) and a source of concern and a stressor for parents of CWE (Coulter & Koester, 1985; Hoare & Russell, 1995; Roberts & Whiting, 2011; Saburi, 2011). In order to mitigate some of the challenges associated with child and parental epilepsy disclosure, during their engagements with families, HCPs and support organisations should discuss and address the barriers to disclosure faced by CWE and parents of CWE as identified in phase one of the study. Specifically, amongst CWE there is a need for the provision of child-directed healthcare services and meaningful engagements with HCPs, with a view to enhancing CWE's ability to verbally represent their condition to others. Furthermore, in considering parents of CWE, it seems particularly salient for HCPs and support organisations to assist parents in coming to terms with the child's epilepsy diagnosis by providing tailored support and counselling to parents at the initial time point of diagnosis. Additionally, the evidence suggests that in both CWE and parent populations, the adoption of a more holistic approach to resolve internalised negative attitudes towards epilepsy (i.e. felt epilepsy-related stigma) is required. Moreover, advocacy efforts should be heightened, with HCPs, patient advocacy groups, support organisations and healthcare organisations taking a more active role in striving to: 1) increase the visibility of epilepsy within the public domain; 2) tackle misconceptions that encircle epilepsy; and 3) enhance public knowledge and understanding of epilepsy.

To conclude, whilst the first phase of the present study represents the first attempt to comprehensively explore the complex, yet important, concept of epilepsy disclosure amongst CWE and parents of CWE, research pertaining to this topic is very much in its infancy. Further research is required that focuses on investigating other aspects of epilepsy disclosure amongst CWE and parents of CWE, such as the consequences of the adoption of various disclosure management strategies, and the relationship between the disclosure behaviours of CWE and the disclosure behaviours of their parents. The second phase of the present study will address these gaps, amongst others, in epilepsy literature through the quantitative assessment of such issues.

Chapter 7: Phase Two: Quantitative Method

7.0 Introduction

This chapter discusses the method employed in the second phase of the study. In particular, the following methodological details are reported: 1) study design; 2) aims, objectives and hypotheses for phase two; 3) participant selection criteria; 4) study procedure; 5) survey design process; 6) survey piloting procedure; 7) data analysis procedure; and 8) ethical considerations.

7.1 Design

The second phase of this sequential exploratory mixed methods study involved a quantitative cross-sectional survey of CWE (aged 8-18 years) and parents of CWE.

7.2 Aims, Objectives and Hypotheses for Phase Two

7.2.1 Aim of Phase Two

The aim of this second phase was to conduct a quantitative survey that assessed epilepsy disclosure amongst CWE and parents of CWE. In doing so, the aim was to quantitatively capture comprehensive descriptive data pertaining to the epilepsy disclosure experiences of CWE and their parents, and to determine patterns of relationships between CWE's and parents' epilepsy disclosure behaviours and their demographic/clinical characteristics, psychosocial wellbeing and illness attitudes.

7.2.2 Objectives for Phase Two

The objectives for phase two were:

1) To create a profile of the disclosure behaviours of CWE and parents of CWE.
2) To assess the content and situational context of CWE's and parents' disclosure exchanges with others.
3) To identify contextual factors that facilitated and/or hindered CWE's or parents' disclosure of the child's epilepsy condition to others.
4) To examine the consequences of epilepsy disclosure for CWE and parents of CWE, and the feelings disclosure exchanges with others outside the immediate family unit elicit in CWE and their parents.
5) To psychometrically evaluate two newly developed scales that measure CWE's and parents' epilepsy disclosure behaviours (i.e. the degree to which they tell and talk to others about the child's condition).

6) To investigate the relationship between CWE's epilepsy disclosure behaviours and their self-reported demographic and clinical characteristics.
7) To investigate the relationship between parents' disclosure behaviours surrounding their child's epilepsy and their self-reported demographic characteristics, as well as their child's demographic and clinical characteristics (parent-reported).
8) To assess the relationship between CWE's epilepsy disclosure behaviours and their perceived stigmatisation, illness attitudes, self-perception, HRQoL, social support, degree of epilepsy-related communication with their parents, need for epilepsy-related information and support, and satisfaction with the level of epilepsy-related information received during their engagements with HCPs.
9) To assess the relationship between parents' disclosure behaviours surrounding their child's epilepsy and parents' stigma perceptions, response to their child's epilepsy, general tendency to disclose distressing information to others, perceived social support, reported degree of epilepsy-related communication with their child, reported level of epilepsy-related disability and activity restrictions experienced by their CWE, perceived impact of epilepsy on the child and the family, need for epilepsy-related information and support, and satisfaction with the level of epilepsy-related information received during their interactions with HCPs.
10) To assess the relationship between CWE's and parents' epilepsy disclosure behaviours.
11) To assess the relationship between CWE's epilepsy disclosure behaviours and parent-reported psychosocial and illness attitude variables.
12) To assess the relationship between parents' epilepsy disclosure behaviours surrounding their child's epilepsy and child-reported psychosocial and illness attitude variables.

7.2.3 Hypotheses for Phase Two

In relation to objectives number eight and nine, based on a review of the existing empirical evidence (see chapter two) and the findings from the qualitative phase of the study (see chapter five), a number of hypotheses were posited that are presented in Tables 7.1 and 7.2 below. Table 7.1 summarises the hypotheses postulated in relation to the association between CWE's epilepsy disclosure behaviours (as captured by the newly developed Epilepsy Disclosure Scale – Youth Version) and a number of child-reported psychosocial and illness attitude variables. Table 7.2 presents the hypotheses posited with regard to the relationship between parents' disclosure behaviours surrounding their child's epilepsy (as captured by the newly developed Epilepsy Disclosure Scale – Parent Version) and a number of parent-reported clinical, psychosocial and illness attitude variables.

Table 7.1: Hypotheses posited for CWE in relation to Objective 8

Measure	Hypotheses pertaining to Epilepsy Disclosure Behaviours (as measured by the newly developed Epilepsy Disclosure Scale – Youth Version [EDS-Y])
Child Stigma Scale (CSS)	1. CWE's CSS scores will positively correlate with their score on the EDS-Y (i.e. increased stigma perceptions amongst CWE will be significantly related to greater epilepsy concealment amongst CWE).
Child Attitude toward Illness Scale (CATIS)	2. CWE's scores on the CATIS will negatively correlate with their scores on the EDS-Y (i.e. children who possess negative attitudes towards their illness will endorse greater epilepsy concealment).
Self-Perception Profile for Children (SPPC)	3. CWE's scores on the SPPC will negatively correlate with their scores on the EDS-Y (i.e. positive self-perceptions amongst CWE will be significantly related to more open epilepsy disclosure).
Health-Related Quality of Life measure for children with epilepsy (CHEQOL-25)	4. CWE's scores on the CHEQOL-25 will negatively correlate with their scores on the EDS-Y (i.e. lower HRQoL amongst CWE will be significantly associated with greater epilepsy concealment).
Social Support Scale for Children and Adolescents (SSSCA)	5. CWE's scores on the SSSCA will negatively correlate with their scores on the EDS-Y (i.e. CWE who perceive lower levels of social support will report greater epilepsy concealment).
Child-reported Level of Epilepsy-related Communication with Parents	6. CWE's scores on the Child-reported Level of Epilepsy-related Communication with Parents items will negatively correlate with their scores on the EDS-Y (i.e. CWE who report communicating to a greater extent with their parents about their epilepsy will endorse more open epilepsy disclosure to others external to the nuclear family).
Child Need for Information and Support: Subscale of the Parent Report of Psychosocial Care Scale	7. CWE's scores on the Need for Information and Support subscales of the Child Report of Psychosocial Care Scale will positively correlate with their scores on the EDS-Y (i.e. CWE who report a greater need for epilepsy-related information and support will report greater epilepsy concealment).
Child Information Received: Subscale of the Parent Report of Psychosocial Care Scale	8. CWE's scores on the Child Information Received Subscale of the Child Report of Psychosocial Care Scale will negatively correlate with their scores on the EDS-Y (i.e. CWE who were less satisfied with the level of information received during their interactions with HCPs will endorse greater epilepsy concealment).

Table 7.2: Hypotheses posited for Parents of CWE in relation to Objective 9

Measure	Hypotheses pertaining to Epilepsy Disclosure Behaviours (as measured by the newly developed Epilepsy Disclosure Scale – Parent Version [EDS-P])
Seizure Severity Scale (SSS)	9. Parents' scores on the SSS will negatively correlate with their scores on the EDS-P (i.e. parents of CWE with less severe seizures [i.e. those perceived as less disruptive/intrusive in terms of their impact on the child's everyday life] will endorse greater concealment of their child's epilepsy).
Parent Stigma Scale (PSS)	10. Parents' PSS scores will positively correlate with their score on the EDS-P (i.e. increased parental stigma perceptions will be significantly related to greater parental concealment of the child's epilepsy).
Parent Response to Child Illness Scale (PRCI)	11. Parents' scores on the PRCI will negatively correlate with their scores on the EDS-P (i.e. parents who report having responded negatively to their child's illness will report greater concealment of their child's epilepsy).
Distress Disclosure Index (DDI)	12. Parents' scores on the DDI will negatively correlate with their scores on the EDS-P (i.e. parents with a greater tendency to disclose generally distressing information to others will endorse more open disclosure of their child's epilepsy).
Multidimensional Scale of Perceived Social Support (MSPSS)	13. Parents' scores on the MSPSS will negatively correlate with their scores on the EDS-P (i.e. parents who perceive lower levels of social support will report greater concealment of their child's epilepsy).
Parent-reported Level of Epilepsy-related Communication with Child	14. Parents' scores on the Parent-reported Level of Epilepsy-related Communication with Child item will negatively correlate with their scores on the EDS-P (i.e. parents who report communicating to a greater extent with their child about his/her epilepsy will endorse more open disclosure of the child's epilepsy to others external to the nuclear family).
Hague Activity Restrictions in Childhood Epilepsy Scale (HARCES)	15. Parent' scores on the HARCES will negatively correlate with their scores on the EDS-P (i.e. parents who report that their child experiences less disability due to parent- or doctor- imposed activity restrictions to avoid epilepsy-related injuries will engage in greater concealment surrounding their child's epilepsy).
Impact of Pediatric Epilepsy Scale (IPES)	16. Parents' scores on the IPES will correlate with their scores on the EDS-P. Directionality of the relationship not hypothesised because the extent to which parents' perceived epilepsy as impacting on the psychosocial wellbeing of the family varied in terms of whether parents perceived it as a barrier or a factor that encouraged them to disclose their child's epilepsy in phase one of the study.
Parent Need for Information and Support: Subscale of the Parent Report of Psychosocial Care Scale	17. Parents' scores on the Need for Information and Support subscales will correlate with their scores on the EDS-P. The directionality of this relationship was not hypothesised because parental need for epilepsy-related information and support emerged as both a barrier and a factor that encouraged parental disclosure of the child's epilepsy in phase one of the study.

Measure	Hypotheses pertaining to Epilepsy Disclosure Behaviours (as measured by the newly developed Epilepsy Disclosure Scale – Parent Version [EDS-P])
Parent Information Received: Subscale of the Parent Report of Psychosocial Care Scale	18. Parents' scores on the Parent Information Received Subscale of the Parent Report of Psychosocial Care Scale will negatively correlate with their scores on the EDS-P (i.e. parents who were less satisfied with the level of information received during their engagements with HCPs will endorse greater concealment of their child's epilepsy).

There was an absence of empirical evidence assessing the relationships between CWE's and parents' epilepsy disclosure behaviours and their demographic and clinical characteristics, as well as the relationships between CWE's epilepsy disclosure behaviours and their parents' epilepsy disclosure behaviours, or CWE's epilepsy disclosure behaviours and parent-reported psychosocial and illness attitude variables (or vice versa). Consequently, specific hypotheses were not proposed with regard to objectives six, seven, ten, eleven or twelve. Rather, two-tailed exploratory correlational and group difference analyses were performed to assess the relationships between such variables.

7.3 Participants

The sample for phase two consisted of 47 CWE and 72 parents of CWE. A detailed breakdown of the CWE and parent participants' characteristics is provided in chapter 8 in section 8.1.

7.3.1 Inclusion and Exclusion Criteria

Children aged between 8 and 18 years who had a diagnosis of any type of epilepsy (inclusive of genetic epilepsies, structural/metabolic epilepsies and epilepsies of no known cause) and had a prescription for AEDs were eligible to participate. Children presenting with significant intellectual disabilities or developmental delays and/or additional significant medical conditions (other than epilepsy) were ineligible to participate. Parent participants were required to be the parents of eligible children.

The age range (8-18 years) for eligible CWE participants for phase 2 was selected because of the readability and age-appropriateness of the measures to be utilised and to account for the fact that during phase 1 recruitment, it was evident that many young people with long-term health conditions in the Irish context remain under care in paediatric services up to the age of 18 years old.

Children/adolescents with gross cognitive, developmental or behavioural deficits and/or other significant medical conditions were excluded to avoid confounding findings due to how such issues can present their own unique challenges in terms of communicating with others.

7.4 Procedure

7.4.1 Ethical Approval

Prior to commencing data collection for phase two, ethical approval was sought and obtained from the research ethics committees in DCU, TSCUH, Our Lady of Lourdes Hospital, Drogheda, and St. James's Hospital, Dublin (see Appendices N.1-N.4).

7.4.2 Recruitment

As no central database/list of CWE in Ireland currently exists that questionnaires could be distributed to, participants were recruited via two routes;

Route 1: Recruitment through Paediatric Neurology Department TSCUH, Paediatric Department, Our Lady of Lourdes Hospital, Drogheda and Adult Neurology Department, St. James's Hospital, Dublin

Potential participants (families) who met the inclusion criteria for phase two were identified during clinic hours by nominated clinical personnel at each site. Once eligible participants were identified, the nominated clinical personnel at each site posted a survey packet (comprising a cover letter, child and parent questionnaires and age-appropriate methodological information in the form of child and parent plain language statements - see Appendices O.1 and O.2) to CWE and their parents. It was clearly emphasised to potential participants that their participation was entirely voluntary and confidential. Therefore, their decision as to whether to participate in the study would not affect their care in any way. If CWE and their parents decided to participate in the study, they were offered the option of completing the questionnaires at home and returning them directly to the researcher in the stamped addressed envelope provided or of completing the questionnaire online on the Qualtrics online survey platform (the survey hyperlink was provided in the survey pack).

Route 2: Recruitment through Epilepsy Ireland (the Irish Epilepsy Association)

CWE and their parents were recruited through EI in two ways. First, a number of participants were recruited voluntarily via advertisements on the EI website (see Appendix P), social media pages (i.e. Facebook and Twitter) and in the members' print newsletter. For this method of recruitment, contact details for the researcher were included so that parents and CWE who wished to participate or who had further queries could contact the researcher directly. Participants were provided with information regarding the inclusion/exclusion criteria and the study procedure, and were offered the opportunity to either: 1) complete the questionnaire online via the Qualtrics survey link provided in the newsletter or on the EI website; or 2) request a hard copy by telephone or through the project email. In cases where prospective participants requested hard copies of the questionnaires, the researcher took the name and

address of the interested parties and posted out the survey packet with a stamped addressed envelope to facilitate return of the surveys. A second way in which participants were recruited through the national epilepsy association was through contact with a communications officer from EI. Members of EI eligible to participate were identified and contacted by the communications officer. Families who were interested in the study and were willing for their contact details to be shared were then contacted by the researcher at a time convenient for them. Subsequent to communicating with the researcher, if families were happy to participate in the study, the researcher either sent them out the survey packet for hard copy completion or directed them to the online survey link. All potential participants were assured of the voluntary and confidential nature of the research and that their decision as to whether to participate in the study would not affect their future engagements with EI in any way.

The dual recruitment pathway was employed in order to: 1) capture the experiences of a diverse group of CWE who were not merely linked to one neurology clinic or service provider (i.e. children cared for in rural communities by primary care providers); and 2) ensure that a maximum variation sample was obtained so that the situational context and variations of CWE's and parents' perspectives of disclosure were captured. This allowed for an enriched understanding of the concept of disclosure.

For both recruitment routes, in addition to being able to complete hard copy or online versions of the questionnaire, all participants were also offered the option of face-to-face or telephone assistance with survey completion. In the case of hard copy completion, a separate envelope was enclosed in the survey packet for CWE participants should they wish to keep their responses private from their parents. Similar to Dyson et al.'s (2010) strategy, a tick box question was included in the demographics section of the child questionnaires for CWE to self-report who completed the survey (i.e. survey completed by child alone, by parents only, or by both child and parent). Parents were also asked to specify whether their child with epilepsy was present or not while they completed the surveys. In order to optimise response rates, two follow-up thank you letters were distributed - the first after a one month time frame and the second two months subsequent to the original mail out of the survey packs - to thank those who had already completed and returned the survey and as a reminder and repeat invitation for those who had yet to complete and return the surveys to do so if they wished to participate in the study (see Appendices Q.1 and Q.2).

7.5 Designing the Surveys

The surveys for CWE (see Appendix R.1) and parents (see Appendix R.2) were developed from an amalgamation of: 1) existing valid and reliable age-appropriate instruments (outlined in sections 7.5.1 [child instruments] and 7.5.2 [parent instruments] below) measuring constructs

that were deemed pertinent to epilepsy disclosure based on the findings from phase one of the study; and 2) new Epilepsy Disclosure Questionnaires designed specifically for this study that consisted of: (a) items drawn from pre-existing measures and developed based on the evidence from the systematic review and the qualitative interviews; and (b) newly developed scales investigating CWE's and parents' epilepsy disclosure behaviours (that is, the extent to which CWE and parents tell and talk to others (or not) about the child's epilepsy) (see section 7.5.3 below). The surveys aimed to establish a profile of CWE's and parents' epilepsy disclosure experiences, self-perceptions, illness attitudes, response to illness, perceived stigmatisation, HRQoL, perceived social support, degree of parent/child epilepsy-related communication, epilepsy-related information and support needs, satisfaction with level of epilepsy-related information received during engagements with HCPs, and seizure severity.

Alongside these tools, the following demographic and clinical details were recorded: age, gender, ethnicity, geography, parent education level, family history of epilepsy, epilepsy terminology used, aetiology of epilepsy, type of epilepsy, age at illness onset, duration of time since diagnosis, seizure type (e.g. tonic-clonic, absence, complex partial, simple partial), seizure frequency, length, timing (e.g. nocturnal), severity and visibility, medication management and satisfaction with epilepsy care. Finally, in order to link child/parent dyads, CWE and their parents were asked to provide unique non-identifiable codes at the outset of the survey. Matching codes were indicative of a child/parent dyad and thus facilitated the researchers in linking dyadic data.

Overall, CWE surveys comprised a total of 250 items, whilst parent surveys comprised a total of 251 items. The employment of several psychometric instruments, with many items for completion, has previously been successfully implemented with CWE and parent populations examining psychosocial outcomes for families living with epilepsy (e.g. Frizzell, Connolly, Beavis, Lawson & Bye, 2011; Jantzen et al., 2009; Räty, Larsson & Söderfeldt, 2003; Van Empelen, Jennekens-Schinkel, Van Rijen, Helders & Van Nieuwenhuizen, 2005).

7.5.1 Pre-validated Child Instruments

Seven pre-validated child self-report instruments (comprising a total of 124 items) were used in the survey. All measures have been successfully implemented with CWE previously, have been validated with the child age ranges the data were collected from (i.e. children aged 8-18 years) and are reliable and valid. The instruments are outlined in Table 7.3 below. Further information on each of the instruments is presented in Appendix S.1, alongside detail of their psychometric properties.

Table 7.3: Phase Two: Pre-Validated Instruments Included in the Child Survey

Name of Scale *(Authors)*	Number of Items	Subscales	Construct Examined
Child Stigma Scale (CSS) *(Austin et al., 2004)*	8	Not applicable	Children's epilepsy-related stigma perceptions.
Child Attitude toward Illness Scale (CATIS) *(Austin & Huberty, 1993)*	13	Not applicable	Children's positive and negative feelings towards living with a chronic health condition.
Self-Perception Profile for Children (SPPC) *(Harter, 1985)*	36	Scholastic Competence (6 items) Social Competence (6 items) Athletic Competence (6 items) Physical Appearance (6 items) Behavioral Conduct (6 items) Global Self-Worth (6 items)	Children's global self-worth, in addition to their self-esteem and competence in five specific domains.
Health-Related Quality of Life measure for Children with Epilepsy (CHEQOL-25) *(Ronen, Streiner & Rosenbaum, 2003)*	25	Interpersonal Social Consequences (5 items) Worries and Concerns (5 items) Intrapersonal/Emotional Issues (5 items) Epilepsy: My Secret (5 items) Quest for Normality (5 items)	Children's HRQoL across 5 specific domains.
Social Support Scale for Children and Adolescents (SSSCA) *(Harter, 1985)*	24	Parental Support (6 items) Classmate Support (6 items) Teacher Support (6 items) Close Friends Support (6 items)	Children's perceptions of social support from four sources.
Child Need for Information and Support: Subscale of the Child Report of Psychosocial Care Scale *(Austin, Dunn, Huster & Rose, 1998)*	12	Need for Information Subscale (6 items) Need for Support Subscale (6 items)	Children's need for information and support related to their seizure condition.
Child Information Received: Subscale of the Child Report of Psychosocial Care Scale *(Austin et al., 1998)*	6	Not applicable	Children's satisfaction with the level of epilepsy-related information received during their engagements with HCPs.

7.5.2 Pre-validated Parent Instruments

Nine pre-validated parent self-report instruments (comprising a total of 116 items) were used in the survey. All measures have been successfully implemented with parents previously. The instruments are described in Table 7.4 below. Furthermore, additional information on each of the instruments is presented in Appendix S.2, alongside detail of their psychometric properties.

Table 7.4: Phase Two: Pre-Validated Instruments Included in the Parent Survey

Name of Scale ***(Authors)***	**Number of Items**	**Subscales**	**Construct Examined**
Seizure Severity Scale (SSS) *(Baker et al., 1991; Austin et al., 2004)*	9	Not applicable	The degree to which seizures disrupt the everyday lives of the CWE.
Parent Stigma Scale (PSS) *(Austin et al., 2004)*	5	Not applicable	Parents' epilepsy-related stigma perceptions.
Parent Response to Child Illness Scale (PRCI) *(Austin et al., 2008)*	35	Child Support (8 items) Family Life/Leisure (10 items) Condition Management (5 items) Child Autonomy (6 items) Child Discipline (6 items)	Parents' responses and perceptions related to the onset of epilepsy in a child.
Distress Disclosure Index (DDI) *(Kahn and Hessling, 2001)*	12	Not applicable	Parents' tendency and willingness to disclose (versus conceal) personally distressing information to others.
Multidimensional Scale of Perceived Social Support (MSPSS) *(Zimet, Dahlem, Zimet & Farley, 1988)*	12	Significant Other (4 items) Family (4 items) Friends (4 items)	Parents' perceived level of social support from three sources.
Hague Restrictions in Childhood Epilepsy Scale (HARCES) *(Carpay et al., 1997)*	10	Not applicable	Parental perceptions of child disability due to epilepsy-related restrictions imposed in order to reduce the risk of seizure-related injuries.
Impact of Pediatric Epilepsy on the Family (IPES) *(Camfield, Breau & Camfield, 2001)*	11	Not applicable	Parents' perceptions of the psychosocial impact of paediatric epilepsy on the family

Name of Scale *(Authors)*	Number of Items	Subscales	Construct Examined
Parent Need for Information and Support: Subscale of the Parent Report of Psychosocial Care Scale *(Austin et al., 1998)*	12	Need for Information Subscale (6 items) Need for Support Subscale (8 items)	Parents' need for information and support related to their child's seizure condition.
Parent Information Received: Subscale of the Parent Report of Psychosocial Care Scale *(Austin et al., 1998)*	6	Not applicable	Parents' satisfaction with the level of epilepsy-related information received during their engagements with HCPs.

7.5.3 Child and Parent Epilepsy Disclosure

A key objective of the current study was to quantitatively measure CWE's and parents' epilepsy disclosure behaviours, disclosure targets, the content of their disclosure exchanges, the situational context of their disclosure exchanges, their motivations for and against disclosure, the factors they perceived as enabling or posing barriers to their disclosure, the emotions implicated in the disclosure process, and the consequences of their disclosure exchanges with others outside the immediate family context. While a number of subscales in the aforementioned pre-validated child and parent instruments incorporate items related to CWE's epilepsy disclosure (e.g. the CSS, CHEQOL-25 and the Child Need for Information and Support subscale) and parents' disclosure surrounding their child's epilepsy (e.g. the PRCI), no specific pre-validated scale or subscale was identified which would suitably assess all of these aspects of child and parent epilepsy disclosure. In fact, as identified in the systematic review, pre-existing measures employed for use in epilepsy populations lacked comprehensiveness and sensitivity in terms of encapsulating the complex process of disclosure (see section 2.3.3).

In the absence of any single pre-existing suitable measure, a number of scales were identified and reviewed which could be adapted for use with CWE and their parents inclusive of the Disclosure Practices Questionnaire (Adolescents with Epilepsy: Westbrook, Silver, Coupey & Shinnar, 1991), the Patient Profile Questionnaire (Breast Cancer Survivors; Henderson, Davison, Pennebaker, Gatchel & Baum, 2002) and the Questionnaire for Young People with Sickle Cell Disorder (Dyson et al., 2010). Adapting items from these scales particularly facilitated: 1) the examination of CWE's and parents' disclosure targets; and 2) the development of two scales to measure child and parent epilepsy disclosure behaviours; discussed at greater length in Appendices T and U, respectively.

In addition to adapting items from the aforementioned scales, items that were developed based on thematic analysis of the data that emerged from the qualitative phase of the study (comprising interviews with children living with epilepsy [*n*=29] and their parents [*n*=34]) were included on the questionnaires to capture information related to: 1) when disclosure exchanges occur for CWE and their parents; 2) what it is in relation to the child's epilepsy the child or parent discloses to others; 3) the rationale underlying the adoption of specific disclosure management strategies by CWE and their parents; 4) what factors facilitate or act as barriers to disclosure for CWE and their parents; 5) affective responses related to disclosure for CWE and their parents; and 6) previous reactions to disclosure by others. Incorporating the experiences of CWE and their parents and employing language originating from direct quotes in the item development process of this questionnaire enhances the face and content validity of the items on this questionnaire, as well as its applicability to the population.

Overall, information pertaining to CWE's and parents' epilepsy disclosure was captured in the present study employing newly designed Child and Parent Epilepsy Disclosure Questionnaires, with items developed based on thematic analysis of the qualitative data from the first phase of the study and drawn from three pre-existing measures identified on review of the literature. The questionnaires examined disclosure targets, the content of disclosure exchanges, the situational context of disclosure exchanges, motivations for/against disclosure, contextual factors informing disclosure decisions, affective responses and others' reactions to disclosure. The questionnaires also incorporated the newly developed six-item youth and parent versions of the Epilepsy Disclosure Scale (EDS) in order to capture CWE's and parents' epilepsy disclosure versus concealment behaviours specifically, with items identifying the extent to which CWE and parents tell and talk to others (or not) about the child's epilepsy (see Appendix U for further detail on the measure development process). Items on this scale are rated on a 4-point Likert-type response scale, with scores ranging from 0-3. Higher scores reflect greater concealment of the child's epilepsy, whilst lower scores are indicative of more open disclosure behaviours surrounding the child's epilepsy. The psychometric evaluation of these newly developed measures is reported in section 8.4.

In total, the child version of the Epilepsy Disclosure Questionnaire comprised 109 disclosure items, while the parent version of this questionnaire consisted of 105 disclosure items (in both versions, as the study is exploratory in nature, items were included which offered participants the option to provide open-ended responses). Table 7.5 provides a full breakdown of the Child and Parent Epilepsy Disclosure Questionnaires, inclusive of information pertaining to the aspects of disclosure measured, the number of items incorporated to measure each aspect of disclosure, and detail regarding where items were positioned in the questionnaires.

Table 7.5: Breakdown of the Child and Parent Epilepsy Disclosure Questionnaires

Aspect of Disclosure Measured	Child Version: No. of Items	Parent Version: No. of Items
Epilepsy Disclosure Behaviours (EDS –Youth and Parent Versions)	6 **(B1-B3; B5; B7-B8)**	6 **(B1-B3; B5; B7-B8)**
Disclosure Management Strategies	1 **(B4)**	1 **(B4)**
Desire to Talk to Someone about Epilepsy	1 **(B6)**	1 **(B6)**
Written Disclosure	2 **(B9-B10)**	2 **(B9-B10)**
Disclosure Targets	3 **(B11-B13)**	1 **(B11)**
Context of Disclosure Exchanges with Others	15 **(B14-B28)**	16 **(B12-B27)**
Content of Disclosure Exchanges with Others	13 **(B29-B41)**	14 **(B28-B41)**
Motivations For/Against Disclosure	21 **(B42-B62)**	22 **(B42-B63)**
Enablers/Barriers for Disclosure	17 **(B63-B79)**	17 **(B64-B80)**
Emotions Prior to Disclosure Exchanges with Others	9 **(B80-B88)**	8 **(B81-B88)**
Consequences of Disclosure Exchanges with Others	10 **(B89-B98)**	8 **(B89-B96)**
Affective Responses to Others' Reactions to Disclosure	11 **(B99-B109)**	9 **(B97-B105)**

7.6 Piloting the Surveys

The surveys were piloted with six families (i.e. CWE aged 7-14 years and one or both of their parents) who were recruited when parent feedback regarding phase one findings (see Appendix V) was distributed to families who participated in the qualitative interviews. If families expressed interest in partaking in the survey piloting, they were offered the option of either completing the surveys in the presence of the researcher and offering verbal feedback or of completing the surveys alone and providing written feedback via post (three families selected to pilot the surveys using each option). Piloting of the surveys continued until such a stage that no new issues with the surveys or queries about the surveys were being raised by CWE or their parents. Surveys were not only piloted to assess the construct validity of the newly developed youth and parent versions of the EDS (see Appendix U) but also to help in establishing the clarity of instructions, question readability and understanding, and the actual length of time the surveys took to complete. Following piloting with families, a number of minor changes were made, particularly to the Child and Parent Epilepsy Disclosure Questionnaires. For example, CWE and their parents identified that in the initial versions of the questionnaires there were no 'not applicable, I always tell others' or 'not applicable, I never tell others' response options. Thus, some of the participants reported feeling forced to select between options that did not

accurately represent their experiences or views. Consequently, such options were incorporated into the final versions of the questionnaires. In addition, a few minor amendments were made throughout the surveys to enhance question readability and comprehension. Finally, CWE and parents of CWE who partook in piloting of the surveys approximated that the survey completion time was one hour. This information was included in the child and parent plain language statements (see Appendices O.1 and O.2) in order to provide prospective participants with as accurate a reflection as possible of the time commitment involved in partaking in the study.

7.7 Data Analysis

The quantitative data from phase two were analysed using the IBM statistical software package SPSS (Version 22.0; 2013). First, descriptive statistics were performed on individual items, subscales and scales to assess total and mean scores, standard deviations and frequencies. Subsequently, reliability analyses were conducted using Cronbach's alpha statistic to examine the internal consistency of each scale and subscale (see Appendix W). Normality testing was then performed to investigate whether the various data points merited parametric or non-parametric statistics. The decision regarding whether parametric or non-parametric statistics were appropriate for analysis of data on each demographic and clinical variable, as well as on each scale/subscale, was made by analysing the skewness of the data in the present study (see Appendix X for skewness data). In accordance with the recommendations of Bulmer (1979), where skewness values were between +/-1 for the demographic or clinical variables or scales/subscales under investigation, normality was assumed and parametric statistics were utilised; whilst demographic and clinical variables or scales/subscales that produced skewness values above or below +/-1 were considered non-normal and consequently analysed using non-parametric statistics. A series of correlations and group difference analyses were performed to explore the relationship between child and parent epilepsy disclosure behaviours and demographic and clinical variables, as well as psychosocial and illness attitude variables. Two-tailed exploratory correlational and group difference analyses were performed where there was a lack of pre-existing empirical evidence on which to base a-priori assumptions and to draw hypotheses. Where there was existing empirical evidence on which to base hypotheses (see section 7.2.3), one-tailed tests were performed.

Whilst there were some missing data, there appeared to be no particular pattern to missing data (i.e. data seemed to be missing at random). Pairwise deletion was thus employed to deal with missing data (i.e. analysis was only conducted for cases where there were data available for each variable under investigation).

Finally, the significance level (α) was set at 0.05. This decision was made based on the fact that, as a general rule, an alpha level of 5% provides a good balance in terms of minimising the

risk of type I error (i.e. the erroneous rejection of the null hypothesis) without increasing the likelihood of type II error (i.e. the erroneous rejection of the alternative hypothesis).

7.8 Ethical Considerations

Key issues for ethical consideration in this second phase of the study included the issues of assent/consent, anonymity and potential harm to participants as a result of their involvement in the study. With regard to assent/consent, as the research involved a non-invasive method of data collection (i.e. surveys), with the researcher having no direct contact with CWE in most instances, formal parental consent was not required for child participants. Rather, it was outlined to parents within the information pack that they were under no obligation to share the survey packet with their CWE but that doing so implied their consent for their CWE to participate. Additionally, CWE were provided with age-appropriate materials outlining the research process to ensure that they were capable of understanding and thus assenting to their own participation in the research. Informed consent/assent was obtained from all participants through the inclusion of a series of tick-box formatted questions at the start of the surveys (see Appendices R.1 and R.2). These questions asked participants to confirm that they had read the plain language statement, fully understood what their involvement in the study entailed and provided their full consent to participate. Furthermore, participants were advised that completion and return of the questionnaire implied consent/assent.

Regarding the anonymity of the questionnaires, because consent was provided via the aforementioned series of 'yes' or 'no' formatted questions at the beginning of the surveys, the anonymity of all participants was ensured as no identifiable data was collected.

Finally, in relation to any potential risks associated with participating in the present study, as the research was non-therapeutic and non-invasive in nature, it was anticipated that there would be no adverse effects to any child/parent participants of this phase of the study. However, bearing in mind the sensitive nature of the topics under investigation in the surveys, CWE and parents were provided with details of appropriate follow-up support networks in resource sheets that were included at the end of the surveys (see Appendices Y.1 and Y.2). In addition, the researcher was cognisant that the children and parents in this study were service users. Thus, it was clearly emphasised at all times that the care they received, and/or their engagements with the National Epilepsy Association or HCPs in any of the four clinical recruitment sites, would not be affected whatsoever by their decision to participate (or not) in the study.

Chapter 8: Phase Two: Quantitative Results

8.0 Introduction

This chapter reports the findings from the second phase of the study which involved a cross-sectional survey of CWE aged 8-18 years and their parents in order to examine: 1) their epilepsy disclosure; and 2) the relationship between child and parent epilepsy disclosure behaviours and demographic, clinical, psychosocial and illness attitude variables. Furthermore, the psychometric evaluation of the newly developed Epilepsy Disclosure Scale (youth and parent versions) is outlined.

8.1 Sample Characteristics, Survey Distribution Details and Response Rates

8.1.1 CWE: Demographic Profile and Seizure Characteristics

Forty-seven CWE (mean age=13.19 years; *S.D.*=2.82), 31.9% of whom were living in Dublin, returned or submitted surveys. CWE's self-reported age at the time of their first seizure ranged from 7 months to 16 years, with CWE reporting a mean time since diagnosis of 4.15 years (*S.D.*=2.95). Over half of CWE (51.1%) experienced multiple seizure types, whilst approximately 60% had visually disruptive seizures (i.e. tonic-clonic, complex partial, tonic or clonic seizure types). When CWE were asked to self-report their seizure frequency, the majority (31.9%) identified themselves as being in the occasional bracket (classified as experiencing seizures less than monthly), followed by 29.8% who placed themselves in the rarely/never bracket (which includes CWE who report themselves to be seizure free). Thirty-six CWE (76.6%) reported having had seizures in the presence of others external to the nuclear family. Furthermore, 37 CWE (78.7%) had experienced absences from school as a result of their epilepsy, with CWE's approximations of days missed over the previous academic year ranging from 0-74 days. 91.5% of CWE (*n*=43) cited that they were receiving treatment or taking medication for their epilepsy at the time of survey completion, with just over half (51.1%) on a monotherapy medication regime. Further detail regarding the demographic and clinical characteristics of the CWE sample is presented in Table 8.1 below.

Table 8.1: CWE's Self-reported Demographic and Seizure Characteristics (N=47)

Demographic/Seizure Characteristics	N	
Child Gender		
Male	22	46.8%
Female	25	53.2%
Child Age		
Mean	47	13.19 years (*S.D.*=2.82)
Range	47	8-18 years
Primary School Aged (8-12 years)	17	36.2%
Secondary School Aged (13-18 years)	30	63.8%
Child Ethnicity		
Caucasian/White Irish	46	97.9%
Unspecified	1	2.1%
Geographic Location		
Living in Dublin	15	31.9%
Living outside Dublin[6]	24	48.9%
Unspecified	8	17.0%
Age at Onset (Years)		
Mean	47	9.04 years (*S.D.*=3.64)
Range	47	0.58-16 years
Time Since Diagnosis (Years)		
Mean	47	4.15 years (*S.D.*=2.95)
Range	47	0-12 years
Seizure Type(s)/Activity		
Tonic-Clonic	22	46.8%
Absence	30	63.8%
Simple Partial	8	17%
Complex Partial	11	23.4%
Myoclonic	10	21.3%
Atonic	2	4.3%
Tonic	4	8.5%
Clonic	5	10.6%
Electrical Status Epilepticus in Sleep (ESES)	1	2.1%
One versus Multiple Seizure Types		
One Seizure Type Only	21	44.7%
Multiple Seizure Types	24	51.1%
Visual Disruptiveness of Seizure Types		
Disruptive Seizure Types	28	59.6%
More Benign Seizure Types	17	36.2%
Seizure Frequency		
Daily Seizures (once a day or more)	3	6.4%
Frequent Seizures (several times a week)	3	6.4%
Weekly Seizures (about once a week)	3	6.4%
Monthly Seizures (about once a month)	2	4.3%
Occasional Seizures (less than monthly)	15	31.9%
Yearly Seizures (about once a year)	5	10.6%
Rare Seizures or Seizure Free (less than yearly/seizure free)	14	29.8%
Unspecified	2	4.3%
Seizure Visibility (Have had Seizures in the Presence of Others External to the Nuclear Family)		
Yes	36	76.6%
No	7	14.9%
Unspecified	4	8.5%

[6] Inclusive of the following counties in the Republic of Ireland: Carlow, Clare, Cork, Donegal, Galway, Kerry, Kildare, Laois, Limerick, Louth, Mayo, Meath, Sligo, Waterford, Westmeath.

Demographic/Seizure Characteristics	N	
School Absences as a Consequence of Epilepsy		
Yes	37	78.7%
No	10	21.3%
Receiving Treatment/Taking Medication at Time of Survey		
Yes	43	91.5%
No	3	6.4%
Unspecified	1	2.1%
Type of Medication Therapy		
Monotherapy (1 AED only)	24	51.1%
Polytherapy (≥2 AEDS)	17	36.2%
Unspecified	3	6.4%
Experience of Medication Side Effects		
Yes	31	66%
No	16	34%

Thirty-one CWE (66%) had experienced side-effects as a result of epilepsy treatments or medications. Side effects self-reported by CWE via open-ended responses were inclusive of somatic complaints (e.g. dizziness and blurred vision), behavioural issues (e.g. hyperactivity), emotional impacts (e.g. aggressiveness, anger and sadness), weight loss/gain, tiredness, nausea, and cognitive deficits (e.g. problems with concentration and memory).

When asked how they described epilepsy in their own words, CWE reported employing varied language and terminology; from referring to seizures as 'turns', 'episodes', 'blank outs', 'random messages travelling from my brain that are going the wrong way', 'funny feeling in my head' and 'freezes' to replacing the word 'epilepsy' in their vocabulary with other terms such as 'the stupid thing in the back of my head' and 'dreamy thing'.

In relation to CWE's perceptions pertaining to the medical care they receive with regard to their epilepsy, 93.6% (n=44) found talking to doctors and nurses satisfactory.

In terms of survey completion, the majority of CWE reported completing the survey at home (97.9%) in the presence of their parent(s) (78.7%). Forty-five CWE completed the hard copy version of the survey, while two CWE completed the survey electronically on the Qualtrics online survey platform.

8.1.2 Parents: Demographic Profile and Child Seizure Characteristics

Seventy-two parents (90.3% mothers; 8.3% fathers) of CWE returned or submitted surveys. All parent participants reported being the biological mother or father of the CWE. The majority of parent participants (75%) placed themselves in the 41-55 years age category. All parent participants identified themselves as Caucasian/White Irish. As with the child sample, geographically, the majority of parent participants (31.9%) were from Dublin. However, parents came from a further 15 counties in the Republic of Ireland. With regard to parental level of

education, the majority had either attained the Leaving Certificate (23.6%) or a Higher Certificate (26.4%).

Parents reported that their CWE ranged in age from 8-18 years (mean age=13.2 years; *S.D.*=3.02), with a fairly evenly distributed gender representation (48.6% female; 44.4% male). 80.6% of parents reported that their child had experienced seizures in the presence of others outside the immediate family unit (e.g. in a school context or with friends, caregivers and/or extended family members etc.). Most parents (69.4%) reported that their child had missed school as a consequence of his/her epilepsy, with estimations of days missed in the year prior to survey completion ranging from 0 to 80 days. Over half (56.9%) of the parent respondents reported that prior to their child's diagnosis there was no family history of epilepsy. A full breakdown of parents' demographics characteristics, as well as parent-reported demographic and seizure characteristics for their CWE is presented in Table 8.2.

Table 8.2: Parent Demographics and Parent-Reported Demographic/Seizure Characteristics for their CWE (N=72)

Demographic/Seizure Characteristics	**N**	
Parent Gender		
Male	6	8.3%
Female	65	90.3%
Unspecified	1	1.4%
Parent Age		
25 years or under	1	1.4%
26-40 years	13	18.1%
41-55 years	54	75%
56 years or older	3	4.2%
Unspecified	1	1.4%
Parent Ethnicity		
Caucasian/White Irish	72	100%
Geographic Location		
Living in Dublin	23	31.9%
Living outside Dublin[7]	39	54.2%
Unspecified	10	13.9%
Parent Level of Education		
Less than Junior Certificate	2	2.8%
Junior Certificate	7	9.7%
Leaving Certificate	17	23.6%
Higher Certificate	19	26.4%
Ordinary Bachelor Degree	5	6.9%
Honours Bachelor Degree	7	9.7%
Higher Diploma	7	9.7%
Master's Degree	6	8.3%
Doctoral Degree	1	1.4%
Unspecified	1	1.4%
Child Age		
Mean	69	13.20 years (*S.D.*=3.02)
Range	69	8-18 years

[7] Inclusive of the following counties in the Republic of Ireland: Carlow, Clare, Cork, Donegal, Galway, Kerry, Kildare, Laois, Limerick, Louth, Mayo, Meath, Sligo, Waterford, Westmeath.

Demographic/Seizure Characteristics	N	
Child Age (continued)		
Primary School Aged (8-12 years)	26	37.7%
Secondary School Aged (13-18 years)	43	62.3%
Child Gender		
Male	32	44.4%
Female	35	48.6%
Unspecified	5	6.9%
Child Age at Onset (Years)		
Mean	69	8.00 years (*S.D.*=4.20)
Range	69	0-16 years
Time Since Child's Diagnosis (Years)		
Mean	66	4.93 years (*S.D.*=3.77)
Range	66	0-18 years
Child's Seizure Type(s)/Activity		
Tonic-Clonic	41	56.9%
Absence	42	58.3%
Simple Partial	16	22.2%
Complex Partial	25	34.7%
Myoclonic	16	22.2%
Atonic	9	12.5%
Tonic	10	13.9%
Clonic	16	22.2%
Electrical Status Epilepticus during Sleep (ESES)	1	1.4%
One versus Multiple Seizure Types Experienced by Child		
One Seizure Type Only	45	62.5%
Multiple Seizure Types	25	34.7%
Visual Disruptiveness of Child's Seizure Types		
Disruptive Seizure Types	53	73.6%
More Benign Seizure Types	19	26.4%
Child's Seizure Frequency		
Daily Seizures (once a day or more)	8	11.1%
Frequent Seizures (several times a week)	4	5.6%
Weekly Seizures (about once a week)	3	4.2%
Monthly Seizures (about once a month)	1	1.4%
Occasional Seizures (less than monthly)	21	29.2%
Yearly Seizures (about once a year)	9	12.5%
Rare Seizures or Seizure Free (less than yearly/seizure free)	21	29.2%
Unspecified	5	6.9%
Seizure Severity Scale Scores		
Mean	56	17.16 (*S.D.*=5.08)
Range	56	9-26
Child's Seizure Visibility (Have had Seizures in the Presence of Others External to the Nuclear Family)		
Yes	58	80.6%
No	14	19.4%
A History of the Child Missing School due to Epilepsy		
Yes	50	69.4%
No	17	23.6%
Unspecified	5	7%
Child Receiving Treatment/Taking Medication at Time of Survey		
Yes	68	94.4%
No	4	5.6%
Type of Medication Therapy		
Monotherapy (1 AED only)	39	54.2%
Polytherapy (≥2 AEDS)	27	37.5%
Unspecified	2	2.8%

Demographic/Seizure Characteristics	N	
Child Experience of Medication Side Effects		
Yes	49	68.1%
No	19	26.4%
Unspecified	4	5.6%
Family History of Epilepsy		
Yes	22	30.6%
No	41	56.9%
Unsure	6	8.3%
Unspecified	3	4.2%

As evidenced in Table 8.2, more than two thirds of parents reported that their CWE experienced side-effects related to taking AEDs. Parent-reported side effects included somatic complaints (e.g. rashes, pains/aches, blurred vision, headaches, nausea and weight gain/loss), behavioural changes (e.g. hyperactivity), emotional concerns (e.g. irritability, aggression, mood swings, anxiety, depression and self-harm), tiredness, lethargy, insomnia, co-ordination issues and cognitive problems (e.g. inattention, inability to concentrate, memory loss and speech/language difficulties).

With regard to parents' perceptions of their child's epilepsy care, collectively the findings denoted largely positive parental experiences, although approximately 10-20% of parents could have benefitted from improved services and more satisfactory experiences. The majority of parents (76.3%) found it either 'very easy', 'somewhat easy', or 'okay' to access epilepsy-related healthcare services for their CWE. However, approximately 16% expressed that they had experienced some difficulties in accessing epilepsy-related services for their CWE. Only four parents (5.6%) reported that their child had not seen a neurologist in relation to his/her epilepsy. The child's epilepsy diagnosis experience was satisfactory for 73.6% of parents. However, 19.4% were dissatisfied with the diagnosis experience. Finally, 80.6% of parents reported finding communicating with HCPs at hospital appointments satisfactory.

Similar to their CWE, parents reported utilising varying terminology in describing their child's epilepsy and/or seizures. For instance, some parents substituted the word 'epilepsy' in their vocabulary with terms such as 'an electrical storm in her brain', 'his little setback' and 'a nuisance'; whilst others replaced the word 'seizure' with terms such as 'freezes', 'funnies', 'turns', 'brain blocks' or 'collapses'.

With reference to survey completion, 95.8% of parents reported completing the survey at home, whilst 1.4% reported completing it in various locations (inclusive of in the car), and a further 2.8% did not specify where they had completed the survey. One third of parents cited that their child with epilepsy was present as they completed the survey. A total of 60 parents completed

the hard copy version of the survey, while 12 completed the survey on the Qualtrics survey platform.

8.1.3 Participating Dyadic Families

For every child who participated in this quantitative phase of the study, one of his/her parents also participated. Thus, in total, there were 47 parent-child dyads whose data were matched via the non-identifiable codes provided by CWE and their parents at the outset of the surveys. Appendix Z presents demographic data specifically for the 47 parents for whom dyadic data were available, as well as the parent-reported demographic and clinical data they provided for their CWE.

8.1.4 Survey Distribution Details and Response Rates

As discussed in Chapter 7, surveys were distributed via four recruitment channels. The majority of child and parent participants were recruited via either TSCUH or Epilepsy Ireland (see Figures 8.1 and 8.2 below).

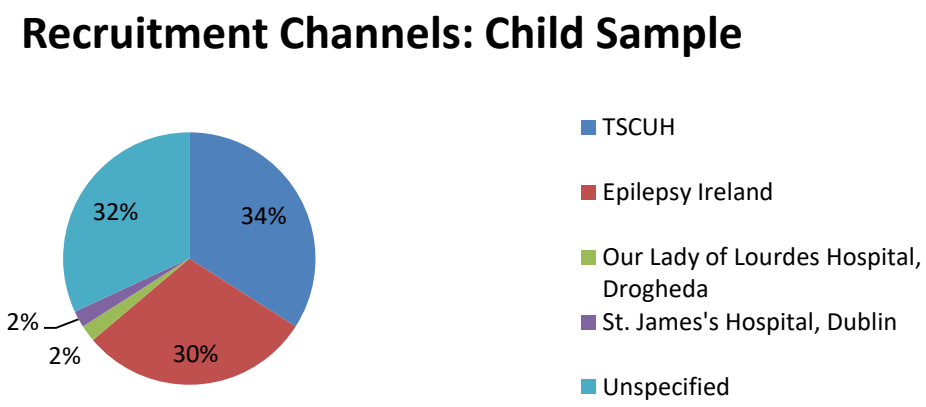

Figure 8.1: Phase Two: Breakdown of Recruitment Channels: Child Sample

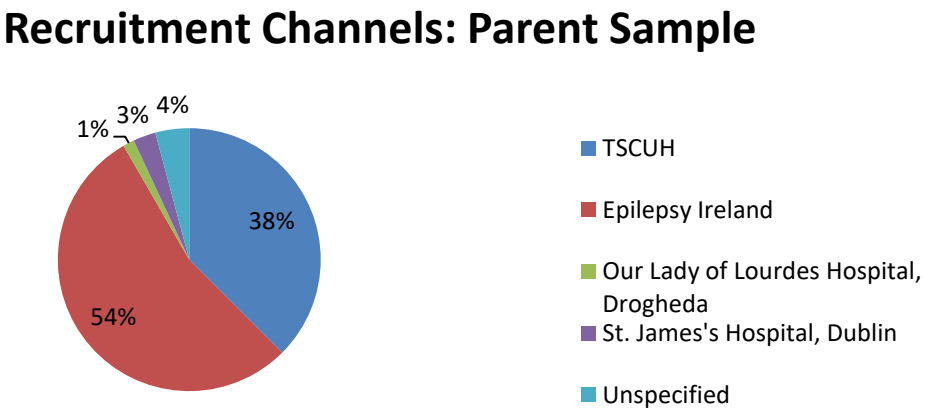

Figure 8.2: Phase Two: Breakdown of Recruitment Channels: Parent Sample

It is not possible to calculate overall survey response rates for this phase of the study. Whilst Qualtrics yields statistics regarding the number of clicks on survey hyperlinks, there is no way of discerning whether individuals who clicked on the survey were directed there via the hyperlinks provided in survey packs distributed by post or via online advertisements (e.g. EI website), or indeed whether individuals who clicked onto the survey were eligible to participate or clicked on multiple times prior to completing the survey online. In terms of the 165 survey packs distributed to families living with epilepsy via post, 45 CWE returned hard copy questionnaires (27.27% response rate); and 60 parents returned hard copy questionnaires (36.36% response rate).

8.2 Epilepsy Disclosure amongst CWE

In this section, descriptive data as captured by the child surveys will be presented on: 1) CWE's epilepsy disclosure behaviours inclusive of the items from the youth version of the Epilepsy Disclosure Scale [EDS-Y] (which particularly assesses the extent to which CWE tell and talk to others (or not) about their epilepsy) and items that capture their written disclosure behaviours; 2) their disclosure targets; 3) the situational context of their disclosure exchanges; 4) the content of their disclosure exchanges; 5) the rationale underlying their disclosure decisions; 6) their perceived barriers to and enablers of disclosure; 7) their emotions surrounding disclosure; and 8) the consequences of their disclosure.

8.2.1 Disclosure Behaviours amongst CWE

As demonstrated in Table 8.3, CWE in the present study varied widely in their epilepsy disclosure behaviours. Approximately 77% reported having kept their epilepsy a secret from others on at least one occasion (as indicated by a 'rarely', 'sometimes' or 'often' response to item 1), whilst approximately 47% reported rarely or never talking to those external to their nuclear family about their epilepsy. Approximately 15% of CWE reported that none of their friends were informed about their epilepsy, whilst 44.7% reported that all of their friends were informed (see Table 8.3).

CWE largely reported that others learned about their condition via voluntary disclosure (68.1%), 17% of participants reported that others became aware of their epilepsy via indirect telling (i.e. by others informing them about the condition), whilst a further 4.3% identified that individuals external to the nuclear family became knowledgeable about their epilepsy via an unplanned revelation (i.e. as a result of others witnessing them having seizures).

The majority of CWE reportedly experienced no or few difficulties in terms of speaking with others about their epilepsy. However, for 30.4%, such conversations were somewhat or very difficult. When CWE were asked to what degree they had a desire to speak to others about their experiences with epilepsy, 67.4% reported that they had little or no desire. However, 32.6% of

CWE reported having some desire or a strong desire to speak to others external to the nuclear family about their experiences with epilepsy.

As depicted in Table 8.3, CWE wished to keep their epilepsy a secret to a greater extent than they actually kept their epilepsy a secret. Just over one out of every five CWE wanted to keep their epilepsy a secret from others to a great extent, whilst only one out of every ten CWE actually reported keeping their epilepsy a secret from others to this same extent. 41.3% of CWE reported that they had not kept their epilepsy a secret from others at all. However, 58.7% reported keeping their epilepsy a secret from others to at least some degree.

Table 8.3: Disclosure Behaviours amongst CWE: Valid Responses

Item no.	Descriptor	N	Responses			
			Never	***Rarely***	***Sometimes***	***Often***
1	When you can, do you keep your epilepsy a secret from others?	47	23.4%	12.8%	44.7%	19.1%
2	How frequently do you talk to people outside your family about your epilepsy?	47	17%	29.8%	40.4%	12.8%
			All	***Some***	***Few***	***None***
3	Do any of your friends know that you have epilepsy?	47	44.7%	27.7%	12.8%	14.9%
			You tell them	***You have a seizure and then you explain it***	***You have a seizure and they see it***	***Someone else tells them about it***
4	When people find out you have epilepsy, it is usually because…	47	68.1%	10.6%	4.3%	17%
			Not at all	***A little***	***Somewhat***	***Very***
5	How difficult has it been for you to talk to others about what you are going through?	46	34.8%	34.8%	15.2%	15.2%
			Not at all	***A little***	***Somewhat***	***A lot***
6	How much have you wanted someone to talk to about your experience with epilepsy?	46	37%	30.4%	15.2%	17.4%
7	To what degree have you *wanted to keep* your epilepsy a secret?	46	32.6%	37%	8.7%	21.7%
8	To what degree have you *actually kept* your epilepsy a secret?	46	41.3%	30.4%	17.4%	10.9%

Item no.	Descriptor	N	Responses			
			Not at all	***A little***	***Somewhat***	***A lot***
9	How much have you written about your epilepsy (such as in a diary, journal, letters or online in support groups or on social media i.e. Facebook, Twitter, Tumblr, blogs etc.)?	45	71.1%	17.8%	6.7%	4.4%

Amongst 45 CWE who responded to the question regarding written disclosure, only 4.4% reported having written a lot about their epilepsy. The sources and/or platforms wherein CWE reported engaging in written disclosure (whether for their own personal consumption [i.e. written emotional disclosure in diaries and/or journals] and/or as a means of disclosing their epilepsy diagnosis to others outside the immediate family unit) are outlined in Table 8.4.

Table 8.4: Written Sources of Disclosure for CWE: Valid Responses

Item No.	If you have written about your epilepsy, where have you written about it?	N	Yes
1	Diary/Journal	32	34.4%
2	Letters	26	11.5%
3	Facebook	27	18.5%
4	Twitter	26	3.8%
5	Tumblr	26	3.8%
6	Epilepsy Support Groups	26	7.7%

8.2.2 Disclosure Targets for CWE

Table 8.5 below presents information regarding the extent to which CWE reported speaking to specific individuals in their lives about their epilepsy. For these items, a 'not applicable' response option was also provided, however, only applicable responses are tabulated in Table 8.5.

Outside of the nuclear family, the top three categories of individuals to whom CWE were likely to talk about their epilepsy experience either somewhat or very much with, were: 1) doctors (76.2%); 2) nurses (65.9%); and 3) close female friends (65.7%). When HCPs were factored out of the equation, the three categories of individuals outside the immediate family to whom CWE reported speaking to the greatest extent about their epilepsy (as indicated by the items that received the highest cumulative percentages of 'very much' and 'somewhat' responses) were: 1) close female friends (65.7%); 2) grandparents (42.1%); and 3) close male friends (40.5%). On

the contrary, the three categories of people most frequently cited by CWE as those with whom they did not converse at all about their epilepsy were: 1) employers (66.7%); 2) neighbours (61.1%) and; 3) principals (55.6%).

Table 8.5: Disclosure Targets for CWE: Valid Responses

Item No.	Please indicate the degree to which you have talked with each of the following individuals about your experience with epilepsy since your diagnosis:	N[8]	Not at all	A little	Somewhat	Very much
1	Boyfriend or Girlfriend	11	18.2%	45.5%	9.1%	27.3%
2	Close male friend(s)	37	27%	32.4%	21.6%	18.9%
3	Close female friend(s)	32	15.6%	18.8%	43.8%	21.9%
4	Male friend(s)	37	40.5%	40.5%	8.1%	10.8%
5	Female friend(s)	37	43.2%	32.4%	16.2%	8.1%
6	Neighbour(s)	36	61.1%	25%	8.3%	5.6%
7	Classmates	43	37.2%	37.2%	14%	11.6%
8	Therapist/Counsellor	18	16.7%	33.3%	16.7%	33.3%
9	Adults with epilepsy	17	52.9%	41.2%	0.0%	5.9%
10	Doctors	42	7.1%	16.7%	23.8%	52.4%
11	Nurses	41	4.9%	29.3%	22%	43.9%
12	Co-workers	4	25%	50%	0.0%	25%
13	Grandparents	38	26.3%	31.6%	13.2%	28.9%
14	Aunts/Uncles	40	20%	45%	15%	20%
15	Cousins	40	50%	27.5%	7.5%	15%
16	Employers	3	66.7%	33.3%	0.0%	0.0%
17	Your friends' parents	36	50%	41.7%	2.8%	5.6%
18	Your teacher(s)	42	35.7%	26.2%	19%	19%
19	Your principal	36	55.6%	30.6%	2.8%	11.1%
20	Your sports club coaches	29	44.8%	31%	17.2%	6.9%
21	Your sports team members	31	41.9%	45.2%	9.7%	3.2%
22	Other young people with epilepsy	22	50%	22.7%	18.2%	9.1%
23	Your child-minder/nanny/au pair	14	42.9%	35.7%	7.1%	14.3%
24	Young people with other illnesses	25	52%	28%	12%	8%
25	Young people with something that makes them different	24	45.8%	37.5%	8.3%	8.3%

[8] Refers to the number of CWE who answered the question for whom the disclosure target was applicable

When CWE were asked about which adults in their lives were aware of their epilepsy, the majority of CWE reported that, to their knowledge, all adults in their lives had been informed about their condition (see Table 8.6 where only applicable responses were tabulated).

Table 8.6: CWE's Perceptions regarding which Adults in their Lives are Aware of their Epilepsy: Valid Responses

Item No.	As far as you are aware, which of the following adults know that you have epilepsy?	N	Yes	No
1	The principal	44	90.9%	9.1%
2	Your head of year teacher	37	91.9%	8.1%
3	Your class teachers overall	45	91.1%	8.9%
4	Your P.E. teacher	38	92.1%	7.9%
5	Your sports coaches	36	88.9%	11.1%
6	Your friends' parents	45	73.3%	26.7%
7	Your babysitter	17	70.6%	29.4%
8	Your child-minder/nanny/au-pair	16	81.3%	18.8%
9	Your grandparents	42	97.6%	2.4%
10	Your aunts/uncles	45	97.8%	2.2%
11	Your parents' friends	44	88.6%	11.4%

Finally, with regard to CWE's peers within a school context, 44.2% of CWE reported that to their knowledge most of the other children in their class were aware of their condition, whilst 25.6% of CWE answered that most of the children in their school were cognisant that they had epilepsy. 30.2% of CWE cited that within a school context either no children knew about their epilepsy or a select few of their friends within their immediate peer group were aware of their epilepsy (see Table 8.7).

Table 8.7: CWE's Reports regarding which Children within a School Context are Aware of their Epilepsy: Valid Responses

Item No.	Descriptor	N	None of the other children know	My best friends only	My few best friends only	Most of the other children in my class only	Most of the other children in the school
1	As far as you are aware, which of the following children at school or college know that you have epilepsy?	43	11.6%	2.3%	16.3%	44.2%	25.6%

8.2.3 Situational Context of Disclosure Exchanges for CWE

With regard to the situational context of CWE's disclosure exchanges, the three main contexts under which epilepsy-related conversations with others external to the nuclear family unfolded for CWE (as denoted by the items that received the highest cumulative percentages of 'really true for me' and 'sort of true for me' responses) comprised situations and/or instances when: 1) they had recent or upcoming hospital appointments (82.2%); 2) others asked questions (72.8%); and/or 3) the child was starting a new activity or sport (71.1%). Least commonly cited contexts for disclosure exchanges reported by CWE (as indicated by the items that received the highest percentages of 'not at all true for me' responses) included circumstances when: 1) they needed support (46.7%); 2) their friends were telling them their secrets (46.7%); and 3) their medications were causing them difficulties (42.2%). See Table 8.8 for a breakdown of this data.

Table 8.8: Situational Context of Disclosure Exchanges for CWE: Valid Responses

Item No.	I usually tell and talk to others about my epilepsy when…	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply to me, I never talk to others about my epilepsy
1	I have had a seizure that others have seen (e.g. in school etc.)	45	33.3%	31.1%	24.4%	11.1%
2	I have had a seizure that others have not seen (e.g. at home etc.)	45	35.6%	31.1%	28.9%	4.4%
3	I feel like I might have a seizure	44	29.5%	27.3%	36.4%	6.8%
4	Others see me taking my medication	45	28.9%	37.8%	31.1%	2.2%
5	Others ask me questions	44	27.3%	45.5%	20.5%	6.8%
6	My medication is causing me difficulties	45	13.3%	40%	42.2%	4.4%
7	I have a hospital appointment coming up or I have recently had a hospital appointment	45	40%	42.2%	11.1%	6.7%
8	I cannot take part in an activity because of my epilepsy	44	25%	31.8%	36.4%	6.8%
9	I miss school because I have had a seizure	45	26.7%	26.7%	37.8%	8.9%
10	I need support	45	17.8%	31.1%	46.7%	4.4%
11	Epilepsy comes up in conversation	45	20%	44.4%	31.1%	4.4%
12	I am starting a new activity or sport	45	31.1%	40%	20%	8.9%
13	I am meeting new people	45	8.9%	51.1%	33.3%	6.7%
14	My friends are telling me their secrets	45	11.1%	37.8%	46.7%	4.4%

8.2.4 Content of Disclosure Exchanges for CWE

The three main conversation topics that CWE reportedly raised during their disclosure exchanges with others external to the nuclear family (as highlighted by the items that received the highest cumulative percentages of 'really true for me' and 'sort of true for me' responses) comprised: 1) seizure manifestations (i.e. describing what happens during seizures) (84.1%); 2) definitions of epilepsy (i.e. describing what epilepsy is) (77.8%); and 3) how seizures affect and impact on them (75.5%). Topics that CWE reported being least likely to discuss during their disclosure exchanges with others (as denoted by the items with the highest percentages of 'not at all true for me' responses) pertained to: 1) seizure control (40.9%); 2) medication side-effects (37.8%); 3) feelings about having epilepsy (36.4%); 4) hospital appointments (36.4%); and 5) restrictions imposed on them due to the epilepsy diagnosis (36.4%). See Table 8.9 for a breakdown of these data.

Table 8.9: Content of Disclosure Exchanges for CWE: Valid Responses

Item No.	When I talk to others about my epilepsy, I talk to others about…	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply to me, I never talk to others about my epilepsy
1	What epilepsy is	45	42.2%	35.6%	11.1%	11.1%
2	The type of epilepsy I have	44	36.4%	34.1%	22.7%	6.8%
3	What happens when I have a seizure (e.g., what I look like)	44	45.5%	38.6%	9.1%	6.8%
4	How seizures affect me	45	33.3%	42.2%	17.8%	6.7%
5	What they should do if I have a seizure	45	55.6%	8.9%	28.9%	6.7%
6	My medication	44	18.2%	52.3%	25%	4.5%
7	The medication side-effects	45	15.6%	37.8%	37.8%	8.9%
8	My hospital appointments	44	13.6%	45.5%	36.4%	4.5%
9	Things I cannot take part in because of my epilepsy	44	22.7%	34.1%	36.4%	6.8%
10	Whether my seizures are controlled or not	44	18.2%	34.1%	40.9%	6.8%
11	Whether I will grow out of my epilepsy	44	22.7%	47.7%	22.7%	6.8%
12	How I feel about having epilepsy	44	27.3%	29.5%	36.4%	6.8%

8.2.5 Rationale Underlying the Selection of Specific Disclosure Management Strategies by CWE

The three most common reasons why CWE disclosed their epilepsy to others external to the nuclear family (as indicated by the items with the highest cumulative percentages of 'really true

for me' and 'sort of true for me' responses) were: 1) they wanted others to know that seizures might occur (72.1%); 2) disclosure made them feel more comfortable (71.1%); and 3) they wanted others to know how to react in the event of a seizure occurring in their presence (65.9%). In contrast, the least common reasons for CWE's epilepsy disclosure (as indicated by the items with the highest percentages of 'not at all true for me' responses) included CWE telling others about their epilepsy because: 1) it helped them to educate themselves about epilepsy (60%); 2) it made them feel better (46.7%); and/or 3) they had a desire for others to learn about epilepsy (38.6%). See Table 8.10 for a breakdown of these data.

Table 8.10: Reasons for Disclosure Exchanges amongst CWE: Valid Responses

Item No.	I tell others about my epilepsy because…	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply to me, I never tell others about my epilepsy
1	I want them to know I might have a seizure	43	41.9%	30.2%	23.3%	4.7%
2	I want them to know what to do if I have a seizure	44	40.9%	25%	27.3%	6.8%
3	I want others to learn about epilepsy	44	20.5%	31.8%	38.6%	9.1%
4	Talking to others about my epilepsy makes me feel better	44	22.7%	22.7%	47.7%	6.8%
5	Talking to others about my epilepsy helps me to learn more about epilepsy	45	8.9%	24.4%	60%	6.7%
6	It makes me feel more comfortable when others know about my epilepsy	45	40%	31.1%	22.2%	6.7%

The three most common reasons for epilepsy concealment reported by CWE (as denoted by those items with the highest cumulative percentages of 'really true for me' and 'sort of true for me' responses) were inclusive of: 1) worry regarding others treating them differently (48.9%); 2) the condition (and disclosure of the condition) eliciting feelings of sadness (48.9%); and 3) fear of how others will react (47.7%). The least commonly cited reasons for CWE's concealment of their epilepsy, as denoted by the items with the highest percentages of 'not at all true for me' responses, included: 1) their parents conveying to them that their epilepsy is something that they should keep private (73.3%); 2) their perception that epilepsy is a private matter (64.4%); 3) their perception that other people might tease them (53.3%); and 4) the view that others do not think good things about epilepsy (53.3%). See Table 8.11 for a breakdown of these data.

Table 8.11: Reasons for Concealment amongst CWE: Valid Responses

Item No.	I don't tell others about my epilepsy because…	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply to me, I always tell others about my epilepsy
1	It makes me feel different	45	22.2%	24.4%	42.2%	11.1%
2	I am worried others will treat me differently	45	13.3%	35.6%	40%	11.1%
3	I am scared of how people will react	44	25%	22.7%	40.9%	11.4%
4	I think people might tease me	45	8.9%	24.4%	53.3%	13.3%
5	I don't want people to spread it around	45	20%	22.2%	42.2%	15.6%
6	Others do not think good things about epilepsy	45	13.3%	17.8%	53.3%	15.6%
7	It makes me sad	45	17.8%	31.1%	37.8%	13.3%
8	My parents think that epilepsy is something we should keep private	45	2.2%	8.9%	73.3%	15.6%
9	Nobody else I know has epilepsy	45	15.6%	22.2%	44.4%	17.8%
10	Others cannot see that I have epilepsy	45	17.8%	28.9%	42.2%	11.1%
11	Others do not need to know I have epilepsy	45	11.1%	35.6%	42.2%	11.1%
12	My epilepsy is private/secret	45	2.2%	17.8%	64.4%	15.6%
13	I don't want to seem like I am looking for attention	45	24.4%	17.8%	44.4%	13.3%

8.2.6 Barriers and Enablers for Disclosure amongst CWE

The three factors that CWE endorsed most as helping them to disclose their epilepsy to others were: 1) hearing that public figures (i.e. famous people) have epilepsy (53.3%); 2) their level of knowledge about epilepsy (37.8%); and 3) media coverage (i.e. radio or T.V.) of epilepsy (33.3%). In contrast, the factors that CWE most frequently highlighted as making it challenging to disclose their epilepsy to others included: 1) how epilepsy makes them feel (34.1%); 2) their perception of how others might consequently treat them (34.1%); 3) their personal feelings about epilepsy (31.1%); and 4) the level of understanding of epilepsy possessed by others (31.1%). Finally, the factors that were most often reported by CWE as having no impact on their epilepsy disclosure behaviours were: 1) the child's seizure frequency (68.9%); 2) others' perceptions of epilepsy (65.9%); and 3) the child knowing others with epilepsy (60%) (see Table 8.12 below).

Table 8.12: Barriers and Enablers for Disclosure amongst CWE: Valid Responses

Item No.	Do any of the following things help or make it challenging for me to tell and talk to other people about my epilepsy?	N	This helps me	This makes it difficult	This makes no difference
1	How often I have seizures	45	11.1%	20%	68.9%
2	How I feel about epilepsy	45	20%	31.1%	48.9%
3	How much I know about my epilepsy	45	37.8%	13.3%	48.9%
4	Knowing others with epilepsy	45	31.1%	8.9%	60%
5	How others have reacted when I have told them about my epilepsy in the past	45	26.7%	15.6%	57.8%
6	How much others know about epilepsy	45	24.4%	22.2%	53.3%
7	If other people have something that makes them different	44	31.8%	9.1%	59.1%
8	Whether other people can see that I have epilepsy (e.g., if I have had seizures in front of them or not)	44	22.7%	27.3%	50%
9	How long I have had epilepsy	44	27.3%	15.9%	56.8%
10	How well I can explain epilepsy	44	29.5%	27.3%	43.2%
11	How epilepsy makes me feel	44	11.4%	34.1%	54.5%
12	How other people might treat me	44	11.4%	34.1%	54.5%
13	What other people think about epilepsy	44	9.1%	25%	65.9%
14	Whether other people understand epilepsy	45	13.3%	31.1%	55.6%
15	When epilepsy is on T.V. or on the radio	45	33.3%	15.6%	51.1%
16	When I hear that famous people have epilepsy	45	53.3%	2.2%	44.4%

8.2.7 CWE's Emotions Prior to Disclosure

As depicted in Table 8.13, the three most frequent emotions that CWE reported experiencing prior to their epilepsy disclosure exchanges with others outside the immediate family unit were: 1) braveness (55.8%); 2) differentness (50%); and 3) hopefulness (50%). The majority of CWE reported that prior to disclosing their epilepsy to others they didn't feel afraid (65.9%), embarrassed/ashamed (62.8%) and/or worried/nervous (56.8%).

Table 8.13: How CWE Feel Prior to Disclosure Exchanges with Others: Valid Responses

Item No.	Before telling others about my epilepsy I feel…	N	Yes	No	Does not apply, I never tell others about my epilepsy
1	Worried/Nervous	44	38.6%	56.8%	4.5%
2	Embarrassed/Ashamed	43	32.6%	62.8%	4.7%
3	Different	44	50%	45.5%	4.5%

Item No.	Before telling others about my epilepsy I feel…	N	Yes	No	Does not apply, I never tell others about my epilepsy
4	Afraid	44	29.5%	65.9%	4.5%
5	Uneasy	44	43.2%	52.3%	4.5%
6	Confident	44	40.9%	52.3%	6.8%
7	Hopeful	44	50%	40.9%	9.1%
8	Brave	43	55.8%	34.9%	9.3%

8.2.8 Consequences of Disclosure for CWE

CWE reported that their disclosure exchanges with others generally yielded positive consequences for them (see Table 8.14), with others' reactions largely comprising them being kind about it (97.7%), asking questions (81.8%) and making the child feel better about his/her diagnosis (81%). Amongst CWE who had disclosed their epilepsy condition to others external to the nuclear family, few reported negative reactions by others. Indeed, no CWE reported that others were mean to them as a result. However, 47.7% of CWE reported that others had difficulties in terms of understanding their epilepsy diagnosis, whilst a further 15.9% reported that they were treated differently by others following their disclosure exchanges, and 9.1% reported that others responded in a way that suggested that they were scared of them.

Table 8.14: Others' Reactions to Epilepsy Diagnosis Disclosure by CWE: Valid Responses

Item No.	In the past, when I have told others about my epilepsy they have…	N	Yes	No	Does not apply, I have never told others about my epilepsy
1	Been kind about it	44	97.7%	0.0%	2.3%
2	Been mean about it	43	0.0%	95.3%	4.7%
3	Asked me questions	44	81.8%	13.6%	4.5%
4	Made me feel better about it	42	81%	11.9%	7.1%
5	Found it difficult to understand	44	47.7%	45.5%	6.8%
6	Laughed at or teased me about it	44	6.8%	86.4%	6.8%
7	Treated me differently	44	15.9%	79.5%	4.5%
8	Made me feel left out	44	6.8%	88.6%	4.5%
9	Been scared of me	44	9.1%	84.1%	6.8%

CWE reported that others' positive reactions to their epilepsy disclosure resulted in them feeling better (90.7%), and elicited feelings of relief (85.7%) and happiness (81.4%) in them (see Table 8.15).

Table 8.15: CWE's Emotions Surrounding Positive Reactions to Disclosure: Valid Responses

Item No.	After telling others about my epilepsy, when they react well I feel…	N	Yes	No	Does not apply, others have never reacted well	Does not apply, I never tell others about my epilepsy
1	Happy	43	81.4%	11.6%	2.3%	4.7%
2	Better	43	90.7%	4.7%	0.0%	4.7%
3	Relieved	42	85.7%	9.5%	0.0%	4.8%

Despite the fact that negative responses to disclosure were uncommonly reported by CWE, when such instances did occur, the main emotions such reactions evoked in CWE included embarrassment/shame (29.5%), worry (28.9%), sadness (26.7%) and feelings of differentness (26.7%). Interestingly, whilst negative responses to disclosure elicited negative emotions in some CWE, for approximately 15-25% of CWE, others' negative reactions to disclosure did not evoke any of the negative feelings highlighted in Table 8.16 below.

Table 8.16: CWE's Emotions Surrounding Negative Reactions to Disclosure: Valid Responses

Item No.	After telling others about my epilepsy, when they react poorly I feel…	N	Yes	No	Does not apply, others have never reacted poorly	Does not apply, I never tell others about my epilepsy
1	Embarrassed/ Ashamed	44	29.5%	20.5%	43.2%	6.8%
2	Different	45	26.7%	15.6%	51.1%	6.7%
3	Silly	45	20%	24.4%	48.9%	6.7%
4	Sad	45	26.7%	17.8%	48.9%	6.7%
5	Angry/Mad	45	22.2%	20%	51.1%	6.7%
6	Worried	45	28.9%	13.3%	51.1%	6.7%

8.3 Epilepsy Disclosure amongst Parents of CWE

This section presents the disclosure behaviours of parents of CWE, their disclosure targets, the situational context of their disclosure exchanges, the content of their disclosure exchanges, the reasons underlying their disclosure decisions, the factors that encourage and/or deter their epilepsy disclosure, their emotions surrounding disclosure and the consequences of their disclosure.

8.3.1 Disclosure Behaviours amongst Parents of CWE

As depicted in Table 8.17, the disclosure behaviours of parents of CWE in the present study varied considerably. The majority of parents reported adopting open disclosure behaviours

surrounding their children's epilepsy, with 64.3% of parents reporting that they never kept their child's epilepsy a secret from others and 32.9% citing that they often spoke to others about their child's epilepsy. However, approximately 36% of parents reported having kept their child's epilepsy a secret from others external to the nuclear family on at least one occasion (as denoted by the cumulative percentage of parents who responded 'rarely', 'sometimes' or 'often' to item 1), whilst 14.3% of parents reported rarely talking to others outside the immediate family unit about their child's epilepsy (see Table 8.17). All parents of CWE reported that at least some of their friends were aware of their child's epilepsy, with the majority (72.9%) citing that all of their friends were informed (see Table 8.17).

The majority of parents of CWE reported that others learned about their child's condition through their voluntary verbal disclosure of the child's epilepsy (see Table 8.17), although approximately 6% cited that others became aware of their child's epilepsy condition as a result of the child experiencing seizures, with such seizures necessitating explanation. A further 2.8% identified that individuals external to the nuclear family became knowledgeable about their child's epilepsy either via an unplanned revelation (i.e. as a consequence of others witnessing their child having a seizure) or through indirect telling (i.e. as a result of others informing them about the child's condition).

Parents largely reported that speaking with others about their experiences of living with the child's epilepsy condition posed little or no difficulties for them. However, for 25% of parents of CWE, engaging in conversations with others external to the nuclear family about the child's epilepsy proved somewhat or very difficult (see Table 8.17). When parents were asked to specify the extent to which they had a desire to speak to others outside the immediate family unit about their experiences with their child's epilepsy, 45.8% reported that they had little or no desire. However, 54.2% of the parent respondents reported possessing some desire or a strong desire to talk to others about their experiences with their child's epilepsy.

As evidenced in Table 8.17, parents' desire to keep their child's epilepsy a secret from others did not necessarily align directly with the extent to which they actually kept their child's epilepsy a secret from others outside the immediate family unit, with parents wishing to keep their child's epilepsy a secret to a greater extent than they actually kept it secret. Just over one out of every ten parents reported having either some or a strong desire to keep their child's epilepsy a secret from others, whilst less than one out of every twenty parents of CWE actually reported having kept it a secret from others to this same extent. 76.4% of parents reported that they had not kept their child's epilepsy a secret from others at all. However, approximately 23% of parents reported having engaged to at least some degree in concealment behaviours by keeping their child's epilepsy a secret from others.

Table 8.17: Disclosure Behaviours amongst Parents of CWE: Valid Responses

Item no.	Descriptor	N	Responses			
			Never	*Rarely*	*Sometimes*	*Often*
1	When you can, do you keep your child's epilepsy a secret from others?	70	64.3%	8.6%	21.4%	5.7%
2	How frequently do you talk to people outside your family about your child's epilepsy?	70	0.0%	14.3%	52.9%	32.9%
			All	*Some*	*Few*	*None*
3	Do any of your friends know about your child's epilepsy?	70	72.9%	24.3%	2.9%	0.0%
			You tell them	*Your child has a seizure and then you explain it*	*Your child has a seizure and they see it*	*Someone else tells them about it*
4	When people find out about your child's epilepsy, it is usually because…	72	91.7%	5.6%	1.4%	1.4%
			Not at all	*A little*	*Somewhat*	*Very*
5	How difficult has it been for you to talk to others about what you and your child are going through?	72	41.7%	33.3%	15.3%	9.7%
			Not at all	*A little*	*Somewhat*	*A lot*
6	How much have you wanted someone to talk to about your experience with your child's epilepsy?	72	13.9%	31.9%	26.4%	27.8%
7	To what degree have you *wanted to keep* your child's epilepsy a secret?	71	74.6%	14.1%	9.9%	1.4%
8	To what degree have you *actually kept* your child's epilepsy a secret?	72	76.4%	20.8%	2.8%	0.0%
9	How much have you written about your child's epilepsy (such as in a diary, journal, letters or online in support groups or on social media i.e. Facebook, Twitter, Tumblr, blogs etc.)?	71	38.0%	36.6%	11.3%	14.1%

With regard to written disclosure, as demonstrated in Table 8.17, 14.1% of parents reported having written a lot about their child's epilepsy. Parents primarily reported having engaged in written disclosure either for their own personal use (i.e. as a form of written emotional disclosure in diaries or journal), or for medical purposes in instances where parents reported maintaining records of the child's seizures (e.g. in seizure control journals to be shared with the child's clinician and medical team), rather than as a means of disclosure to those outside the immediate family unit. However, a number of parents cited having shared written information with others about their child's epilepsy via letters, or indeed on social media platforms such as Facebook, Twitter or online epilepsy support forums (see Table 8.18 below).

Table 8.18: Written Sources of Disclosure for Parents of CWE: Valid Responses

Item No.	If you have written about your child's epilepsy, where have you written about it?	N	Yes
1	Diary/Journal	29	63.0%
2	Seizure control journals	34	73.9%
3	Letters	13	37.1%
4	Epilepsy support groups	13	38.2%
5	Facebook	10	30.3%
6	Twitter	2	6.5%

8.3.2 Disclosure Targets for Parents of CWE

Table 8.19 depicts the degree to which parents of CWE reported conversing with specific categories of individuals about their child's epilepsy. For these items, a 'not applicable' response option was also provided, however, only applicable responses are tabulated.

The three categories of individuals external to the nuclear family to whom parents of CWE reported speaking with to the greatest extent about their child's epilepsy (as denoted by the items that received the highest cumulative percentages of 'very much' and 'somewhat' responses) were: 1) their child's nannies, child-minders and/or au-pairs (88%); 2) their siblings (i.e. the parent's brothers and sisters) (83.3%); and 3) their child's teachers (83.1%). In contrast, the three categories of individuals to whom parents of CWE reported speaking to least about their child's epilepsy (as reflected by the items that obtained the highest percentages of 'not at all' responses) were: 1) parents of children with other chronic illnesses or disabilities (36.2%); 2) therapists/counsellors (34.2%); and 3) male friends (33.9%).

Table 8.19: Disclosure Targets for Parents of CWE: Valid Responses

Item No.	Please indicate the degree to which you have talked with each of the following individuals about your experience with epilepsy since your child's diagnosis:	N[9]	Not at all	A little	Somewhat	Very much
1	Close male friend(s)	55	20.0%	36.4%	27.3%	16.4%
2	Close female friend(s)	69	0.0%	20.3%	26.1%	53.6%
3	Male friend(s)	59	33.9%	33.9%	13.6%	18.6%
4	Female friend(s)	70	2.9%	38.6%	24.3%	34.3%
5	Neighbour(s)	63	20.6%	33.3%	23.8%	22.2%
6	Other people with epilepsy	52	25.0%	38.5%	11.5%	25.0%
7	Doctors	70	2.9%	17.1%	28.6%	51.4%
8	Nurses	66	4.5%	27.3%	28.8%	39.4%
9	Your parent(s)	58	1.7%	24.1%	22.4%	51.7%
10	Your sibling(s)	66	1.5%	15.2%	22.7%	60.6%
11	Therapist/Counsellor	38	34.2%	18.4%	13.2%	34.2%
12	Co-workers	51	15.7%	39.2%	29.4%	15.7%
13	Your child's friends' parents	68	14.7%	36.8%	25.0%	23.5%
14	Your child's teachers	71	2.8%	14.1%	29.6%	53.5%
15	Your child's principal	71	8.5%	16.9%	35.2%	39.4%
16	Babysitters	31	12.9%	16.1%	22.6%	48.4%
17	Nannies/Child-minders/Au pairs	25	4.0%	8.0%	20.0%	68.0%
18	Your child's sports club coaches	51	0.0%	37.3%	15.7%	47.1%
19	Your employer	44	18.2%	45.5%	20.5%	15.9%
20	Your in-laws	63	4.8%	25.4%	17.5%	52.4%
21	Other parents of children with epilepsy	48	31.3%	18.8%	22.9%	27.1%
22	Parents of children with other chronic illnesses or disabilities	47	36.2%	34.0%	12.8%	17.0%

8.3.3 Situational Context of Parental Disclosure Exchanges

Specific details pertaining to the situational contexts in which parents reported being most and/or least likely to disclose their child's epilepsy to others outside the immediate family unit are reported in Table 8.20 below. Parents of CWE reported that the three main situational contexts under which they spoke to others external to the nuclear family about their child's epilepsy (as denoted by the items with the highest cumulative percentages of 'really true for me'

[9] Refers to the number of parents who answered the question for whom the disclosure target was applicable

and ‘sort of true for me’ responses) were inclusive of circumstances and/or situations when: 1) others would be responsible for the child (95.8%); 2) others asked questions (94.5%); and 3) the topic of epilepsy came up in conversation with others (90.3%) (see Table 8.20). Comparatively, the three contexts that were reported by parents of CWE to be those under which disclosure exchanges with others least commonly unfolded (as indicated by those with the highest percentages of ‘not at all true for me’ responses) included circumstances where: 1) others witnessed their child having a seizure (34.3%); 2) their child’s medication was causing difficulties (33.8%); and 3) their child could not partake in an activity due to his/her epilepsy (33.8%).

Table 8.20: Situational Context of Parental Disclosure Exchanges: Valid Responses

Item No.	I usually talk to others about my child’s epilepsy when…	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply to me, I never talk to others about my child’s epilepsy
1	They have seen my child having a seizure	70	34.3%	25.7%	34.3%	5.7%
2	I think my child might be at risk of having a seizure	72	50.0%	27.8%	20.8%	1.4%
3	They see my child taking his/her medication	72	34.7%	34.7%	29.2%	1.4%
4	They ask me questions	72	63.9%	30.6%	5.6%	0.0%
5	My child has a hospital appointment coming up or has recently had a hospital appointment	72	45.8%	40.3%	12.5%	1.4%
6	My child’s medication is causing difficulties	71	35.2%	29.6%	33.8%	1.4%
7	My child cannot partake in an activity due to his/her epilepsy	71	33.8%	29.6%	33.8%	2.8%
8	My child misses school because he/she has had a seizure	70	34.3%	35.7%	25.7%	4.3%
9	I need support	72	30.6%	43.1%	26.4%	0.0%
10	I need information	72	37.5%	38.9%	23.6%	0.0%
11	Epilepsy comes up in conversation	72	41.7%	48.6%	9.7%	0.0%
12	My child is entering a new environment or starting a new activity	72	63.9%	23.6%	12.5%	0.0%
13	Others will be responsible for my child	72	72.2%	23.6%	4.2%	0.0%
14	There is a change in my child’s behaviour due to his/her epilepsy	70	54.3%	28.6%	14.3%	2.9%
15	Others are speaking about their children’s difficulties	72	37.5%	48.6%	11.1%	2.8%

8.3.4 Content of Parental Disclosure Exchanges

Parents reported that the three conversation topics that they most frequently raised during their epilepsy disclosure exchanges with others external to the nuclear family (as highlighted by the items that received the highest cumulative percentages of 'really true for me' and 'sort of true for me' responses) comprised: 1) seizure first aid protocols (i.e. explaining to others what to do in the event of the child having a seizure in their presence) (95.8%); 2) the child's seizure manifestations (i.e. describing what happens and how their child appears during seizures) (95.8%); and 3) the child's type of epilepsy (93.1%). Information that parents of CWE reported being least likely to discuss during their disclosure exchanges with others (as denoted by the items with the highest percentages of 'not at all true for me' responses) pertained to: 1) medication side-effects (25.4%); 2) their feelings about their child having epilepsy (25%); and 3) epilepsy-related restrictions imposed on the child due to the diagnosis (23.6%). See Table 8.21 for additional detail.

Table 8.21: Content of Parental Disclosure Exchanges: Valid Responses

Item No.	When I talk to others about my child's epilepsy, I talk to others about…	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply to me, I never talk to others about my child's epilepsy
1	What epilepsy is	70	50.0%	42.9%	7.1%	0.0%
2	The type of epilepsy my child has	72	68.1%	25.0%	6.9%	0.0%
3	What happens/how my child appears when he/she is having a seizure	70	72.9%	22.9%	4.3%	0.0%
4	How seizures impact on my child	72	65.3%	27.8%	6.9%	0.0%
5	What to do in the event of my child having a seizure	72	73.6%	22.2%	4.2%	0.0%
6	My child's medication	72	48.6%	38.9%	12.5%	0.0%
7	Medication side-effects	71	38.0%	35.2%	25.4%	1.4%
8	My child's hospital appointments	72	37.5%	45.8%	16.7%	0.0%
9	Restrictions my child experiences due to his/her epilepsy	72	34.7%	38.9%	23.6%	2.8%
10	My child's seizure control (or lack thereof)	72	50.0%	27.8%	19.4%	2.8%
11	Whether my child will grow out of his/her epilepsy	72	45.8%	36.1%	16.7%	1.4%
12	How I feel about my child having epilepsy	72	31.9%	40.3%	25%	2.8%
13	How my child feels about having epilepsy	72	30.6%	47.2%	22.2%	0.0%

8.3.5 Rationale Underlying the Selection of Specific Disclosure Management Strategies by Parents

As depicted in Table 8.22, the three most common reasons for parental disclosure exchanges with others (as reflected by the items that obtained the highest cumulative percentages of 'really true for me' and 'sort of true for me' responses) as cited by parents themselves related to: 1) their desire for others to know what to do in the event of their child having a seizure in their presence (94.4%); 2) their wish for others to be aware of the potential risk of their child having a seizure (94.4%); and 3) their desire to ensure that others are comfortable with their child's epilepsy (91.7%). Comparatively, as indicated by the items that received the highest percentages of 'not at all true for me' responses, parents of CWE reported being least likely to disclose their child's epilepsy to others because: 1) it helped them to learn more about epilepsy (29.2%); 2) it offered them emotional support (26.4%); and/or 3) they wanted to explain changes in their child's behaviour (23.6%).

Table 8.22: Reasons for Parental Disclosure Exchanges: Valid Responses

Item No.	I tell others about my child's epilepsy because…	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply to me, I never tell others about my child's epilepsy
1	I want them to be aware that my child may have a seizure	72	72.2%	22.2%	5.6%	0.0%
2	I want them to know what to do in the event of my child having a seizure	72	81.9%	12.5%	5.6%	0.0%
3	I want to ensure others do not overreact if my child has a seizure in front of them	72	75%	13.9%	11.1%	0.0%
4	I want to raise awareness about epilepsy	72	51.4%	31.9%	16.7%	0.0%
5	I want to make sure people are comfortable with my child's epilepsy	72	68.1%	23.6%	6.9%	1.4%
6	I want to explain the changes in my child's behaviour	72	47.2%	29.2%	23.6%	0.0%
7	Talking to others helps me to learn about epilepsy	72	36.1%	34.7%	29.2%	0.0%
8	Talking to others offers me emotional support	72	31.9%	41.7%	26.4%	0.0%

Item No.	I tell others about my child's epilepsy because…	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply to me, I never tell others about my child's epilepsy
9	It makes me feel comfortable when others know about my child's epilepsy	72	52.8%	31.9%	15.3%	0.0%

The three most common reasons for parental concealment of their child's epilepsy (as denoted by the items with the highest cumulative percentages of 'really true for me' and 'sort of true for me' responses) were inclusive of: 1) the fact that other people are misinformed about epilepsy (47.9%); 2) the fact that epilepsy is seldom spoken about within the public domain (47.2%); and 3) the invisible nature of the child's epilepsy (47.2%). Conversely, the least commonly cited reasons for parental epilepsy concealment, as denoted by the items with the highest percentages of 'not at all true for me' responses, included: 1) parents' fear of how others would react (54.9%); 2) their child's desire for others not to know about their epilepsy (51.4%); and 3) parents' perception that their child's epilepsy is a private matter (51.4%).

Table 8.23: Reasons for Parental Concealment: Valid Responses

Item No.	I don't tell others about my child's epilepsy because…	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply to me, I always tell others about my child's epilepsy
1	I am afraid of how others will react	71	7.0%	16.9%	54.9%	21.1%
2	I am anxious that my child will be discriminated against or excluded	71	15.5%	28.2%	40.8%	15.5%
3	Other people are misinformed about epilepsy	71	22.5%	25.4%	39.4%	12.7%
4	Other people have difficulty understanding epilepsy	72	16.7%	29.2%	37.5%	16.7%
5	Epilepsy is rarely spoken about in public	72	15.3%	31.9%	38.9%	13.9%
6	It makes me upset	72	12.5%	19.4%	50.0%	18.1%
7	My child does not want others to know about his/her epilepsy	72	9.7%	20.8%	51.4%	18.1%
8	My child's epilepsy is not visible (i.e. he/she does not have seizures in public or during the day)	70	22.9%	24.3%	34.3%	18.6%

Item No.	I don't tell others about my child's epilepsy because…	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply to me, I always tell others about my child's epilepsy
9	I do not feel that it is necessary for others to know about my child's epilepsy	72	9.7%	19.4%	48.6%	22.2%
10	My child's epilepsy is a private matter	70	2.9%	20.0%	51.4%	25.7%
11	I do not want to seem attention-seeking	72	12.5%	19.4%	44.4%	23.6%

8.3.6 Barriers and Enablers for Parental Disclosure

As demonstrated in Table 8.24, the three factors that were most frequently reported to encourage parents to disclose their child's epilepsy to others outside the immediate family unit were inclusive of: 1) parents' ability to explain the condition to others (60.9%); 2) the fact that epilepsy is a medical condition (60%); and 3) the level of information parents possessed about their child's epilepsy (60%). In contrast, the factors that were most commonly identified by parents as presenting a barrier to their disclosure of their child's epilepsy included: 1) their perception of how others would treat or view their child (34.3%); 2) public perceptions of epilepsy (31.4%); and 3) public understanding of epilepsy (26.5%). Finally, the factors that were most often reported by parents as having no impact on their disclosure behaviours regarding their child's epilepsy were: 1) their experiences with epilepsy prior to their child's diagnosis (54.3%); 2) the emotions talking to others about their child's epilepsy elicited in them (47.8%); and 3) the level of visibility of their child's epilepsy (47.1%).

Table 8.24: Barriers and Enablers for Parental Disclosure: Valid Responses

Item No.	Do any of the following encourage or discourage you to talk about your child's epilepsy with others?	N	This encourages me	This discourages me	Not applicable, this has no impact on how much I talk about my child's epilepsy
1	Epilepsy is a medical condition	70	60.0%	2.9%	37.1%
2	My child's seizures are well controlled	70	51.4%	4.3%	44.3%
3	My child's epilepsy is mild in comparison to others	70	58.6%	4.3%	37.1%
4	My child's epilepsy is not visible to others	68	47.1%	5.9%	47.1%
5	The level of information I have about my child's epilepsy	70	60.0%	5.7%	34.3%

Item No.	Do any of the following encourage or discourage you to talk about your child's epilepsy with others?	N	This encourages me	This discourages me	Not applicable, this has no impact on how much I talk about my child's epilepsy
6	The amount of time that has passed since my child's diagnosis	68	50.0%	7.4%	42.6%
7	Portrayals of epilepsy in the media	70	44.3%	14.3%	41.4%
8	My own attitudes towards epilepsy	69	56.5%	5.8%	37.7%
9	Experiences I have had with epilepsy prior to my child's diagnosis	70	31.4%	14.3%	54.3%
10	The reactions from others when I've talked about my child's epilepsy in the past	69	44.9%	14.5%	40.6%
11	Public perceptions of epilepsy	70	34.3%	31.4%	34.3%
12	My ability to explain epilepsy to others	69	60.9%	4.3%	34.8%
13	How I feel others will treat/perceive my child	70	28.6%	34.3%	37.1%
14	How talking to others about my child's epilepsy makes me feel	69	36.2%	15.9%	47.8%
15	Public understanding about epilepsy	68	36.8%	26.5%	36.8%
16	Whether my child wants others to know about his/her epilepsy	70	37.1%	25.7%	37.1%

8.3.7 Parental Emotions Prior to Disclosure

As represented in Table 8.25, parents experienced largely positive feelings prior to their epilepsy disclosure exchanges with others external to the nuclear family. The three most commonly reported feelings included: 1) confidence (77.1%); 2) optimism (60%) and 3) anxiety (33.3%). In this context, feelings of pessimism, uncomfortableness and fearfulness were those that were least commonly reported by parents of CWE.

Table 8.25: How Parents Feel Prior to Disclosure Exchanges with Others: Valid Responses

Item No.	Before telling others about my child's epilepsy I feel…	N	Yes	No
1	Anxious	72	33.3%	66.7%
2	Optimistic	70	60.0%	40.0%
3	Uncomfortable	70	20.0%	80.0%
4	Pessimistic	69	7.2%	92.8%

Item No.	Before telling others about my child's epilepsy I feel…	N	Yes	No
5	Confident	70	77.1%	22.9%
6	Fearful	70	21.4%	78.6%
7	Unsure	70	31.4%	68.6%

8.3.8 Consequences of Parental Disclosure

Amongst parents of CWE, the main reactions they reported experiencing in response to their disclosure of their child's epilepsy to others external to the nuclear family were positive ones (see Table 8.26), including others: 1) asking questions (98.6%); 2) responding in a positive manner (85.9%); and 3) providing reassurance (85.9%). Few parents (<15%) reported that others reacted in a negative manner. However, just over two out of every five parents identified that others found it difficult to understand the child's condition, just under one out every three of parents reported that others treated their child differently as a result of their epilepsy disclosure, and approximately one out of every five parents highlighted that a consequence of their disclosure was others excluding and/or discriminating against their child.

Table 8.26: Others' Reactions to Parental Epilepsy Disclosure: Valid Responses

Item No.	In the past, when I have told others about my child's epilepsy others have mostly…	N	Yes	No
1	Reacted positively	71	85.9%	14.1%
2	Asked questions	71	98.6%	1.4%
3	Reassured me	71	85.9%	14.1%
4	Had difficulty understanding the condition	71	43.7%	56.3%
5	Reacted negatively	71	14.1%	85.9%
6	Treated my child differently	71	29.6%	70.4%
7	Excluded or discriminated against my child	72	22.2%	77.8%

Others' positive reactions to their disclosure of their child's epilepsy condition evoked feelings of reassurance (94.3%), happiness (94.2%) and relief (91.3%) in parents (see Table 8.27).

Table 8.27: Parental Emotions Surrounding Positive Reactions to Disclosure: Valid Responses

Item No.	After telling others about my child's epilepsy, when they react well I feel…	N	Yes	No	Does not apply, others have never reacted well
1	Happy	69	94.2%	5.8%	0.0%
2	Reassured	70	94.3%	4.3%	1.4%
3	Relieved	69	91.3%	7.2%	1.4%

Whilst, approximately 30% of parents reported that others had never reacted poorly to their disclosure of their child's epilepsy, the most common emotions reported by parents of CWE following others responding poorly were frustration (52.9%), upset (51.4%) and anger (43.7%) (see Table 8.28).

Table 8.28: Parental Emotions Surrounding Negative Reactions to Disclosure: Valid Responses

Item No.	After telling others about my child's epilepsy, when they react poorly I feel…	N	Yes	No	Does not apply, others have never reacted poorly
1	Frustrated	70	52.9%	18.6%	28.6%
2	Angered	71	43.7%	28.2%	28.2%
3	Upset	70	51.4%	20.0%	28.6%
4	Worried	69	42.0%	29.0%	29.0%

8.4 Psychometric Testing of the Youth and Parent Versions of the Newly Developed Epilepsy Disclosure Scale (EDS)

In this section, the newly developed Epilepsy Disclosure Scales are described. Descriptive statistics pertaining to CWE's and parents' scores on the individual items of the scales are provided, and details regarding psychometric testing of the youth and parent versions of the scale, including principal components analyses (PCA) and reliability analyses, are outlined.

A total of six items with the specific purpose of measuring CWE's and parents' disclosure behaviours surrounding epilepsy (i.e. the extent to which they tell and talk [or not] to others external to the nuclear family about the child's epilepsy) were included in the newly developed youth and parent EDS measures (see section 7.5.3 in chapter seven and Appendix U for information regarding the measure development process). Child and parent participants rated the six items on their respective scales on a 4-point Likert scale, with scores ranging from 0-3, where higher scores were reflective of greater epilepsy concealment and lower scores were reflective of more open epilepsy disclosure. The mean and standard deviations for each of the six items in the youth and parent versions of the EDS respectively are outlined in Table 8.29.

Table 8.29: Means and Standard Deviations for Each Item on the Youth and Parent Versions of the EDS

Item No.	Descriptor	CWE		Parents	
		M	***SD***	***M***	***SD***
1	When you can, do you keep your *(child's)* epilepsy a secret from others?	1.60	1.06	0.69	1.00
2	How frequently do you talk to people outside your family about your *(child's)* epilepsy?	1.51	0.93	0.81	0.67
3	Do any of your friends know that you *(-r child)* have *(has)* epilepsy?	0.98	1.09	0.30	0.52
4	How difficult has it been for you to talk to others about what you *(and your child)* are going through?	1.11	1.06	0.93	0.98
5	To what degree have you *wanted to keep* your *(child's)* epilepsy a secret?	1.20	1.13	0.38	0.72
6	To what degree have you *actually kept* your *(child's)* epilepsy a secret?	0.98	1.02	0.26	0.50

8.4.1 PCA and Reliability Analysis of the Epilepsy Disclosure Scale - Youth Version

Employing principal component analysis (PCA), the six items on the youth version of the EDS were analysed in order to assess whether all items on the scale represented a single construct. Prior to the conduct of PCA on the EDS-Y data, the appropriateness of performing PCA was established by: 1) observing the correlation matrix as well as the anti-correlation matrix; 2) conducting a Kaiser-Meyer-Oklin analysis; and 3) running Bartlett's Test of Sphericity. On initial inspection of the correlation matrix, many coefficients of 0.3 and above were observed signifying that the data may be suitable for PCA. Statistical significance was achieved for Bartlett's Test of Sphericity (χ^2 (15) = 110.54, $p < .05$) (Bartlett, 1954), further supporting the data's suitability for PCA. Additionally, the Kaiser-Meyer-Oklin (KMO) value was 0.79 which exceeds the recommended value of 0.60 (Kaiser, 1974). Finally, all of the Measures of Sampling Adequacy (MSA) values produced in the anti-image correlation matrix exceeded the recommended value of 0.70 (in accordance with the recommendations of Pett, Lackey & Sullivan, 2003), thus supporting the inclusion of each item in the PCA. Given the aforementioned indicators, it was consequently deemed suitable to perform PCA on all six items.

A unidimensional factor structure was identified on inspection of the unrotated PCA solution for the six items (i.e. only one component with an Eigenvalue exceeding 1 was revealed). The scree plot for this analysis revealed a clear break after the first component (see Figure 8.3 below).

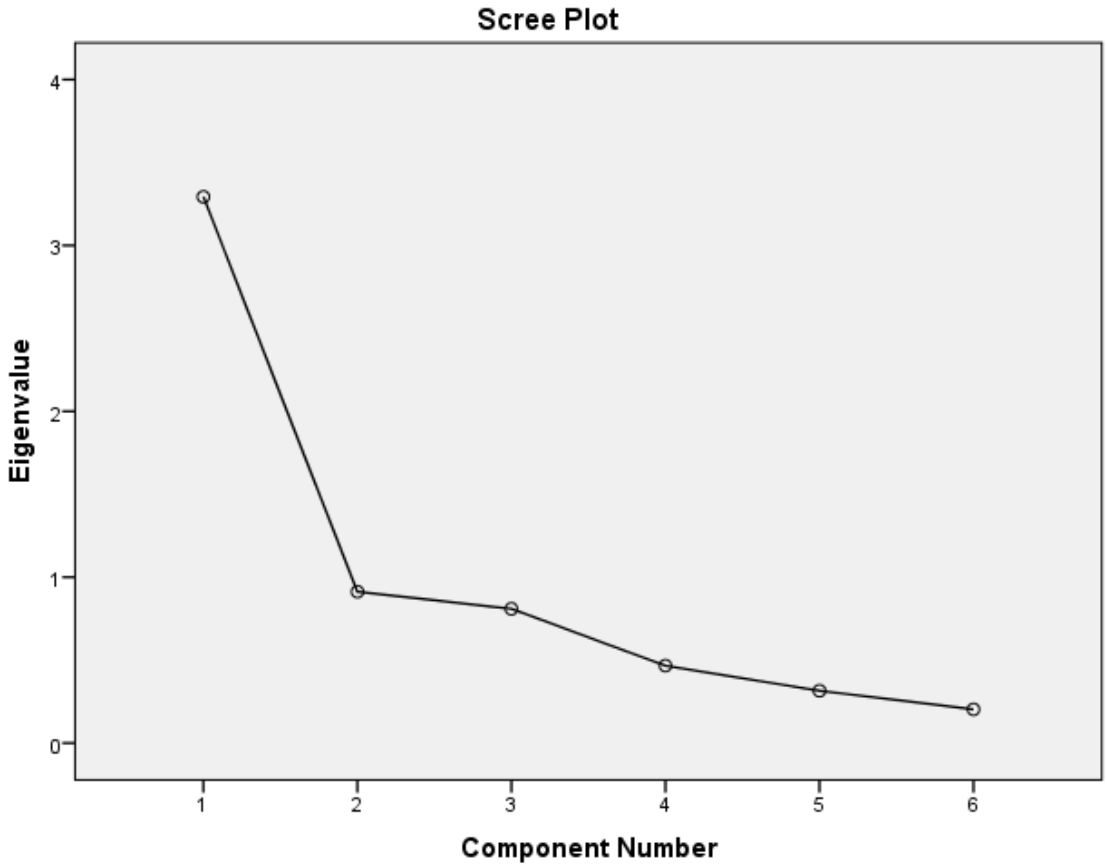

Figure 8.3: Scree Plot for PCA of the Epilepsy Disclosure Scale – Youth Version

All six items loaded onto this one component (see Table 8.30) that accounted for 54.89% of the variance alone. This falls into the 50-60% expected range of explained variance for social science research as posited by Pett et al. (2003). Reliability analysis performed on these six items revealed a Cronbach's Alpha of 0.83, suggesting that the resultant component was reliable.

Table 8.30: Factor Loadings from the PCA on the 6-item Solution of the Epilepsy Disclosure Scale – Youth Version

Item	Component 1
1. To what degree have you wanted to keep your epilepsy a secret?	0.90
2. To what degree have you actually kept your epilepsy a secret?	0.86
3. How difficult has it been for you to talk to others about what you are going through?	0.72
4. How frequently do you talk to people outside your family about your epilepsy?	0.69
5. Do any of your friends know that you have epilepsy?	0.69
6. When you can, do you keep your epilepsy a secret from others?	0.54

8.4.2 PCA and Reliability Analysis of the Epilepsy Disclosure Scale – Parent Version

Using PCA, the six items on the parent version of the EDS were analysed in order to assess whether all items on the scale represented a single construct. Prior to the conduct of PCA on the

EDS-P data, the suitability of performing PCA was assessed by: 1) inspecting the correlation matrix in addition to the anti-correlation matrix; 2) performing a Kaiser-Meyer-Oklin analysis; and 3) conducting Bartlett's Test of Sphericity. Initial observation of the correlation matrix revealed many coefficients of 0.3 and above, indicating that the data may be suitable for PCA. Bartlett's Test of Sphericity (Bartlett, 1954) achieved statistical significance (χ^2 (15) = 104.40, p < .05), providing additional support for the data's suitability for PCA. The KMO value was 0.79, exceeding the recommended value of 0.60 (Kaiser, 1974). Furthermore, all of the MSA values that were produced in the anti-image correlation matrix exceeded the recommended value of 0.70 (in accordance with the recommendations of Pett et al., 2003). Consequently, it was deemed appropriate to perform PCA on all six items.

On inspection of the unrotated PCA solution for the six items, the presence of one single component was revealed (i.e. there was only one component with an Eigenvalue exceeding one). Examination of the scree plot for this analysis also revealed a clear break after the first component (see Figure 8.4).

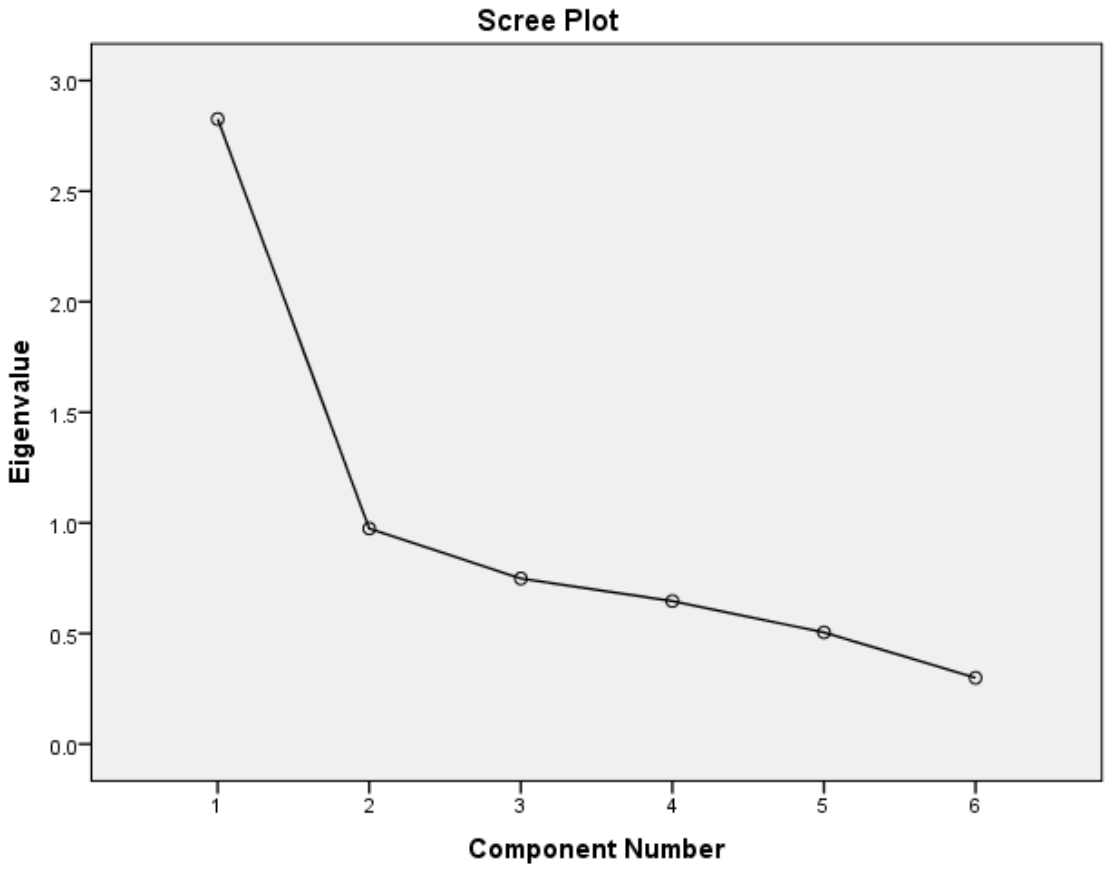

Figure 8.4: Scree Plot for PCA of the Epilepsy Disclosure Scale – Parent Version

All six items adequately loaded onto this one component (see Table 8.31 for factor loadings). This single component accounted for 47.1% of the variance alone. Reliability analysis

performed on these six items revealed a Cronbach's Alpha of 0.74, suggesting that the resultant component had acceptable internal consistency.

Table 8.31: Factor Loadings from the PCA on the 6-item Solution of the Epilepsy Disclosure Scale – Parent Version

Item	Component 1
1. To what degree have you wanted to keep your child's epilepsy a secret?	0.84
2. To what degree have you actually kept your child's epilepsy a secret?	0.82
3. When you can, do you keep your child's epilepsy a secret from others?	0.74
4. How frequently do you talk to people about your child's epilepsy?	0.62
5. How difficult has it been for you to talk to others about what you and your child are going through?	0.58
6. Do any of your friends know that your child has epilepsy?	0.44

8.5 Descriptive Statistics

Table 8.32 presents descriptive statistics for the EDS-Y and each of the child-reported psychosocial and illness attitude variables examined.

Table 8.32: Child-reported Disclosure, Psychosocial and Illness Attitude Variables: Descriptive Statistics

Variable	N	Possible Score Range	Actual Score Range	Mean *(S.D.)*	Median	Interquartile Range
Epilepsy Disclosure Scale – Youth Version						
Total Scale Score *(open disclosure - concealment)*	46	0-18	0-17	7.28 *(4.59)*	6.50	8.00
Child Stigma Scale						
Total Scale Score *(lesser – greater perceived stigma)*	43	8-40	8-36	17.77 *(8.35)*	16.00	11.00
Child Attitudes Towards Illness Scale						
Total Scale Score *(negative – positive illness attitudes)*	38	13-65	24-59	42.37 *(8.91)*	41.00	13.00
Self-Perception Profile for Children Scale						
Scholastic Competence *(lower – higher perceived competence)*	37	6-24	6-24	14.59 *(4.99)*	14.00	8.50
Social Competence *(lower – higher perceived competence)*	36	6-24	8-24	17.47 *(4.24)*	18.00	5.00
Athletic Competence *(lower – higher perceived competence)*	37	6-24	7-24	16.62 *(5.11)*	18.00	9.00
Physical Appearance *(lesser – greater satisfaction)*	35	6-24	6-24	16.83 *(5.54)*	17.00	10.00
Behavioral Conduct *(lesser – greater satisfaction)*	37	6-24	8-24	16.92 *(4.02)*	17.00	4.50

Variable	N	Possible Score Range	Actual Score Range	Mean *(S.D.)*	Median	Interquartile Range
Self-Perception Profile for Children Scale (continued)						
Global Self-Worth *(lower- higher self-worth)*	36	6-24	7-24	18.58 *(4.54)*	19.50	6.75
Total Scale Score (*negative – positive self-perception)*	32	36-144	53-132	101.66 *(21.21)*	101.00	33.25
Quality of Life Measure for Children with Epilepsy						
Interpersonal/Social Consequences *(poorer–greater HRQoL)*	36	5-20	6-20	16.44 *(3.88)*	17.50	6.00
Worries and Concerns *(poorer–greater HRQoL)*	37	5-20	6-20	13.27 *(3.85)*	13.00	7.00
Intrapersonal/Emotional Issues *(poorer–greater HRQoL)*	38	5-20	5-19	11.61 *(3.73)*	12.00	6.25
Epilepsy: My Secret *(poorer–greater HRQoL)*	39	5-20	7-20	14.95 *(3.82)*	15.00	6.00
Quest for Normality *(poorer–greater HRQoL)*	36	5-20	8-20	16.31 *(3.19)*	17.00	5.00
Total Scale Score *(poorer–greater HRQoL)*	30	25-100	39-91	71.23 *(15.13)*	71.50	29.25
Children's and Adolescents' Perceived Social Support Scale						
Parental Support *(lesser– greater perceived support)*	38	6-24	15-24	22.21 *(2.59)*	23.00	3.00
Classmate Support *(lesser – greater perceived support)*	38	6-24	11-24	20.74 *(3.28)*	21.50	4.25
Teacher Support *(lesser – greater perceived support)*	38	6-24	12-24	20.05 *(3.62)*	21.00	6.00
Close Friend Support *(lesser – greater perceived support)*	38	6-24	6-24	20.45 *(5.19)*	23.00	4.25
Total Scale Score *(lesser – greater perceived support)*	37	24-96	60-96	83.27 *(10.90)*	89.00	17.50
Level of Epilepsy-related Communication with Parents						
Level of Epilepsy-related Communication with Mother *(lesser-greater communication)*	42	1-4	2-4	3.64 *(0.66)*	4.00	1.00
Level of Epilepsy-related Communication with Father *(lesser-greater communication)*	42	1-4	1-4	3.36 *(0.93)*	4.00	1.00
Total Level of Epilepsy-related Communication with Parents *(lesser-greater communication)*	42	2-8	3-8	7.00 *(1.48)*	8.00	2.00

Variable	N	Possible Score Range	Actual Score Range	Mean *(S.D.)*	Median	Interquartile Range
Child Need for Information and Support						
Need for Information (*greater – lesser need)*	41	6-12	6-12	8.66 *(2.01)*	8.00	3.00
Need for Support (*greater – lesser need)*	40	6-12	6-12	9.68 *(2.12)*	10.00	3.00
Total Scale Score (*greater – lesser need)*	39	12-24	12-24	18.26 *(3.47)*	19.00	6.00
Child Satisfaction with Level of Epilepsy-related Information Received						
Total Scale Score *(dissatisfied - satisfied)*	43	6-12	6-12	10.09 *(1.70)*	10.00	3.00

Table 8.33 depicts descriptive statistics for the EDS-P and each of the parent-reported psychosocial and illness attitude variables.

Table 8.33: Parent-reported Disclosure, Psychosocial and Illness Attitude Variables: Descriptive Statistics

Variable	N	Possible Score Range	Actual Score Range	Mean *(S.D.)*	Median	Interquartile Range
Epilepsy Disclosure Scale – Parent Version						
Total Scale Score *(open disclosure - concealment)*	69	0-18	0-13	3.43 *(3.03)*	3.00	4.00
Parent Stigma Scale						
Total Scale Score *(lesser – greater perceived stigma)*	71	5-25	5-25	12.44 *(3.96)*	12.00	5.00
Parent Response to Child Illness Scale						
Child Support *(lesser-greater provision of illness-related emotional support to the child)*	71	8-40	26-40	34.14 *(3.60)*	34.00	5.00
Family Life and Leisure *(lesser-greater family participation in leisure activities)*	68	10-50	19-50	38.57 *(7.80)*	40.00	12.00
Condition Management *(lesser-greater parental confidence in their ability to manage their child's illness)*	68	6-30	16-30	24.63 *(2.87)*	24.00	4.00
Child Autonomy *(lesser-greater parental encouragement of their child's independence)*	69	6-30	7-26	18.93 *(4.28)*	20.00	6.00
Child Discipline *(lesser-greater parental confidence in their ability to manage their child's behaviour)*	70	5-25	10-24	18.69 *(3.52)*	19.00	6.00

Variable	N	Possible Score Range	Actual Score Range	Mean *(S.D.)*	Median	Interquartile Range
Parent Response to Child Illness Scale (continued)						
Total Scale Score *(most negative-most positive overall response to the child's illness)*	65	35-175	101-163	134.38 *(15.31)*	136.00	21.50
Distress Disclosure Index						
Total Scale Score *(lesser-greater tendency to disclose distressing information to others)*	71	12-60	17-58	41.07 *(8.72)*	42.00	15.00
Multidimensional Perceived Social Support Scale						
Significant Other *(lesser-greater perceived support)*	72	4-28	12-28	23.24 *(3.89)*	24.00	5.75
Family *(lesser-greater perceived support)*	71	4-28	4-28	21.92 *(5.32)*	24.00	6.00
Friends *(lesser-greater perceived support)*	71	4-28	7-28	21.72 *(4.51)*	23.00	4.00
Total Scale Score *(lesser-greater perceived support)*	71	12-84	28-84	66.80 *(11.71)*	69.00	14.00
Level of Epilepsy-related Communication with Child						
Total Scale Score *(lesser-greater communication)*	70	1-4	2-4	3.51 *(0.68)*	4.00	1.00
Hague Restrictions in Childhood Epilepsy Scale						
Total Scale Score *(lesser-greater restrictions and disability)*	68	10-40	10-36	18.84 *(7.70)*	16.00	11.00
Impact of Pediatric Epilepsy Scale						
Total Scale Score *(lesser-greater impact on the child and family)*	66	0-33	0-27	10.03 *(7.69)*	8.00	12.25
Parent Need for Information and Support						
Need for Information *(lesser-greater need)*	68	6-18	6-18	9.21 *(3.02)*	9.00	3.75
Need for Support *(lesser-greater need)*	68	8-24	8-22	13.35 *(3.97)*	13.50	6.00
Total Scale Score *(lesser-greater need)*	67	14-42	14-40	22.43 *(6.07)*	22.00	8.00
Parent Satisfaction with Level of Epilepsy-related Information Received						
Total Scale Score *(dissatisfied - satisfied)*	66	8-16	8-16	13.58 *(2.77)*	15.00	5.00

8.6 Correlational and Group Difference Analyses

In order to address the research objectives for phase two (see section 7.2.2) and to test specific hypotheses (see section 7.2.3), a series of correlations and group difference analyses were performed to explore the relationship between child and parent epilepsy disclosure and demographic and clinical variables, as well as psychosocial and illness attitude variables. Where there was a lack of pre-existing empirical evidence on which to base a-priori assumptions and to draw hypotheses, two-tailed exploratory correlational and group difference analyses were performed. Where there was existing empirical evidence on which to base hypotheses (see section 7.2.3), one-tailed tests were performed.

8.6.1 Children's Epilepsy Disclosure Behaviours and Child-reported Demographic and Clinical Variables

Table 8.34 outlines the relationship between CWE's epilepsy disclosure behaviours and their self-reported demographic and clinical characteristics. In terms of seizure type, Mann-Whitney U-tests indicated that epilepsy concealment was greater (as indicated by higher scores on the EDS-Y) for CWE with complex partial seizures (*Mdn*=9.50) than for CWE without complex partial seizures (*Mdn*=6.00); and for CWE with tonic seizures (*Mdn*=14.50) than for CWE without tonic seizures (*Mdn*=6.00). Furthermore, there was: 1) a significant negative correlation observed between CWE's EDS-Y scores and their age at illness onset; and 2) a significant positive correlation observed between CWE's EDS-Y scores and time since diagnosis. These findings suggest that the younger the age the child was at illness onset and the longer the duration of time that had passed since the child's diagnosis, the greater the degree of epilepsy concealment reported by the child.

Table 8.34: Correlational and Group Difference Analyses: CWE's Epilepsy Disclosure Scale Scores and Child-reported Demographic and Clinical Variables

Epilepsy Disclosure Scale –Youth Version Total Score	**N**	**Test Statistic**	**P**
		***r* or ρ or t or U**	**(2-tailed)**
Child Age			
Years	46	-.178 (*r*)	.236
Primary versus Secondary School Aged	46	1.40 (t)	.170
Child Gender			
Female/Male	46	-.251 (t)	.803
Child Seizure Type(s)/Activity			
Tonic-Clonic	44	-.776 (t)	.442
Absence	44	-.154 (t)	.878
Simple Partial	44	92.50 (U)	.241
Complex Partial	44	92.00 (U)	.028*
Myoclonic	44	143.00 (U)	.689
Atonic	44	16.50 (U)	.171
Tonic	44	22.50 (U)	.014*
Clonic	44	34.50 (U)	.062
Child's Seizure Characteristics			
Multiple Seizure Types versus One Seizure Type	44	-.333 (t)	.740

Epilepsy Disclosure Scale –Youth Version Total Score	N	Test Statistic *r* or ρ or t or U	P (2-tailed)
Child's Seizure Characteristics (continued)			
Disruptive versus more Benign Seizure Types	44	-.060 (t)	.952
Seizure Frequency (Daily to Seizure Free)	44	-.242 (*r*)	.113
A History of having Seizures in the Presence of Others			
Yes/No	42	94.50 (U)	.353
Experience of Medication Side Effects			
Yes/No	46	.152 (t)	.880
Age at Onset (Years)	46	-.381 (*r*)	.009**
Time Since Diagnosis (Years)	46	.301 (*r*)	.042*

*p<.05
** p<.01

8.6.2 Children's Epilepsy Disclosure Behaviours and Child-reported Psychosocial and Illness Attitude Variables

In order to test hypotheses 1-8 (see Table 7.1 in section 7.2.3), correlational and group difference analyses were performed. Table 8.35 outlines the relationship between CWE's epilepsy disclosure behaviours (as measured by the EDS-Y) and child-reported psychosocial and illness attitude variables.

Table 8.35: Correlations between CWE's Epilepsy Disclosure Scale Scores and Child-reported Psychosocial and Illness Attitude Variables

Epilepsy Disclosure Scale –Youth Version Total Score	N	Correlation Coefficient *r* or ρ	P (1-tailed)
Child Stigma Scale			
Total Scale Score (*higher scores indicate greater perceived stigma)*	43	.569 *(r)*	.000**
Child Attitudes Towards Illness Scale			
Total Scale Score *(higher scores indicate more positive illness attitudes)*	38	-.374 *(r)*	.010*
Self-Perception Profile for Children Scale			
Scholastic Competence *(higher scores indicate greater perceived competence)*	37	-.018 (*r*)	.458
Social Competence *(higher scores indicate greater perceived competence)*	36	-.112 (*r*)	.258
Athletic Competence *(higher scores indicate greater perceived competence)*	37	.437 (*r*)	.003**
Physical Appearance *(higher scores indicate greater satisfaction)*	35	.184 (*r*)	.145
Behavioral Conduct *(higher scores indicate greater satisfaction)*	37	-.279 (*r*)	.047*
Global Self-Worth *(higher scores indicate greater self-worth)*	36	-.063 (*r*)	.358
Total Scale Score *(higher scores indicate more positive self-perceptions)*	32	.021 (*r*)	.455
Quality of Life Measure for Children with Epilepsy			
Interpersonal Social Consequences *(higher scores indicate greater HRQoL)*	36	-.284 (ρ)	.047*
Worries and Concerns *(higher scores indicate greater HRQoL)*	37	.171 (*r*)	.156
Intrapersonal Emotional Issues *(higher scores indicate greater HRQoL)*	38	-.406 (*r*)	.006**

Epilepsy Disclosure Scale –Youth Version Total Score	N	Correlation Coefficient *r* or ρ	P (1-tailed)
Quality of Life Measure for Children with Epilepsy (continued)			
Epilepsy: My Secret *(higher scores indicate greater HRQoL)*	39	-.664 (*r*)	.000**
Quest for Normality *(higher scores indicate greater HRQoL)*	36	-.210 (*r*)	.109
Total Scale Score *(higher scores indicate greater HRQoL)*	30	-.491 (*r*)	.003**
Children and Adolescents' Perceived Social Support Scale			
Parental Support *(higher scores indicate greater perceived support)*	38	-.107 (ρ)	.262
Classmate Support *(higher scores indicate greater perceived support)*	38	-.131 (ρ)	.217
Teacher Support *(higher scores indicate greater perceived support)*	38	-.104 (*r*)	.267
Close Friend Support *(higher scores indicate greater perceived support)*	38	-.124 (ρ)	.230
Total Scale Score *(higher scores indicate greater perceived support)*	37	-201 (*r*)	.116
Level of Epilepsy-related Communication with Parents			
Level of Epilepsy-related Communication with Mother *(higher scores indicate greater communication)*	43	-.287 (ρ)	.031*
Level of Epilepsy-related Communication with Father *(higher scores indicate -greater communication)*	43	-.347 (ρ)	.011*
Total Level of Epilepsy-related Communication with Parents *(higher scores indicate-greater communication)*	42	-.366 (ρ)	.009**
Child Need for Information and Support			
Need for Information (*higher scores indicate less need)*	41	.124 (*r*)	.220
Need for Support (*higher scores indicate less need)*	40	-.190 (*r*)	.120
Total Scale Score (*higher scores indicate less need)*	39	-.057 (*r*)	.365
Child Satisfaction with Level of Epilepsy-related Information Received			
Total Scale Score *(higher scores indicate greater satisfaction)*	43	.142 (*r*)	.182

*p<.05
** p<.01

Consistent with hypothesis 1, CWE's CSS scores were significantly positively correlated with their scores on the EDS-Y, indicating that increased stigma perceptions amongst CWE were associated with CWE reporting greater epilepsy concealment.

Hypothesis 2 was also supported with a moderate negative correlation observed between CWE's EDS-Y scores and their scores on the CATIS; that is, positive illness attitudes amongst CWE were significantly associated with more open epilepsy disclosure behaviours amongst CWE.

Hypothesis 3 only received partial support as counter to what was hypothesised, CWE's epilepsy disclosure behaviours did not significantly correlate with: 1) their perceived scholastic competence; 2) their perceived social competence; 3) their perceived physical appearance; 4) their global self-worth; or 5) their self-perceptions overall. Furthermore, contrary to what was hypothesised, a significant moderate positive correlation was observed between CWE's EDS-Y scores and their scores on the Athletic Competence subscale of the SPPC, indicating that greater epilepsy concealment by CWE was associated with CWE perceiving themselves as being more athletically competent. However, as hypothesised, CWE's scores on the EDS-Y were significantly negatively correlated with their scores on the Behavioral Conduct subscale of the SPPC, suggesting that greater epilepsy concealment amongst CWE was significantly associated with CWE perceiving themselves as being less capable of behaving in an appropriate manner.

In support of hypothesis 4, CWE's scores on the EDS-Y were significantly negatively correlated with their scores on: 1) the Interpersonal/Social Consequences subscale of the CHEQOL-25; 2) the Intrapersonal/Emotional Issues subscale of the CHEQOL-25; 3) the Epilepsy: My Secret subscale of the CHEQOL-25; and 4) the total CHEQOL-25 scale. These findings suggest that greater epilepsy concealment amongst CWE is associated with CWE experiencing more negative intrapersonal/social consequences due to the illness, more negative intrapersonal/emotional issues as a result of the condition, greater issues in terms of maintaining secrecy around the condition and poorer HRQoL overall. Contrary to hypothesis 4, CWE's EDS-Y scores were not significantly associated with their scores on the Worries and Concerns subscale of the CHEQOL-25 or on the Quest for Normality subscale of the CHEQOL-25, indicating that CWE's epilepsy disclosure behaviours were not significantly related to their epilepsy-related worries and concerns or their perceived ability to live a normal life.

Hypothesis 5 was unsupported as non-significant correlations were observed between CWE's epilepsy disclosure behaviours (captured by the EDS-Y) and their perceived social support (measured by the SSSCA) overall, and from the four following sources: 1) their parents; 2) their classmates; 3) their teachers; and 4) their close friends.

As hypothesised (see hypothesis 6 in chapter 7), CWE's EDS-Y scores were significantly negatively correlated with their self-reported scores on items that assessed their level of epilepsy-related communication with: (i) their mothers; (ii) their fathers; and (iii) both of their parents collectively. These findings indicate that greater epilepsy concealment by CWE was associated with CWE communicating to a lesser extent with their parents about their epilepsy.

Counter to hypothesis 7, CWE's epilepsy disclosure behaviours were not significantly correlated with their: 1) need for epilepsy-related information; 2) need for epilepsy-related support; and/or 3) total need for epilepsy-related information and support.

Finally, despite hypothesis 8 predicting a negative correlation between CWE's scores on the EDS-Y and their scores on the Child Information Received subscale of the Child Report of Psychosocial Care Scale, a non-significant correlation was observed between CWE's epilepsy disclosure behaviours and CWE's satisfaction with the level of epilepsy-related information received during their interactions with doctors and nurses.

8.6.3 Parents' Epilepsy Disclosure Behaviours and Parent-reported Demographic and Clinical Variables

Table 8.36 outlines the relationship between parental epilepsy disclosure behaviours and parents' demographic characteristics, as well as their CWE's demographic and clinical characteristics. In terms of seizure type, an independent t-test indicated differences in parents' epilepsy disclosure behaviours according to whether their CWE had complex partial seizures or not, with epilepsy concealment greater amongst parents (as indicated by higher scores on the EDS-P) of CWE with complex partial seizures (M=4.48, S.D.=3.62) when compared to parents of CWE without complex partial seizures (M=2.84, S.D.=2.49). Parents' epilepsy disclosure behaviours did not significantly correlate with or yield any significant group differences in terms of any further: 1) parent demographic characteristics; 2) child demographic characteristics (parent-reported); or 3) child clinical characteristics (parent-reported).

Furthermore, hypothesis 9 was not supported. That is, parents' scores on the EDS-P did not significantly correlate with the scores they reported on the Seizure Severity Scale. This finding suggests that parental epilepsy disclosure behaviours were not significantly associated with the severity of their child's seizure condition.

Table 8.36: Correlational and Group Difference Analyses: Parents' Epilepsy Disclosure Scale Scores and Parent-reported Demographic and Clinical Variables

Epilepsy Disclosure Scale –Parent Version Total Score	**N**	**Test Statistic**	**P**
		***r* or ρ or t or U**	**(1-tailed or 2-tailed)**
Parent Age			
Youngest-Oldest	69	.174 (*r*)	.153 (2-tailed)
Parent Gender			
Female/Male	69	127.50 (U)	.463 (2-tailed)
Parent Level of Education			
Less than Junior Certificate to Doctoral Degree	68	.117 *(r)*	.342 (2-tailed)
Child Age			
Years	68	-.027 (*r*)	.825 (2-tailed)
Primary versus Secondary School Aged	62	.900 (t)	.373 (2-tailed)
Child Gender			
Female/Male	66	-.005 (t)	.996 (2-tailed)
Child Seizure Type(s)/Activity			
Tonic-Clonic	69	-1.48 (t)	.147 (2-tailed)
Absence	69	.449 (t)	.655 (2-tailed)
Simple Partial	69	313.00 (U)	.177 (2-tailed)
Complex Partial	69	2.22 (t)	.030 (2-tailed)
Myoclonic	69	343.00 (U)	.363 (2-tailed)
Atonic	69	169.50 (U)	.159 (2-tailed)

Epilepsy Disclosure Scale –Parent Version Total Score	N	Test Statistic	P
		***r* or ρ or t or U**	**(1-tailed or 2-tailed)**
Child Seizure Type(s)/Activity (continued)			
Tonic	69	232.00 (U)	.279 (2-tailed)
Clonic	69	350.00 (U)	.289 (2-tailed)
Child's Seizure Characteristics			
Multiple Seizure Types versus One Seizure Type	68	.711 (t)	.480 (2-tailed)
Disruptive versus more Benign Seizure Types	69	403.50 (U)	.589 (2-tailed)
Seizure Frequency (Daily to Seizure Free)	65	-.074 (*r*)	.560 (2-tailed)
A History of the Child having Seizures in the Presence of Others			
Yes/No	69	349.00 (U)	.588 (2-tailed)
Experience of Medication Side Effects			
Yes/No	67	392.00 (U)	.484 (2-tailed)
Family History of Epilepsy			
Yes/No	62	-.300 (t)	.765 (2-tailed)
Child Age at Illness Onset (Years)	66	-.133 (*r*)	.287 (2-tailed)
Child Time Since Diagnosis (Years)	65	.130 (ρ)	.301 (2-tailed)
Seizure Severity Scale			
Total Scale Score (least-most severe)	54	-.119 (*r*)	.195 (1-tailed)

*p<.05
** p<.01

8.6.4 Parents' Epilepsy Disclosure Behaviours and Parent-reported Psychosocial and Illness Attitude Variables

A series of one-tailed and two-tailed correlations were conducted with a view to testing hypotheses 10-18 postulated in Chapter 7 (see section 7.2.3) and ascertaining whether parents' disclosure behaviours surrounding their CWE's epilepsy (as measured by the EDS-P) significantly negatively or positively correlated with parent-reported psychosocial variables (see Table 8.37 below).

Table 8.37: Correlations between Parents' Epilepsy Disclosure Scale Scores and Parent-reported Psychosocial and Illness Attitude Variables

Epilepsy Disclosure Scale –Parent Version Total Score	N	Correlation Coefficient	P
		***r* or ρ**	**(1-tailed or 2-tailed)**
Parent Stigma Scale			
Total Scale Score *(higher scores indicate greater perceived stigma)*	68	.306 (*r*)	.006** (1-tailed)
Parent Response to Child Illness Scale			
Child Support *(higher scores indicate greater parental provision of illness-related emotional support to the child)*	68	-.205 (*r*)	.046* (1-tailed)
Family Life and Leisure *(higher scores indicate greater family participation in leisure activities)*	65	-.229 (*r*)	.033* (1-tailed)
Condition Management *(higher scores indicate greater parental confidence in their ability to manage their child's illness)*	65	-.231 (*r*)	.032* (1-tailed)
Child Autonomy *(higher scores indicate -greater parental encouragement of their child's independence)*	66	-.166 (*r*)	.091 (1-tailed)

Epilepsy Disclosure Scale –Parent Version Total Score	N	Correlation Coefficient	P
		***r* or ρ**	**(1-tailed or 2-tailed)**
Parent Response to Child Illness Scale (continued)			
Child Discipline *(higher scores indicate greater parental confidence in their ability to manage their child's behaviour)*	67	-.293 (*r*)	.008** (1-tailed)
Total Scale Score *(higher scores indicate more positive parental responses to the child's illness overall)*	62	-.375 (*r*)	.001** (1-tailed)
Distress Disclosure Index			
Total Scale Score *(higher scores indicate a greater tendency to disclose distressing information to others)*	68	-.134 (*r*)	.139 (1-tailed)
Multidimensional Perceived Social Support Scale			
Significant Other *(higher scores indicate greater perceived support)*	69	-.132 (*r*)	.139 (1-tailed)
Family *(higher scores indicate greater perceived support)*	68	-.276 (ρ)	.011* (1-tailed)
Friends *(higher scores indicate greater perceived support)*	68	-.230 (ρ)	.030* (1-tailed)
Total Scale Score *(higher scores indicate greater perceived support)*	68	-.173 (*r*)	.079 (1-tailed)
Parent-reported Level of Epilepsy-related Communication with Child			
Total Score *(higher scores indicate greater communication)*	68	-.285 (ρ)	.009** (1-tailed)
Hague Restrictions in Childhood Epilepsy Scale			
Total Scale Score *(higher scores indicate greater restrictions and disability)*	65	.156 (*r*)	.107 (1-tailed)
Impact of Pediatric Epilepsy Scale			
Total Score *(higher scores indicate a greater perceived impact of illness on the child and family)*	63	.127 (*r*)	.322 (2-tailed)
Parent Need for Information and Support			
Need for Information *(higher scores indicate greater need)*	65	-.038 (ρ)	.765 (2-tailed)
Need for Support *(higher scores indicate greater need)*	65	.177 (*r*)	.158 (2-tailed)
Total Scale Score *(higher scores indicate greater need)*	64	.048 (*r*)	.706 (2-tailed)
Parent Satisfaction with Level of Epilepsy-related Information Received			
Total Scale Score *(higher scores indicate greater satisfaction)*	63	.036 (*r*)	.390 (1-tailed)

*p<.05
** p<.01

In line with hypothesis 10, a significant positive relationship was observed between parents' scores on the PSS and their scores on the EDS-P, indicating that increased parental stigma perceptions were associated with greater levels of epilepsy concealment by parents of CWE.

Hypothesis 11 was partially supported whereby parental EDS-P scores were significantly negatively correlated with their scores on: 1) the Child Support subscale of the PRCI; 2) the Family Life and Leisure subscale of the PRCI; 3) the Condition Management subscale of the PRCI; 4) the Child Discipline subscale of the PRCI; and 5) the total PRCI scale. Overall, these

findings indicate an association between greater parental epilepsy concealment and parents: 1) feeling less competent in their ability to provide their CWE with adequate illness-related emotional support; 2) reporting doing less as a family and engaging in fewer leisure activities due to the child's epilepsy diagnosis; 3) perceiving themselves to be less capable of appropriately managing their child's health condition; 4) viewing themselves as being less effective in terms of disciplining their child; and 5) having responded less positively to their child's illness overall. Parental EDS-P scores did not however significantly correlate with their scores on the Child Autonomy subscale of the PRCI.

Contrary to hypothesis 12, parents' epilepsy disclosure behaviours (as captured by the EDS-P) were not significantly correlated with their general tendency to disclose distressing information to others (as captured by the DDI).

Hypothesis 13 received partial support with parents' EDS-P scores significantly negatively correlating with their scores on the Family subscale of the MSPSS, and the Friends subscale of the MSPSS, but not with their scores on the Significant Other subscale of the MSPSS, or their total scores on the MSPSS. That is, greater parental epilepsy concealment was associated with parents perceiving less social support from family and friends, but not from their significant others or generally.

As hypothesised (hypothesis 14), increased parental EDS-P scores were significantly negatively correlated with parents' reported level of epilepsy-related communication with their child; that is, greater parental epilepsy concealment was associated with parents communicating with their CWE to a lesser extent about the epilepsy diagnosis.

Hypothesis 15 was unsupported i.e. no significant relationship was observed between parents' epilepsy disclosure behaviours (captured by the EDS-P) and their perceptions regarding the level of activity restrictions and disability imposed on their CWE as a result of their epilepsy diagnoses (measured employing the HARCES).

Hypothesis 16 was also unsupported. A non-significant correlation was observed between parental EDS-P scores and their scores on the IPES, indicating that parents' epilepsy disclosure behaviours were not associated with their perceptions of the impact the condition had on the child and the family.

Contrary to hypothesis 17, parental EDS-P scores did not significantly correlate with their scores on the: 1) Need for Information subscale; 2) Need for Support subscale; and/or 3) total Need for Information and Support subscale. These findings indicate that parents' disclosure behaviours surrounding their child's epilepsy are not related to their need for epilepsy-related information and support.

Finally, hypothesis 18 was also unsupported with a non-significant correlation observed between parental EDS-P scores and their scores on the Information Received subscale of the Parent Report of Psychosocial Care Scale, thus indicating that the level of epilepsy-related information parents received from doctors and nurses did not relate to their disclosure behaviours surrounding their child's epilepsy.

8.6.5 Children's Epilepsy Disclosure Behaviours and Parent-reported Variables

In order to explore whether CWE's disclosure behaviours surrounding their epilepsy (as measured by EDS-Y) were significantly associated with any parent-reported variables including parents' epilepsy disclosure behaviours, their stigma perceptions, their response to the child's illness and their perceived social support, a number of two-tailed correlations were conducted across the parent-child dyadic data (see Table 8.38 below).

Table 8.38: Correlations between CWE's Epilepsy Disclosure Scale Scores and Parent-reported Variables

Epilepsy Disclosure Scale –Youth Version Total Score	**N**	**Correlation Coefficient**	**P**
		***r* or ρ**	**(2-tailed)**
Epilepsy Disclosure Scale - Parent Version			
Total Scale Score *(higher scores indicate greater concealment)*	45	.444 (*r*)	.002**
Parent Stigma Scale			
Total Scale Score (*higher scores indicate greater perceived stigma)*	46	.306 (*r*)	.039*
Parent Response to Child Illness Scale			
Child Support *(higher scores indicate greater parental provision of illness-related emotional support to the child)*	46	-.113 (*r*)	.455
Family Life and Leisure *(higher scores indicate greater family participation in leisure activities)*	44	-.398 (ρ)	.007**
Condition Management *(higher scores indicate greater parental confidence in their ability to manage their child's illness)*	43	-.013 (*r*)	.936
Child Autonomy *(higher scores indicate greater parental encouragement of their child's independence)*	45	-.390 (*r*)	.008**
Child Discipline *(higher scores indicate greater parental confidence in their ability to manage their child's behaviour)*	46	-.131 (*r*)	.387
Total Scale Score *(higher scores indicate more positive parental responses to the child's illness overall)*	42	-.426 (*r*)	.005**
Distress Disclosure Index			
Total Scale Score *(higher scores indicate a greater tendency to disclose distressing information to others)*	46	-.086 (*r*)	.570
Multidimensional Perceived Social Support Scale			
Significant Other *(higher scores indicate greater perceived support)*	46	-.233 (*r*)	.119
Family *(higher scores indicate greater perceived support)*	46	-.357 (ρ)	.015*

Epilepsy Disclosure Scale –Youth Version Total Score	N	Correlation Coefficient	P
		***r* or ρ**	**(2-tailed)**
Multidimensional Perceived Social Support Scale (continued)			
Friends *(higher scores indicate greater perceived support)*	46	-.240 (*r*)	.109
Total Scale Score *(higher scores indicate greater perceived support)*	46	-.316 (*r*)	.032*
Parent-reported Level of Epilepsy-related Communication with Child			
Total Score *(higher scores indicate greater communication)*	44	-.199 (ρ)	.195
Hague Restrictions in Childhood Epilepsy Scale			
Total Scale Score *(higher scores indicate greater restrictions and disability)*	44	.107 (ρ)	.490
Impact of Pediatric Epilepsy Scale			
Total Score *(higher scores indicate greater perceived impact of illness on the child and family)*	41	.352 (*r*)	.024*
Parent Need for Information and Support			
Need for Information *(higher scores indicate greater need)*	44	-.202 (*r*)	.189
Need for Support *(higher scores indicate greater need)*	44	.435 (*r*)	.003**
Total Scale Score *(higher scores indicate greater need)*	43	.191 (*r*)	.220
Parent Satisfaction with Level of Epilepsy-related Information Received			
Total Scale Score *(higher scores indicate greater satisfaction)*	42	-.029 (*r*)	.853

*p<.05
** p<..01

CWE's scores on the EDS-Y significantly and positively correlated with their parents' scores on: 1) the EDS-P; 2) the PSS; 3) the IPES; and 4) the Need for Support subscale of the Parent Report of Psychosocial Care Scale. That is, higher levels of epilepsy concealment amongst CWE were significantly associated with their parents: 1) reporting higher levels of epilepsy concealment; 2) perceiving greater epilepsy-related stigma; 3) perceiving the condition as having a greater impact on the child and family; and 4) needing greater support in relation to the child's epilepsy.

Additionally, CWE's scores on the EDS-Y significantly and negatively correlated with their parents' scores on: 1) the Family Life and Leisure subscale of the PRCI; 2) the Child Autonomy subscale of the PRCI; 3) the PRCI; 4) the Family subscale of the MSPSS; and 5) the MSPSS. These findings suggest that more open epilepsy disclosure behaviours amongst CWE were associated with their parents reporting: 1) engaging in more activity and leisure pursuits as a family; 2) affording their child more independence; 3) having responded more favourably to the child's epilepsy diagnosis; 4) greater levels of perceived social support from family; and 5) greater levels of perceived social support overall.

8.6.6 Parents' Epilepsy Disclosure Behaviours and Child-reported Variables

In order to examine whether parents' disclosure behaviours surrounding their child's epilepsy (as measured by the EDS-P) were significantly related to child-reported variables including CWE's epilepsy disclosure behaviours, their illness attitudes and psychosocial variables (e.g. self-perception, HRQoL etc.), a series of two-tailed correlations were performed across parent-child dyads (see Table 8.39).

Table 8.39: Correlations between Parents' Epilepsy Disclosure Scale Scores and Child-reported Variables

Epilepsy Disclosure Scale –Parent Version Total Score	**N**	**Correlation Coefficient**	**P**
		***r* or ρ**	**(2-tailed)**
Epilepsy Disclosure Scale - Youth Version			
Total Scale Score *(higher scores indicate greater concealment)*	45	.444 (*r*)	.002**
Child Stigma Scale			
Total Scale Score (*higher scores indicate greater perceived stigma)*	42	.150 (*r*)	.342
Child Attitudes Towards Illness Scale			
Total Scale Score *(higher scores indicate more positive illness attitudes)*	37	-.027 (*r*)	.873
Self-Perception Profile for Children Scale			
Scholastic Competence *(higher scores indicate greater perceived competence)*	37	-.108 (*r*)	.525
Social Competence *(higher scores indicate greater perceived competence)*	36	-.106 (*r*)	.538
Athletic Competence *(higher scores indicate greater perceived competence)*	37	.052 (*r*)	.760
Physical Appearance *(higher scores indicate greater satisfaction)*	35	.252 (*r*)	.144
Behavioral Conduct *(higher scores indicate greater satisfaction)*	37	.048 (*r*)	.778
Global Self-Worth *(higher scores indicate greater self-worth)*	36	.149 (*r*)	.384
Total Scale Score *(higher scores indicate more positive self-perceptions)*	32	.040 (*r*)	.826
Quality of Life Measure for Children with Epilepsy			
Interpersonal Social Consequences *(higher scores indicate greater HRQoL)*	36	-.039 (ρ)	.823
Worries and Concerns *(higher scores indicate greater HRQoL)*	37	.333 (*r*)	.044*
Intrapersonal Emotional Issues *(higher scores indicate greater HRQoL)*	38	.034 (*r*)	.840
Epilepsy: My Secret *(higher scores indicate greater HRQoL)*	39	-.007 (*r*)	.965
Quest for Normality *(higher scores indicate greater HRQoL)*	36	.034 (*r*)	.843
Total Scale Score *(higher scores indicate greater HRQoL)*	30	.127 (*r*)	.504
Children and Adolescents' Perceived Social Support Scale			
Parental Support *(higher scores indicate greater perceived support)*	38	-.151 (ρ)	.366
Classmate Support *(higher scores indicate greater perceived support)*	38	-.053 (ρ)	.751

Epilepsy Disclosure Scale –Parent Version Total Score	N	Correlation Coefficient	P
		***r* or ρ**	**(2-tailed)**
Children and Adolescents' Perceived Social Support Scale (continued)			
Teacher Support *(higher scores indicate greater perceived support)*	38	-.062 (*r*)	.712
Close Friend Support *(higher scores indicate greater perceived support)*	38	-.010 (ρ)	.950
Total Scale Score *(higher scores indicate greater perceived support)*	37	.034 (*r*)	.842
Level of Epilepsy-related Communication with Parents			
Level of Epilepsy-related Communication with Mother *(higher scores indicate greater communication)*	42	-.163 (ρ)	.301
Level of Epilepsy-related Communication with Father *(higher scores indicate greater communication)*	42	-.151 (ρ)	.339
Total Level of Epilepsy-related Communication with Parents *(higher scores indicate greater communication)*	41	-.168 (ρ)	.295
Child Need for Information and Support			
Need for Information (*higher scores indicate less need)*	40	.028 (*r*)	.863
Need for Support (*higher scores indicate less need)*	39	-.006 (*r*)	.972
Total Scale Score (*higher scores indicate less need)*	38	.001 (*r*)	.994
Child Satisfaction with Level of Epilepsy-related Information Received			
Total Scale Score *(higher scores indicate greater satisfaction)*	42	-.132 (*r*)	.404

*p<.05
** p<..01

As demonstrated in Table 8.39, parents' EDS-P scores significantly and positively correlated with their children's scores on: 1) the EDS-Y; and 2) the Worries and Concerns domain of the CHEQOL-25. That is, greater parental concealment of the child's epilepsy was significantly associated with their CWE reporting greater epilepsy concealment and experiencing higher levels of epilepsy-related worry and concern (or conversely more open parental disclosure was related to CWE reporting more open epilepsy disclosure and lower levels of epilepsy-related worry and concern).

Two-tailed correlations revealed non-significant findings in terms of the relationship between parental epilepsy disclosure and any other aspects of CWE's HRQoL assessed by the CHEQOL-25 or children's stigma perceptions, illness attitudes, self-perceptions, perceived social support, self-reported level of epilepsy-related communication with their parents, need for epilepsy-related information and support, and satisfaction with the level of epilepsy-related information they had received during their engagements with HCPs.

8.6.7 Summary of Correlational and Group Difference Analyses Findings

The findings of significance that emerged through the conduct of correlational and group difference analyses are summarised for CWE and parents of CWE in Tables 8.40 and 8.41, respectively.

Table 8.40: Profile of Child Epilepsy Disclosure as it relates to other key variables

Greater concealment amongst CWE (as reflected by higher scores on the EDS-Y) was associated with the child:
• **Having complex partial seizures** • **Having tonic seizures** • **Having been diagnosed with epilepsy at a younger age** • **Reporting that a greater amount of time had passed since the diagnosis** • **Perceiving greater epilepsy-related stigma** • **Possessing less positive attitudes towards their illness** • **Perceiving themselves as being more athletically competent** • **Perceiving themselves as being less capable of behaving appropriately** • **Reporting poorer HRQoL in terms of interpersonal/social consequences** • **Reporting poorer HRQoL in terms of intrapersonal/emotional issues** • **Reporting poorer HRQoL related to keeping epilepsy a secret** • **Reporting poorer HRQoL overall (total scale score)** • **Communicating to a lesser degree about their epilepsy with both of their parents collectively, as well as with their mothers and fathers individually**
Furthermore, greater concealment amongst CWE was correlated with their parents:
• **Reporting higher levels of concealment** • **Perceiving greater epilepsy-related stigma** • **Perceiving the epilepsy to have a greater impact in terms of family life and leisure (i.e. such parents reported doing less as a family due to the child's epilepsy diagnosis)** • **Reporting that they afforded the child less autonomy due to the epilepsy** • **Having responded to the child's illness less positively overall** • **Perceiving less social support from family and overall** • **Reporting that the epilepsy had a greater impact on the child and family** • **Requiring more support surrounding the child's epilepsy**

Table 8.41: Profile of Parent Epilepsy Disclosure as it relates to other key variables

Amongst parents of CWE, greater concealment surrounding their child's epilepsy (as indicated by higher scores on the EDS-P) was associated with them:
• **Having a child with complex partial seizure types** • **Perceiving greater epilepsy-related stigma** • **Perceiving themselves as less being capable of offering illness-related support to their child** • **Perceiving greater impact in terms of family life and leisure (i.e. they reported doing less as a family due to the child's epilepsy)** • **Reporting themselves as being less competent in terms of the management of their child's condition** • **Perceiving themselves as being less competent in terms of managing their child's behaviour and disciplining their child** • **Having responded less positively overall to their child's illness** • **Perceiving less social support from two sources; namely, their family and friends** • **Reporting that they communicated to a lesser degree with their child about the child's epilepsy**

Furthermore, amongst parents who reported concealing their child's epilepsy from others external to the nuclear family to a greater degree, such behaviours were associated with their children:

- **Reporting higher levels of concealment**
- **Experiencing greater levels of worry and concern about their epilepsy**

Chapter 9: Phase Two: Discussion of the Quantitative Findings

9.0 Introduction

The purpose of phase two was to quantitatively assess epilepsy disclosure by CWE and parents of CWE, and to build on the limited body of existing literature by examining the relationship between CWE's and parents' epilepsy disclosure behaviours and their demographic characteristics, CWE's clinical characteristics and CWE's and parents' attitudes towards epilepsy, response to the illness, stigma perceptions and HRQoL, amongst other variables. In this chapter, the findings of the study with reference to these aims will be discussed, alongside the strengths and limits of this second quantitative phase.

9.1 CWE's and Parents' Epilepsy Disclosure

In this section, the following aspects of CWE's and parents' epilepsy disclosure will be critically discussed: 1) disclosure behaviours; 2) disclosure targets; 3) the situational context of disclosure exchanges; 4) the content of disclosure exchanges; 5) the rationale underlying specific disclosure decisions; 6) enablers of and barriers to disclosure; 7) the emotional components of disclosure; and 8) the consequences of disclosure.

9.1.1 Epilepsy Disclosure Behaviours

Both CWE and parents who participated in phase two engaged in diverse disclosure behaviours surrounding the child's epilepsy. Some CWE and parents reported being completely open and honest with others outside the immediate family unit about the child's epilepsy, whereas others reported favouring selective or concealment disclosure management strategies. Overall, parents were more open and forthcoming with others about the child's epilepsy when compared to CWE. For instance, 63.8% of CWE reported either having 'sometimes' or 'often' kept their epilepsy a secret from others when this option was available to them, whereas only 27.1% of parents reported keeping the child's epilepsy a secret from others to this same extent. One potential explanation for this difference in CWE's and parents' epilepsy disclosure behaviours relates to the onus and responsibility placed on parents to protect their child from harm. Whilst CWE may choose to conceal their epilepsy from others due to concerns surrounding normalcy and potential negative consequences of disclosure (e.g. others responding in an unkind manner), parents (even after contending with similar concerns and challenges) may feel obligated to disclose the child's epilepsy condition to others for fear of the safety of their child being compromised. This supports previous work that has identified that when parents view disclosure as a means to ensure the safety and care of their child, this encourages their epilepsy disclosure

to others (Mu, 2008; Roberts & Whiting, 2011). Parents are also more likely than CWE themselves to encounter formal situations, whereby disclosure of their child's epilepsy to others who might be responsible for the child is necessary (e.g. when enrolling the child in school or signing them up for a new sporting activity); in some instances, this disclosure may be a legal requirement for insurance purposes. A final factor that likely plays a role in accounting for the greater endorsement of epilepsy concealment by CWE than by parents of CWE is their proximity to the stigmatising attribute (i.e. it is they, rather than their parents, who possess the CSI). Whilst parents of CWE may worry about the risk of their child experiencing negative consequences subsequent to epilepsy disclosure, and indeed limited empirical evidence suggests that parents of CWE may be at risk of experiencing courtesy or affiliational stigma as a consequence of their association with the child with epilepsy (Baskind & Birbeck, 2005; Parfene, Stewart & King, 2009; Scambler & Hopkins, 1986), it is probable that there is a lesser likelihood of parents directly encounter stigmatising responses (or threats to: 1) their identity; and 2) their successful formation of peer relationships) on revealing the child's CSI to others.

In relation to written forms of disclosure, whether for their own personal consumption, for medical purposes or as a mechanism via which to disclose the child's condition to others, approximately 62% of parents had written to at least some extent about the child's epilepsy, whilst approximately 29% of CWE reported having written about their condition. In terms of utilising writing as a means to disclose the child's epilepsy to others, the following platforms or sources were referenced: 1) Facebook; 2) letters; 3) Twitter; 4) epilepsy support groups; and 5) Tumblr. Evidently, online platforms were a popular medium via which CWE and parents shared information about the child's epilepsy with others external to the nuclear family. Amichai-Hamburger & Furnham (2007) contend that the internet can serve as a particularly empowering environment for individuals with CSIs due to the anonymity such an approach offers, the control the internet user has over the interaction, and the ease with which one can find similar others. Online, people have a tendency to disclose more deeply intimate information to others (Amichai-Hamburger, McKenna & Tal, 2008). Thus, it is argued that gaining experience in disclosing one's CSI on the internet, particularly through participation in internet stigmatised-identity groups (e.g. online epilepsy forums), can: 1) lead to increased self-acceptance; 2) assist and encourage people's future face-to-face engagements with others about their CSI; 3) enhance their social support systems; and 4) improve their interpersonal relationships (Amichai-Hamburger & Furnham, 2007).

9.1.2 Disclosure Targets

To the author's knowledge, this is the first study to quantitatively assess the extent to which CWE and parents of CWE talked to specific others external to the nuclear family about the child's epilepsy. Indeed, prior to this study, evidence with regard to CWE's and parents' epilepsy disclosure targets was extremely limited. In this quantitative phase, CWE reported

conversing most with HCPs (i.e. doctors and nurses) about their epilepsy. In contrast, the disclosure targets to whom parents reported speaking to the greatest extent about their child's epilepsy were those to whom they relinquished responsibility in terms of caring for the child (i.e. childminders, nannies, au-pairs and teachers).

Child perspectives on disclosure targets indicate that CWE may have limited conversations about their epilepsy with others beyond environments in which such conversations were unavoidable and necessary. This finding provides support for one of the conclusions drawn based on the limited empirical evidence on CWE's epilepsy disclosure behaviours presented in the systematic review, i.e. that epilepsy disclosure is problematic for CWE and thus concealment or selective disclosure management strategies may be preferred by some CWE.

Parent perspectives from phase two with regard to disclosure targets suggest that the safety of the child may take greatest priority for parents in terms of epilepsy disclosure, with the 'duty of care' for their CWE conferred upon others in parents' absence likely underpinning parental decisions regarding disclosure targets. However, it is notable to mention that whilst parents cited childminders, nannies and au-pairs as the category of individuals to whom they spoke with to the greatest degree about their child's epilepsy, CWE perceived this category of adults to be among those adults least likely to be aware of their epilepsy. This discrepancy in perceptions could be explained by the fact that perhaps parents did not deem it necessary to share information with their CWE regarding their epilepsy disclosure exchanges with others and consequently CWE were unaware of who their parents had told about their epilepsy. Indeed, in a study examining parent-child epilepsy-related communication, O'Toole, Lambert, Gallagher, Shahwan & Austin (2016) identified that a number of parents of CWE found conversing with their CWE about epilepsy disclosure challenging. Such difficulties arose for parents due to the dilemma inherent in parents' consideration of whether to respect CWE's wishes for privacy (and consequently conceal or selectively disclose to others) or to assuage their own concerns over the child's safety and inform others who they perceived as needing to know about the child's epilepsy. From a theoretical perspective on disclosure, Petronio's CPM Theory (2002) posits that individuals perceive themselves as owning their private information and presume that co-owners (or shareholders) of this information will abide by the privacy management rules they employed to determine their privacy boundaries, with conflict occurring when such boundaries are violated. Thus, parents of CWE may have avoided telling CWE that they disclosed the child's epilepsy to childminders, nannies and au-pairs in an attempt to avoid conflict due to what may have been perceived by CWE as violations to privacy boundaries in accordance with the propositions underpinning Petronio's CPM theory (2002).

A key quantitative finding in terms of disclosure targets was that both CWE and parents reported speaking to a greater degree about the child's epilepsy to closer friends than to casual

friends and to females rather than males. These findings are consistent with Kleck (1968) who identified differences in adult epilepsy disclosure according to the discloser's perceptions regarding the closeness of their relationships with potential disclosure targets and potential disclosure targets' gender. It is intuitive that CWE and parents speak to a greater extent about the child's epilepsy to closer friends than to more casual acquaintances because close and established friendships probably provided them with reassurance, as well as the ability to better evaluate whether disclosure to such individuals would result in negative consequences (or not). The selection of female disclosure targets may arise from CWE's and parents' perceptions of the probability of receiving appropriate emotional support from such disclosure targets. Research literature in the area of friendship development, social support and communication has consistently reinforced typical gender stereotypes that, in their relationships with others, females are more likely than males to provide others with emotional support, exhibit greater emotional sensitivity, engage in comforting behaviour and adopt more nurturing roles (Barbee et al., 1993; Caldwell & Peplau, 1982; Kunkel & Burleson, 1999; MacGeorge, Gillihan, Samter & Clark, 2003; Whitty, 2002; Wright, 1989). The fact that CWE and parents potentially select disclosure targets based on their perceived capability of providing appropriate social support is important in considering that theoretical literature in the context of disclosure of CSIs suggests that social support is one of three distinct mediating processes in determining the individual, dyadic and social contextual outcomes of interpersonal disclosure exchanges (Chaudoir & Fisher, 2010).

9.1.3 Situational Context of Disclosure Exchanges

In relation to the situational context of epilepsy disclosure exchanges, for CWE, disclosure mainly occurred in the context of impending/recent hospital appointments or when the child was starting a new activity or sport. Parents reported that the main situational contexts under which they revealed their child's epilepsy to others comprised circumstances when others outside the immediate family unit were going to be responsible for the child or when the topic of epilepsy came up in conversation. Others asking questions represented a further key context under which disclosure exchanges with others unfolded, from both CWE and parent perspectives.

In the situational context of recent or impending hospital appointments, CWE may have been compelled to disclose their epilepsy condition to others because others may, for instance, have raised questions about why the child may have been absent from school; that is hospital appointments may have denoted a contextual cue of the medical condition that necessitated explanation. Additionally, in the situational context of a child starting a new activity or sport, it is possible that disclosure may have been required because, as previously mentioned, disclosure of medical conditions can be a legal requirement when registering children for extra-curricular activities or sports. The finding that parents most commonly reveal the child's epilepsy to others when others will be responsible for the child further resonates with the idea that parents' motivations for disclosure largely hinge upon their desire to ensure the safety of their child.

Further key contexts for epilepsy disclosure exchanges included others asking questions or raising the topic of epilepsy. Collectively, the aforementioned findings indicate that it may be that epilepsy disclosure exchanges are most likely to unfold for CWE or parents of CWE in situations where disclosure is somewhat required rather than in circumstances where they desire to spontaneously share information about the child's condition with others. Whilst CWE and their parents might endorse open disclosure policies, voluntary disclosure seems to be less common; that is, they may not consider it necessary to talk about epilepsy unless prompted or questioned by others at which point they are willing to talk about it.

Gaining insights into the situational contexts in which disclosure exchanges with others external to the nuclear family are likely to arise for families living with epilepsy is important in terms of enabling and preparing CWE and their parents to appropriately navigate disclosure in such contexts. To the author's knowledge, this is the first study to quantitatively assess the situational context of CWE's and parents' disclosure exchanges with others.

9.1.4 Content of Disclosure Exchanges

When asked about the content of their epilepsy disclosure exchanges with others, CWE mainly reported: 1) outlining how their seizures manifested; 2) describing epilepsy in general; and 3) discussing the impact of seizures. For parents, aspects relating to the child's epilepsy they most commonly reported discussing with others included: 1) seizure first aid protocols; 2) the child's specific seizure manifestations; 3) the child's type of epilepsy; and 4) the impact of seizures on the child.

The emphasis both CWE and parents placed on relaying information to others about the child's seizure manifestations, as well as their impact on the child, may be linked with ensuring that others would recognise seizure symptomatology if the child were to have a seizure in their presence. Furthermore, CWE and parents also referenced being likely to: 1) describe epilepsy to others (CWE perspective); and 2) specify the child's type of epilepsy (parent perspective). A lack of knowledge about epilepsy within a public forum often necessitates such descriptions and specifications as many members of the public would be unfamiliar with the condition, or more specifically its highly variable symptomatology and extensive consequences (Jacoby et al., 2004).

The finding that parents commonly raised the topic of seizure first aid protocols during their disclosure exchanges with others is consistent with incidental qualitative findings that emerged in two previous studies (Holdsworth & Whitmore, 1974; Roberts & Whiting, 2011), and again is indicative of the fact that ensuring the safety of the child was a primary motivator in informing parental disclosure decisions.

Seizure control was the topic CWE were least likely to discuss with others outside the immediate family unit; a novel finding of the present study. One potential explanation for CWE's avoidance of this topic when conversing with others about epilepsy relates to the unpredictable nature of the condition and consequently the uncertainty it evokes in CWE in terms of seizure control. It may be that CWE are reticent to discuss this topic with others because of their cognisance that there is always the potential for their circumstances to suddenly change with regard to seizure control.

The topic parents most commonly reported steering clear of when conversing with others external to the nuclear family about the child's epilepsy was the topic of medication side effects. Baker et al. (2008) highlighted that over half of a sample of 507 parents/caregivers of CWE worried about the short- and long-term side-effects of AEDs on a regular basis. Thus, it is possibly difficult for parents to discuss this topic with others because it involves one of the negative ramifications of their child's illness and thus can be an emotionally-charged issue.

9.1.5 The Rationale Underlying the Selection of Specific Disclosure Management Strategies

Amongst both CWE and parents, wishing for others to know about the potential risk of the child having seizures in their presence, and ensuring that others were capable of responding appropriately to seizures, were two of the most commonly reported reasons why they engaged in disclosure exchanges with others outside the immediate family unit. The former finding ties in with the concept of preventive disclosure, i.e. telling others about one's epilepsy diagnosis due to the anticipatory risk of detection (Tröster, 1997). However, both of the above findings again resonate with the concept of disclosure as: 1) most important in the context of the child's safety; and 2) a means to protect the child from harm. Furthermore, parents, in particular, commonly reported that they told others about the child's epilepsy in order to minimise the risk of others overreacting to seizure symptomatology. Parents may have perceived that others overreacting to seizures could have resulted in embarrassment and/or fear, amongst other negative consequences, for their child. Thus, ensuring that such a situation did not arise by preventively telling others would protect the child from such experiences. This finding corresponds with the literature, in that parents' protective instincts towards their CWE have been well-documented (Baker et al., 2008; Hanai, 1996; Jantzen et al., 2009; Kwong et al., 2000; Mu, 2008; Roberts & Whiting, 2011; Saburi, 2011).

In contrast, key reasons for epilepsy concealment amongst CWE centred around: 1) their fear of how others might respond; 2) worry regarding others imposing differential treatment; and 3) the condition (and disclosure of the condition) evoking feelings of sadness in the child. The former two findings have been implicated previously in the epilepsy disclosure process engaged in by CWE (Baker et al., 2008; Chen et al., 2010; Houston et al., 2000; Jantzen et al., 2009; Lewis et

al., 1990; McEwan et al., 2004; Moffat et al., 2009; Ronen et al., 1999). A compromised sense of normalcy has been identified as a major source of concern for CWE (Elliott et al., 2005; O'Toole, Lambert, Gallagher, Shahwan & Austin, 2016; Ronen et al., 1999). Thus, it follows that if CWE anticipate threats to normalcy as a consequence of epilepsy disclosure, they may opt against revealing their CSI to others. However, to the author's knowledge, the latter finding - which indicates that CWE's emotional response to their illness informs their epilepsy disclosure behaviours - is a unique finding of the present study.

For parents, key reasons for their endorsement of a strategy of concealment surrounding their child's epilepsy condition related to the misinformation and the misunderstanding that encircles the condition within the public domain. Epilepsy continues to be a poorly understood chronic neurological condition. Even amongst medical students misconceptions about epilepsy are common (Ahmed et al., 2015; Bigelow, Berrett, Kimuli & Katabira, 2015; Kartal, 2016). Thus, it is unsurprising that public perceptions of epilepsy are a cause for concern amongst parents of CWE and encourage their adoption of more closed communicative strategies surrounding the child's epilepsy. Furthermore, the invisibility of epilepsy both in terms of how it is not always physically apparent to others and the fact that it seldom receives attention in the public domain were additional factors underpinning the adoption of concealment strategies for many parents. CSIs differ to conspicuous stigmatized identities as they render the possessor of the socially devalued attribute and his/her family members capable of exerting control over when, or if, they reveal the CSI to others (Joachim & Acorn, 2000). However, those who adopt concealment strategies must contend with worry about the CSI being discovered (Quinn, 2006). The role that the culture of silence that encircles epilepsy in the public domain plays in informing parental disclosure decisions is a novel finding of the present study.

9.1.6 Enablers of and Barriers to Disclosure

When asked about the factors that enabled and/or acted as barriers to disclosure, CWE and parents varied in terms of the weight they placed on individual factors, and differed with regard to the specific factors that they perceived to enable and/or deter them from disclosing the child's epilepsy condition to others external to the nuclear family.

For CWE, epilepsy disclosure was encouraged by their hearing about public figures or famous people living with epilepsy and/or media coverage of epilepsy. These findings are unique in the context of childhood epilepsy disclosure but are unsurprising given: 1) the dominant role that the media plays in the lives of children/adolescents (Strasburger et al., 2013); and 2) the concept of celebrities as key influencers in modern day society (Briggs, Grella, Burton, Yarmuth & Taylor, 2012). However, epilepsy is often misrepresented in the media (Kobau & Price, 2003) and a large proportion of celebrities with recurrent seizures deny having epilepsy, despite abundant evidence suggesting the contrary (Krauss, Gondek, Krumholz, Paul & Shen, 2000).

Therefore, in order to create an environment that is facilitative of epilepsy disclosure for CWE, there is a need to: 1) increase accurate media coverage of epilepsy; and 2) identify and empower role models to speak openly and honestly about their experiences of living with epilepsy within a public forum. Indeed, in 2009, Greg Grunberg (an actor in the U.S.) set up a website entitled Talkaboutit.org in conjunction with the Epilepsy Foundation, wherein a number of celebrities have provided video messages that encourage people with epilepsy to speak up about their condition. However, although several celebrities on this website report that their children or relatives have epilepsy, to the author's knowledge, no celebrities who appear on the website have epilepsy themselves. Nonetheless, directing CWE to this platform could serve to encourage their epilepsy disclosure to others.

For parents, factors that reportedly enabled their epilepsy disclosure included the perceived mildness of their child's epilepsy and the fact that epilepsy is a medical condition. One potential explanation for the former finding is that more mild forms of epilepsy may be easier to minimise when explaining the child's epilepsy to others, consequently making it more probable that others would respond positively. The latter finding might be explained by parental perceptions that medical conditions are more accepted and better understood within the public domain than, for instance, psychological or behavioural conditions; a perspective relayed by parents who participated in phase one of the study.

Both CWE and parents of CWE indicated that their level of knowledge on the topic of epilepsy served to enable their epilepsy disclosure to others. Thus, equipping CWE and their parents with accessible information about the child's complex neurological disease could promote epilepsy disclosure amongst those families who feel less secure with the level of epilepsy-related information they possess.

In contrast, for CWE, key barriers to epilepsy disclosure were inclusive of its emotional implications, as well as their internalised feelings towards the condition, fear of how others might treat them and others' level of understanding about epilepsy. For parents, the main barriers to epilepsy disclosure identified in phase two included fear of how others might subsequently treat or view their CWE, public perceptions and public understanding of epilepsy, and the child's desire (or lack thereof) for others to know about their epilepsy condition.

For both CWE and parents, their perceptions of how others might treat or view the child as denoting a barrier to epilepsy disclosure was a finding that aligned with findings revealed in prior literature in the context of paediatric epilepsy (Baker et al., 2008; Chen et al., 2010; Hanai, 1996; Houston et al., 2000; Jantzen et al., 2009; Kwong et al., 2000; Lewis et al., 1990; McEwan et al., 2004; Moffat et al., 2009; Mu, 2008; Roberts & Whiting, 2011; Ronen et al., 1999; Saburi, 2011). Furthermore, public understanding of epilepsy represented a key barrier to disclosure for both CWE and parents of CWE. In addition, for parents specifically, public

perceptions of epilepsy signified a barrier to epilepsy disclosure. Insufficient public knowledge and poor public perceptions of epilepsy are well-documented findings of research in both the developed and developing countries (Austin et al., 2002; Daoud, Al-Safi, Otoom, Wahba & Alkofahi, 2007; Deresse & Shaweno, 2016; England, Liverman, Schultz & Strawbridge, 2012; Kobau & Price, 2003; Ramasundrum, Mohd Hussin & Tan, 2000). Thus, considered together, these findings would indicate that in order to foster an environment in which epilepsy disclosure does not pose challenges for CWE and their parents, there is a need to enhance public knowledge of epilepsy; and furthermore to tackle persistent misconceptions about the condition in the public domain.

The emotional consequences of epilepsy constitute a significant burden in the lives of CWE (Davies, Heyman & Goodman, 2003), with such consequences also representing a barrier to disclosure for CWE – a novel finding of the present study. Yet, often the emotional consequences of epilepsy are overlooked or neglected during consultations with HCPs (Lewis, Noyes & Mackereth, 2010). The findings from this quantitative phase suggest that future research should focus on how best to alleviate the challenge to disclosure, and indeed the barriers to more positive adjustment to the illness, represented by: 1) CWE's feelings towards the condition; and 2) epilepsy's impact on CWE's emotional wellbeing.

Finally, a further factor of note that posed a specific challenge for parents in disclosing their child's epilepsy condition to others outside the immediate family unit related to the child's lack of desire for others to know about his/her epilepsy. This finding is particularly interesting given that this factor was one of the least commonly reported reasons for parental concealment. Taken together, these findings suggest an interesting dichotomy and indicate that when parents are engaged in the disclosure decision-making process, they may grapple with determining whether the child's safety or their child's desire for privacy should take priority. Petronio's CPM theory (2002) postulates that turmoil can be caused when co-owners or shareholders of private information (i.e. parents of CWE) violate the privacy boundaries determined by the owners of the private information (i.e. CWE). Ultimately, however, it would seem that for parents of CWE in the present study, ensuring the child's safety superseded the difficulty that denying their child's wish for privacy presented. Thus, in the context of childhood epilepsy it may be that parents: 1) perform internal risk-benefit ratio analyses when deciding whether to disclose their child's epilepsy condition to others (Greene, Derlega, Yep & Petronio, 2003; Petronio, 2002); and 2) come to conclude that they are willing to accept turbulence (i.e. challenges) caused by violations to the privacy management boundaries enforced by their CWE if it means that the child is protected from harm.

9.1.7 Emotional Components of Disclosure

Amongst those CWE and parents who disclose the child's epilepsy to others external to the nuclear family, prior to disclosure, both positive (e.g. optimism, confidence) and negative emotions (e.g. fear, uncertainty, anxiety, worry, shame, differentness, pessimism and discomfort) are experienced. Whilst positive emotions were more commonly reported by both CWE and parents, approximately 33-50% of both populations cited experiencing at least some negative feelings prior to disclosure, suggestive of the fact that disclosure represents a challenge for such individuals; thus, further substantiating the findings from phase one. Furthermore, a greater proportion of parents experienced positive emotions prior to disclosure than CWE. This may be as a result of CWE being in possession of the CSI, and as such their cognisance that they were consequently more at risk than their parents of experiencing stigmatising, prejudicial and discriminative responses immediately subsequent to disclosure exchanges with others. Indeed, the feelings of differentness and embarrassment/shame reported by CWE indicate that they themselves may have internalised negative attitudes towards their illness, and thus likely anticipated reactions in line with their own perceptions towards epilepsy from others.

Unsurprisingly, CWE's and parents' emotional responses subsequent to disclosure exchanges with others external to the nuclear family were dictated by the manner in which others reacted. When others reacted positively, CWE and their parents reported feeling relieved, happy and reassured. Relief as a common emotional response to others reacting positively suggests that CWE and parents potentially anticipated that others might not have responded in this manner. In line with previous research examining the disclosure patterns of populations with other CSIs, it also indicates that attempting to keep a CSI hidden has the potential to be psychologically taxing and can take an emotional toll on the individual with the CSI and his/her family members (Beals, Peplau & Gable, 2009; Critcher & Ferguson, 2014; Goffman, 1963; Smart & Wegner, 1999). Thus, disclosure may result in eliciting feelings of relief in CWE and their parents through the alleviation of inhibition mechanism (Chaudoir & Fisher, 2010; Chaudoir et al., 2011) which posits that expressing pent up thoughts and emotions with regard to a CSI can serve as disinhibiting. This mechanism is argued to be one of three distinct processes that mediates the numerous individual, dyadic and social contextual outcomes associated with disclosing a CSI to others in accordance with Chaudoir & Fisher's DPM (2010).

In contrast to circumstances when others reacted in a positive manner, in situations when others reacted poorly, this evoked feelings of embarrassment/shame, worry, sadness and differentness in CWE; and frustration, upset, anger and worry in parents of CWE. Interestingly, of those CWE and parents of CWE who had encountered negative reactions to their disclosures, approximately 15-30% reported not having experienced any negative feelings, which could be suggestive of one of two things. First, these questions may have failed by omission to capture pertinent emotional responses, i.e. it may have been that the negative emotions assessed were

not holistically representative of those CWE and parents experienced. However, the questionnaire was developed based on the experiences of CWE and parents of CWE, directly utilising the language employed by CWE and parents, who participated in the first phase of the study which should have enhanced the questionnaire's applicability and validity. The alternative explanation is that perhaps these CWE and parents of CWE genuinely did not experience negative emotional responses when others reacted poorly to disclosure, either because they were indifferent to others' reactions or because they had predicted others' negative reactions and consequently had emotionally prepared themselves for same.

Although incidental qualitative findings from previous research revealed that fear, apprehension and anxiety are emotions associated with epilepsy disclosure in the context of childhood epilepsy (Chen et al., 2010; Eklund & Sivberg 2003; Jantzen et al., 2009; Wilde & Haslam, 1996), to the author's knowledge, the emotional components of epilepsy disclosure for CWE and parents had not been specifically evaluated to any great extent. Therefore, this is the first study to quantitatively explicate the emotions associated with child and parental epilepsy disclosure.

9.1.8 Consequences of Epilepsy Disclosure Exchanges with Others

Child and parent data pertaining to the consequences of epilepsy disclosure exchanges with others external to the nuclear family revealed a number of findings that were particularly noteworthy. First, approximately 40% of CWE and parents reported that others experienced difficulties in terms of understanding the complex neurological condition. Additionally, upwards of 80% of CWE and parents of CWE highlighted that others responded to their epilepsy disclosure by asking questions. These types of response may have represented particular challenges for CWE because as identified in phase one, CWE struggle in terms of verbally representing the condition to others. Furthermore, some CWE may have perceived others' questioning them as a common response to disclosure as calling into question the legitimacy of their invisible illness. Previous research has shown that the lack of visible evidence of chronic invisible illnesses often threatens the credibility of illness disclosures and sometimes requires individuals with invisible illnesses to defend their status as ill individuals (Moore, 2013; Moss & Dyck, 2002). These findings, although unsurprising considering the fact that public knowledge of epilepsy is lacking (as previously discussed in section 9.1.6), highlight the need for more effective public education campaigns surrounding epilepsy. In enhancing public knowledge and understanding of epilepsy, it would be hoped that the epilepsy disclosure process would be made easier for CWE and parents of CWE, with less individuals consequently: 1) questioning them; and 2) grappling with comprehending epilepsy.

Second, both CWE and parents who had prior experiences of disclosing the child's epilepsy to others identified that others largely (>80%) responded positively or kindly and provided them

with reassurance. Less than 15% of parents reported that others responded in a negative manner, whilst no CWE reported that others were mean about it. Furthermore, only 15.9% of CWE perceived having been treated differently by others subsequent to disclosure exchanges. Interestingly, 29.6% of parents perceived that disclosure had resulted in their child being treated differently, a much higher figure than CWE's own perceptions of same. Taken together, these findings suggest that whilst there are some risks inherent in disclosing the child's epilepsy to others due to the potential for others to respond negatively, as a general rule, others tended to respond positively rather than negatively to epilepsy disclosure. This finding is particularly salient in light of the fact that the findings of the present study revealed that fear of others' reactions serves as a reason for concealment, as well as a barrier to disclosure in both child and parent populations. Considering the collective implications of these findings, the assertion underlying the hidden distress model (Scambler, 1989) - that felt stigma and the anticipation of enacted stigma are more disruptive in the lives PWE than enacted stigma – is supported. Indeed, to the author's knowledge, this is the first study to find support for this proposition of the hidden distress model in the context of paediatric epilepsy. Furthermore, the findings reinforce the position of Jacoby & Austin (2007) who contend that by concealing one's epilepsy from others for fear of experiencing stigmatising responses, one is perpetuating a self-fulfilling prophecy by not testing whether such responses actually materialise.

9.2 How Epilepsy Disclosure Relates to Demographic and Clinical Characteristics, Psychosocial and Illness Attitude Variables

In this section, the relationships between CWE's epilepsy disclosure and child-reported demographic and clinical characteristics (9.2.1), and child and parent-reported psychosocial and illness attitude variables (9.2.2) will be considered. Subsequently, the associations between parental epilepsy disclosure and parent-reported demographic and clinical characteristics (9.2.3), and parent- and child-reported psychosocial and illness attitude variables (9.2.4) will be critically explored.

9.2.1 CWE's Epilepsy Disclosure as it Relates to Demographic and Clinical Characteristics

Epilepsy disclosure amongst CWE (as captured by their scores on the EDS-Y) was not found to significantly relate to any of their self-reported demographic variables. However, significant relationships were observed between CWE's epilepsy disclosure and their self-reported seizure characteristics. In particular, CWE with either complex partial or tonic seizure types endorsed higher levels of epilepsy concealment than CWE without those seizure types. Manifestations of complex partial seizures are often misconstrued (Butler & Zeman, 2005; Restak, 1995). Indeed, according to the Epilepsy Foundation of Victoria (n.d.), members of the general public often

mistake symptoms of complex partial seizures for drug/alcohol-related behaviour or psychiatric symptoms. Consequently, CWE with this specific seizure type may be reluctant to disclose their epilepsy to others due to the fact that this type of epilepsy is poorly understood by others. Furthermore, manifestations of such seizures can comprise bizarre behaviours such as undressing, lip smacking, fumbling, crying, laughing, screaming or repetitive motor movements etc. and consequently can be embarrassing (Schachter, 2009; Sirven & Devinsky, 2013). Thus, CWE may opt against sharing such information with others as a consequence of internalised feelings of shame and embarrassment. With regard to tonic seizures, one potential reason why the association between this seizure type and greater epilepsy concealment by CWE exists, is that such seizures are atypical, can be unpleasant to witness (the child's muscles contract forcefully, consciousness is usually preserved, he/she may briefly stop breathing and consequently become quite distressed) and as a result individuals with this seizure type may wish to keep this information to themselves. Additionally, such seizures largely occur during sleep or immediately subsequent to waking from sleep and thus have the potential to be kept hidden from others. To the authors' knowledge, this is the first study to elucidate the relationship between CWE's epilepsy concealment and their specific seizure types.

CWE's epilepsy disclosure was also related to their age at diagnosis and the amount of time that had lapsed since their diagnosis. Specifically, CWE who reported a younger age at diagnosis and a longer duration of time since diagnosis reported greater epilepsy concealment. It is possible that CWE who received their diagnosis at a young age did not disclose the condition to others from the outset as they were too young to comprehend and verbally represent their condition to others at the time of diagnosis and consequently this pattern of non-disclosure continued on as they progressed through childhood and adolescence. Alternatively, it may be that CWE came to learn that concealing their epilepsy from others was preferable as time progressed, either as a consequence of poor outcomes to prior disclosures or through others (e.g. parents, peers, teachers etc.) coaching them (advertently or inadvertently) to internalise negative attitudes towards the illness. Indeed, younger age at onset of epilepsy and longer duration of epilepsy are both variables that have also been found to be associated with greater epilepsy-related stigma perceptions amongst child, adolescent and adult populations (Austin et al., 2004; Lee, Yoo, Lee & Korean QoL in Epilepsy Group, 2005; Westbrook et al., 1992). Thus, the findings in the present study further reinforce the notion that diagnosis concealment represents an implicit expression of epilepsy-related stigma.

9.2.2 CWE's Epilepsy Disclosure as it Relates to Child-reported and Parent-reported Psychosocial and Illness Attitude Variables

Increased epilepsy concealment was significantly related to CWE's: 1) stigma perceptions; and 2) attitudes towards their illness. These findings add further support to prior literature investigating the disclosure patterns of populations with other CSIs, including populations with

HIV or mental illness, populations of parents of children conceived through donor insemination and attendees of infertility clinics (Bos et al., 2009; Clark, Lindner, Armistead & Austin, 2004; Nachtigall, Tschann, Quiroga, Pitcher & Becker, 1997; Slade, O'Neill, Simpson & Lashen, 2007; Smith, Rossetto & Peterson, 2008). Furthermore, the former finding corroborates the findings of a recent study with adults with epilepsy, whereby a significant relationship between epilepsy concealment and felt-stigma was reported (Aydemir, Kaya, Yıldız, Öztura & Baklan, 2016). However, to the author's knowledge, this is the first study to quantitatively examine and explicate the relationship between CWE's epilepsy disclosure and their stigma perceptions. Furthermore, the present study provides the first empirical, quantitative evidence of a relationship between CWE's illness attitudes and their epilepsy disclosure. Collectively, the two aforementioned relationships indicate that CWE who have internalised more negative attitudes towards their illness and anticipate greater stigma on disclosing the CSI to others will conceal their epilepsy to a greater degree. As posited by Jacoby & Austin (2007), in concealing one's epilepsy, one is denied the opportunity to test whether the stigma one anticipates will in fact materialise and consequently it is likely that such perceptions will persist. This self-fulfilling prophecy warrants further investigation because, particularly in light of the fact that negative consequences of disclosure exchanges with others were uncommonly reported by CWE in phase two, it may be that enabling and empowering CWE to effectively relay information about their epilepsy to others external to the nuclear family could provide an avenue towards reducing internalised stigma perceptions and breaking the *cycle of invisibility* that encircles epilepsy (Lewis & Parsons, 2008).

With regard to CWE's self-perceptions, it had been posited that CWE's scores across all domains of the SPPC would negatively correlate with their scores on the EDS-Y. However, this was only the case for CWE's self-perceptions regarding their behavioural conduct, with more positive self-perceptions amongst CWE in this domain identified as being significantly related to more open epilepsy disclosure. One potential explanation for this relationship is that CWE who conceal their epilepsy from others may consider this an act of misbehaviour, particularly in reference to concealing the condition from adult figures in their lives (e.g. teachers or caregivers) contrary to their parents' wish. Consequently, those who are more open and honest with others about their epilepsy may be unburdened by such feelings. Alternatively, behaviour problems are common in the context of paediatric epilepsy (Austin et al., 2001; Dunn, Harzelak, Ambrosius, Austin & Hale, 2002; Rodenburg, Stams, Meijer, Aldenkamp & Deković, 2005). Thus, it may be that CWE who experience either seizure manifestations that comprise a behavioural component (e.g. complex partial seizures) or behavioural issues as a direct consequence of their epilepsy (or their AED regime) are more prone to concealing the diagnosis from others due to heightened feelings of embarrassment or shame associated with their self-perceived poorer behavioural conduct. One relationship of particular note that yielded a finding

contradictory to what was hypothesised was the relationship between CWE's epilepsy disclosure and their self-perceptions in terms of their athletic competence. CWE's scores on the Athletic Competence subscale of the SPPC positively correlated with their scores on the EDS-Y, indicating that CWE who perceived themselves as being more athletically competent were more likely to conceal their epilepsy from others external to the nuclear family. One potential explanation for this unexpected relationship is that epilepsy concealment is more preferable amongst more athletically competent youths because disclosure has the potential to result in different treatment, with others thinking less of the child's capabilities, and may for instance affect their likelihood of being selected on sports teams by sports coaches. This resonates with the findings from the qualitative phase where similar concerns were expressed by both CWE and their parents in terms of the implications of epilepsy revelations in the context of sporting activities.

As hypothesised, greater epilepsy concealment by CWE was associated with CWE reporting poorer HRQoL in the domains of interpersonal/social consequences, intrapersonal/emotional issues and epilepsy: my secret, and overall, indicative of the fact that epilepsy concealment is related to poorer psychosocial outcomes in CWE. Interestingly however, whilst disclosure of their CSI has been repeatedly identified as a QOL issue for CWE (Hanai, 1996; Hoare et al., 2000; Hoare and Russell, 1995; McEwan et al., 2004; Moffat et al., 2009; Ronen et al., 1999; Zamani et al., 2014) and indeed a number of QOL measures employed for use in paediatric epilepsy populations incorporate items that capture epilepsy disclosure (e.g. the CHEQOL-25 [Ronen et al., 2003] and the Quality of Life Measure for Children with Epilepsy [Sabaz et al., 2000]), to the author's knowledge, this is the first study to explicate the relationship between CWE's epilepsy disclosure and their HRQoL.

More open disclosure behaviours in CWE were significantly correlated with increased levels of parent-child epilepsy-related communication in the context of the family home. This finding suggests that more open epilepsy-related discussions between CWE and parents promote and enable CWE's epilepsy disclosure to others external to the nuclear family. Conversely, the adoption of more closed communicative strategies by parents surrounding the child's epilepsy within the home environment has the potential to convey the message to the child that a similarly silent approach should be adopted in terms of their communicative patterns with others outside the immediate family unit. This further substantiates the concept of parents as potential stigma-coaches in the lives of CWE (Jacoby & Austin, 2007). Based on this evidence, it would seem imperative to examine how CWE and their parents interact about the child's epilepsy diagnosis within the context of the family home. A recently conducted systematic review suggests that empirical evidence in this regard is lacking (O'Toole et al., 2015)

Considering the relationships between CWE's epilepsy disclosure behaviours and parent-reported variables as examined via dyadic data, significant correlations were identified between CWE's EDS-Y scores and their parents': 1) EDS-Y scores; 2) stigma scores and; 3) overall response to their child's illness scores. Collectively, the findings indicated that when parents concealed the child's epilepsy to a greater degree, endorsed less positive attitudes towards the child's illness and/or had adjusted and responded to their child's illness less positively, this seemed to relay the message to their CWE that their epilepsy was something that should not be spoken about with others. This provides further important empirical support for the role parents play in either advertently or inadvertently stigma coaching CWE (Kleck, 1968; Jacoby & Austin, 2007).

Finally, greater epilepsy concealment amongst CWE was also associated with their parents: 1) perceiving less social support from family and overall; 2) requiring greater epilepsy-related support; 3) perceiving the epilepsy as having a greater impact on the child and family; 4) citing engaging in less leisure activities as a family due to the child's epilepsy; and 5) affording CWE with less autonomy as a consequence of the epilepsy.

The two former findings indicate that CWE of parents who felt unsupported contended with greater issues surrounding epilepsy disclosure, adopting more restrictive disclosure management strategies. One potential explanation for this is that parents of such CWE, due to their own support needs being unmet, may have been incapable of assisting their CWE to negotiate the disclosure process. Thus, striving to enhance the support networks of parents following receipt of their child's epilepsy diagnosis could benefit not only parents of CWE, but also their CWE. If parents feel more supported, they may be in a better position to encourage their CWE's positive adjustment to their illness, as well as their disclosure of the condition to others external to the nuclear family.

When considered concurrently, the three latter findings suggest that where epilepsy had a greater impact on the child and family and resulted in negative ramifications for the child due to restrictions imposed either by parents or others, concealment or selective disclosure management strategies were preferred by CWE. It is likely that CWE for whom the condition had a greater impact were more reluctant to disclose the condition to others external to the nuclear family because, in line with the findings from phase one, they wished to avoid the imposition of epilepsy-related restrictions by others. Poorer health outcomes amongst CWE may have been implicated in negatively affecting aspects of the child's and family's everyday life and necessitating greater restrictions. Interestingly, however, correlational and group difference analyses performed to examine the relationship between CWE's epilepsy disclosure and health outcome variables (e.g. seizure frequency and seizure severity) did not yield any findings of statistical significance. Thus, there is also the possibility that epilepsy concealment

may have been perceived as particularly desirable amongst CWE who felt that negative consequences of the condition (i.e. decreased independence and less familial engagement in activities) were caused by parental or others' hypervigilance (i.e. an excessively heightened sense of monitoring, vigilance and protectiveness) as opposed to being consequences that were warranted. Parental hypervigilance is well-documented in paediatric epilepsy literature and has been associated with increased behavioural and emotional problems in CWE (Aytch, Hammond & White, 2001; Carlton-Ford, Miller, Nealeigh & Sanchez, 1997; Iseri et al., 2006; O'Toole et al., 2016).

9.2.3 Parental Epilepsy Disclosure as it Relates to Demographic Variables and Parent-reported Clinical Characteristics of the Child

Parents' epilepsy disclosure behaviours did not significantly relate to their self-reported demographic variables. Although Ryu et al. (2015) identified a weak but significant correlation between maternal concealment of an adolescent's epilepsy and mothers' increased age, in their study age was captured as a continuous variable whereas in the present study, age was captured as a categorical variable. This may have obscured age perspective differences in the present study. However, there is also some evidence to indicate that a U-shaped distribution exists, whereby the highest proportions of misinformation about epilepsy and negative attitudes towards epilepsy are possessed by those at the extremes of age (i.e. the very young and the elderly) (Jacoby et al., 2004; Spatt et al., 2005). Thus, it may be that amongst parents in the present study, there genuinely were no differences in their epilepsy disclosure behaviours according to age because the sample did not include individuals at the extremes of age (i.e. 93.1% of parent participants specified being 26-55 years).

With regard to the relationship between parental epilepsy disclosure and parent-reported clinical characteristics of their CWE, parents of CWE with complex partial seizure types endorsed significantly higher levels of epilepsy concealment than parents of CWE without this seizure type, likely for similar reasons as those outlined in section 9.2.1 (where similar findings were observed for CWE). No significant associations were observed between parents' EDS-P scores and any other demographic and clinical characteristics they reported for their CWE.

9.2.4 Parental Epilepsy Disclosure as it Relates to Parent-reported and Child-reported Psychosocial and Illness Attitude Variables

Greater perceived stigma amongst parents was significantly correlated with increased parental epilepsy concealment, replicating the findings of the Ryu et al. (2015) study. This finding provides further support for the concept of concealment as a form of stigma management in the context of CSIs. In addition, higher levels of parental epilepsy concealment were associated with poorer parental adjustment to the child's condition. That is, parents who endorsed greater epilepsy concealment had responded less positively to the child's illness overall, perceived

themselves as being less capable of emotionally supporting the child, restricted familial participation in activities to a greater degree due to the child's epilepsy, felt less competent in their ability to cope with the child's condition and viewed themselves as being less capable of managing the child's behaviour. The explication of this relationship between parents' epilepsy disclosure and their response to their child's illness is a unique finding of this thesis.

Greater parental epilepsy disclosure was associated with parents perceiving higher levels of social support from family and friends. Disease disclosure has been found to be associated with higher levels of social support in individuals with cystic fibrosis (Borschuk et al., 2016). However, to the author's knowledge this is the first study to identify a relationship between parents' perceived social support and their disclosure of their child's epilepsy to others external to the nuclear family. It is unclear whether this relationship was a consequence of either: (a) parents feeling comfortable to disclose the child's epilepsy to others outside the immediate family unit because they perceived high levels of social support from the outset; or (b) parents perceiving high levels of social support due to epilepsy disclosure exchanges yielding supportive reactions from others. A study employing a longitudinal design would be best placed to ascertain which of the two aforementioned explanations applies. Many contend that in populations with CSIs social support mediates the association between disclosure and well-being (Beals et al., 2009; Chaudoir & Fisher, 2010; Stutterheim et al., 2011; Weisz, Quinn & Williams, 2015). The correlational nature of the data analysis did not lend itself to assessing whether this finding was replicated in parents of CWE.

Increased parental epilepsy concealment was related to decreased levels of parent-reported parent-child epilepsy-related communication in the context of the family home. This finding suggests that where a culture of silence prevails in the home surrounding the child's epilepsy, this silence is likely to also extend beyond the home to interactions with others outside the immediate family unit. To the author's knowledge this is the first study to consider the relationship between parents' communicative patterns surrounding their child's epilepsy internal and external to the context of the family home.

With regard to the relationships identified between parental epilepsy disclosure behaviours and child-reported variables, the endorsement of greater epilepsy concealment by parents was associated with their CWE also adopting more restrictive disclosure management strategies surrounding epilepsy; a finding which provided support for the concept of parental stigma coaching. However, whilst one might anecdotally assume that it is only CWE who take cues from their parents in terms of communicative patterns surrounding epilepsy, it is also possible that a bidirectional relationship exists between child and parental epilepsy disclosure behaviours, whereby in actual fact both CWE and parents mutually engage in a process of taking cues from each other in deciding whether to disclose the child's epilepsy condition to

others outside the immediate family unit (or not). Thus, it is not implausible to suggest that CWE may also play a role in informing parental disclosure decisions. In fact, as previously discussed, a child's lack of desire for others to know about his/her epilepsy was one of the factors identified by parents as presenting the greatest challenges to their epilepsy disclosure. Collectively, the aforementioned findings may denote support for elements of the CPM theory (Petronio, 2002) which propose that: 1) privacy boundary rules (i.e. rules about the flow of private information to others) are co-ordinated by co-owners/shareholders of information regarding an individual's CSI (i.e. CWE and their parents) in order to ensure that private information is co-managed in a manner deemed appropriate to the individual with the CSI (i.e. the CWE); and 2) turbulence exists when privacy boundary rules are violated (i.e. when parents tell other about the CWE's epilepsy against their child's will) or the rules of privacy co-ordination are unclear to co-owners or shareholders of the private information (i.e. when parents are unclear about whether their CWE would be accepting of them telling others external to the nuclear family about the child's epilepsy condition).

A further dyadic finding indicated that greater parental concealment of the child's epilepsy condition was significantly related to CWE reporting poorer HRQoL in the domain of Worries and Concerns. This finding indicates that where epilepsy concealment was endorsed by parents, CWE grappled to a greater degree with ruminating about the condition, its impact, its potential consequences and their parents' epilepsy-related concerns about them. This might have occurred because parents' lack of openness with others surrounding the condition may have inadvertently relayed the message to CWE that they could not approach them with their worries and concerns about their epilepsy, and furthermore that these issues should not be discussed with others external to the nuclear family. In such circumstances, CWE may have perceived themselves as having had no outlet via which to assuage their epilepsy-related worries and concerns, and consequently experienced poorer HRQoL.

9.3 The Newly Developed Epilepsy Disclosure Scale (EDS) – Youth and Parent Versions

One of the objectives of this second phase of the study was to design and psychometrically evaluate two new instruments that assess CWE's and parents' epilepsy disclosure behaviours. Prior to this study there was a lack of empirically supported measures that captured this complex construct (i.e. epilepsy disclosure) despite its identification as a salient HRQoL issue, a source of concern and a parental stressor (Baker et al., 2008; Chen et al., 2010; Coulter & Koester, 1985; Hoare et al., 2000; Hoare & Russell, 1995; Houston et al., 2000; Jantzen et al., 2009; McEwan et al., 2004; Moffat et al., 2009; Roberts & Whiting, 2011; Ronen et al., 1999; Saburi, 2011; Zamani et al., 2014). Results regarding psychometric evaluation of the newly developed scales indicated that both the youth and parent versions of the instruments were

unidimensional scales that demonstrated high internal consistency and reliability, and had satisfactory content and construct validity. Furthermore, empirical support for a number of hypothesised relationships between epilepsy disclosure and key child and parent psychosocial and illness attitude variables also provided evidence for the convergent validity of both versions of the scale. For instance, the expected positive correlations between child and parent epilepsy concealment and elevated stigma perceptions amongst child and parent populations, respectively, were supported. Additionally, hypothesised associations between CWE's greater epilepsy concealment and poorer HRQoL, more negative attitudes towards their illness and lesser epilepsy-related communication with their parents were empirically supported. The former finding validates findings that thus far have largely only emerged in qualitative research in the context of paediatric epilepsy, with epilepsy disclosure theoretically posited as a salient HRQoL issue for CWE in a number of studies (Chen et al., 2010; Hoare et al., 2000; Hoare & Russell, 1995; Houston et al., 2000; McEwan et al., 2004; Moffat et al., 2009; Ronen et al., 1999; Zamani et al., 2014). In addition, empirical support was yielded for the predicted associations between more open parental disclosure of the child's epilepsy and more positive parental responses to the child's illness, parents perceiving higher levels of social support and a greater degree of parental engagement in epilepsy-related communication with their CWE.

From a research perspective, the youth and parent versions of the EDS should be useful in helping researchers to profile the epilepsy disclosure behaviours of CWE and their parents. In addition, these scales could prove beneficial as we endeavour to better explicate the relationship between child and parent disclosure behaviours and their stigma perceptions and illness attitudes, as well as their psychosocial adjustment to the condition. Furthermore, the EDS could be adapted for use to test the disclosure behaviours of populations with other CSIs such as populations living with HIV/AIDS or mental illness, or homosexual populations.

From a clinical standpoint, both youth and parent versions of the EDS developed in the present study could prove useful in clinical practice. The scales are brief and easy to administer in hard copy format or online. Furthermore, scoring the scales is uncomplicated. Neither CWE nor parents experienced problems in comprehending the items or in selecting responses on the rating scale that appropriately represented their views. Obtaining knowledge about the disclosure behaviours of CWE and their parents is important clinically as such knowledge can assist HCPs in establishing whether disclosure is problematic for CWE and their parents. The associations between CWE's and parents' epilepsy disclosure behaviours, and HRQoL and parental responses to the child's illness, respectively, also indicate that addressing the challenges CWE and parents experience with regard to disclosure and assisting them in navigating the disclosure process has the potential to improve child and parental psychosocial adjustment to a child's epilepsy diagnosis. Thus, utilising these brief scales to gain insight into the disclosure behaviours of CWE and their parents, HCPs could: 1) develop interventions to

improve the psychosocial wellbeing of CWE and their parents; and 2) identify avenues towards reducing epilepsy-related stigma perceptions and breaking the *cycle of invisibility* that currently encircles the condition. Finally, the scales may be beneficial clinically in assisting HCPs to individualise and tailor the care and support they provide to patients according to their specific needs.

9.4 Strengths and Limitations of Phase Two

The primary strength of the second phase of this study is the fact that it represents the first in-depth quantitative investigation into various aspects and elements of CWE's and parents' epilepsy disclosure. In particular, CWE's and parents' epilepsy disclosure behaviours, the extent to which they converse with specific categories of disclosure targets about the child's epilepsy, the content and situational context of their epilepsy disclosure exchanges with others, the rationale underlying their selection of specific disclosure management strategies, perceived enablers of and barriers to disclosure, the emotional components of their epilepsy disclosure and the consequences of their epilepsy disclosure exchanges with others, were all explicitly quantitatively assessed for the first time. Providing those working with families living with epilepsy (e.g. HCPs and support organisation personnel) with insight into key contextual and situational factors implicated in the disclosure process engaged in by CWE and parents of CWE could prove particularly valuable as they assist families living with epilepsy to navigate through this complex process. Furthermore, the second phase of this study addresses a gap in health care communication research in the field of childhood epilepsy by quantitatively assessing the associations between child and parental epilepsy disclosure behaviours and demographic, clinical, psychosocial and illness attitude variables. In particular, the findings highlight important associations between CWE's and parents' epilepsy disclosure behaviours and complex partial seizure types, perceived stigmatisation, HRQoL, illness attitudes, response to the illness, social support and parent/child epilepsy-related dialogue within the family unit. The assessment of dyadic perspectives also denotes a strength of the quantitative phase of this study. Gaining an understanding of how child and parental epilepsy disclosure behaviours influence each other, and indeed the psychosocial wellbeing of parents and CWE respectively, is crucial in terms of fully explicating the complex epilepsy disclosure process undertaken by CWE and their parents, as well as the outcomes of their adoption of specific disclosure management strategies. Finally, in the absence of any pre-existing psychometrically sound measures, it was necessary to develop a new measure that could quantitatively assess the epilepsy disclosure behaviours of CWE and parents of CWE. Initial psychometric evaluation of the newly developed Epilepsy Disclosure Scale (youth and parent versions) yielded promising findings. However, further work is warranted in terms of psychometrically testing this scale. Neither the test-retest reliability nor the discriminant or predictive validity of the scale was examined in the

present study. In addition, item analysis was not performed. Future research should endeavour to assess these aforementioned psychometric parameters of the scale, and further evaluate the reliability of the scale, as well as its construct and convergent validity with larger sample sizes. Furthermore, future studies should: 1) assess the applicability of the newly developed EDS (youth and parent versions) within other cultures and ethnicities; and 2) explore whether cultural factors or ethnicity influence epilepsy disclosure behaviours and/or the relationship between epilepsy disclosure behaviours and demographic, clinical, psychosocial and illness attitude variables.

Whilst a number of strengths existed, as with all studies, there were also a number of notable limitations inherent in the quantitative phase of the present study. One limitation was the potential existence of a self-selection bias in sampling. This is particularly salient in light of the opt-in recruitment procedure employed in this second phase, which (in most instances) involved participants having no direct contact with the researcher. As a consequence of this sampling procedure, it is probable that those participants who opted to partake in the study were those who were more likely to be open with others about the child's epilepsy condition than those who were reluctant to discuss the child's epilepsy with others external to the nuclear family.

The poor response rates for survey completion were a further limitation of this second quantitative phase of this two-phased mixed methods study, particularly with reference to the CWE population. In spite of the fact that 165 survey packs were distributed to families living with epilepsy, and notwithstanding the implementation of a number of initiatives to optimise response rates (e.g. the utilisation of a dual recruitment pathway, the provision of an option for CWE and their parents to complete the surveys in hard copy format or online, and the distribution of two follow-up thank you letters and reminders to families at one and two month intervals subsequent to the initial mail out of the survey packs), only 47 CWE and 72 parents of CWE were recruited. Some aspects that may have contributed to the poor response rates included: 1) the extensive nature of the survey questionnaires and consequently the lengthy survey completion times; 2) the specificity of the eligibility criteria; 3) the fact that CWE may not have been informed about the study by their parents as parents were not under any obligation to share the survey pack with their CWE; and 4) other competing demands, such as children's schooling or involvement in extra-curricular activities and sports, taking precedent over the completion of surveys. Future research exploring ways to contravene challenges to achieving optimal survey response rates in CWE and parents of CWE is encouraged.

An additional limitation of the second phase of the study that relates to the issue of poor survey response rates pertains to the increased risk of type II errors that can arise as a function of smaller sample sizes. That is, it is possible in some instances that the null hypothesis was erroneously retained and that significant relationships or group differences were not revealed.

A final limitation of the second phase of the study was its cross-sectional nature. Cross-sectional data does not enable the identification of causal relationships. Future longitudinal research could prove beneficial as it could facilitate the clarification of a number of queries surrounding cause and effect raised by the data in the present study. For example, research employing a longitudinal design could examine whether CWE diagnosed at a young age adopt more restrictive disclosure behaviours surrounding their epilepsy from the outset or whether they become more secretive about their epilepsy over time. Furthermore, longitudinal research could elucidate whether CWE's greater endorsement of epilepsy concealment is a product of parental and/or others' hypervigilance; or whether greater concealment is merely associated with poorer health outcomes amongst CWE (i.e. increased seizure severity and frequency) that consequently warrant the enforcement of greater restrictions on the child's and family's life, with CWE attempting to avoid such restrictions by keeping their epilepsy hidden from others.

9.5 Conclusions

Overall, the second phase of this sequential exploratory mixed methods study represents the first quantitative investigation into the disclosure behaviours of CWE and parents of CWE, as well as the first study to elucidate the relationships between child and parental epilepsy disclosure behaviours and demographic, clinical, psychosocial and illness attitude variables. When considered collectively, a number of key inferences can be drawn from the findings. First, parents' epilepsy disclosure decisions are largely informed by their desire to ensure the safety of their child. For CWE, disclosure decisions are contingent upon much more personalised factors such as their internalised emotions and attitudes towards their chronic neurological disease and their yearning for a sense of normality. Second, both CWE and parents of CWE who conceal the child's epilepsy from others external to the nuclear family experience more negative psychosocial outcomes. It is unclear whether the burdensome and taxing nature of keeping the epilepsy hidden from others is responsible for this relationship or indeed whether epilepsy concealment is a consequence of CWE's and/or parents' poorer psychosocial adjustment to the child's diagnosis. Future research should attempt to explicate the directionality of this relationship. Third and finally, the findings from this second phase provide further support for the concept of parents as either inadvertent or purposeful stigma coaches in the lives of CWE. However, the findings also offer insight into the bidirectional relationship between child and parental epilepsy disclosure behaviours, with CWE potentially playing an influential role in informing their parents' epilepsy disclosure decisions.

In conclusion, the emergent findings of this second phase not only provide valuable insights into the contextual and situational factors implicated in the epilepsy disclosure process engaged in by CWE and their parents, but also represent key avenues via which those working with families living with epilepsy can assist them in navigating through this complex process. Based

on the findings, one could tentatively suggest that more open disclosure management strategies surrounding epilepsy could enhance the psychosocial wellbeing of families living with epilepsy. The practical implications of the findings will be discussed in greater detail in chapter 11, where a number of recommendations will be made for future research and improving clinical practice.

Chapter 10: Integrative Discussion

10.0 Introduction

Whilst the data from each distinct phase of the study has been analysed and critically discussed separately in previous chapters, in this chapter, the data from this two phased mixed methods study will be considered in an integrative fashion. Furthermore, the key findings to emerge on collective consideration of the data across both study phases will be critically discussed, with reference to the initial study aims.

10.1 Integrating the Findings from Phase One and Phase Two

As previously outlined in chapter 3 (section 3.4.1.4), in order to integrate the findings, the findings were triangulated. In this section, in accordance with the recommendations of O'Cathain et al. (2010) and Farmer et al. (2006), findings across both phases of the study will be considered in terms of convergence, dissonance, complementarity and silences.

10.1.1 Convergence

The qualitative and quantitative findings of the present study in terms of CWE's and parents' epilepsy disclosure behaviours were consistent in the sense that in both phases of the study, diverse and varied disclosure management strategies were adopted by CWE and parents - from voluntary disclosure to concealment. Indeed, across both phases there was evidence of at least some participants endorsing the following disclosure management strategies: concealment (from CWE's perspective); selective disclosure; unplanned revelations; indirect telling (from CWE's perspective); preventive disclosure; and voluntary and open disclosure.

In relation to disclosure targets, extended family members, peers (including other CWE or peers with other illnesses, disabilities or personal characteristics deemed as "different"), school personnel, HCPs and sports team coaches or instructors of extra-curricular activities were commonly referenced by CWEs across both phases of the study. From parents' perspectives, extended family members, peers, school personnel, HCPs, caregivers, other families, sports team coaches or instructors of extra-curricular activities, parents of CWE or children with other chronic illnesses or disabilities, employers and co-workers, and sources of help and support were identified as disclosure targets in phases 1 and 2. Moreover, in both phases of the study, CWE and parents highlighted the importance of the closeness of their relationships with peers in their determination of whether such peers were appropriate disclosure targets. Furthermore, in the qualitative and quantitative phases, parents identified those to whom they relinquished responsibility for their child's care (e.g. teachers who are 'in loco parentis' during school hours or childminders, nannies and au pairs) as key disclosure targets. These findings not only

reinforce the salience of considering such individuals as likely disclosure targets, but also lend further support to the notion that, for parents, ensuring the child's safety is a priority and underpins almost all elements of their epilepsy disclosure. Whilst, previously, limited empirical evidence had hinted towards safety factors motivating and promoting epilepsy disclosure amongst parents of CWE (Mu, 2008; Roberts & Whiting, 2011), the extent to which such factors influence parents' epilepsy disclosure, with such factors implicated in close to every single aspect of parental disclosure decisions, is a novel finding of the present study.

Across both phases of the study, from CWE's perspectives, the content of their disclosure exchanges with others constituted descriptions of epilepsy and seizures, and discussion of: 1) the impact of epilepsy on their physical, social and emotional wellbeing, 2) hospital appointments; and 3) AEDs and other epilepsy treatments. For parents, key conversation topics – identified in phases 1 and 2- reportedly discussed during disclosure exchanges with others included: 1) the child's specific diagnosis, seizure symptomatology and level of seizure control; 2) seizure first aid protocols; 3) the impact of epilepsy (beyond seizures); 4) AEDs and AED side-effects; and 5) the emotional impact of the diagnosis. For many CWE, explanations of epilepsy, seizure descriptions and the specific impact of seizures were likely central aspects of their epilepsy-related discussions with others due to others' lack of understanding of epilepsy rousing their curiosity during disclosure exchanges and necessitating the provision of explanations by CWE. However, some CWE articulated experiencing difficulties in terms of relaying certain epilepsy-related information to others – a finding consistent with previous literature (Houston et al., 2000). This indicates the need for the provision of tailored support to CWE in terms of enabling them to effectively communicate with others about these aspects of their epilepsy should they wish to do so. With regard to parents' perspectives, again, there was evidence across both phases that their epilepsy disclosure exchanges with others were largely safety-oriented, as indicated by their reports of often discussing appropriate seizure first aid protocols, describing the child's seizures (to ensure others' recognition of seizures) and specifying the child's type of epilepsy when speaking with others external to the nuclear family.

In both phases of the study, CWE highlighted that disclosure exchanges with others occurred in the following situational contexts: 1) when cues (physical [i.e. seizures or medication] or contextual [i.e. the child's absences from school or activities as a consequence of seizures or hospital appointments] in nature) made the invisible condition visible to others; 2) when others asked questions; 3) when in an environment where the topic of epilepsy was salient; and 4) subsequent to seizure occurrences (inclusive of situations when seizures occurred privately). Across phases 1 and 2, parents of CWE reported engaging in disclosure exchanges with others external to the nuclear family when: 1) the child was entering a new environment and thus others would be responsible for the child; 2) others raised the topic or asked questions; 3) discussing other children's difficulties with parents; 4) hospital appointments had just occurred

or were impending; 5) in the presence of others with experience of epilepsy; 6) periods of emotional struggle that necessitated parental support arose; 7) the child experienced restrictions; and 8) they required epilepsy-related information. Parent perspectives reinforced the salience of the central role safety factors played in their epilepsy disclosure decisions, with situations in which others were going to be responsible for the child identified in both phases of the study as a primary context under which epilepsy disclosure exchanges with others unfolded. In addition, in both study phases, CWE and parents of CWE revealed that others asking questions was a further key situational context whereby disclosure exchanges with others external to the nuclear family occurred. In such contexts, it is likely that subtle or obvious cues of the child's condition fuelled others' curiosity and consequently served as stimuli for disclosure exchanges. This finding further reinforces the notion that cues of epilepsy can make the invisible condition suddenly visible to others, which lends further support to the concept that discovery of epilepsy is always a possibility due to the unpredictable nature of the condition and its many associated cues. Furthermore, according to data across both phases of the study, epilepsy disclosure exchanges with others often occurred for both CWE and parents in the context of impending or recent hospital appointments. It is probable that discussion of the child's epilepsy arose in such contexts either as a consequence of: 1) hospital appointments resulting in CWE and parents of CWE requiring support from others in processing and coming to terms with certain information; or 2) CWE's or parents' absence from school or work, respectively, rousing others' curiosity or necessitating explanation.

From CWE's perspectives, in both phases 1 and 2, challenges associated with disclosure included: 1) CWE's desire for normalcy; 2) the feelings of differentness elicited by the condition; 3) others treating them differently because of epilepsy; 4) the invisibility of epilepsy; 5) others' negative reactions to disclosure (anticipated and/or actual negative reactions); 6) difficulties in explaining epilepsy; 7) others' lack of understanding of epilepsy; 8) parental stigma coaching; and 9) CWE's own perceptions of epilepsy, as well as others' perceptions of epilepsy. In some instances, these served to promote the adoption of more closed communicative strategies surrounding epilepsy amongst CWE. For parents of CWE, there was evidence of the following epilepsy disclosure-related challenges across both phases of the study: 1) their wish to normalise life for their CWE; 2) the invisibility of epilepsy (in terms of how it physically manifests and its lack of presence within the public domain); 3) others' negative reactions to disclosure (anticipated and/or actual negative reactions); 4) poor public perceptions of epilepsy; 5) epilepsy-related stigma; and 6) their emotional response to the child's diagnosis. In both study phases, the emotional consequences of the child's epilepsy diagnosis represented challenges for CWE and parents of CWE when disclosing the child's epilepsy condition to others outside the immediate family unit; a novel finding of the present study. For CWE, this finding was further supported by the significant relationship observed between greater epilepsy

concealment amongst CWE and poorer HRQoL in the domain of intrapersonal/emotional issues. Furthermore, as indicated above, across both study phases, for both CWE and parents of CWE, perceptions of how others might treat or view the child subsequent to disclosure represented a significant challenge. This finding lends support to the conceptualisation of diagnosis concealment as an implicit expression of felt stigma (i.e. a process of self-stigmatisation whereby one internalises negative attitudes towards the socially devalued attribute and fears encountering active discrimination and/or prejudice). Additionally, others' lack of understanding, as well as poor public perceptions of epilepsy, also denoted significant challenges to epilepsy disclosure for CWE and parents of CWE. This finding resonates with the literature pertaining to public understanding and knowledge of epilepsy, and attitudes towards epilepsy, where even in recently conducted studies, there is evidence that: 1) misconceptions persist; and 2) attitudes towards epilepsy are less than favourable (Deresse & Shaweno, 2016; Kartal, 2016).

Finally, from CWE's perspectives, in both phases 1 and 2, others reacting positively in the past and their specific seizure characteristics were factors that were reported as enabling epilepsy disclosure. Additionally, parents of CWE across both phases of the study indicated that factors that enabled their epilepsy disclosure to others external to the nuclear family included: 1) the perception that disclosure enhanced their child's safety and/or others' understanding of the child; 2) positive reactions to disclosure in the past; 3) the child's seizure characteristics; 4) the perception that disclosure serves as an educational tool and represents a method of fighting against epilepsy-related stigma; 5) the amount of time that had passed since the diagnosis; 6) public awareness and media coverage of epilepsy; and 7) the perception that talking to others could result in the receipt of social support. Furthermore, in both phases of the study, both CWE and parents of CWE identified that their own positive perceptions of and pragmatic/accepting attitudes towards epilepsy denoted a salient enabling factor for their epilepsy disclosure to others. Although, this enabling factor was not amongst the most commonly cited by CWE and parents of CWE in phase 2 of the study, further support for these findings in this quantitative phase was revealed via the significant correlations observed between CWE's and parents' epilepsy disclosure behaviours and: 1) children's attitudes towards their illness; and 2) parents' responses to the child's illness, respectively. Such findings further reinforce the influential role CWE's and parents' internalised attitudes towards epilepsy play in their selection of specific disclosure management strategies.

10.1.2 Dissonance

With regard to dissonance in findings across phases one and two of the study, whilst some parents of CWE in the qualitative phase of the study endorsed a policy of total concealment surrounding their child's epilepsy, no parents in the quantitative phase of the study reported never talking to others external to the nuclear family about their child's epilepsy. One potential

explanation for this inconsistency in parental epilepsy disclosure behaviours across the study phases relates to a potentially increased susceptibility to self-selection bias inherent in the quantitative phase of the study as a consequence of the specific sampling procedure employed. In both phases of the study, it is very probable that those who were more open with others about the child's epilepsy were more likely to agree to participate. However, the opt-in sampling method employed in the quantitative phase of the study entirely relied upon families living with epilepsy completing and returning surveys that had been distributed to them by mail. Thus, in most instances families had no direct contact with the researcher. The more direct and personalised recruitment procedure in the qualitative phase of the study may have resulted in enhancing participation likelihood amongst those who may not have usually spoken to others outside the immediate family unit about the child's epilepsy.

A second discrepant finding relates to the association between time since diagnosis and parental epilepsy disclosure behaviours. Qualitative findings revealed that disclosure was particularly challenging for parents in the period of time immediately subsequent to the child's diagnosis and furthermore, that with the progression of time parental disclosure was enabled because they got used to disclosing. Based on these findings, one might have assumed that increased time since diagnosis would correlate with higher levels of parental epilepsy disclosure. Such findings were not indicated in phase two in terms of a quantitative association between parents' epilepsy disclosure behaviours and objective reports of time since diagnosis. However, 50% of parents in phase two did report that the amount of time that passed since their child's diagnosis served to enable their epilepsy disclosure. One potential explanation for this somewhat conflicting finding may relate to the fact that individual parents may vary in terms of the length of time it takes them to come to terms with and positively adjust to their child's epilepsy diagnosis.

The aforementioned findings denote the only notable discrepant findings across Phases 1 and 2 of the study. There was no apparent dissonance in terms of CWE's and parents' disclosure targets, the content of their epilepsy disclosure exchanges with others external to the nuclear family or the situational context of their epilepsy disclosure exchanges.

10.1.3 Complementarity

In relation to the uniqueness of the qualitative and quantitative components of the present study in terms of what insights into CWE's and parents' epilepsy disclosure behaviours each component could offer, the qualitative phase of the study enabled exploration of the nuanced ways in which specific disclosure management strategies (documented in prior literature pertaining to CSIs) manifested in CWE and parents of CWE. It was previously known that PWE endorse a number of disclosure management strategies. However, in the qualitative phase of the present study, knowledge was enhanced about how such disclosure management strategies materialise, whereby in the context of childhood epilepsy distinctions were explicitly made

between: 1) active and passive forms of concealment; 2) open (i.e. being willing to disclose but only doing so if prompted) and voluntary (i.e. volunteering epilepsy-related information to others unprompted) disclosure; 3) selectively disclosing according to: (a) disclosure targets; or (b) the content of disclosure exchanges; and 4) preventively telling as a means to: (a) forestall stigmatisation; or (b) prepare others. The findings from phase two elaborated on the findings from the phase one by illustrating the extent to which CWE and parents of CWE disclosed (or concealed) the child's epilepsy; thus, further extending our understanding of the complex phenomenon of CWE's and parents' epilepsy disclosure in the context of childhood epilepsy. Furthermore, for the first time in the context of childhood epilepsy, distinctions were identified between the proportion of CWE and parents of CWE who wished to keep the child's epilepsy a secret from others external to the nuclear family to a great extent (21.7% and 1.4%, respectively) and the proportion of CWE and parents of CWE who had actually kept the child's epilepsy a secret from others to this same extent (10.9% and 0%, respectively). Additionally, the second phase of this study enhanced knowledge about CWE's and parents' epilepsy disclosure behaviours by exploring: 1) CWE's and parents' written disclosure behaviours surrounding epilepsy; and 2) the relationships between CWE's and parents' epilepsy disclosure behaviours and child- and parent-reported demographic (e.g. age and gender) and clinical characteristics (e.g. time since diagnosis, seizure type and seizure frequency), and psychosocial (e.g. HRQoL and parents' responses to their CWE's illness) and illness attitude variables (e.g. stigma perceptions).

With reference to the complementarity of findings in terms of CWE's and parents' disclosure targets, phase 1 findings highlighted key categories of disclosure targets for CWE and their parents. These were then included in the surveys in phase 2 to elaborate on our understanding of the epilepsy disclosure process by quantitatively assessing information regarding disclosure targets. Additionally, the qualitative nature of the first phase of the present study facilitated the identification of personal characteristics of potential disclosure targets that served to enable or deter CWE's and/or parents' disclosure to such individuals such as gender, age, perceived trustworthiness and the closeness of CWE's or parents' relationships with such individuals, amongst other characteristics. In contrast, the quantitative surveys employed in the second phase of the study enabled the researcher to specifically evaluate the extent to which CWE or parents of CWE talked to specific categories of individuals about the child's epilepsy.

Two notable and illuminating findings emerged via the quantitative assessment of the extent to which CWE, in particular, conversed with specific categories of individuals external to the nuclear family about their epilepsy condition. First, it emerged in Phase 2 that HCPs, inclusive of doctors and nurses, were the category of individuals to whom CWE reported speaking the most about their epilepsy. HCPs, thus, are likely the individuals outside the immediate family unit whom CWE are most reliant on in terms of seeking epilepsy-related support. Although this

finding is unsurprising, it is important in considering that a number of CWE in Phase 1 identified that communicating with HCPs was problematic due to CWE's perception that HCPs did not seem to value their input, instead directing conversation and questioning primarily towards parents during clinical appointments. This finding corresponds with the findings of previous literature (Beresford & Sloper, 2003; Houston et al., 2000) and highlights the need for HCPs to ensure that CWE are included in the consultation process. Second, there was no consensus over the gender of the peers CWE were most likely to discuss their epilepsy condition with in phase one of the study. However, in the second quantitative phase, clarification on this issue was provided, with the majority of CWE reported speaking to a greater extent to female friends (both in terms of close and casual friends) than to male friends. This finding suggests that, in considering appropriate disclosure targets, female gender might be a factor that encourages CWE's epilepsy disclosure.

In relation to the complementarity of findings across the study phases with regard to the content of CWE's and parents' epilepsy disclosure exchanges with others, the qualitative interviews enabled exploration into the specific ways in which CWE and parents transmitted and conveyed epilepsy-related information to others external to the nuclear family (e.g. the language they employed, the explanations they provided, their minimisation, downplaying and normalisation of the child's epilepsy and seizure symptomatology, and their utilisation of humour to put others at ease). Furthermore, in the qualitative component, it was possible to ascertain which elements of certain epilepsy-related topics CWE or parents of CWE were averse to speaking with others external to the nuclear family about (e.g. specific seizure manifestations and information about medications and other treatment types), and which aspects of epilepsy-related topics CWE and parents were comfortable to disclose to others, as well as the reasons why certain topics were off limits during disclosure exchanges with others (e.g. they were deemed embarrassing, overly complex or upsetting) whilst others were open. In contrast, in the quantitative phase of the study, such nuances could not be explored. However, the quantitative phase enabled the identification of the topics of conversation that were most salient to CWE (i.e. seizure descriptions, descriptions of epilepsy and the impact of seizures) and parents (i.e. seizure first aid protocols, seizure descriptions, epilepsy type and the impact of seizures on the child) during their disclosure exchanges with others. Furthermore, it facilitated the identification of those topics that were least commonly discussed by CWE (i.e. seizure control, medication side-effects, their personal feelings towards epilepsy, hospital appointments and epilepsy-related restrictions) and parents (i.e. medication side-effects, their personal feelings towards epilepsy and epilepsy-related restrictions imposed on the child) when disclosing the child's epilepsy condition to others.

In terms of the complementarity of findings with regard to the context of CWE's and parents' epilepsy disclosure exchanges with others, the probative nature of the semi-structured

interviews in phase one enabled the researcher to identify when epilepsy disclosure exchanges with others external to the nuclear family occurred for CWE and their parents. It also permitted exploration of situational factors that influenced the specific context in which epilepsy disclosure exchanges with others unfolded (e.g. the mood of the disclosure target and/or CWE's level of comfort with their relationship with potential disclosure targets). Consequently, these situational contexts were quantitatively assessed in the second phase of the study, whereby situational contexts in which epilepsy disclosure exchanges with others most commonly and least commonly occurred for CWE and parents of CWE were revealed. For CWE, phase two findings revealed that disclosure exchanges most commonly unfolded: 1) in the context of recent or impending hospital appointments; 2) when others asked questions; 3) when the child was starting a new activity or sport. Parents mainly disclosed the child's epilepsy to others external to the nuclear family when: 1) others would be responsible for the child; 2) others asked questions; 3) the topic of epilepsy came up in conversation. The context in which CWE's disclosure exchanges with others least commonly occurred included situations when: 1) they needed support; 2) their friends were telling them secrets; 3) their medications were causing difficulties; and 4) they missed school due to seizures. From parents' perspectives, disclosure exchanges with others surrounding the child's epilepsy least commonly unfolded when: 1) others witnessed the child having a seizure; 2) the child's medication was causing difficulties; 3) epilepsy-related restrictions were present for the child; and 4) other witnessed the child taking his/her medication.

With regard to the challenges associated with epilepsy disclosure for CWE and parents of CWE, each phase of the present study offered distinct contributions that enhanced knowledge about the barriers to disclosure experienced by CWE and parents of CWE. The semi-structured interviews conducted in the qualitative phase facilitated the researcher in gaining an in-depth understanding of how challenges to epilepsy disclosure manifest, and the feelings such challenges elicit in CWE and/or parents of CWE (e.g. sadness, fear, frustration, anger and disappointment). Indeed, challenges associated with disclosure identified in the first phase informed the author's decision regarding which contextual factors to quantitatively assess in phase 2 in terms of identifying whether such factors encouraged or discouraged child and parental epilepsy disclosure. Furthermore, the qualitative findings indicated a number of potential consequences associated with disclosure (e.g. others treating the child differently or imposing unnecessary restrictions on the child), which resultantly informed decisions regarding the consequences to be examined in the survey questionnaires. In contrast, the quantitative phase enabled the researcher to investigate which factors most commonly posed epilepsy disclosure challenges for CWE (i.e. how epilepsy makes them feel; their perceptions of how others might consequently treat them; their personal feelings towards epilepsy; and others' understanding of epilepsy) and parents of CWE (i.e. their perceptions of how others might treat

or view their child; public perceptions of epilepsy; public understanding of epilepsy; and their child's lack of desire for others to know about their epilepsy).

Finally, the qualitative and quantitative phases of the present study each offered unique contributions to empirical evidence in relation to enabling factors for disclosure amongst CWE and parents of CWE. In the qualitative phase, interviews enabled the researcher to collect rich, meaningful data pertaining to enablers of epilepsy disclosure, and furthermore to gain an understanding of why specific factors served to promote epilepsy disclosure amongst child and parent populations. Such factors were subsequently quantitatively assessed in phase 2, with the quantitative survey data facilitating the identification of the most pertinent enabling factors for epilepsy disclosure amongst CWE (i.e. hearing that famous people have epilepsy, their level of knowledge about epilepsy and media coverage of epilepsy) and parents of CWE (i.e. their ability to explain the condition to others, the fact that epilepsy is a medical condition, the level of information they possess about their child's epilepsy and the mildness of their child's epilepsy relative to other epilepsies); findings that could have significant implications for clinical practice and inform recommendations for best practice.

10.1.4 Silences

There were no silences observed in relation to the findings across the qualitative and quantitative phases of the study with regard to the epilepsy disclosure management strategies adopted by CWE and parents of CWE.

In relation to CWE's disclosure targets, therapists/counsellors, co-workers, employers, friends' parents, and childminders, nannies and au-pairs were only identified as categories of individuals to whom CWE spoke about their epilepsy in phase 2 of the study. It is likely that co-workers and employers were not referenced as disclosure targets by any CWE participants in phase 1 of the study because only CWE up to the age of 16 years were included in this phase whereas 16-18 year old CWE participated in phase 2. Within an Irish context, under the *Protection of Young Persons (Employment) Act 1996* (Ire), employers are not permitted to employ children under 16 years of age in regular full-time jobs.

With respect to the content of child and parental disclosure exchanges with others, a number of silences across the study phases were evidenced. The following topics of conversation were unreported by CWE in phase 1 of the study but resonated with at least some CWE in phase 2: 1) how others should respond to seizures; 2) medication side effects; and 3) seizure control. Furthermore, from parents' perspectives, in phase 2 a number of parents reported discussing the following aspects when disclosing the child's epilepsy condition – aspects not explicitly reported as being discussed with others external to the nuclear family by parents in phase 1: 1) what epilepsy is; 2) the child growing out of epilepsy; and 3) the child's feelings about epilepsy.

In terms of the situational context of CWE's' epilepsy disclosures, in phase 2 the following were revealed as key contexts in which epilepsy disclosure exchanges with others arose for some CWE, but in phase 1, such situational contexts were not explicitly reported by CWE: 1) when they felt like seizures might occur; 2) when medications were causing issues; 3) when they could not partake in activities due to epilepsy; 4) when starting a new activity or sport; 5) when meeting new people; and 6) when their friends were telling them their secrets. Similarly, from parents' perspectives, despite the salience of the following contexts with regard to a number of parents' epilepsy disclosure exchanges with others in phase 2, parent-reported data from phase 1 was silent in regard to disclosure exchanges unfolding in situations when: 1) the child missed school due to seizures; and 2) others saw the child taking his/her medication.

In terms of the challenging aspects of epilepsy disclosure indicated by CWE and parents of CWE, two findings reported as barriers to epilepsy disclosure by a number of CWE and parents of CWE in phase 2, with phase 1 silent in terms of such barriers, are as follows: 1) T.V. or radio coverage of epilepsy; and 2) fear of being perceived as attention seeking. Furthermore, the finding in the quantitative phase of the study that CWE's lack of desire for others to know about their epilepsy represented a significant challenge for parental epilepsy disclosure represented one further notable silence in terms of phase 1 findings, i.e. no parents in phase 1 explicitly reported this factor as a challenge associated with epilepsy disclosure.

In relation to perceived enabling factors for child and parental epilepsy disclosure, media coverage of epilepsy, famous people having epilepsy, CWE's own level of knowledge about epilepsy as well as others' level of knowledge about epilepsy, and their ability to explain epilepsy were identified in phase two as being amongst the most salient enabling factors for epilepsy disclosure amongst CWE; findings unreported by CWE in phase 1. Additionally, whilst parents in phase 1 of the study proxy-reported that open and positive familial communication about epilepsy served to enable and encourage their CWE to speak more openly and honestly about their epilepsy with others external to the nuclear family, CWE did not specifically self-report this as an enabling factor in either the qualitative or quantitative phase of the study. Parents' perspectives in this regard were however validated by the emergence of a significant correlation between CWE's increased epilepsy disclosure and greater levels of epilepsy-related communication with their parents. Furthermore, in the qualitative phase of the study, parents of CWE did not indicate that their ability to explain the condition to others, and the level of information about epilepsy they possessed, served to enable them to disclose the child's epilepsy condition to others outside the immediate family unit, whereas in the quantitative phase of the study, these factors denoted two of the most commonly reported enabling factors for disclosure amongst parents of CWE. Finally, some parents in phase 2 also indicated that their perceptions of how others might consequently treat their child, how talking to others about their child's epilepsy made them feel, public understanding of epilepsy and their

child's desire for others to know about the epilepsy also served to enable their epilepsy disclosure. However, the data from phase 1 of the study was silent in terms of such findings.

10.1.5 Summary of the Integrative Analysis

Integrating the findings to emerge across both phases of the study was important because it enabled the identification of convergent, dissonant, complementary and silent findings. Convergence across findings strengthened the salience and centrality of: 1) specific factors implicated in the disclosure process; and 2) elements of epilepsy disclosure behaviours, thus enhancing the generalisability and transferability of specific findings (Johnson & Onwuegbuzie, 2004). Dissonant findings may be explained by differences in recruitment procedures and differing perspectives. The complementarity of findings across the study phases yielded a more holistic picture of the epilepsy disclosure process engaged in by CWE and their parents. That is, each phase of the study offered unique contributions in terms of further elaborating, enhancing, illustrating and/or clarifying knowledge and/or understanding of the phenomenon of epilepsy disclosure in the context of childhood epilepsy. In particular, the qualitative phase enabled the collection of rich, meaningful data pertaining to aspects of CWE's and parents' epilepsy disclosure, which were then quantitatively assessed to identify the most common and important aspects of these elements of CWE's and parents' epilepsy disclosure. Furthermore, the quantitative phase facilitated the researcher in receiving clarification on issues on which no consensus was revealed in phase one. Finally, silences in findings may have arisen because of: 1) sampling differences; or 2) the strengths associated with the varying methods in terms of examining specific aspects of epilepsy disclosure. Silences served in a similar manner to complementary findings by increasing understanding and knowledge of the topic of epilepsy disclosure in the context of childhood epilepsy.

10.2 Key Findings of the Present Study

The findings from each phase of the study have been critically discussed in previous chapters. However, in this section, the key findings to emerge on collective consideration of the data across both study phases will be presented. The rationale for conducting this two-phased, mixed methods sequential exploratory study will be revisited, the original aims of the study will be restated, and key findings in light of these original aims will be outlined.

10.2.1 Study Rationale and Aims

Epilepsy is a highly stigmatised condition with epilepsy-related stigma often reported as detrimentally impacting on psychosocial wellbeing (Jacoby et al., 2005; Jacoby and Austin, 2007; De Boer et al., 2008). According to De Boer (2010), the most significant problems encountered by PWE in daily life are not those related to the severity of the condition, but rather are those that stem from public perceptions of the condition. Many PWE have the capacity to

keep the condition hidden from others as it is only when symptoms of the condition manifest (e.g. seizures) or when cues of the condition arise (e.g. drug-taking) within a public context that it becomes overtly visible to others. Therefore, epilepsy is an example of a CSI.

One way in which epilepsy-related stigma is implicitly expressed is through diagnosis concealment. However, diagnosis concealment can be problematic. It not only has implications for the child's safety; it can also serve to feed into a *cycle of invisibility* that encircles the condition whereby the unwillingness of PWE to speak openly and honestly about it with others contributes to the lack of public knowledge about epilepsy, exacerbating misconceptions and heightening the likelihood of active discrimination towards PWE (Lewis & Parsons, 2008).

Prior to this study, the limited evidence available from previous research in childhood epilepsy and epilepsy disclosure suggested that epilepsy disclosure represents a QOL issue, a source of concern, a stressor and a complex and significant factor in the lives of CWE and their parents (McEwan et al., 2004; Moffat et al., 2009; Ronen et al., 1999; Saburi, 2011). However, little had been documented in terms of what the disclosure process involves for CWE and their parents, and no studies had been conducted where the investigation of child and parental disclosure behaviour was a primary aim. Therefore, the present study aimed to explore the epilepsy disclosure process engaged in by CWE and parents of CWE. More specifically, the primary aims of the present study were to: 1) identify whether CWE and their parents disclose (or not) the child's epilepsy condition to others external to the nuclear family; 2) examine the contextual and situational factors that inform disclosure decisions amongst these populations; 3) investigate the consequences of disclosure for CWE and/or their parents; and 4) explore the relationship between CWE's and parents' epilepsy disclosure behaviours and demographic, clinical, psychosocial and illness attitude variables (e.g., age, gender, seizure type, time since diagnosis, level of parent/child interaction about epilepsy within the context of the family home, parent response to the illness, perceived stigmatisation, CWE's self-perceptions and HRQoL). Understanding the complex process of epilepsy disclosure is important because finding ways to promote disclosure amongst child and parent populations could ultimately result in the condition becoming more visible within a public domain. This, in turn, could improve public perceptions of epilepsy and decrease epilepsy-related stigma.

10.2.2 To Tell or not to Tell

With regard to the first central aim of the present study, child and parent perspectives revealed that whilst some CWE and parents of CWE endorsed policies of open and voluntary disclosure in relation to the child's epilepsy, others favoured more restrictive disclosure management strategies, such as concealment or selective disclosure. However, although both CWE and parents adopted diverse and varied disclosure management strategies, the motivation systems

underlying their selection of specific disclosure management strategies had some fundamental differences. These are discussed below.

10.2.2.1 Safety versus Normalcy: The Motivations Underpinning CWE's and Parents' Disclosure Behaviours

There was a notable dichotomy in parental disclosure behaviours revealed in the findings across both phases of the study. Some parents adopted open, voluntary or preventive disclosure management strategies, with such decisions largely contingent upon safety factors. Indeed, a number of parents recognised that diagnosis concealment can be problematic due to the inherent health and safety hazards posed as a consequence of others' resultant lack of awareness about the child's propensity towards having seizures. For other parents, more restrictive disclosure management strategies (i.e. selective disclosure or concealment) were endorsed due to their desire to protect the psychosocial wellbeing of the child and in an attempt to evade negative reactions from others and stigmatisation of the child. The CPM theory (Petronio, 2002) posits that one of the key decision criteria considered by individuals in developing privacy management rules and boundaries is the risk-benefit ratio analysis criterion, whereby individuals calculate the risks and benefits associated with revealing or concealing when determining the appropriateness of disclosure. The aforementioned findings provide support for this proposition of the CPM theory (Petronio, 2002). That is, when parents perceive that the benefits related to ensuring the child's safety outweigh any potential risks, they reveal the child's epilepsy condition to others; whereas when parents of CWE perceive that the risk of their child experiencing stigmatisation and adverse reactions subsequent to disclosure outweigh the benefits of disclosing, they conceal the child's epilepsy condition from others. Ultimately, the motivations underlying parental disclosure behaviours hinged around the concepts of child protection, and parent responsibility and duty.

Interestingly, CWE participants in the present study seemed to either be unaware of or unconcerned with the safety implications of more restrictive disclosure management strategies. Instead, CWE's disclosure decisions appeared to be a lot more personalised and nuanced, with threats to normalcy and enduring and equal relationships with peers, their internalised attitudes towards epilepsy, and the potential for stigmatising responses from others, playing a much more integral role in influencing their selection of specific disclosure management strategies.

Collectively, these findings would suggest that in considering how best to assist CWE and parents of CWE to navigate the complex disclosure process, different approaches are required to account for the differing motivations underlying their disclosure behaviours. For instance, during engagements with parents, emphasis should be placed on arming them with information pertaining to safety factors (e.g. seizure first aid protocols) and child protection, whereas for CWE equipping them with knowledge on how to convey their epilepsy to others in a way that

minimises the risk of others treating them differently or reacting in a negative manner and elicits feelings of empowerment should take priority.

10.2.3 Contextual and Situational Factors that Influence Epilepsy Disclosure

With reference to the second specified aim, a number of contextual and situational factors were revealed that informed epilepsy disclosure decisions amongst CWE and parents of CWE. A number of unique situational factors that acted as stimuli for CWE's and parents' epilepsy disclosure exchanges with others were revealed for the first time in the present study, including: 1) cues of the condition making the invisible condition visible to others (e.g. physical cues such as medical safety bracelets or medication) or necessitating explanation (e.g. contextual cues such as school absences due to hospital appointments or seizures); 2) the topic of epilepsy and/or disability being salient; and 3) others sharing personally private or distressing information with them. Enabling factors for epilepsy disclosure amongst CWE or parents of CWE included the internalisation of positive or accepting attitudes towards the illness, open and positive familial communication about epilepsy, and the perception that epilepsy disclosure serves as an educational tool and a method of confronting and tackling epilepsy-related stigma; novel findings of the present study. Furthermore, factors that were revealed as posing barriers to epilepsy disclosure were inclusive of: 1) threats to normalcy; 2) the culture of silence that exists around epilepsy within the public domain; and 3) child and parental desire to maintain privacy around the epilepsy. Three key findings in relation to the contextual and situational factors that play an influential role in CWE's and parents' epilepsy disclosure process are discussed in further detail below.

10.2.3.1 The Media as an Influential Force in Shaping CWE's and Parents' Disclosure Behaviours

One theme that consistently emerged across both phases of the study was the influential role of media coverage of epilepsy in relation to CWE's and parents' epilepsy disclosure. Both CWE and parents highlighted how epilepsy is invisible within the public domain, expressing their dismay over the fact that coverage of the topic of epilepsy on media channels (such as radio and/or T.V.) is extremely rare. The message such silence conveyed to them was not a positive one; rather, CWE and parents perceived this lack of media coverage as indicative of others' lack of interest and desire to engage with and learn about the complex neurological disease. Furthermore, CWE and parents expressed frustration over the fact that, in their opinion, coverage of other chronic illnesses and/or diseases was much more common and prevalent in mainstream media.

Whilst the silence surrounding epilepsy within the public domain - as reflected by this lack of media coverage - reportedly posed challenges for CWE and parents of CWE with regard to epilepsy disclosure, both CWE and parents of CWE relayed how increased media coverage of

epilepsy could serve to enable and promote their epilepsy disclosure. Thus, the findings from this study hint towards the fact that increased media coverage of epilepsy could reap benefits in terms of creating a more facilitative environment in fostering open child and parental epilepsy disclosure exchanges with others external to the nuclear family.

Numerous reports have highlighted the need to bring epilepsy 'Out of the Shadows' (De Boer, 2002; Jallon, 1997; Meinardi et al., 2001; Reynolds, 2000; WHO, 1997; WHO, 2000). However, in a systematic review conducted by Herrmann et al. (2016), it was identified that in Western countries, interventions to reduce epilepsy-related misconceptions and stigma, and enhance public attitudes towards epilepsy, have been limited in terms of their target audiences (i.e. such interventions were mainly implemented in healthcare and education settings). Furthermore, Hermann et al. (2016) highlighted that the delivery systems via which messages about epilepsy were disseminated largely involved utilising a didactic approach which was time consuming in nature, thus curtailing the feasibility of such interventions for broad scale implementation. Thus, it would seem that little emphasis has been placed on utilising mainstream media as a vehicle for the delivery of messages that could enhance public knowledge and understanding of epilepsy and tackle epilepsy-related stigma, as well as the silence that encircles the condition. This is despite the fact that adopting such a broad scale approach to destigmatising epilepsy would seem practical and intuitive, particularly given that mass media has been identified as common source of epilepsy-related information (Hermann et al., 2016). Indeed, limited empirical evidence pertaining to the effect of televised public service announcements about epilepsy on public knowledge and attitudes towards epilepsy, indicates that subsequent to exposure to such announcements about epilepsy, knowledge about epilepsy is enhanced and attitudes towards epilepsy become increasingly positive amongst members of the public (Martiniuk, Secco, Yake & Speechley, 2010).

Therefore, in considering the evidence collectively, it seems likely that the advantages of increased media coverage of epilepsy would be multi-faceted, with not only those living with the chronic neurological disease positively affected, but also members of the general public. Future research should explicitly examine the potentially mutually transformative role that increased media coverage of epilepsy could play, not only in terms of affecting epilepsy disclosure behaviours, but also in terms of the impact it could have on improving public perceptions of epilepsy directly (by increasing public knowledge about epilepsy and dispelling public misconceptions about epilepsy) and indirectly (by tackling the *cycle of invisibility* that encircles the condition).

10.2.3.2 The Emotional Impact of Receiving a Diagnosis of Childhood Epilepsy Implicated in Parents' Disclosure Behaviours

A further notable finding with regard to the second aim was the finding that the emotional impact of epilepsy was a factor that was particularly salient in considering parental disclosure behaviours specifically. Indeed, emotionally coming to terms with the child's diagnosis and grieving the 'loss' of their healthy child represented a barrier to epilepsy disclosure for many parents. Moreover, the emotional impact of the diagnosis denoted the content of some parents' disclosure exchanges with others external to the nuclear family. Additionally, a number of parents identified periods of emotional struggle surrounding the child's epilepsy as a specific context under which they revealed the child's epilepsy condition to others. Whilst the emotional implications of receiving and contending with a child's epilepsy diagnosis are well-documented in the literature (Cushner-Weinstein et al., 2008; Iseri et al., 2006; Lv et al., 2009; Reilly, Taft, Nelander, Malmgren & Olsson, 2015; Rodenburg et al., 2007; Thompson & Upton, 1992), to the author's knowledge, the findings from this study denote the first empirical evidence that suggest their involvement in parents' disclosure decisions. These findings further reinforce the fact that, on receipt of a child's epilepsy diagnosis, parents endure profound emotional struggles. Yet, it would seem that many parents receive little to no support from HCPs in addressing the emotional components of the child's epilepsy diagnosis and thus they may seek such support from others outside the immediate family unit. There is a need for future research to focus on how best to support parents as they grapple with the emotional implications of their child's epilepsy diagnosis.

10.2.3.3 The Complexity of Epilepsy as Posing Challenges for CWE's Epilepsy Disclosure

A third interesting finding that relates to the second central aim of the present study pertains to the difficulties CWE experienced in: 1) comprehending their chronic neurological disease; and 2) verbally relating such information to others (particularly in reference to peers). It is unsurprising that CWE grappled with such issues because the condition is highly complex and heterogeneous, comprising extremely variable seizure manifestations. HCPs overreliance on medical jargon during engagements with CWE reportedly exacerbated the disclosure challenges CWE experienced because the use of such complex language increased their own misunderstanding of the condition and consequently the difficulties they experienced in verbally representing the condition to others. Advising parents of CWE and those who work with families living with epilepsy (e.g. HCPs and epilepsy support organisations) of the need to take cognisance in ensuring that CWE: 1) understand the information imparted to them during clinical appointments; and 2) are capable of regurgitating and restating such information in their own words, could prove beneficial. Furthermore, epilepsy's association with the brain and the invisible nature of the condition posed challenges in terms of peers reconciling their perceptions

of how sick people should appear with the seemingly 'normal' physical appearance of CWE. Considered together, these findings would suggest that there is a need to identify unique and novel ways via which to enhance CWE's perceived ability to disclose their epilepsy condition to others outside the immediate family unit. Jantzen et al. (2009) found that CWE's ability to disclose their epilepsy diagnosis to others (as proxy-reported by their parents) significantly increased subsequent to their participation in a psychoeducational training program. Thus, CWE within an Irish context could benefit from engaging in similar programs. However, whilst participation in this program enhanced CWE's ability to disclose their epilepsy diagnosis to others, an assessment of whether this increased ability to disclose also increased disclosure likelihood was not undertaken. Future research should investigate whether disclosure ability predicts disclosure likelihood amongst CWE. Finally, equipping CWE with accessible, child-friendly, simplistic and personalised explanations of information pertaining to their epilepsy, seizures and medications is imperative in fostering CWE's confidence in disclosing their condition to others should they desire to do so. Lessons can be learnt from CWE in this regard, with a number of CWE in the present study reporting employing unique and interesting language and descriptions when conveying information pertaining to their epilepsy, seizure symptomatology and/or medications to others.

10.2.4 Consequences of CWE's and Parents' Epilepsy Disclosure

In terms of the third central aim of the present study which involved examining the consequences of epilepsy disclosure exchanges with others outside the immediate family unit, it emerged that others' reactions to epilepsy disclosure exchanges were largely positive. Furthermore, the findings suggested that whilst CWE and their parents may have anticipated negative responses to disclosure, such responses were uncommon. These findings lend further support to the propositions of Scambler's (1989) Hidden Distress Model in terms of substantiating the more salient and influential role played by felt or internalised forms of stigma in the lives of PWE than enacted forms of stigma. While acknowledging the numerous institutional and public global campaigns internationally endeavouring to break the cycle of invisibility encircling epilepsy and bring epilepsy 'out of the shadows', the main focus of these campaigns has been to tackle enacted forms of epilepsy-related stigma by raising public awareness and understanding of epilepsy and dispelling epilepsy-related myths (De Boer, 2002; ILAE/IBE/WHO, 1999; Mecarelli et al., 2014; Reynolds, 2000). Potentially, this has neglected to address the psychosocial needs and internalised perceptions of stigma amongst PWE. Addressing such needs, tackling felt and internalised stigma perceptions amongst CWE and their parents and enabling their epilepsy disclosure may offer a salient avenue for effectively reducing and ultimately eradicating epilepsy-related stigma.

This is the first study to explicitly examine the consequences of child and parental epilepsy disclosure exchanges with others. However, on inspection of the articles included in the

systematic review (see chapter 2), limited empirical evidence (comprising mostly incidental, qualitative findings) corroborate the findings from the present study in this regard in that they denote that the consequences of disclosing a child's epilepsy condition to others are largely positive for CWE (Hightower et al., 2002) and parents of CWE (Roberts & Whiting, 2011); while, conversely, the consequences of concealing the child's epilepsy from others external to the nuclear family are largely negative for CWE (Holdsworth & Whitmore, 1974; Kleck, 1968; Ryu et al., 2015) and parents of CWE (Mu, 2008). Thus, based on the findings of the present study and previous empirical evidence in the context of childhood epilepsy, one could infer that the benefits associated with child and parental disclosure of the child's epilepsy condition to others outside the immediate family unit - in terms of alleviating inhibition (Chaudoir & Fisher, 2010), enhancing the child's safety and others' understanding of the child, preparing others to appropriately respond to seizures, receiving social support from others, and making a contribution towards tackling the *cycle of invisibility* that encircles epilepsy (Lewis & Parsons, 2008) - may outweigh the risks associated with: 1) epilepsy disclosure; or 2) concealing the child's epilepsy from others.

10.2.5 How Epilepsy Disclosure relates to others Variables

With regard to the fourth central aim of the present study, many novel significant relationships were revealed, with CWE's and parents' epilepsy disclosure behaviours identified as being significantly associated with specific seizure types, stigma perceptions, illness attitudes and level of parent/child epilepsy-related communication, amongst other variables. In particular, two key conclusions can be drawn based on the evidence in this regard - these are discussed below.

10.2.5.1 The Association between Child and Parental Epilepsy Concealment and Poorer Psychosocial Outcomes

First, as a general rule, greater epilepsy concealment by CWE and parents of CWE was related to poorer outcomes - i.e. higher levels of perceived epilepsy-related stigma, more negative internalised attitudes towards the illness, poorer HRQoL (particularly in relation to negative interpersonal/social consequences, greater intrapersonal/emotional issues and increased concern over keeping the epilepsy a secret), less positive parental response to the child's illness, and less perceived social support. Although the correlational nature of the data analysis in the quantitative phase of the study did not lend itself to assessing the directionality of such relationships, in Figure 10.1, the author tentatively posits a model (based on the cumulative evidence gathered in the present study and prior literature in the context of disclosure amongst populations with CSIs) that postulates the directionality of the relationships between child and parental epilepsy disclosure behaviours and their internalised attitudes towards epilepsy, and psychosocial outcomes. The author suggests that a bidirectional relationship exists between CWE's and parents' attitudes towards epilepsy (i.e. their stigma perceptions and illness attitudes) and their disclosure behaviours. That is, internalised negative attitudes towards

epilepsy enhance CWE's and parents' likelihood of concealing the epilepsy due to heightened feelings of personal shame and greater fear pertaining to others' reactions (both of which were identified as barriers to disclosure in the present study). Yet, greater concealment results in the reinforcement of negative internalised attitudes towards epilepsy as a consequence of concealment: 1) denying one the opportunity to test whether the stigmatising response one anticipates will materialise (Jacoby & Austin, 2007); and 2) resulting in greater rumination on the illness due to the burden associated with keeping the illness hidden from others (Stiles, 1995). The author argues that the converse occurs where open disclosure behaviours are concerned. Furthermore, the author contends that greater concealment directly deleteriously affects CWE's and parents' psychosocial wellbeing because of the physiologically and emotionally taxing nature of keeping the condition hidden from others (Quinn et al., 2014). Indeed, there is some evidence to indicate that concealment as a stigma management strategy is ineffective and has ironic interpersonal consequences. Newheiser & Barreto (2014) identified that concealing one's CSI in expecting to secure feelings of acceptance and belonging actually has the opposite effect, decreasing feelings of belonging – an effect that is mediated by felt inauthenticity and reduced general self-disclosure (i.e. the disclosure of information about the self that is not confined to information about the CSI). The author further argues that, in contrast, more open disclosure behaviours have the potential to positively impact on CWE's and parents' psychosocial adjustment to the condition due to the hypothetical benefits associated with the increased likelihood of their consequently receiving social support from others and additionally, through the alleviation of inhibition mechanism (Chaudoir & Fisher, 2010). Indeed, in the present study: 1) parents relayed how they disclosed the child's epilepsy to others in situational contexts in which they required social support related to the child's epilepsy; and 2) CWE and parents reported experiencing feelings of relief subsequent to disclosing the child's epilepsy condition to others. Finally, the author posits that a feedback loop exists similar to the one proposed by Chaudoir & Fisher as part of the DPM (2010), whereby if others react positively to disclosure it may reinforce - or act as a stimulus to - the internalisation of positive attitudes towards the illness, encourage future disclosures and enhance psychosocial wellbeing, with the opposite likely occurring if others react negatively. In the present study, others' past reactions to disclosure served to both deter and encourage CWE and parents of CWE from engaging in future disclosure exchanges with others. This model is the first to hypothesise how CWE's and parents' epilepsy disclosure behaviours inform psychosocial outcomes and illness attitudes. Future research should attempt to: 1) more fully explicate the directionality of relationships between child and parental epilepsy disclosure behaviours and psychosocial and illness attitude variables by longitudinally assessing such variables and thus determining cause/effect of relationships; and 2) test the model posited in Figure 10.1.

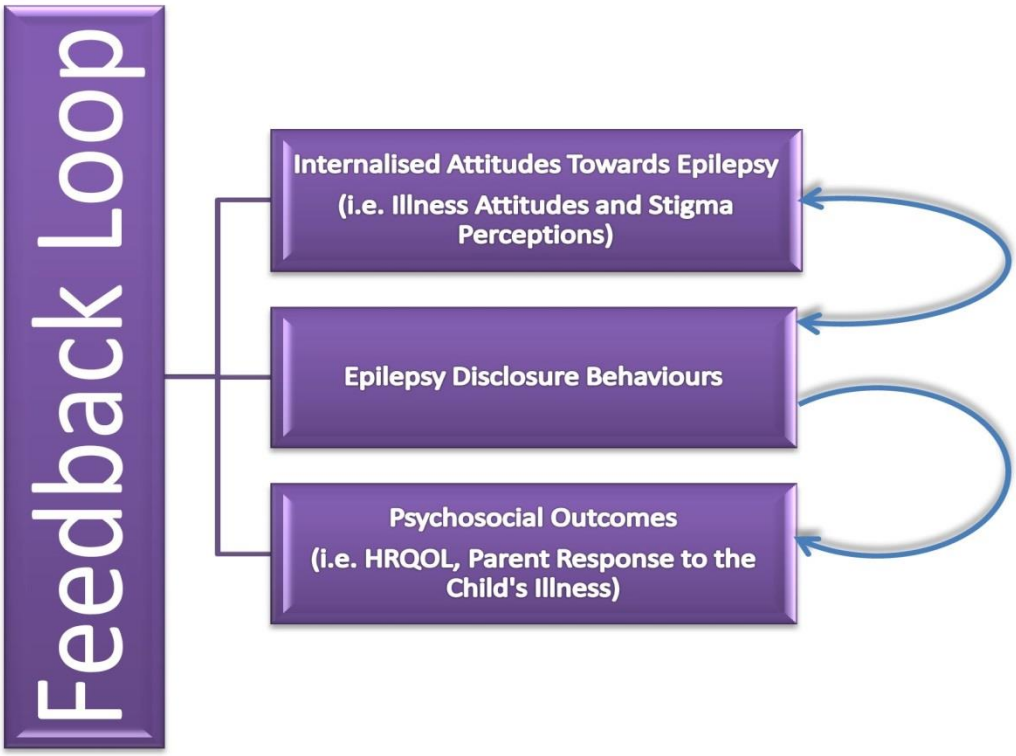

Figure 10.1: A Preliminary Model Explaining the Relationships between Epilepsy Disclosure Behaviours, Internalised Attitudes towards Epilepsy and Psychosocial Outcomes

10.2.5.2 Stigma Coaching and the Role of Child/Parent Epilepsy-Related Communication

A final finding of particular interest that emerged with regard to the fourth central aim of the present study relates to the concept of parental stigma coaching. In the qualitative phase of the study, consistent with previously limited empirical evidence in this regard (Kleck, 1968), there was some evidence of parental stigma coaching, with CWE reporting that one of the key challenges associated with epilepsy disclosure pertained to their parents' perceptions that epilepsy was something that should be kept private. In the second, quantitative phase of the study, a number of findings provided further support for the concept of parents as potential stigma coaches in the lives of their CWE. For instance, greater epilepsy concealment amongst CWE was correlated with their parents: 1) also reporting higher levels of epilepsy concealment; and 2) perceiving greater epilepsy-related stigma. Additionally, higher levels of epilepsy concealment amongst CWE was also associated with CWE reporting that they communicated to a lesser degree about their epilepsy with both parents, as well as with their mothers and fathers individually. These findings collectively indicate that CWE may internalise cues based on their parents' communicative behaviours surrounding epilepsy, within and external to the context of the family home, with parental silence surrounding the child's epilepsy conveying to CWE that their epilepsy condition is something to be ashamed of and that it should not be

spoken about. The potential role that parents may play in stigma coaching their CWE warrants further investigation because it is probable that, in most instances, it is not the intention of parents to transmit such a message to their CWE. Indeed, it is very possible that parents of CWE are unaware that their communicative behaviours surrounding the child's epilepsy can have such an effect on their CWE. Thus, parental stigma coaching is a disclosure challenge that could likely be addressed by HCPs and support organisations during their engagements with families living with epilepsy. Furthermore, the relationship between CWE's and parents' communicative patterns internal and external to the nuclear family surrounding the child's epilepsy requires attention because, to the author's knowledge, the present study denotes the first explication of such relationships.

10.3 Conclusions

In summary, in considering the data in an integrative fashion, there was evidence that the findings across both phases of the study largely converged, further reinforcing the salience of certain aspects of CWE's and parents' epilepsy disclosure behaviours. However, the two-phased mixed method sequential exploratory design employed in the present study enabled the researcher to not only obtain a more complete understanding of the complex phenomenon of epilepsy disclosure amongst CWE and parents of CWE; each phase of the study also offered unique insights and contributions to empirical knowledge where complementarity or silences across phases occurred. Thus, the findings lend further support to the notion that mixed methods research designs enable researchers to more comprehensively address research problems than single method studies, particularly in the domain of research in the context of healthcare (Farquhar et al., 2011).

Key findings to emerge on examination of the data across both study phases were as follows: 1) the motivational systems underlying CWE's and parents' epilepsy disclosure behaviours are fundamentally different - a finding that has important implications for practice; 2) the media, the emotional impact of epilepsy and the complexity of epilepsy are factors that play a particularly salient role in influencing CWE's and parents' epilepsy disclosure decisions; 3) the consequences of epilepsy disclosure to others external to the nuclear family are mostly positive; 4) epilepsy concealment is largely associated with negative outcomes for CWE and parents; 5) parents can advertently or inadvertently stigma coach their CWE by creating a culture of silence around the child's epilepsy; and 6) CWE's and parents' communicative patterns internal and external to the nuclear family surrounding the child's epilepsy are significantly related.

Chapter 11: Conclusions

11.0 Introduction

In this concluding chapter of the thesis, the original contribution the present study makes will be considered, the strengths and limitations of this sequential exploratory two-phased mixed-method study will be identified and implications of the findings will be outlined.

11.1 The Original Contribution of the Present Study

The core contributions this doctoral thesis makes in the domains of theoretical knowledge, empirical evidence, method, research context (i.e. the setting or domain in which research is undertaken) and knowledge of practice (i.e. what the findings reveal in terms of the phenomenon under investigation, how such findings can be applied and their implications for clinical practice) are outlined in table 11.1 below (adapted from Farndale, 2004). More specifically, contributions are delineated in terms of whether they contribute to the aforementioned domains by: 1) supporting previous research or literature; 2) developing and/or expanding on previous research or literature; or 3) denoting new and original contributions to empirical research and clinical practice.

In the domain of theoretical knowledge, the present study made an original contribution as it represents the first study to posit a model depicting the directionality of quantitative associations between CWE's and parents' epilepsy disclosure behaviours and: 1) their internalised attitudes towards epilepsy (i.e. stigma perceptions and illness attitudes); and 2) psychosocial outcomes (HRQoL and parental response to the child's illness). This model provides a tentative foundation for theory surrounding child and parental epilepsy disclosure behaviours and the consequences of the adoption of specific disclosure management strategies. Furthermore, the findings from the present study support a number of propositions underlying theories previously postulated in the context of adult epilepsy (i.e. the Hidden Distress Model [Scambler, 1989]) or other CSIs such as Chaudoir & Fisher's DPM (2010) and Petronio's CPM theory (2002), with the present study considering the applicability of such propositions to CWE and parents of CWE for the first time.

In terms of the original contribution the present study makes to empirical evidence, a number of previously unidentified contextual and situational factors that play a role in informing the disclosure decisions of CWE and parents of CWE by enabling or acting as barriers to disclosure were identified. Factors that were identified for the first time in the present study as enabling epilepsy disclosure amongst CWE and parents of CWE included media coverage of epilepsy, specific seizure characteristics amongst CWE (i.e. mild or infrequent seizures) and CWE's or

parents' level of knowledge about epilepsy. Novel barriers to disclosure revealed in the present study were inclusive of CWE's and parents' emotions surrounding the child's epilepsy and epilepsy's perceived absence in the media and in the public domain. In addition, empirical evidence pertaining to the consequences of the adoption of various disclosure management strategies was explicitly gathered for the first time, whereby it was revealed that others largely responded in a positive or kind manner to epilepsy disclosure and negative responses to disclosure were uncommon. The findings from this study also provide more nuanced insights into how CWE and their parents navigate the complex disclosure process in terms of the disclosure management strategies they adopt, who they select as disclosure targets (and perceived personal characteristics of individuals that discourage [e.g. unreliable] or encourage [e.g. trustworthy] CWE or parents to disclose to such individuals) and the content and situational context of their disclosure exchanges with others. Prior empirical evidence pertaining to these aspects of disclosure in the context of childhood epilepsy reflected that conceptualisations of the epilepsy disclosure process were only in their infancy and required further development. Furthermore, the findings of the present study identified unique findings with regard to the significance of relationships between CWE's epilepsy disclosure behaviours and complex partial or tonic seizure types, as well as their age at illness onset, time since diagnosis, HRQoL, illness attitudes, stigma perceptions, self-perceptions in the domains of athletic competence and behavioural conduct and level of epilepsy-related communication with their parents. In addition, novel findings were revealed in relation to the emergence of significant correlations between parental epilepsy disclosure behaviours and their CWE's complex partial seizure type, as well as parents' stigma perceptions, response to the illness, perceived social support from family and friends, and level of epilepsy-related communication with their CWE. Finally, phase two of the present study explored child and parental disclosure behaviours surrounding a child's epilepsy condition from a dyadic perspective for the first time, whereby a significant relationship was revealed between CWE's and parents' epilepsy disclosure behaviours. It was identified that CWE's epilepsy disclosure behaviours were related to parental stigma perceptions, parental responses to the illness, parents' perceived social support, parent-reported impact of epilepsy and parents' need for epilepsy-related information. Moreover, parents' epilepsy disclosure behaviours were related to CWE's HRQoL in the domain of worries and concerns.

In relation to where the present study makes perhaps the most significant and impactful original contribution, with reference to method, two new quantitative instruments were developed during the course of the present study, namely the youth and parent versions of the Epilepsy Disclosure Scale (EDS). These two six-item measures assess the epilepsy disclosure behaviours of CWE and parents of CWE, respectively. The process of designing these instruments involved the conduct of: 1) a systematic literature review on disclosure in the context of paediatric epilepsy;

2) a scoping review to assess the feasibility of adapting existing pre-validated tools which measured disclosure in other chronic illnesses or diseases (e.g. sickle cell disorder; asthma, cancer); and 3) qualitative interviews with CWE (aged 6-16 years; *n*=29) and their parents (*n*=34). These measures underwent psychometric evaluation to assess their appropriateness, with the suitability, validity and reliability of such measures supported by positive indicators, such as a high Cronbach's Alpha (representative of good internal consistency) and the confirmation of a number of hypothesised relationships between epilepsy disclosure and psychosocial and illness attitude variables (demonstrative of their convergent validity). Prior to the development of these instruments, no measures existed that could suitably and comprehensively capture complex disclosure behaviours amongst populations living with epilepsy.

With reference to the study's original contribution in terms of the research context, to the author's knowledge, this study denotes the first study within an Irish context to capture the voices and lived experiences of CWE and their parents. Additionally, this is the first study internationally to be conducted with the primary aim of examining the disclosure behaviours and experiences of child and parent populations within the context of epilepsy. Prior to the conduct of the present study, child and parental epilepsy disclosure had either been assessed as a sub-focus or lesser component of larger quantitative studies or findings pertaining to disclosure amongst such populations had emerged as incidental findings in qualitative studies that were exploring broader topics.

Finally, in relation to the contribution the present study makes in terms of knowledge of practice, the present study provides key insights into how families living with epilepsy navigate the disclosure process, and the factors that challenge or enable their epilepsy disclosure to others external to the nuclear family. Based on such insights, findings from this study will inform elements of the National Epilepsy Care Programme which was developed in 2011 with the purpose of improving care and the QOL of individuals living with epilepsy in Ireland across all aspects of their lives. Furthermore, findings from this study will facilitate and inform the development of an evidence-based website (www.talkingaboutepilepsy.com) that will serve as a resource for: 1) families living with epilepsy as they navigate the complex disclosure process; and 2) HCPs, school personnel, peers and other individuals commonly identified as being likely disclosure targets for CWE and/or parents of CWE. These aspects will be discussed further in section 11.3.

Table 11.1: Original Contribution of the Present Study

Domains of Contribution	**Supported**	**Developed**	**New**
Theoretical Knowledge	-Support for conceptualisations of felt-stigma, i.e. diagnosis concealment as an implicit expression of internalised stigma. -Supports theoretical perspectives that argue that distinctions should be made between conspicuous and concealable stigmatised identities when considering the ramifications of stigma and the disclosure process for individuals with visible versus invisible stigmatised identities (Joachim & Acorn, 2000). -Support for the concept that a *cycle of invisibility* encircles epilepsy (Lewis & Parsons, 2008), whereby individuals with epilepsy dislike the silence that surrounds epilepsy but actively contribute towards such silence by keeping their condition hidden from others, which serves to reinforce negative public perceptions of epilepsy and exacerbate epilepsy-related stigma.	-The use of previously posited disclosure management strategies as a framework under which to investigate disclosure experiences within the context of paediatric epilepsy.	-Examines previously unexplored relationships between CWE's and parents' disclosure behaviours and their internalised attitudes towards the illness (i.e. stigma perceptions and illness attitudes) and psychosocial outcomes (HRQoL and parents' responses to CWE's illness), which provide a tentative foundation for theory surrounding child and parental epilepsy disclosure behaviours and the consequences of the adoption of specific disclosure management strategies.

Table 11.1: Original Contribution of the Present Study

Domains of Contribution	**Supported**	**Developed**	**New**
Theoretical Knowledge (continued)	-Supports the applicability of the propositions underlying Scambler's Hidden Distress Model (1989) to populations of CWE and parents of CWE - i.e. as a consequent net effect of attempts to pass as 'normal' and to avoid enacted stigma by concealing the child's epilepsy child's condition from others, felt stigma, and the fear of enacted stigma, is more disruptive to the lives of CWE and parents of CWE than enacted stigma. -Support for the following propositions which underpin the DPM (Chaudoir & Fisher, 2010) that has been posited as a framework under which to examine when and why interpersonal disclosure of a CSI may be beneficial: 1) a feedback loop exists whereby prior disclosures determine and inform future disclosures; 2) the alleviation of inhibition mechanism, changes in social information and social support are distinct processes that mediate disclosure outcomes at individual, dyadic and social contextual levels.		

Table 11.1: Original Contribution of the Present Study

Domains of Contribution	**Supported**	**Developed**	**New**
Theoretical Knowledge (continued)	-Supports a number of the propositions underlying Petronio's CPM theory (2002) which was posited as a framework to consider how individuals make decisions to disclose private information to others and how this interpersonal process is co-ordinated. In particular, support was garnered for the following tenets of this theory in the context of paediatric epilepsy: 1) people employ privacy management rules which determine the ranges of privacy boundaries; 2) there is the assumption that co-owners of the private information will follow existing privacy management rules; 3) turbulence occurs subsequent to violations of privacy boundaries; and 4) in the development of privacy management rules, a key decision criterion considered is the risk-benefit ratio analysis criterion.		

Table 11.1: Original Contribution of the Present Study

Domains of Contribution	**Supported**	**Developed**	**New**
Empirical Evidence	Supports previous qualitative research that has indicated that disclosure is a challenge, a stressor and a QOL issue for populations living with concealable stigmatised identities.	Develops a more nuanced understanding of how CWE and parents of CWE navigate the complex epilepsy disclosure process and of the situational and contextual factors involved in their selection of specific disclosure management strategies.	-The identification of previously unidentified: disclosure targets (and perceived personal characteristics that encourage or discourage disclosure to specific individuals); situational contexts under which disclosure exchanges with others unfold; content of disclosure exchanges; and barriers and enablers to epilepsy disclosure, for CWE and parents of CWE. -Investigates the emotions implicated in the disclosure process for CWE and parents. -Examines the consequences of CWE's and parents' disclosure of the child's condition. -Explicates the relationship between child and parental epilepsy disclosure behaviours and demographic, clinical, psychosocial and illness attitude variables. -Explores the relationship between child and parental epilepsy disclosure behaviours. -Assesses the relationships between CWE's epilepsy disclosure behaviours and parent-reported psychosocial/illness attitude variables; as well as the relationships between parental epilepsy disclosure behaviours and child-reported psychosocial/illness attitude variables.

Table 11.1: Original Contribution of the Present Study

Domains of Contribution	**Supported**	**Developed**	**New**
Method	-Supports the use of an exploratory mixed methods research design in healthcare research. -Supports the use of creative methods as a stimulus for conversation in child interviews where sensitive topics are under investigation.		-The development and psychometric testing of two new quantitative instruments (EDS – youth and parent versions) to assess child and parent disclosure behaviours. -The development of survey items which enabled the quantitative assessment of CWE's and parents' disclosure management strategies, disclosure targets, the content and situational context of disclosure exchanges, enablers and barriers for disclosure, reasons for epilepsy disclosure or concealment, emotions implicated in the disclosure process and consequences of disclosure.
Research Context	Supports research in the context of concealable stigmatised identities.	Expands on limited research pertaining to disclosure in the context of paediatric epilepsy.	-Represents the first study (internationally) to explore epilepsy disclosure with CWE and parents of CWE as a primary focus -Represents the first study within an Irish context to capture the perspectives of CWE and parents of CWE with regard to living with the chronic neurological disease.
Knowledge of Practice	Supports a growing body of work examining disclosure and the implications of the adoption of specific disclosure management strategies amongst populations with concealable stigmatised identities.	Provides insights into how families living with epilepsy navigate the disclosure process and the factors that challenge or enable them in doing so.	-The findings from this research will facilitate and inform the development of an evidence-based website (www.talkingaboutepilepsy.com) to assist CWE and parents to navigate the epilepsy disclosure process and to serve as a resource for others seeking information on how to respond to epilepsy disclosures or assist others with epilepsy disclosures.

Table 11.1: Original Contribution of the Present Study

Domains of Contribution	**Supported**	**Developed**	**New**
Knowledge of Practice (continued)			-Recommendations from this research will inform elements of the National Epilepsy Care Programme (2011) which endeavours to improve the QOL of individuals living with epilepsy.

11.2 Strengths and Limitations of the Mixed Methods Study

In this section the overarching strengths and limitations of this mixed methods study are discussed (strengths and limitations for each individual study phase were outlined in sections 6.7 - Phase One - and 9.4 - Phase Two). The mixed methods design of the present study denotes a key strength of the overall study as it enabled a comprehensive investigation into the complex epilepsy disclosure process that CWE and parents of CWE engage in; a topic that had previously received inadequate attention in paediatric epilepsy literature. The qualitative phase of the study facilitated the exploration of key contextual and situational factors that played a role in influencing child and parental epilepsy disclosure behaviours – factors which informed the researcher's decisions with regard to the variables to be assessed in the second quantitative phase of the study. Also, CWE's and parents' perspectives from the qualitative phase of the study informed the development of two new scales to assess child and parental epilepsy disclosure behaviours, respectively. In contrast, the quantitative phase of the study offered its own unique insights into key aspects of child and parental epilepsy disclosure behaviours, e.g. findings with regard to the extent to which CWE and parents spoke to particular categories of individuals about the child's epilepsy were specific to the quantitative phase of the study. Additionally, the quantitative surveys enabled the author to explicate, for the first time, the relationship between child and parental epilepsy disclosure behaviours and child- and parent-reported demographic, clinical, psychosocial and illness attitude variables.

In spite of the strengths of the present study, a number of limitations also existed. First, across both phases of the present study, CWE, and parents of CWE, with significant intellectual or behavioural difficulties and/or any other significant medical conditions were excluded to avoid confounding findings due to how such issues can present their own unique challenges in terms of communicating with others. However, many CWE also present with co-morbid cognitive, behavioural and/or medical difficulties (Pellock, 2004). Furthermore, a number of conditions that are neurological, somatic or psychiatric/neuropsychiatric in nature tend to co-exist with epilepsy (Ekinci, Titus, Rodopman, Berkem & Trevathan, 2009; Tellez-Zenteno, Matijevic & Wiebe, 2005; Zaccara, 2009). Future research should endeavour to capture the perspectives of CWE with co-morbidities, and their parents, in relation to epilepsy disclosure. In order to do so, careful thought would be required when considering which data collection methods would be most appropriate in facilitating researchers to explore the epilepsy disclosure experiences of these important groups. Additionally, fathers were underrepresented in the self-selected parent populations across both phases of the study. Thus, when interpreting the findings it is important to note the over-representation of mothers which may have obscured gender perspective differences. This is particularly salient given the significant negative correlation that was

revealed between CWE's epilepsy disclosure and their level of epilepsy-related communication with their fathers in phase two of the study. The absence of fathers' voices in paediatric research is well-documented (Phares, 1992; Phares, Lopez, Fields, Kamboukos & Duhig, 2005) and at times is a product of lower levels of paternal involvement in childrearing (Phares, Fields & Kamboukos, 2009). Future research should aim to: 1) specifically capture the voices of fathers; and 2) assess the disclosure behaviours of this elusive population, and elucidate whether such behaviours are linked to CWE's epilepsy disclosure behaviours and their psychosocial wellbeing. Finally, the cross-sectional nature of the present study denotes a further limitation because it only enabled exploration into CWE's or parents' epilepsy disclosure at a given point in time. Thus, it was not possible to assess whether CWE's and parents' epilepsy disclosure behaviours or other aspects of epilepsy disclosure (e.g. disclosure targets, and the content and situational context of disclosure exchanges) remained consistent or whether they changed over time. Furthermore, the causality of specific relationships between CWE's and parents' epilepsy disclosure behaviours and other variables could not be determined; that is, only correlational relationships could be identified.

Whilst limitations for the present study existed, because of the very difficult nature of accessing CWE and parent of CWE populations in the absence of a national epilepsy database or register, it is posited that rather than being actual weaknesses of the study and substantially detracting from the value of the findings in the present study, the limitations are issues that researchers could aim to address within future studies.

11.3 Implications of the Findings of the Present Study

In this section, the implications of the findings of the present study will be highlighted with regard to implications for practice, future research, education and policy.

11.3.1 Implications for Practice

In considering the practical implications of the findings of the present study, a number of key recommendations for practice can be made:

- Offering HCPs and support organisation personnel insights into common disclosure targets for CWE and parents of CWE, and the likely content and situational contexts of CWE's and parents' epilepsy disclosure exchanges with others external to the nuclear family (as identified in the present study) is important in terms of enabling such individuals to equip and prepare CWE and their parents to navigate disclosure exchanges with others in such circumstances.

- Considering the challenge that epilepsy disclosure represents for CWE and their parents, discussion of the topic during child and parental engagements with HCPs and/or support organisations should occur. In particular, a number of valuable insights have been provided in the present study into the aspects of disclosure that pose issues for CWE and their parents (e.g. the emotional implications of the diagnosis, CWE's inability to verbally represent the condition to others, parental stigma coaching and the invisibility of the condition). In helping families living with epilepsy to overcome such challenges through the provision of tailored support and assistance informed by the findings of this research, HCPs and support organisations could consequently improve the psychosocial wellbeing of CWE and their parents.
- In reflecting on the *cycle of invisibility* that encircles epilepsy (Lewis & Parsons, 2008), one could infer that increasing disclosure likelihood amongst PWE could represent an avenue via which to tackle persistent remnants of epilepsy-related stigma in modern day society. Implementing key insights gleaned from the present study with regard to enabling factors for disclosure into practice could result in the endorsement of more open disclosure polices by CWE and parents of CWE which, in turn, could serve to enhance public familiarity with epilepsy; dispelling misconceptions and improving public knowledge and attitudes towards epilepsy. In particular, the author posits that increasing accurate media coverage of epilepsy, and identifying role models and famous PWE who are willing to publicly speak up about it and empower others, could work towards tackling this *cycle of invisibility*.
- There is an apparent need for HCPs to be cognisant of the language they utilise during clinical appointments, particularly in reference to how they discuss epilepsy with CWE. Overly complex language and medical jargon should be avoided by HCPs or support organisation personnel when speaking with CWE about epilepsy because such language has the potential to result in misunderstanding and only exacerbates the difficulties CWE may have in verbalising the complex neurological disease. Parents can also be involved in the process of helping their CWE to understand their condition. Epilepsy Ireland (EI) currently have a brochure on their website (www.epilepsy.ie) that offers parents advice on how to talk to children about epilepsy. However, to access this resource, it is likely that one would already have to be engaged with this support organisation. Thus, it could be beneficial for HCPs to refer parents to this resource if they perceive that CWE are struggling to understand their epilepsy.

11.3.2 Research Implications

Recommendations for future research include the following:

- Longitudinal research is required to: 1) examine whether the disclosure management strategies adopted by CWE and parents of CWE change over time (and if so, whether it is more common for CWE and parents to become more open or more secretive about the child's epilepsy over time); 2) tease out the long-term consequences of specific disclosure management strategies for CWE and parents of CWE; 3) explore whether the adoption of concealment and/or selective disclosure management strategies by CWE and/or parents of CWE serve to protect the child's psychosocial wellbeing or whether they result in negative long-term outcomes for CWE.
- The perspectives of the following groups should be systematically captured in relation to epilepsy disclosure: 1) fathers of CWE; 2) culturally diverse CWE and parents of CWE (to investigate whether culturally specific differences exist in child and parental epilepsy disclosure behaviours); 3) CWE with well-controlled epilepsy (or epilepsy in remission) and their parents; and 4) CWE with co-morbid medical, psychiatric/neuropsychiatric, behavioural or cognitive issues and their parents.
- Future research should endeavour to elucidate whether CWE's epilepsy disclosure behaviours are related to (or predicted by) the following: 1) their disclosure ability; 2) their perceptions that parents and/or others are hypervigilant about their epilepsy.
- Future research should explore whether parents are cognisant of their potential role as "stigma coaches" for their CWE.
- The replicability of the findings of the present study should be assessed in studies with larger sample sizes.
- The directionality of relationships between child and parental epilepsy disclosure behaviours and psychosocial (e.g. HRQ OL and parent response to the child's illness) and illness attitude (e.g. stigma perceptions) variables should be explicated.
- The role perceived social support plays in parental epilepsy disclosure behaviours should be further investigated.
- Emphasis should be placed on identifying how felt or internalised epilepsy-related stigma can best be eradicated amongst CWE and parent of CWE populations.

11.3.3 Implications for Education

With regard to implications for education, the following is recommended:

- For both CWE and parents of CWE, the level of epilepsy-related knowledge they possessed encouraged epilepsy disclosure, whilst for CWE, their perceived lack of

competence in their ability to epilepsy to others denoted a barrier to disclosure. Thus, educating CWE and their parents about the child's epilepsy and equipping them with accessible information about the child's complex neurological disease (which they can subsequently impart to others during disclosure exchanges) would seem critical.

- Parents of CWE, HCPs and epilepsy support organisation personnel should ensure that CWE: 1) comprehend their epilepsy condition to the best of their ability; and 2) are capable of talking about and explaining their epilepsy to others.
- The findings from the present study reinforce the fact that work is still required to improve public knowledge and understanding of epilepsy. Thus, the findings indicate that there is a need for the widespread dissemination of information about epilepsy to members of the public, particularly with reference to specific seizure symptomatology and the consequences of the condition. In disseminating epilepsy-related information, particular emphasis should be placed on enhancing public awareness of the fact that epileptic seizures manifest in varying ways and ensuring that others recognise seizure symptomatology in PWE. For CWE, this is particularly important in the context of the school environment. Thus, teachers and school personnel should be particular targets of educational campaigns surrounding epilepsy.

In order to address some of the aforementioned education issues and to support the translation of research evidence into practice, subsequent to the completion of this study, the intention is to develop a suite of educational and informative resources based on the empirical evidence unearthed in the present study with regard to child and parental epilepsy disclosure. Accessibility, appropriateness and equitability will be central to all developed resources which will be delivered online via a designated website (www.talkingaboutepilepsy.ie).

The resources will be tailored and accessible to different target audiences which will include: CWE; parents of CWE; clinicians who provide paediatric epilepsy services including but not limited to epileptologists, neurologists, paediatricians and clinical epilepsy nurse specialists; other professionals who engage with CWE (e.g. schoolteachers and special needs assistants); voluntary support organisations and public advocates for epilepsy (e.g. Epilepsy Ireland); and members of the general public (e.g. CWE's peers or extended family members). The use of a web-based platform will afford flexibility and creativity in delivering the information and education materials in such a way that will accommodate different learning styles and literacy levels; including health and I.T. literacy.

While the website content will be derived from the empirical findings of the present study, various technological mediums will be used to disseminate data and educate others. A pragmatic approach will be adopted and there will be no costs to knowledge users to access

resources as familiar technologies will be used (e.g. YouTube, iBooks Author, iBooks and SoundCloud, Layar – Augmented Reality, and Comic Life). Resources will be intuitive to use; however, where necessary, instruction and guidance for users will be devised.

To assist with the selection of technological mediums and with the process of design, development and evaluation of the learning resources, a small group of knowledge users (i.e. CWE and their parents, paediatric epileptologist(s)/neurologist(s), epilepsy nurse specialist(s), Epilepsy Ireland staff and the national clinical lead in epilepsy) will be created. It is envisaged that this group would naturally evolve into a sustainable Community of Practice (CoP) (i.e. a group of people with a common interest who interact, learn about and shape best practice; Hildreth & Kimble, 2002); the focus of which will be to improve/evaluate the care and support offered to CWE and their parents as they navigate the complex disclosure process. Such CoP's have previously been successfully established and sustained (e.g. www.happybones.ie and www.bonehealth.co).

11.3.4 Implications for Policy

At a policy level, based on the findings of the present study, the following is recommended:

- Findings from this study should inform elements of the National Epilepsy Care Programme (implemented in 2011). Primary objectives of this programme are to improve: 1) access to expert epilepsy-related care and information; and 2) quality of epilepsy-related care across the healthcare spectrum. In endeavouring to meet such objectives, the provision of emotional support to CWE and parents of CWE at the time point of diagnosis as they come to terms with and grapple with the consequences of the epilepsy diagnosis is highly recommended. It would be hoped that, by receiving support during this critical period, not only would CWE and parents adjust more positively to the condition, but also they would be better enabled to disclose the child's epilepsy to others.
- Currently, CWE struggle to identify and access similar others (i.e. other CWE or adult PWE) which only serves to exacerbate feelings of differentness; a factor which deters epilepsy disclosure. Epilepsy support organisations (such as Epilepsy Ireland) should take cognisance of the need to develop support groups, peer mentoring or buddy systems, specifically for CWE (in the form of either monitored online forums or face-to-face meetings) in order to facilitate CWE's identification with similar others and to empower CWE. Mentoring, peer-led interventions and buddy systems have proven useful in the context of other chronic illnesses in childhood and adulthood such as diabetes, asthma, spina bifida and HIV (Merianos, King, Vidourek & Nabors, 2015; Rotheram-Borus et al., 2012; Williams et al., 2006); however, to the author's

knowledge, no such options are available to CWE (particularly those in the younger age category) within an Irish context.

11.4 Concluding Comments

This study presents the first in-depth investigation into the topic of epilepsy disclosure amongst CWE and parents of CWE. A two-phased mixed methods sequential exploratory design was employed to: 1) explore the disclosure experiences and behaviours of CWE and parents of CWE; and 2) assess the relationship between child and parental epilepsy disclosure behaviours and child- and parent-reported demographic, clinical, psychosocial and illness attitude variables. The present study makes an original contribution because it provides unique insights into the disclosure process engaged in by CWE and their parents, and additionally the factors implicated in CWE's and parents' epilepsy disclosure to others external to the nuclear family. Furthermore, it substantiates the very limited empirical evidence that existed prior to the conduct of this study by reinforcing the fact that epilepsy disclosure represents a challenge and stressor for CWE and parents of CWE. Finally, the findings from this research suggest for the first time that there is a relationship between CWE's and parents' epilepsy disclosure and their internalised attitudes towards epilepsy and psychosocial wellbeing, findings which have significant clinical implications. By disseminating empirical evidence from this research to HCPs and support organisation personnel, they will be better placed to assist CWE and parents of CWE to navigate the complex epilepsy disclosure process. This could subsequently improve the psychosocial wellbeing of CWE and their parents, and furthermore contribute towards breaking the *cycle of invisibility* that encircles epilepsy.

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Appendices

Authors (year)/Country	Aim/objective	Design	Data collection	Sample	Details of disclosure measures (if applicable)
Abulhamail et al. (2014) Saudi Arabia	Examined primary school teachers' knowledge and attitudes towards epilepsy and identified areas where further teacher training and education were required	Cross-sectional quantitative	Survey questionnaires	Teachers N=615 primary school teachers (47% male, 53% female; mean age=36.0 years) in public (58%) or private (42%) schools; 28% of whom had knowingly taught a child with epilepsy	Not reported.
Austin et al. (2004) USA	Examined the psychometric properties of two scales developed to measure felt stigma in children with epilepsy and their parents	Cross-sectional quantitative	Structured computer-assisted telephone interviews	Children *n*=173 children with chronic epilepsy Mean age=11.8 years Parents *n*=173 parents of children with chronic epilepsy *n*=224 parents of children with new-onset seizures *No items captured disclosure of epilepsy on the parent stigma scale	Two items on the child stigma scale examined aspects of disclosure (i.e., secrecy and conversation avoidance). This scale demonstrated strong internal consistency (α=.81) and construct validity.
Baker et al. (2008) International study conducted across 16 countries	Investigated the impact of epilepsy and its treatment on quality of life, depression and opportunities for children/teenagers with epilepsy	Cross-sectional quantitative	Survey questionnaires	Children *n*=212 young people with epilepsy Mean age=15 years (74% aged 12+; 23% aged < 12; 3% did not report age) Parents *n*=507 parents/caregivers	Not reported.
Bannon et al. (1992) UK	Examined teachers' attitudes, perceptions and knowledge/awareness of childhood epilepsy	Cross-sectional quantitative	Survey questionnaires	Teachers N=142 teachers (44 male, 98 female) in 12 mainstream schools; 57% of whom had knowingly taught a child with epilepsy	Not reported.
Butau & Piachaud (1993) Zimbabwe	Assessed knowledge and beliefs about epilepsy in mothers of children with epilepsy, as well as maternal attitudes towards the child with epilepsy, and maternal engagement with services	Cross-sectional quantitative	Semi-structured interviews guided by questionnaires	Parents N=22 mothers of children with epilepsy	Parental attitudes towards disclosure (to teachers specifically) were measured by parents rating the following statement on a 5-point Likert scale (with a score of 5 indicative of the highest level of agreement with the statement): "Parents should talk to the child's school teacher about his/her epilepsy"
Chen et al. (2010) Taiwan	Explored the lived experiences of school-aged children living with epilepsy in Taiwan	Qualitative exploratory phenomenological	Semi-structured interviews	Children *n*=15 children with well-controlled epilepsy Aged 7-12 years Mean age=9.6 years Epilepsy diagnosis ≥6 months	Not applicable (a qualitative study).

Authors (year)/Country	Aim/objective	Design	Data collection	Sample	Details of disclosure measures (if applicable)
Coulter & Koester (1985) USA	Tested the hypothesis that there are unmet needs amongst parents of children with epilepsy due to a lack of appreciation of what parental needs are amongst physicians	Cross-sectional quantitative	Interviews/Q-Sort methodology	Parents *n*=24 primary caregivers (19 mothers, 4 fathers and 1 grandmother) of children with epilepsy aged 6-16 years (mean age=9.4 years) Physicians *n*=5 physicians who were faculty members of the department of neurology or still involved in neurological training, all of whom had direct experience in caring for children with epilepsy	The following items pertaining to disclosure, identified as concerns by parents, were ranked by parents and physicians in terms of degree of concern (where -4 was indicative of no concern and +4 was indicative of very concerned) to assess parent-physician agreement: -'Telling teacher about child's epilepsy' -'How to talk to friends about child's seizures'
Gazibara et al. (2014) Serbia	Assessed parental knowledge, attitudes and behaviours in those living with a child with epilepsy	Cross-sectional quantitative	Survey questionnaires	Parents *n*=213 parents (aged 24-69 years) of children with epilepsy aged ≤6-18 years (mean age=13.4 years)	Attitudes towards disclosure were measured by one item on a parental attitudes scale with parents rating the following statement on a 5-point Likert scale (higher scores denote higher levels of agreement with the statement): "I want my family and friends to know that my child is suffering from epilepsy."
Hanai (1996) Japan	Examined problems in daily life for children with epilepsy, the level of understanding of families and teachers of children living with epilepsy, and need for medical care	Cross-sectional quantitative	Survey questionnaires	Parents *n*=344 parents/family members of children living with epilepsy 73% of these children attended ordinary classes; 27% attended special classes or schools for disabled children Teachers *n*=1808 teachers in Japan	Not reported.
Hightower et al. (2002) USA	Explored school-aged children's perspectives of the impact of epilepsy on their lives	Qualitative descriptive	Semi-structured interviews	Children N=8 CWE Aged 9-12 years Diagnosed with epilepsy for at least 1 year; AED prescription	Not applicable (a qualitative study).
Hoare & Russell (1995) UK	Adapted a pre-existing questionnaire in order to facilitate a more holistic assessment of the impact of epilepsy on the quality of life of children with epilepsy and their families; and provided a preliminary evaluation of the questionnaire via testing with a selected group of families of CWE.	Cross-sectional quantitative	Questionnaires	Parents N=21 parents of children with chronic epilepsy (minimum treatment duration of 2 years) aged 6-17 years Mean age=11 years *Proxy-reports provided by parents for their children	As part of a section of the 'Impact of Childhood Illness Scale' that looks at the impact of the illness on the parents, parents were asked to rate the following statement on a 3-point Likert scale in terms of: (1) how frequently the problem arises; and (2) how much concern the problem causes: "It is difficult to explain my child's illness to others."

Authors (year)/Country	Aim/objective	Design	Data collection	Sample	Details of disclosure measures (if applicable)
Hoare et al. (2000) UK	Evaluated an instrument in terms of its efficacy in assessing quality of life among children with epilepsy or diabetes and their families; and compared the quality of life of children with epilepsy and their families to that of children with diabetes and their families	Cross-sectional quantitative	Questionnaires	Parents *n*=102 parents of children with epilepsy (mean age=9.66 years) *n*=148 parents of children with diabetes (mean age=12 years) *Proxy-reports provided by parents for their children	As part of a section of the 'Impact of Childhood Illness scale' that examines the impact of the illness on the parents, parents were asked to rate the following statement on a 3-point Likert scale in terms of: (1) how frequently the problem arises; and (2) how stressful or important the problem is: "It is difficult to explain my child's illness to others."
Hodgman et al. (1979) USA	Investigated the coping skills employed by adolescents with epilepsy with respect to family, school and social functioning; and medical care	Exploratory cross-sectional quantitative	-Semi-structured interviews (answers quantitatively scored on a three-point scale) -Neurologic rating and seizure control quantitatively scored on a five-point scale.	Children *n*=25 CWE with a diagnosis of grand mal epilepsy Aged 14-18 years Mean age=16.4 years Parents The parent(s) of the recruited children. *Disclosure of the child's diagnosis to those external to the nuclear family seemingly not examined for the parent population.	Not reported.
Holdsworth & Whitmore (1974) UK	Examined the level of information about epilepsy and attitudes towards epilepsy possessed by teachers of children attending ordinary schools	Qualitative descriptive	Survey questionnaire	Teachers The head-teachers and class-teachers of 85 children with epilepsy attending 60 ordinary schools	Not applicable (a qualitative study).
Houston et al. (2000) UK	Investigated what children with epilepsy, asthma or diabetes knew about their condition, where they obtained this information from and how they felt the condition affected their life	Qualitative exploratory	Semi-structured interviews	Children with Epilepsy *n*=22 CWE (i) 5-10 years (*n*=13) (ii) > 10 years with a learning difficulty; developmental level of a 5-10 year old (*n*=9) Children with Asthma *n*=10 children Aged 5-10 years Children with Diabetes *n*=10 children Aged 5-10 years	Not applicable (a qualitative study).

Authors (year)/Country	Aim/objective	Design	Data collection	Sample	Details of disclosure measures (if applicable)
Jantzen et al. (2009) Germany	Developed the content and structure of the FLIP&FLAP epilepsy programme and evaluated the outcomes of the programme in terms of its efficacy in increasing knowledge of epilepsy, reducing parents' epilepsy-related worries, improving children's self-management skills, independence and communication skills, and enhancing health-related quality of life	Mixed-method, feasibility study	Development of the programme: -*Phase 1 (Programme development):* Exploratory interviews -*Phase 2 (Programme piloting):* Interviews, focus-groups, video feedback Programme Evaluation: Questionnaires/Telephone interviews	Development of the programme-Children -*Phase 1: n*=7 children/adolescents with epilepsy aged 8-18 years -*Phase 2: n*=37 children/adolescents with epilepsy Development of the programme-Parents -*Phase 1: n*=7 mothers of children with epilepsy aged 8-18 years -*Phase 2: n*=54 parents of children with epilepsy Programme Evaluation-Children* -*Intervention group: n*=65 children/adolescents with epilepsy aged 8-16 years -*Waiting control group: n*=70 children/adolescents with epilepsy aged 8-16 years Programme Evaluation-Parents* -*Intervention group: n*=72 parents of children/adolescents with epilepsy aged 8-16 years -*Waiting control group: n*=72 parents of children/adolescents with epilepsy aged 8-16 years *Figures reflect final numbers participating at follow-up (loss to follow-up was less than 10% in all subgroups of the sample)	In the quantitative evaluation component of the study, the child and main carer were asked to rate the ability of the child to explain his/her epilepsy well to others (disclosure ability) on a 5-point response scale.
Kleck (1968) USA	Examined self-revelation patterns of people with epilepsy, who had their seizures under medication control	Mixed-method, exploratory, cross-sectional	-Self-disclosure questionnaire -Interviews	Adult – Questionnaires *n*=32 adults living with epilepsy Adult - Interviews *n*=18 adults living with epilepsy	A self-disclosure questionnaire comprising 24-items assessed the extent to which adults with epilepsy confided in others about six topic areas: (1) tastes; (2) attitudes; (3) interpersonal relations; (4) personality; (5) concern with appearance; and (6) health problems.
Kwong et al. (2000) China	Investigated problems faced by children with epilepsy at home and in school, the degree to which the condition was understood by families and the need for improvement	Cross-sectional quantitative	Questionnaires	Parents N=86 parents of CWE (aged 3-17 years; mean age=9.5 years)	Not reported.

Authors (year)/Country	Aim/objective	Design	Data collection	Sample	Details of disclosure measures (if applicable)
Lewis et al. (1990) Chile	Tested the efficacy of a child-centred, family-oriented educational program for children with epilepsy and their parents that aimed to increase children's knowledge, perceptions of competency, and skills related to dealing with seizures	Randomized controlled trial (RCT)	Pilot A child-parent educational intervention program piloted for usability /needs assessment. RCT Efficacy of child-parent educational intervention program quantitatively assessed via structured interviews five months after completion of the program. Experimental vs. control groups compared.	Pilot – Children *n*=40 CWE Aged 7-12 years Pilot - Parents Parents of the CWE (*only child outcomes examined) RCT - Children *n*=252 children Aged 7-14 years *236 CWE completed pre- & post-testing* RCT - Parents Parents of the CWE (*only child outcomes examined)	Not reported.
McEwan et al. (2004) UK	Described adolescents' experiences of having epilepsy; the impact of epilepsy on quality of life (QoL) in adolescence; and changes in QoL issues as the adolescent progresses towards adulthood	Qualitative exploratory	Focus groups	Children N=22 adolescents with epilepsy Aged 12-18 years Mean age=14 years 1 month Epilepsy diagnosis >6 months; at least one seizure in the past year	Not applicable (a qualitative study).
Mecarelli et al. (2011) Italy	Evaluated primary and secondary school teachers' level of knowledge about epilepsy and attitudes towards children with epilepsy	Cross-sectional quantitative	Structured telephone interviews	Teachers N=600 primary (*n*=300) and secondary school teachers (*n*=300) aged 22-70 years (14% male, 86% female; mean age=49.3 years); 44% of whom had knowingly taught a child with epilepsy	Teachers who reported teaching or having taught a CWE provided evidence of parental disclosure by rating the following statement in terms of frequency: "How often have you been informed by parents of the form of epilepsy their child has?"
Mecarelli et al. (2014) Italy	Investigated the impact of a nationwide educational campaign about epilepsy on Italian primary school teachers' knowledge and attitudes towards the condition	Cross-sectional quantitative	Survey questionnaires	Teachers N=582 primary school teachers aged 25-64 years (2.1% male, 97.9% female; median age=47.0 years); 47.6% of whom had knowingly taught a child with epilepsy	Teachers reported on parental disclosure practices within a school context by responding 'yes' or 'no' to the following statement: "Are you often informed by parents of the child's epilepsy?"

Authors (year)/Country	Aim/objective	Design	Data collection	Sample	Details of disclosure measures (if applicable)
Moffat et al. (2009) UK	Investigated the impact of childhood epilepsy on QoL from children's perspectives; and the concerns of children with epilepsy	Qualitative exploratory	Focus groups	Children N=22 CWE in mainstream school with epilepsy diagnosis >6 months Aged 7 to 12 years Mean age=9 years 6 months In mainstream school with epilepsy diagnosis >6 months	Not applicable (a qualitative study).
Mu (2008) Taiwan	Investigated the family health-illness transition experience from the perspective of parents of children with epilepsy	Qualitative phenomenological	Semi-structured interviews	Parents N=10 couples* who were the parents (and primary caregivers) of children aged 3-7 years who had been diagnosed and medically treated for epilepsy within the past six months *In two instances, fathers could not participate due to work commitments	Not applicable (a qualitative study).
Ojinnaka (2002) Nigeria	Examined teachers' perceptions of epilepsy in rural communities in Nigeria with respect to their knowledge, attitudes and beliefs	Cross-sectional quantitative	Survey questionnaires	Teachers N=125 primary or secondary school teachers aged 25+ years (43.2% male, 56.8% female); 23.2% of whom had knowingly taught a child with epilepsy	Any teachers who had ever taught a child with epilepsy were asked to respond to the following statement in order to assess how they came to learn about the child's condition: "I knew about the child's illness from (a) the child (b) the parent/guardian (c) when he/she had a convulsion in the class"
Pala & Vankar (1997) India	Investigated primary school teachers' attitudes towards and knowledge about epilepsy	Cross-sectional quantitative	Survey questionnaires	Teachers N=113 primary school teachers (11.5% male, 88.5% female); 27.4% of whom had knowingly taught a child with epilepsy	Not reported.
Prpic et al. (2003) Croatia	Assessed primary school teachers' level of knowledge about epilepsy and perceptions of children with epilepsy	Cross-sectional quantitative	Survey questionnaires	Teachers N=216 primary school teachers (39% male, 61% female; mean age=42 years); 100% of whom had come across a child with epilepsy during their working career	Not reported.
Roberts & Whiting (2011) Canada	Explored the perceptions and experiences of the primary caregivers of children with epilepsy regarding their interaction with schools; and aimed to identify how families think schools can best support, accommodate and prepare for children with epilepsy and their families	Qualitative phenomenological	Semi-structured interviews	Parents *n*=7 parents/caregivers of children with epilepsy aged 5-12 years (mean age=9.0 years)	Not applicable (a qualitative study).

Authors (year)/Country	Aim/objective	Design	Data collection	Sample	Details of disclosure measures (if applicable)
Ronenet al. (1999) Canada	Explored different elements of health-related quality of life in childhood epilepsy	Qualitative exploratory	Focus groups	Children *n*=29 CWE Aged 6-10 years Mean age=9.2 years In mainstream school/regular class with active epilepsy (at least two seizures in the past two years) Parents *n*=42 parents of CWE (28 mothers, 14 fathers) *No findings regarding disclosure of epilepsy reported from parent perspectives	Not applicable (a qualitative study).
Ryu et al. (2015) Korea	Examined the relationship between adolescents' perceived stigma of, and knowledge about, epilepsy and maternal perceptions of epilepsy-associated stigma	Cross-sectional quantitative	Survey questionnaires	Children *n*=243 adolescents with epilepsy Aged 13-18 years Mean age=15.1 years Middle or high school students with any type of epilepsy who had been treated for at least one year Parents *n*=243 mothers of adolescents with epilepsy	Maternal disclosure was examined via the Disclosure Management Scale (DMS). This 4-item measure was originally developed for use in adolescents with epilepsy [68] but was adapted for use in mothers in this study.
Saburi (2011) Zimbabwe	Investigated the stressors of caregivers of school-aged children with epilepsy; and explored whether parental use of community resources serves to alleviate or contributes to caregiver stress	Cross-sectional quantitative	Structured interviews	Caregivers N=46 caregivers (predominately mothers) of children with epilepsy (epilepsy diagnosis >1 year) aged 6-17 years	Parents were asked to provide 'yes' or 'no' responses to three questions: 1) 'Do you talk openly about your child's seizures to members of the extended family?' 2) 'Do you talk openly about your child's seizures to schoolteachers and other school personnel?' 3) 'Do you talk openly about your child's seizures to your friends and neighbours?'
Zamani et al. (2014) Iran	Assessed quality of life in adolescents with epilepsy within the context of Iran	Cross-sectional quantitative	Version of the QOL in Epilepsy Inventory for Adolescents 48 (QOLIE-AD-48) translated to the Farsi language	Children N=187 adolescents Aged 11-17 years Mean age=14.28 years	No details specific to the items on the QOLIE-AD-48 that capture disclosure practices reported.

Appendix B: Key Findings from the Papers included in the Systematic Review pertaining to Child and Parent Disclosure of a Paediatric Epilepsy Diagnosis

Authors (year)	How disclosure findings emerged	Disclosure practices	Enablers for disclosure	Barriers to disclosure	Impact/consequences of disclosure	Relationship between disclosure & other variables
Abulhamail et al. (2014)	Sub-foci of larger study; examined via the questionnaire	• Of the primary school teachers who had encountered a child with epilepsy in their class, 14% learned about the diagnosis through unplanned revelations (i.e., witnessing the child having a seizure in the classroom). This would indicate the adoption of concealment strategies by some parents surrounding the child's epilepsy diagnosis.	-	-	-	-
Austin et al. (2004)	Sub-foci of larger study; examined via two items on an eight-item scale	• When children were asked how often they tried to keep their epilepsy a secret from others, the mean score was 2.60, i.e., the mean child response was between "not often" and "sometimes". • When children were asked how often they avoided talking to others about their epilepsy, the mean score was 2.70, i.e., the mean child response was between "not often" and "sometimes".	-	-	-	-
Baker et al. (2008)	Sub-foci of larger study; examined via the questionnaire	• 23% of parents and caregivers had kept their child's epilepsy a secret from others • 36% of children/teenagers maintained secrecy around their epilepsy at some time.	-	Parents • Fear of others treating the child differently (62%) - teachers & family members viewed as most likely to alter behaviour towards the CWE Children • Fear of being treated differently (38%) - classmates perceived by CWE as most likely to treat them differently • Believing others should not know (47%)	-	-

Authors (year)	How disclosure findings emerged	Disclosure practices	Enablers for disclosure	Barriers to disclosure	Impact/consequences of disclosure	Relationship between disclosure & other variables
Bannon et al. (1992)	Sub-foci of a larger study; investigated via the questionnaire	• From the 81 teachers who had to their knowledge taught a child with epilepsy, 49% learned of the epilepsy diagnosis via parental voluntary disclosure, 30% learned as a result of witnessing the child having a seizure (unplanned revelations; this would indicate that concealment strategies were employed by some parents/children) and 14% learned via discussion with either the school nurse or doctor.	-	-	-	-
Butau & Piachaud (1993)	Sub-foci of a larger study; investigated via the questionnaire	• Out of a possible score of 5 (indicating the highest level of attitudinal agreement), parents reported a mean score of 1.80 in response to the statement that 'parents should talk to the child's school teacher about his/her epilepsy', providing some evidence that they wished to keep the diagnosis a secret and experienced difficulties talking about the child's epilepsy.	-	-	-	-
Chen et al. (2010)	Emerged incidentally via the exploration of peer relationships	• Some children reported keeping their epilepsy diagnosis a secret from their peers. • One child mentioned fearing that others would learn about her illness through an unplanned revelation by witnessing seizures within the school context. • Selective disclosure in terms of disclosure targets were highlighted with one child specifically not telling good friends about his diagnosis.	-	• Fear of teasing • The perception that disclosure would result in scaring peers • Previous negative reactions from others e.g., fear of infection, doubt • Experiences of social exclusion and teasing	-	-
Coulter & Koester (1985)	Emerged incidentally as a parent-reported concern	• Sources of concern identified by parents included concerns about: (1) telling teachers about the child's epilepsy; and (2) how to talk to friends about the child's seizures.	-	-	-	-

Authors (year)	How disclosure findings emerged	Disclosure practices	Enablers for disclosure	Barriers to disclosure	Impact/consequences of disclosure	Relationship between disclosure & other variables
Gazibara et al. (2014)	Sub-foci of larger study; examined via one item on a seven-item parental attitudes questionnaire	• Positive parental attitudes towards disclosure were demonstrated with parents obtaining a mean score of 4.3 out of 5 (denoting a high level of agreement) when asked to rate a statement assessing whether they wanted family and friends to be aware of their child's epilepsy diagnosis.	-	-	-	-
Hanai (1996)	Sub-foci of a larger study; investigated via a questionnaire	• 91% of parents/family members of children attending special classes or schools for disabled children informed the school of the name of the child's disease. • Only 48% of parents/family members of children attending normal classes/mainstream schools informed the school about the name of the child's disease.	-	• Fear of prejudice and discrimination • Concern that the child's future would be affected • Worry that restrictions would be imposed on the child in terms of physical education and participation in school events • The view that confidentiality is inadequate • Concerns regarding violations to privacy	-	-
Hightower et al. (2002)	Emerged incidentally as a sub-theme	• Disclosure occurred through the child with epilepsy voluntarily telling others or through others (e.g., parents) disclosing the diagnosis.	-	• Previous reactions of others e.g., crying after witnessing seizures	• Educating and telling friends about epilepsy and seizures resulted in greater feelings of acceptance, peers advocating on their behalf and less people "picking" on the children with epilepsy	-
Hoare & Russell (1995)	Sub-foci of a larger study; investigated via one item on the questionnaire	• The difficulty of explaining the child's epilepsy to others was one of the most common recurrent problems reported by parents in this study (n=5).	-	The difficulty of explaining the child's epilepsy to others.	-	-

Authors (year)	How disclosure findings emerged	Disclosure practices	Enablers for disclosure	Barriers to disclosure	Impact/consequences of disclosure	Relationship between disclosure & other variables
Hoare et al. (2000)	Sub-foci of a larger study; investigated via one item on the questionnaire	• When compared to parents of children with diabetes, parents of children with epilepsy more frequently reported that explaining their child's illness to others was: (1) sometimes or often difficult (37% vs. 54%, respectively); and (2) sometimes or very stressful (37% vs. 41%, respectively).	• 46% of parents rarely found it difficult to explain their child's epilepsy to others • 59% of parents reported that explaining the child's epilepsy to others was not stressful	• 34% of parents sometimes found it difficult to explain the child's epilepsy to others; and 20% often found it difficult • 27% of parent reported that explaining the child's epilepsy to others was sometimes stressful; and 14% reported that it was very stressful	-	-
Hodgman et al. (1979)	Sub-foci of a larger study; investigated via one question scored on a three point scale	-	-	Better seizure control correlated with: • adolescents having fewer friends aware of his/her epilepsy diagnosis (r=-0.50) • adolescents having less desire to speak openly about epilepsy diagnosis to parents or siblings (r=-0.55).	-	Better seizure control correlated with adolescents having fewer friends aware of his/her epilepsy diagnosis (r=-0.50).

Authors (year)	How disclosure findings emerged	Disclosure practices	Enablers for disclosure	Barriers to disclosure	Impact/consequences of disclosure	Relationship between disclosure & other variables
Holdsworth & Whitmore (1974)	Sub-foci of a larger study; investigated via items on the questionnaire	• Head-teachers had been informed about the child's epilepsy diagnosis for 62% of the children, whilst for 36% head-teachers were initially unaware of the diagnosis. • Disclosure of the child's epilepsy diagnosis to head-teachers occurred via unplanned revelations (i.e., they witnessed the child having a seizure), or by chance, for 23 of the 85 children; for only two of these children the seizure in school was the first manifestation of their epilepsy (indicating the adoption of concealment strategies by some parents). • Participation in this study brought the child's epilepsy to the attention of the head-teachers for seven children. • 25 parents informed the school about the child's epilepsy diagnosis. • Some parents informed teachers about what to do in the event of the child having a seizure, sometimes providing unorthodox seizure management tips (e.g., 'put his feet in warm water', 'put a spoon in his mouth and leave him', 'pour cold water over him' and 'smack her if she has a fit').	-	-	• As a result of the adoption of concealment strategies by one child's family, one head-teacher reported being negatively affected by an experience where he had called the police to report that the child was taking drugs in the toilet; only to learn that the child had been taking anti-epileptic medication.	-
Houston et al. (2000)	Emerged incidentally as a subtheme	• All children with asthma and diabetes disclosed their condition to their peers. • Only four children with epilepsy told their friends about their epilepsy diagnosis.	• Knowing someone with epilepsy (e.g., a relative or friend)	• Fear of how others would react • Fear of teasing • Fear of being perceived as stupid • Fear of being treated differently • Previous experiences of being bullied due to epilepsy • Negative portrayals of epilepsy on a TV programme and as a result fear of social rejection	-	Knowing someone with epilepsy (e.g., a relative or friend) was an enabling factor for disclosure for some CWE but not for other CWE; thus not directly associated with disclosure practices.

Authors (year)	How disclosure findings emerged	Disclosure practices	Enablers for disclosure	Barriers to disclosure	Impact/consequences of disclosure	Relationship between disclosure & other variables
Jantzen et al. (2009)	Sub-foci of a larger study; explored via interviews and one question on the child and parent questionnaires	<u>Child perspectives:</u> • Some adolescents opted to conceal their epilepsy diagnosis from others. • Some children feared unplanned revelations via others witnessing seizures. <u>Parent perspectives:</u> • Many families reported the adoption of defensive attitudes when dealing with the child's epilepsy in public.	• Following participation in the FLIP&FLAP psycho-educational programme, parents in the intervention group reported that the ability of their child to disclose their epilepsy diagnosis to others increased significantly when compared to parents in the waiting control group. • Children's and adolescents' self-reported ability to disclose the diagnosis to others also increased (although not significantly).	<u>Child perspectives:</u> • A lack of ability to represent the condition to other • Fear of others' reactions to seizures • Fear of social exclusion <u>Parent perspectives:</u> • Fear of stigmatisation • The child's epilepsy resulting in actual experiences of rejection	-	-
Kleck (1968)	Primary focus of the study	• Concealment strategies employed by parents ranged from parents physically hiding the child from others to parents prohibiting family members from discussing the condition outside of the immediate family. • 78% of adults with epilepsy indicated that during their childhood one or both of their parents were "secretive" in regard to their epilepsy.	-	• An unwillingness by parents to accept the condition • Negative parental attitudes and feelings towards the child having epilepsy e.g., shame	• Parents' attitudes towards disclosure significantly impacted on the child's attitudes towards their condition and disclosure. • Concealment strategies reinforced feelings of shame & stigma and promoted secrecy.	-
Kwong et al. (2000)	Sub-foci of larger study; explored via the questionnaire	• The majority of parents informed their child's school about his/her epilepsy diagnosis (93% of parents of children in special schools for handicapped children; 82% of parents of children in mainstream schools).	-	• Fear of stigmatisation • Disclosure of the child's epilepsy to others perceived as unhelpful	-	-

Authors (year)	How disclosure findings emerged	Disclosure practices	Enablers for disclosure	Barriers to disclosure	Impact/consequences of disclosure	Relationship between disclosure & other variables
Lewis et al. (1990)	Sub-foci of larger study; explored via structured interview questions	Pilot • Children were reluctant to disclose their epilepsy diagnosis to their peers; consequently many adopted concealment strategies. • Some children told one or two friends.	-	Pilot: • Fear of peer rejection • Feelings of embarrassment regarding having seizures in public • Previous experiences of negative reactions by others to seizures	-	RCT: A family-oriented psychoeducational program aiming to educate children how to communicate with others about their epilepsy and promote disclosure (amongst other things) had no significant impact on children's disclosure to friends/others.
McEwan et al. (2004)	Emerged as incidental sub-theme	• The decision to disclose epilepsy to others was a complex and significant factor for all adolescents. • Selective disclosure was reported by one participant who had only told one friend. • Two younger participants had not disclosed their epilepsy diagnosis to any of their friends, with one engaging in active concealment behaviours to maintain this secrecy (e.g., taking epilepsy medication in the toilet).	• Friends knowing as a supportive factor (n=7) • Positive reactions from peers to disclosure (such as interest in learning more about: (i) the condition; and (ii) what to do in the event of a seizure).	• Actual experiences of rejection due to epilepsy (n=8) • Fear of experiencing rejection from peers, boyfriends and girlfriends due to epilepsy (n=11). • Fear of others' perceptions • Epilepsy's association with the brain. • Others' fear of epilepsy • Lack of public knowledge about epilepsy and prejudice as a result • Fear of others broadcasting the epilepsy diagnosis	-	Disclosure decisions appeared to be contingent upon a number of factors including seizure frequency, time spent with friends and safety.
Mecarelli et al. (2011)	Sub-foci of a larger study; examined via one item on a 28-item questionnaire	• Only 2/3 of teachers who were teaching or had taught a child with epilepsy reported receiving information about the disease from the child's parents, indicative of parental concealment of the child's diagnosis by some parents within a school context.	-	-	-	-
Mecarelli et al. (2014)	Sub-foci of a larger study; examined via one item on a 28-item questionnaire	• Of the teachers who had or have had students with epilepsy, 87.4% were informed by parents of the child's epilepsy. This indicates some degree of concealment of the child's epilepsy diagnosis from school teachers amongst some parents.	-	-	-	-

Authors (year)	How disclosure findings emerged	Disclosure practices	Enablers for disclosure	Barriers to disclosure	Impact/consequences of disclosure	Relationship between disclosure & other variables
Moffat et al. (2009)	Emerged as incidental sub-theme	• 50% (*n*=11) of children with epilepsy reported an unwillingness to tell peers about their epilepsy diagnosis. • All participants had disclosed their epilepsy to their best friend. • Two participants reported not wanting to tell others about hospital appointments.	• Enhanced feelings of safety (*n*=2) • Friends helping and supporting the CWE (*n*=4)	• Fear of word spreading about their epilepsy (*n*=3) • Previous experiences where disclosure resulted in word spreading at school (*n*=3) • Previous negative reactions to seizures (*n*=7) • Peers asking questions about medication and seizures (*n*=3) • Previous experiences of bullying, teasing and being laughed at due to epilepsy (*n*=7) • Perceptions of how others view them negatively due to epilepsy (*n*=2)	-	-
Mu (2008)	Emerged as incidental sub-theme	• The word 'yan-dan-fun' or 'epilepsy' was rarely used by parents and the condition was seldom openly discussed within or external to the family context. • Active concealment strategies were reported by some parents e.g., passing epilepsy symptoms as 'febrile' seizures or not bringing the child to social occasions. • Some parents reported not informing friends, relatives or teachers. • Parents referred to assisting the child in maintaining secrecy around his/her epilepsy diagnosis. • Parents maintained secrecy by preparing the child prior to social engagements i.e., ensuring seizures were controlled and assessing the environment for acceptability • Voluntary disclosure/open discussion occurred with teachers for some parents of children with epilepsy. • One mother reported telling the child's peers in order to explain his behaviour and foster understanding and support.	• Disclosure viewed as enhancing others' understanding, and the safety and care of the child • Perceptions of disclosure as assisting the child's entry into society	• Negative parental perceptions of epilepsy i.e., parents viewing the condition as unacceptable, damaging to the family's social image, shameful and detrimentally affecting the bloodline and the child's future, • Parental feelings of shock, anger, despair and/or guilt due to the child's diagnosis • Worry that disclosure will result in the child suffering negative consequences i.e., being rejected • An inability to control society's reaction to the condition • Cultural attitudes towards epilepsy in the traditional society • Parents hoping the child will recover from the illness prior to entering school/society • Parental awareness of epilepsy-related stigma/fear of stigmatisation	• Parents acknowledging that if seizures occur in school, due to the teacher's lack of knowledge, the teacher will be ill prepared	-

Authors (year)	How disclosure findings emerged	Disclosure practices	Enablers for disclosure	Barriers to disclosure	Impact/consequences of disclosure	Relationship between disclosure & other variables
Ojinnaka (2002)	Sub-foci of a larger study; examined via one item on a larger questionnaire	• Teachers who had taught a child with epilepsy learned about the child's condition via voluntary disclosure by the child (24.1%), voluntary disclosure by the parent/guardian (27.6%) or by witnessing the child having a seizure in the class (48.3%). This high proportion of unplanned revelations hints at the adoption of concealment disclosure management strategies by some parents and/or children.	-	-	-	-
Pala & Vankar (1997)	Sub-foci of a larger study; investigated via the questionnaire	• Most of the 31 teachers who had taught a child with epilepsy learned about the child's diagnosis when the child had a seizure in school i.e., via unplanned revelations. This is indicative of the adoption of parental concealment strategies surrounding the child's epilepsy diagnosis. • Two of the 31 teachers learned about the child's epilepsy diagnosis via voluntary disclosure by the parents.	-	-	-	-
Prpic et al. (2003)	Sub-foci of a larger study; examined via one item on a larger questionnaire	• Teachers were not informed by parents about the child's disease in the majority of cases (59.7%), but rather received information about the child's illness from other sources.	-	-	-	-

Authors (year)	How disclosure findings emerged	Disclosure practices	Enablers for disclosure	Barriers to disclosure	Impact/consequences of disclosure	Relationship between disclosure & other variables
Roberts & Whiting (2011)	Emerged incidentally as a sub-theme	• Disclosure decisions were difficult for some parents. • Many parents reported being required to tell the school about the child's epilepsy at registration or after the diagnosis. • Parents discussed their frustration regarding the disclosure process within schools i.e., having to fill in a multitude of forms at registration or at the time of diagnosis. For one family, despite filling out this multitude of forms at registration, the child's teacher did not become aware of the diagnosis until the mother informed her personally. • Every family spoke of the importance of having all staff members within a school context (including care takers and administrative staff) aware of their child's epilepsy diagnosis rather than just the classroom teacher. • Parents highlighted having to explain medication routines and seizure first aid to other families if their child was visiting friends.	• Parental desire to ensure the safety of the child • Teachers responding positively i.e., conveying an openness to learn about epilepsy	• Parental fear that teachers would treat the child differently • Parental fear that others would only focus on the child's epilepsy	• Positive responses from teachers resulted in parental relief. • Some parents reported that disclosure resulted in teachers feeling anxious and becoming overprotective. • A number of parents discussed how other families responded to disclosure with fear due to the possibility of the child having a seizure in their care.	-
Ronen et al. (1999)	Emerged as incidental sub-theme	-	-	• Fear of how others will react • Fear of social exclusion • One participant reported: *"Sometimes if you have friends, and you tell them (you have epilepsy), they won't be your friend anymore."*	-	-

Authors (year)	How disclosure findings emerged	Disclosure practices	Enablers for disclosure	Barriers to disclosure	Impact/consequences of disclosure	Relationship between disclosure & other variables
Ryu et al. (2015)	Sub-foci of a larger study; examined via a four-item questionnaire	• The mean disclosure management scale score was 5.4 (out of a possible total of 11). • Maternal concealment behaviours were high. • 61% of mothers reported that they often, or sometimes, keep their adolescent's epilepsy a secret from others. • 64% of mothers reported that none or few of their friends knew about the adolescent's epilepsy diagnosis	-	-	• Higher maternal concealment behaviour (measured with the DMS) was identified as an independent factor predicting higher perceptions of stigma amongst adolescents with epilepsy.	• Maternal disclosure management scale scores were weakly but significantly related to age of mother (r=0.132, p=.044) but were not related to the education level of the mother, the school that their children were attending or the gender of their child. The maternal disclosure management scale score was significantly related to the parent stigma scale score. • For adolescents living with epilepsy, maternal disclosure management was identified as an independent factor contributing to perceived stigmatisation (captured via the Child Stigma Scale).
Saburi (2011)	Sub-foci of a larger study; examined via structured interview questions	• All but one parent reported disclosing the child's diagnosis to the extended family. • 11% of parents reported that they didn't disclose the child's diagnosis to the school. • 91% of parents (*n*=42) reported disclosing the child's diagnosis to friends and neighbours; whilst 8.7% kept the diagnosis a secret from others.	-	• Fear of stigmatisation • The perception that keeping the diagnosis concealed from others serves to protect the child from physical and emotional hurt	-	-
Zamani et al. (2014)	Sub-foci of larger study; explored via the QOLIE-AD-48 questionnaire	• 65.8% of adolescents never talked to their friends or teachers about their epilepsy.	-	-	-	-

Appendix C: Themes Identified through Examination of the 32 Papers in the Systematic Review and the Frequency of their Occurrence

Themes	Frequency of Occurrence (% Coverage)	Relevant References
Disclosure Management Strategies adopted or reported as being desirable by CWE and their Parents		
Concealment	25 (78.13%)	Abulhamail et al. (2014); Austin et al. (2004); Baker et al. (2008); Bannon et al. (1992); Butau & Piachaud (1993); Chen et al. (2010); Hanai (1996); Holdsworth & Whitmore (1974); Houston et al. (2000); Jantzen et al. (2009); Kleck (1968); Kwong et al. (2000); Lewis et al. (1990); McEwan et al. (2004); Mecarelli et al. (2011); Mecarelli et al. (2014); Moffat et al. (2009); Mu (2008); Ojinnaka (2002); Pala & Vankar (1997); Prpic et al. (2003); Ronen et al. (1999); Ryu et al. (2015); Saburi (2011); Zamani et al. (2014)
Voluntary Disclosure	12 (37.5%)	Bannon et al. (1992); Hanai (1996); Hightower et al. (2002); Holdsworth & Whitmore (1974); Kwong et al. (2000); Mecarelli et al. (2011); Mecarelli et al. (2014); Mu (2008); Ojinnaka (2002); Pala & Vankar (1997); Roberts & Whiting (2011); Saburi (2011)
Unplanned Revelations	5 (15.63%)	Abulhamail et al. (2014); Bannon et al. (1992); Holdsworth & Whitmore (1974); Ojinnaka (2002); Pala & Vankar (1997)
Indirect Telling (via others)	5 (15.63%)	Bannon et al. (1992); Hightower et al. (2002); Holdsworth & Whitmore (1974); Mu (2008); Prpic et al. (2003)
Selective Disclosure	3 (9.38%)	Chen et al. (2010); Lewis et al. (1990); McEwan et al. (2004)
Preventive Disclosure	1 (3.13%)	Mu (2008)
Disclosure Targets for CWE and their Parents (i.e. who CWE and their parents disclose the diagnosis to)		
The child's teachers	12 (37.5%)	Bannon et al. (1992); Hanai (1996); Holdsworth & Whitmore (1974); Kwong et al. (2000); Mecarelli et al. (2011); Mecarelli et al. (2014); Mu (2008); Ojinnaka (2002); Pala & Vankar (1997); Roberts & Whiting (2011); Saburi (2011); Zamani et al. (2014)
The child's peers	7 (21.88%)	Chen et al. (2010); Houston et al. (2000); Lewis et al. (1990); McEwan et al. (2004); Moffat et al. (2009); Mu (2008); Zamani et al. (2014)
The parents' friends	2 (6.25%)	Ryu et al., (2015); Saburi (2011)
Extended family	1 (3.13%)	Saburi (2011)
Neighbours	1 (3.13%)	Saburi (2011)
Other families	1 (3.13%)	Roberts & Whiting (2011)
Disclosure Exchange Content for CWE and their Parents (i.e. what CWE and their parents disclose to others about the child's diagnosis)		
Seizure first aid protocols	2 (6.25%)	Holdsworth & Whitmore (1974); Roberts & Whiting (2011)
The child's medication regime	1 (3.13%)	Roberts & Whiting (2011)
Attitudes towards Disclosure amongst CWE and their Parents		
Disclosure perceived as difficult	3 (9.38%)	Hoare et al. (2000); Hoare & Russell (1995); Roberts & Whiting (2011)
An unwillingness/reluctance to disclose the diagnosis to others	2 (6.25%)	Lewis et al. (1990: Moffat et al. (2009)
Fear of discovery via others witnessing seizures	2 (6.25%)	Chen et al. (2010); Jantzen et al. (2009)
Disclosure perceived as positive	2 (6.25%)	Gazibara et al. (2014); Roberts & Whiting (2011)
Disclosure perceived as a source of concern	1 (3.13%)	Coulter & Koester (1985)

Appendix C: Themes Identified through Examination of the 32 Papers in the Systematic Review and the Frequency of their Occurrence

Themes	Frequency of Occurrence (% Coverage)	Relevant References
Attitudes towards Disclosure amongst CWE and their Parents (Continued)		
Disclosure perceived as a stressful aspect associated with the child having epilepsy	1 (3.13%)	Hoare et al. (2000)
Disclosure perceived as complex and a significant factor in the lives of adolescents	1 (3.13%)	McEwan et al. (2004)
The disclosure process within a school context perceived as an arduous task	1 (3.13%)	Roberts & Whiting (2011)
Disclosure to the child's school teacher perceived as unnecessary	1 (3.13%)	Butau & Piachaud (1993)
Factors that Act as Barriers to Disclosure for CWE and their Parents		
Fear of peer rejection, social exclusion and/or bullying or teasing	6 (18.75%)	Chen et al. (2010); Houston et al. (2000); Jantzen et al. (2009); Lewis et al. (1990); McEwan et al. (2004), Ronen et al. (1999)
Fear of stigmatisation	5 (15.63%)	Hanai (1996); Jantzen et al. (2009); Kwong et al. (2000); Mu (2008); Saburi (2011)
Fear of different treatment and/or the imposition of unnecessary restrictions	4 (12.50%)	Baker et al. (2008); Hanai (1996); Houston et al. (2000); Roberts & Whiting (2011)
Negative responses to disclosure in the past	4 (12.50%)	Chen et al. (2010); Jantzen et al. (2009); Lewis et al. (1990); McEwan et al. (2004)
Others' negative perceptions of epilepsy (anticipated and/or experienced)	3 (9.38%)	Houston et al. (2000); McEwan et al. (2004); Moffat et al. (2009)
Anticipated negative reactions to disclosure	3 (9.38%)	Houston et al. (2000); Jantzen et al. (2009); Ronen et al. (1999)
Difficulties associated with explaining the condition to others	3 (9.38%)	Hoare et al. (2000); Hoare & Russell (1995); Jantzen et al. (2009)
Previous experiences of CWE being bullied, teased or laughed at due to epilepsy	3 (9.38%)	Chen et al. (2010); Houston et al. (2000); Moffat et al. (2009)
Negative reactions from others to seizures in the past	3 (9.38%)	Hightower et al. (2002); Lewis et al. (1990); Moffat et al. (2009)
Concern about how the child's future would be affected	2 (6.25%)	Hanai (1996); Mu (2008)
Fear and/or experience of others broadcasting the condition	2 (6.25%)	McEwan et al. (2004); Moffat et al. (2009)
Negative parental attitudes towards epilepsy	2 (6.25%)	Kleck (1968); Mu (2008)
Cultural attitudes towards epilepsy (in Taiwan)	1 (3.13%)	Mu (2008)
A perceived inability to control others' reactions to disclosure	1 (3.13%)	Mu (2008)
The perception that disclosure is unhelpful	1 (3.13%)	Kwong et al. (2000)
The perception that disclosure is stressful	1 (3.13%)	Hoare et al. (2000)
The perception that concealment serves to protect the child from physical/emotional harm	1 (3.13%)	Saburi (2011)
The perception that disclosure would instil fear in the child's peers	1 (3.13%)	Chen et al. (2010)

Appendix C: Themes Identified through Examination of the 32 Papers in the Systematic Review and the Frequency of their Occurrence

Themes	Frequency of Occurrence (% Coverage)	Relevant References
Factors that Act as Barriers to Disclosure for CWE and their Parents (continued)		
The perception that others would only focus on the child's epilepsy and not on his/her other attributes thereafter	1 (3.13%)	Roberts & Whiting (2011)
Others responding with questions about medications or seizures	1 (3.13%)	Moffat et al. (2009)
Epilepsy's association with the brain	1 (3.13%)	McEwan et al. (2004)
Concerns regarding confidentiality and violations to privacy (particular to the school context)	1 (3.13%)	Hanai (1996)
The belief that others should not know about the diagnosis	1 (3.13%)	Baker et al. (2008)
Lack of public knowledge about epilepsy	1 (3.13%)	McEwan et al. (2004)
Feelings of embarrassment	1 (3.13%)	Lewis et al. (1990)
Better seizure control and thus a perceived lack of need to disclose	1 (3.13%)	Hodgman et al. (1979)
Parental desire for secrecy and/or the invisibility of epilepsy at home due to lack of familial discussion about the condition	1 (3.13%)	Mu (2008)
Negative portrayals of epilepsy in the media	1 (3.13%)	Houston et al. (2000)
Parental hope that the child will grow out of the condition before disclosure becomes necessary	1 (3.13%)	Mu (2008)
Parental non-acceptance of the child's diagnosis	1 (3.13%)	Kleck (1968)
Parental worry that the child would suffer negative consequences	1 (3.13%)	Mu (2008)
Factors that Enable and/or Promote Disclosure amongst CWE and their Parents		
The perception that disclosure results in enhancing the child's safety	3 (9.38%)	Moffat et al. (2009); Mu (2008); Roberts & Whiting (2011)
Positive responses to disclosure in the past	2 (6.25%)	McEwan et al. (2004); Roberts & Whiting (2011)
Disclosure resulting in the receipt of help and support from others	2 (6.25%)	McEwan et al. (2004); Moffat et al. (2009)
The perception that explaining the condition to others is not difficult or stressful	1 (3.13%)	Hoare et al. (2000)
The view that disclosure is necessary to assist the child's successful entry into society	1 (3.13%)	Mu (2008)
The perception that disclosure helps to reduce anxiety and stigma	1 (3.13%)	Roberts & Whiting (2011)
The view that disclosure prepares others in the event of a seizure occurring in their presence	1 (3.13%)	Saburi (2011)

Appendix C: Themes Identified through Examination of the 32 Papers in the Systematic Review and the Frequency of their Occurrence

Themes	Frequency of Occurrence (% Coverage)	Relevant References
Factors that Enable and/or Promote Disclosure amongst CWE and their Parents(continued)		
Participation in a psychoeducational programme resulting in improvements in CWE's ability to explain their condition to others	1 (3.13%)	Jantzen et al. (2009)
The perception that disclosure can serve to prevent others from making hurtful remarks	1 (3.13%)	Saburi (2011)
Knowing others with epilepsy	1 (3.13%)	Houston et al. (2000)
The view that disclosure results in enhancing others' understanding of the child	1 (3.13%)	Mu (2008)
Consequences of the Disclosure Practices adopted by CWE and their Parents		
Disclosure resulting in greater acceptance	1 (3.13%)	Hightower et al. (2002)
Disclosure resulting in feelings of advocacy	1 (3.13%)	Hightower et al. (2002)
Disclosure resulting in fewer people bullying/teasing CWE	1 (3.13%)	Hightower et al. (2002)
Disclosure resulting in teachers feeling anxious and becoming overprotective	1 (3.13%)	Roberts & Whiting (2011)
Disclosure resulting in others reacting in a fearful manner due to the possibility of the child having a seizure in their presence	1 (3.13%)	Roberts & Whiting (2011)
Concealment resulting in embarrassment and misunderstandings	1 (3.13%)	Holdsworth & Whitmore (1974)
Positive responses to disclosure resulting in parental relief	1 (3.13%)	Roberts & Whiting (2011)
Concealment resulting in others being ill-prepared in the event of a seizure occurring	1 (3.13%)	Mu (2008)
Parental concealment resulting in CWE feeling pressured to maintain secrecy around the condition	1 (3.13%)	Kleck (1968)
Parental concealment conveying to CWE that epilepsy is something that is shameful and a deservedly stigmatised condition	1 (3.13%)	Kleck (1968)
Maternal concealment behaviours predicting greater perceived stigma amongst adolescents with epilepsy	1 (3.13%)	Ryu et al. (2015)

Appendix D.1: Phase One: Ethical Approval from Dublin City University Research Ethics Committee

Ollscoil Chathair Bhaile Átha Cliath
Dublin City University

DCU

Ms. Ailbhe Benson
School of Nursing and Human Sciences

14th March 2013

REC Reference: DCUREC/2013/010

Proposal Title: **A qualitative exploratory study of the experiences of disclosure in children living with epilepsy: Phase One of a study entitled: Breaking the cycle of invisibility: a mixed methods inquiry of disclosure challenges faced by children living with epilepsy**

Applicants: Dr. Veronica Lambert, Ms. Ailbhe Benson

Dear Ailbhe,

Further to expedited review, the DCU Research Ethics Committee approves this research proposal. Materials used to recruit participants should note that ethical approval for this project has been obtained from the Dublin City University Research Ethics Committee. Should substantial modifications to the research protocol be required at a later stage, a further submission should be made to the REC.

Yours sincerely,

DCU
Research & Innovation

Dónal O'Mathúna

Dr. Donal O'Mathuna
Chairperson
DCU Research Ethics Committee

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Appendix D.2: Phase One: Ethical Approval from Temple Street Children's University Hospital Research Ethics Committee

Children's University Hospital
TEMPLE STREET, DUBLIN

DEPARTMENT OF RESEARCH
Children's University Hospital
Temple Street, Dublin 1
Tel: +353 1 892 1787
Email: research@cuh.ie Web: www.cuh.ie

Dr. Amre Shahwan
Consultant Clinical Neurophysiologist and Epileptologist
Neurology Department
Children's University Hospital
Temple Street
Dublin 1

10th December 2012

Re: 12.040. A qualitative exploratory study of the experiences of disclosure in children living with epilepsy: Phase One of the study entitled: Breaking the cycle of invisibility: a mixed methods inquiry of disclosure challenges faced by children living with epilepsy.

Dear Amre,

Your proposal was discussed by the members of the Research Committee at its meeting held on Tuesday 4th December 2012.

The Committee recognizes the excellence of the proposal in terms of drafting and reading. No issues were raised and consequently the Committee is happy to grant you approval for your study. Your proposal will be forwarded to the Ethics Committee for their review.

Yours sincerely,

pp/ Aránzazu Bartolomé
Dr. Adrienne Foran MD MRCPI (Paeds) FRCPCH
Chairperson
Research Committee

C.c. Professor Philip Mayne, Hon. Secretary, Ethics Committee.

Appendix E.1: Phase One: Child/Young Person Interview Schedule

Item	Prompts
1. Tell me what it is like for you to live with epilepsy every day?	➢ *Seizures (frequency, when, where, feeling etc.)* ➢ *Medications (when, where, how etc.)* ➢ *Going to school (absences from school)* ➢ *Attending hospital/clinic appointments* ➢ *Meeting friends* ➢ *Being able to participate or not participate in different things*
2. Tell me what it is like when you talk to other people (e.g. brothers/sisters, mam/dad, granny/granddad, friends, teachers in school, doctors/nurses etc.) about your epilepsy?	➢ *Who, what, why, how, when do you tell other people about your epilepsy?* ➢ *What is good/not so good about talking to other people about epilepsy?* ➢ *What things help/stop you telling other people about your epilepsy?* ➢ *What things do you not mind telling other people about your epilepsy?* ➢ *What things bother you most about telling other person about your epilepsy?*
3. Can you tell me a story about a time when you told another person that you have epilepsy?	➢ *What did they do? Can you give me an example of when this happened?* ➢ *What did they say? Can you give me an example of when this happened?* ➢ *Why do you think they did/said that? How did this make you feel?*
4. Are there people you have not told, or would you not like to, tell about your epilepsy?	➢ *Can you think of a time when you did not tell someone that you have epilepsy?* ➢ *Can you tell me more about this time?* ➢ *What made you decide not to tell this person about having epilepsy?* ➢ *Why would you not like to tell this person about your epilepsy?*

Use of Art-Based Activities within Interviews

Children were given the choice of engaging in art-based activities throughout the interview. While the art-based activities were driven by the interview context, the following was a guide for what children were asked to create.

Design a picture/collage about living with epilepsy and/or about what happens when you tell other persons (e.g. friends etc.) about your epilepsy.

Prompts: The same prompts outlined related to the questions above will be used throughout the child's creative design process.

When finished their designs, children were asked to tell, or write, a story about the meaning of their designs (e.g. stories about times when they told, did not tell, other people about their epilepsy).

Prompts:

Tell me about your design? What were you thinking about when you drew this picture/made this collage [or a particular aspect of the design etc.]
What is going on in this picture/collage?
What are the people in the picture/collage doing?
What are the people in the picture/collage saying?
How do the people in this drawing/collage feel?
If the people in the drawing/collage could speak, what would they say?
What title/name would you give this picture/collage?
Is there anything that is missing from this drawing/collage?

Appendix E.2: Phase One: Parent Interview Schedule

Item	Prompts
1. Tell me about your experience of your child's diagnosis.	➢ *First seizure (when, where, how, feeling)* ➢ *Talking to Neurologist (When, where, feeling etc.)* ➢ *Child's reaction* ➢ *Your reaction*
2. Tell me what it is like for your child to live with epilepsy every day?	➢ *Seizures (frequency, when, where, feeling etc.)* ➢ *Medications (when, where, how etc.)* ➢ *Going to school (absences from school)* ➢ *Attending hospital/clinic appointments* ➢ *Meeting friends* ➢ *Being able to participate or not participate in different things*
3. Tell me what does the term disclosure of epilepsy mean to you?	➢ *Is it just talking to other people about the condition?* ➢ *Is there more to disclosure than just talking?*
4. Tell me about what it is like for your child to tell other people (e.g. brothers/sisters, aunts/uncles, granny/granddad, friends, teachers in school, doctors/nurses etc.) about his/her epilepsy.	➢ *Who, what, why, how, when does he/she tell other people about his/her epilepsy?* ➢ *What does he/she find challenging/unchallenging about talking to other people about epilepsy?* ➢ *What things enable/prevent him/her telling other people about his/her epilepsy?* ➢ *What are the kinds of things that he/she does not mind telling other people about his/her epilepsy?* ➢ *What things bother him/her most about telling other person about his/her epilepsy?*
5. Are there people he/she has not told, or he/she would not like to, tell about his/her epilepsy?	➢ *Can you think of a time when he/she did not tell someone that he/she has epilepsy?* ➢ *Can you tell me more about this time?* ➢ *What do you think made him/her decide not to tell this person about having epilepsy?* ➢ *Why do you think would your child not like to tell this person about their epilepsy?*
6. Tell me about what it is like for you to tell other people (e.g. brothers/sisters, parents, in-laws, extended family members, friends, colleagues, teachers, doctors/nurses etc.) about your child's epilepsy.	➢ *Who, what, why, how, when do you tell other people about your child's epilepsy?* ➢ *What do you find challenging/unchallenging about talking to other people about your child's epilepsy?*

Item	Prompts
	➢ *What things enable/prevent you from telling other people about your child's epilepsy?* ➢ *What are the kinds of things that you do not mind telling other people about your child's epilepsy?* ➢ *What things bother you most about telling other people about your child's epilepsy?*
7. Are there people you have not told, or you would not like to, tell about your child's epilepsy?	➢ *Can you think of a time when you did not tell someone that your child has epilepsy?* ➢ *Can you tell me more about this time?* ➢ *What do you think made you decide not to tell this person about your child having epilepsy?* ➢ *Why do you think would you not like to tell this person about your child's epilepsy?*

Appendix F: Phase One: Demographic Questionnaire

Demographic Information for Families Participating in Interviews:

Interview No.:

_____

- Gender: Male/Female
- Age: _____ Years
- Class in School:
- Diagnosis (i.e. has your child been diagnosed as having a specific or non-specific type of epilepsy?):

- Age at Diagnosis: _____ Years
- Type of Seizures:

- Frequency of Seizures:

- Time since last seizure:

- Seizure Severity:

- Current Medications/Treatments:

- Previous Medications/Treatments:

- Family History of Epilepsy:

- Any Other Medical Condition(s):

- Epilepsy Terminology Used with/by Child with Epilepsy:

Appendix G: Phase One: Recruitment Advertisement

Talking about Epilepsy

I am trying to find out what it is like for children living with epilepsy and their parents.

Who is involved? My name is Ailbhe Benson and I am a PhD student at DCU. I am doing a project (in collaboration with Epilepsy Ireland) and I am looking for children and young people (aged 6-15 years) with a diagnosis of epilepsy (for more than 6 months) as well as their parents to participate.

What will the study involve? The study will involve child/ young person and parent interviews. Don't worry- child interviews will be fun! We will do art and make collages together and you can tell me your story.

When will the interviews take place? The interviews will take place as soon as is convenient, at a time that suits you and your family.

Where will the interviews take place? The interviews will take place wherever you choose, whether that be in your home, at a public place or in DCU.

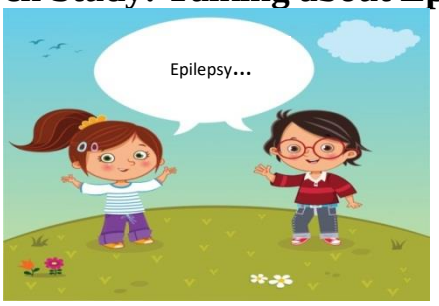
Why is this study beneficial? This study will allow us to learn more about the challenges (positive and negative) that face children living with epilepsy. Such information will help us to tackle the negative challenges faced by children living with epilepsy in the future and ultimately it will help us to raise awareness about epilepsy in children.

How do we participate? If you are interested in knowing more or you think you would like to participate , please contact me by phone on 087 3124218 or by email at ailbhe.benson2@mail.dcu.ie. Although your participation would be appreciated, you do not have to take part- it is completely up to you.

This project is being funded by the Health Research Board with the grant awarded to Dr. Veronica Lambert, School of Nursing and Human Sciences, DCU.

Appendix H.1: Phase One: Plain Language Statement for Parents and Guardians

Research Study: Talking about Epilepsy



What is this study about?
We are doing this study to find out more about you and your child's experiences of living with epilepsy. We are particularly interested in hearing about you and your child's experiences of telling/not telling, or talking/not talking, to others (e.g. friends, family members, teachers etc.) about epilepsy.

Who is conducting this study?
This study is being carried out by Ailbhe Benson (which is me the researcher) and Dr. Veronica Lambert and Professor Pamela Gallagher from the School of Nursing and Human Sciences at Dublin City University (DCU). This Health Research Board funded study was developed in collaboration with the Children's University Hospital, Temple Street and Epilepsy Ireland.

I (Ailbhe) am currently a postgraduate research student at DCU and am the person you, and your child, will have most contact with if you, and your child, agree to take part. I am completing this work as part of my PhD studies and I am being supervised by Dr Veronica Lambert and Professor Gallagher.

If I give consent for my child/children and myself to take part what will we be asked to do?

- We would like to have an opportunity to speak with you as parents and any children in your family who are **between 6 and 15 years of age** and who have been diagnosed with epilepsy for more than 6 months. If you give consent for your child/children to take part, we will remind them that this does not mean they *have* to take part, just that if they want to take part, you have said it is OK for them to do so.
- Your child/children will also receive an information letter. It will be a simple, easier to read version. We would encourage you to discuss the information letter with your child/children.

How long will it take?

- If you and your child/children would like to take part, we will arrange a time and place in the next few weeks that suits you for the interview
- The interview should take no longer than 45-60 minutes depending on how much your child/children and you as parents wish to speak to us about. You will have a chance to talk to me again before the interview itself.

What if we don't take part?

We understand that not all families will have the time to take part in our study, and some families may not be interested. If you choose not to take part in the study, this will in *no way* affect your child's treatment in the Children's University Hospital, Temple Street, nor will it prevent you from being a part of any support groups/ activities organised by Epilepsy Ireland in the future.

What type of questions will we be asked?

- I will sit down with you as parents and your child or children who are **6 years** or older and conduct interviews.
- Your child/children will be given the option of having their parents' with them at the time of interview or of being interviewed alone (if you do not wish to be present during the interview please let us know in advance). This will allow your child/children to personally voice their views on what it is like to have epilepsy and to tell, or not to tell, other people about their condition.
- Additionally if both parents wish to participate you will also be given the option of being interviewed separately or together.
- You and your child/children will be asked questions e.g. what are the things that are helpful or unhelpful in letting others know about their condition. This interview will be audio-recorded, with your and your child's permission.

What will be done with the information collected from us?

- Only the research team and possibly the examiners of my thesis will have access to your answers and these will be treated in the strictest of confidence.
- Any recordings of interviews will be transcribed and made anonymous (i.e. the written version of the interview will not have your or your child's name on it, but will be numbered so we can identify it later). All information from the study (i.e. recordings, consent forms, name keys etc.) will be destroyed after my thesis has been examined. However, the transcribed interviews (which will now be completely anonymous) will be archived by Dr. Lambert.
- Any personal details recorded during the interview process pertaining to you and your child such as demographic information or signed consent forms will be stored separate to the audio recordings.
- All information will be stored in locked filing cabinets and/or on password-protected computers in DCU.
- The information we collect from all the families who take part will be used to write a report on the findings and I will write my thesis using information we gather from families involved in this research. The HRB who are funding the project will receive annual reports and the findings from the study may be published in journals whereby direct quotes from the interviews may be used in the write up. However, no information that might identify you or your family will be used.

- Anything you and your child/ children say to us will be kept private between the research team and your family. We will only break this privacy if there is a concern for a child's safety. In this situation, we are obliged to bring this to the attention of staff in Temple Street/Epilepsy Ireland. You and your child/children will be made aware of this need should the situation arise.

What use will this study be to me and my children?

While there may be no immediate benefits to you, and your child/children, from taking part in the study, the researchers hope that studies such as this one can be used to identify the needs of children living with epilepsy and thus inform and develop new services for families who have a child with a chronic illness. It is an opportunity for you and your child/children to share your experience with others.

Are there any risks or downsides to taking part?

- There is a chance that while you or your child/ children are talking about your experiences, you or your child/children may feel upset. If you or your child/children become upset when talking to me, we will ask you and your child/children if you want to stop, take a break or for child interviews if they would like to have a parent sit with them to make them feel more comfortable. We will let you know if your child becomes upset at any stage.
- After the study, if you feel it might help to talk to somebody about any of the issues that came up, we can put you in touch with someone (e.g. your local Community Resource Officer in Epilepsy Ireland) who can advise you on next steps.

What if I, or my child, change their mind?

If you and your child/children agree to take part but later change your minds, all you have to do is let me know by a phone call or email. You do not have to give a reason for withdrawing and withdrawing from the study will in *no way* affect your involvement in Epilepsy Ireland/Children's University Hospital, Temple Street.

Is there anything else I need to know?

If you would like to talk informally with me about any questions or queries you may have about this research, my contact details are below.

You can contact me with any questions you have about this research on 087-3124218 or ailbhe.benson2@mail.dcu.ie. I would be more than happy to address any questions or concerns that you may have.

Additionally, you can contact my supervisor at veronica.lambert@dcu.ie.

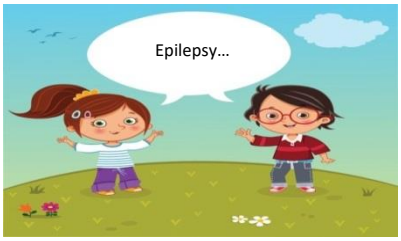
If participants have concerns about this study and wish to contact an independent person, please contact:

The Secretary,
Dublin City University Research Ethics Committee,
c/o Research and Innovation Support,
Dublin City University,
Dublin 9.
Tel 01-7008000

Appendix H.2: Phase One: Child Plain Language Statement (Participants aged 6-10 years)

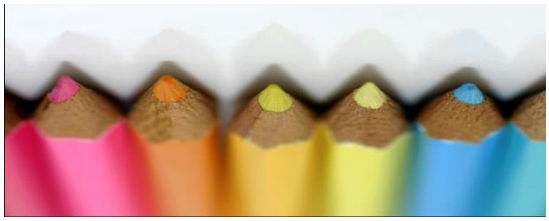
Would you like to help me with my project?

TALKING ABOUT EPILEPSY



Hi, my name is Ailbhe and I am doing a project about what is like for children to have epilepsy.

1. What will I do in the project?



I would like to come and chat to you about what it is like to have epilepsy.

You can draw me pictures and tell me your story.

Don't worry it will be fun!

2. Where will we meet?

I will come to meet you at your house or wherever you and your parents choose.

3. How long will all this take?

Not too long, maybe about half an hour.

4. Why do I want this information?

I want to know what are the things that make it ok and what are the things that make it difficult to have epilepsy.

5. What will happen to my answers?

I will be writing a long essay about what you tell me but I won't mention your name in the essay.

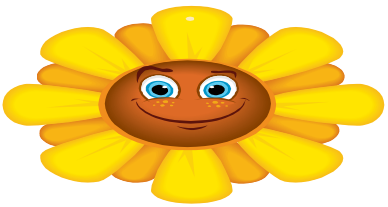
There are no right or wrong things to say or draw, I am really interested in knowing your story.

6. Can one of my parents stay with me while we chat?

Yes of course.

7. What if I don't want to talk to you when you visit me?

That is fine. I won't mind at all.



I'd be very happy to answer any questions you have. Just ask your parents if you can contact me.

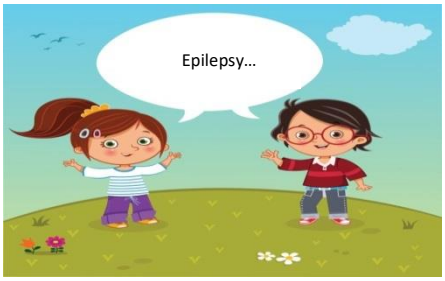
My name is Ailbhe Benson and I am a student at Dublin City University.

My phone number is 087 3124218
My email address is ailbhe.benson2@mail.dcu.ie

Appendix H.3: Phase One: Young Person's Plain Language Statement (Participants aged 11-16 years)

Would you like to help me with my project?

TALKING ABOUT EPILEPSY



Hi, my name is Ailbhe and I am doing a study about what is like for young people like you to have epilepsy.

What will I do in the project?

I would like to come and talk to you about what it is like to have epilepsy.

You can make a collage and tell me your story.

I believe what you tell me will be very important so I will record our conversation on my iPod so I don't forget anything.

Where will we meet?

I will come speak to you at your house or wherever you and your parents

How long will this all take?

Probably about 45 minutes but it really depends on how little or much you have to say.

Why do I want this information?

I want to know what are the things that make it ok and what are the things that make it difficult to have epilepsy. Then, I can help young people just like you in the future.

What will happen to my answers?

Your answers will be kept locked up safely so that no one else can see them.

I will be writing a long essay about what you tell me but I won't mention your name in the essay.

There are no right or wrong things to say, I am just really interested in hearing your story.

How many young people are helping me?

I will be talking to about 30 young people aged between 6 and 15 years. I will also be talking to all the young people's parents.

Can one of my parents stay with me while we chat?

Yes of course.

What should I do if I don't want to talk to you when you visit me?

That is fine. I will respect your wishes. I won't mind at all.

If you have any questions you want to ask me before I visit you can ask your parents if it is ok for you to contact me. I'd be very happy to answer any questions you have.

My name is Ailbhe Benson and I am a student at Dublin City University.

My phone number is 087-3124218
My email address is ailbhe.benson2@mail.dcu.ie

Appendix I: Phase One: Ethical Protocols Devised/Implemented (where appropriate)

1. *In the Instance of a Child showing signs of Upset/Anxiety/Tiredness*

Due to the non-invasive nature of the data collection procedure, it was deemed unlikely that any child participants would experience significant adverse effects. However, it was appreciated that they may become upset or anxious if the discussions evoked distressing memories of negative disclosure experiences. Before undertaking interviews, the researcher verified with the parents and child that the child was in full health. Nevertheless, the researcher was cognisant that as child participants had a chronic illness, they may show signs of tiredness during the interview. The following protocol was observed in order to effectively manage the potential risk of children experiencing upset/anxiety or tiredness during interviews:

- The researcher was continuously alert for any signs of unforeseen events i.e. an anxious/upset/tired/unwell child.
- At the outset of the interview the researcher agreed a hand signal with the child that the child could use to halt the interview.
- Should any child become upset or tired, his/her participation in the interview was stopped and he/she was offered the opportunity to take a break, reschedule his/her participation in the study or withdraw from the study.
- The researcher provided reassurance and comfort to the child, the child's parent(s) (if not already in attendance at the interview) were informed immediately and the child was reunited with his/her family.
- Once ready the researcher returned to talk with the child and his/her parent(s) to ensure that they understood that halting the interview or withdrawing from the study would have no impact on any future care the child may require or their future engagements with the National Epilepsy Association.
- With parental agreement, if the child wished to continue his/her involvement with the study he/she could either do so once he/she was happy to continue or alternatively, another opportunity to be interviewed was offered. If the opportunity to participate further was declined, the child was thanked for his/her contribution to the study.

2. *In the Instance of a Parent showing signs of Upset/Anxiety/Tiredness*

As with CWE participants, it was deemed very unlikely that the present study would cause any harm to parent participants. Again, however, it was appreciated that they may become upset or anxious if the discussions evoked distressing memories of negative disclosure experiences for their child/children or indeed for themselves. Bearing this potential risk in mind, the following procedure was followed:

- The researcher was continuously alert for any signs of unforeseen events i.e. an anxious/upset parent.
- Should any parent become upset, his/her interview was stopped and he/she was offered the opportunity to take a break, reschedule his/her participation in the study or withdraw from the study.
- The researcher spoke with the parent to ensure that he/she understood that halting the interview or withdrawing from the study would have no impact on any future care his/her child may require or any future engagements with the National Epilepsy Association.
- If the parent wished to continue his/her involvement with the study he/she was allowed to do so as long as he/she expressed his/her willingness to continue. Alternatively, if preferred, another opportunity to be interviewed was offered. If the opportunity to participate further was declined, the parent was thanked for his/her contribution to the study.

3. <u>In the Instance of Child Protection Issues Arising</u>

It was stressed at the outset of the study to parents and children that absolute confidentiality could not be guaranteed if child protection issues arose. If the child disclosed any information that suggested that he/she or anyone else was at risk (i.e. abusive behaviour), the researcher was obliged under the Children First: National Guidance for the Protection and Welfare of Children (Department of Children and Youth Affairs, 2011) to safeguard the welfare of the child, regardless of the effect this would have on the study.

In accordance with the Department of Children and Youth Affairs Children's First document (2011), the below protocol was devised that was to be followed if any child disclosed issues relating to safety:

1. "……[name of child], you've told me that …….. [e.g. someone is hurting you]. This is something that I can't keep private between us, I need to tell, so that someone can help you. You are very brave to have told me though. I have to tell……[name of designated person in TSCUH/DCU/Epilepsy Ireland] about this so that she/he can arrange things, so that you can be helped."
2. The researcher would gently end the interview, ensuring that the child was not distressed or allowing him/her time to recover if he/she was distressed.
3. Depending on the nature of the disclosure, the researcher would make a judgement, based on the best interests of the child, whether or not to inform the parent/s of this disclosure.
4. Agreed staff member at TSCUH/DCU/Epilepsy Ireland would be informed of disclosure as soon as is possible (preferably immediately). Any concern of abuse etc. would be reported to the on-duty social worker of the appropriate health board.
5. Outside normal hours or if there was a serious threat to the child or other children the Gardaí would be informed immediately
6. Information would be accurately recorded using templates from the National Guidelines for reporting such allegations.

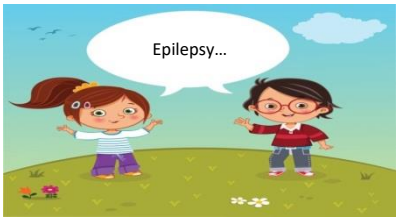
4. *In the Instance of a Child becoming Unwell or having a Seizure*

Due to the chronic nature of the epilepsy condition that child participants lived with, it was possible that children may have become unwell or have had a seizure during the interviews. The following protocol was put in place and adhered to in instances when such incidents occurred:

- The interview was immediately halted and if the parent of the child had not stayed in the room during the interview they were called in straight away.
- The interviewer stayed with the child and made sure that he/she was ok until the parent came into the room. If necessary, appropriate first aid actions were taken.
- The interviewer ensured that the parent and child were ok before leaving the room (if that was what the child and parent desired).
- If the child and his/her parent still wished for the child or parent to continue with interviews once the child had recovered, this was facilitated only after ensuring that the child was capable of doing so.
- If the child/parent still wished to participate at a later date the interviewer advised the family that they would call to reschedule.
- If the child/parent did not wish to participate thereafter, the interviewer thanked them for their time.

Appendix J.1: Phase One: Parent Consent Form

Research Study: Talking about Epilepsy



Parental Consent form

We are doing this study to try and find out more about you and your child's experiences of living with epilepsy. In particular, we are interested in you and your child's experiences of telling/talking to others about his/her condition and how these experiences of disclosure/non-disclosure were for you and your child.

This Health Research Board (HRB) funded study is being carried out by Ailbhe Benson (which is me the researcher) and Dr. Veronica Lambert and Professor Pamela Gallagher from the School of Nursing and Human Sciences at Dublin City University (DCU). The research was developed in conjunction with the Children's University Hospital, Temple Street and Epilepsy Ireland.

Participants name (s) *(please list here your name(s) and the full names of all your children aged 6-15 living with epilepsy who you consent to participate)***:**

Parent Name 1: _____
Parent Name 2: _____
Child Name: _____
Child Name: _____
_____ _____
_____ _____

I confirm that I have read and understood the Information Leaflet for this research study and have received an explanation of the nature, purpose, duration of the study, what myself and my child/children's involvement will be and any possible risks to myself or my family.

I have had time to consider whether I want myself and my child/children to take part in this research. I understand that participation in the study is voluntary, (that is, I have a choice as to whether I consent to my child/children and I taking part). I have the contact details of the researchers and they have answered any questions I might have.

I understand also that I am free to end my participation at any time by contacting Ailbhe and this will not affect my family's or my child's present or future association with any of the services connected with the research, including medical care.

I confirm that I have explained the research to my child/children.

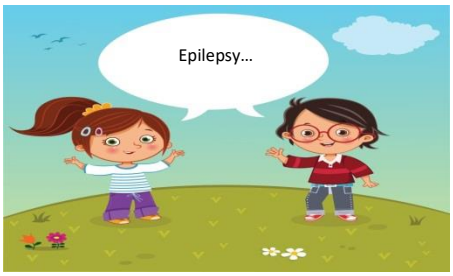
☐ **I give consent for my child/children as named above to take part in this research.**
(If you choose this option, thank you and please complete the details overleaf)

☐ **I give consent for my own participation in this research**
(one or two parent/s please sign below)

_____	_____	_____
Your name	Date	Signature
_____	_____	_____
Your name	Date	Signature
_____	_____	_____
Researcher's name	Date	Signature

Appendix J.2: Phase One: Child Assent Form (Participants aged 6-10 years)

TALKING ABOUT EPILEPSY



CHILDREN'S ASSENT FORM

1. **I,_____, am happy to take part in this project, to chat to Ailbhe and to draw pictures about what it is like to have epilepsy.**
2. **I understand that there are no right or wrong things to say or draw. Ailbhe just really wants to know my story.**
3. **I know that what I tell Ailbhe might help other children in the future.**
4. **I know that I don't have to take part in this project even if my Mum and Dad are ok with me taking part. No one will be annoyed if I decide to stop at any time.**
5. **I have been promised that anything I tell Ailbhe will be kept as secret as possible.**
6. **I know that I can ask questions at any time, now or later.**

I REALLY WANT TO TAKE PART IN THIS PROJECT.

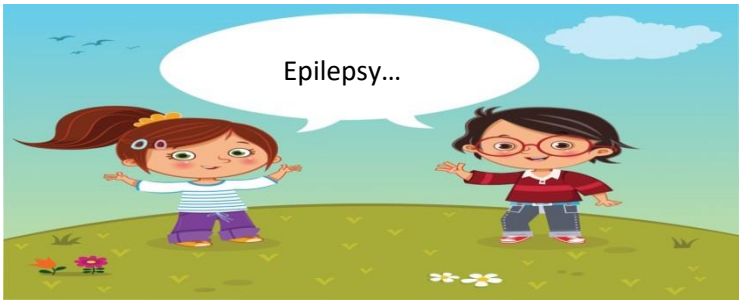
CHILD SIGNATURE:_____

RESEARCHER SIGNATURE:_____

DATE AND TIME:_____

Appendix J.3: Phase One: Young Person Assent Form (Participants aged 11-16 years)

TALKING ABOUT EPILEPSY



Young Person's Assent Form

1. **I,_____ have agreed to take part in this project to help others to find out what it is like to have epilepsy.**
2. **I understand that Ailbhe is going to talk to me about my epilepsy. There are no right or wrong things to say. Ailbhe just really wants to know my story.**
3. **I know this project might help other young people living with epilepsy in the future.**
4. **I know that I don't have to take part in this project even if my parents are ok with me taking part. It is completely up to me whether I wish to decide to stop at any time. No one will be annoyed if I stop at any time.**
5. **I have been promised that anything I tell Ailbhe will be kept as confidential as possible.**
6. **I know that I can ask questions at any time, now or later.**

I REALLY WANT TO TAKE PART IN THIS RESEARCH PROJECT.

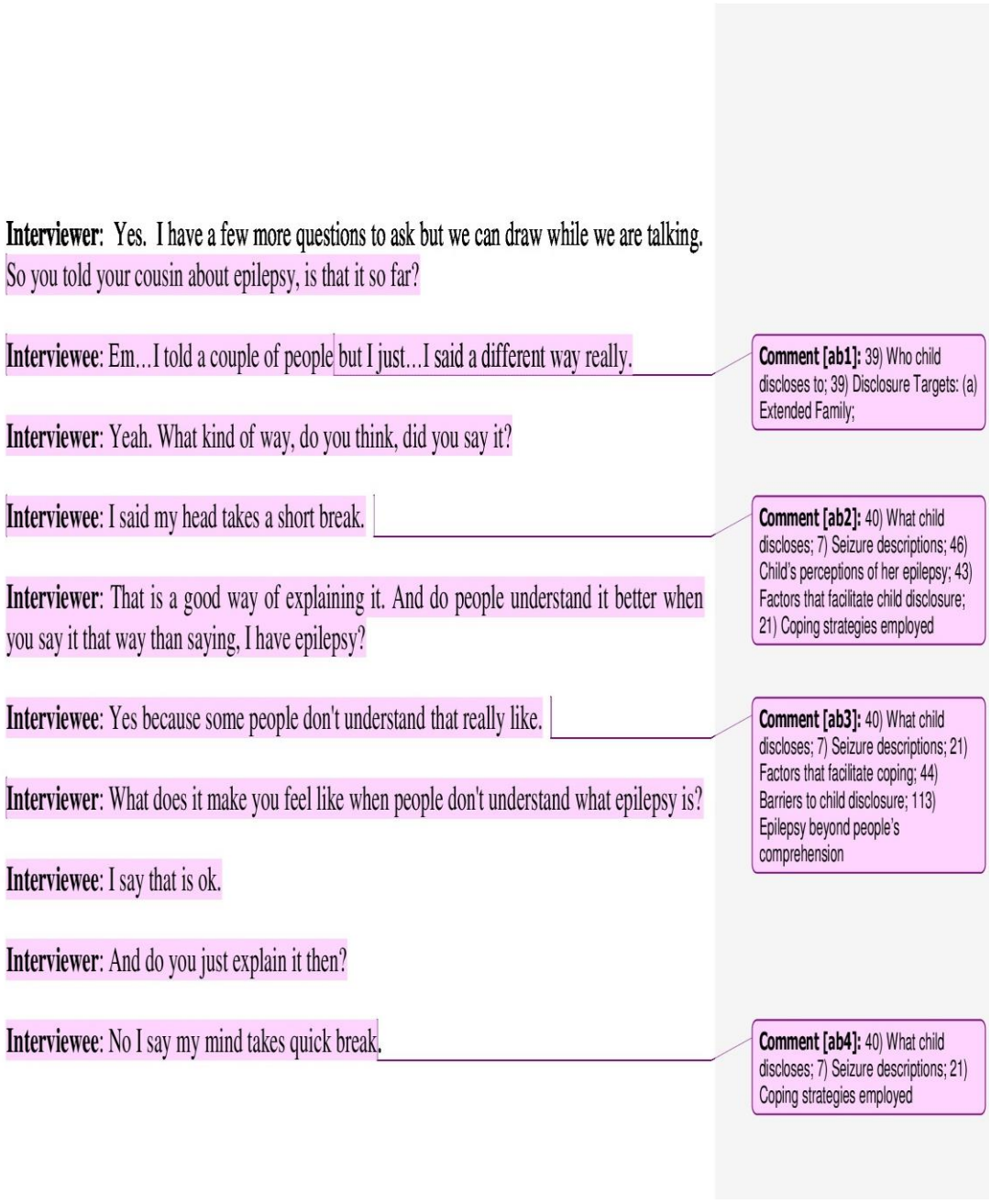
YOUNG PERSON'S SIGNATURE:_____

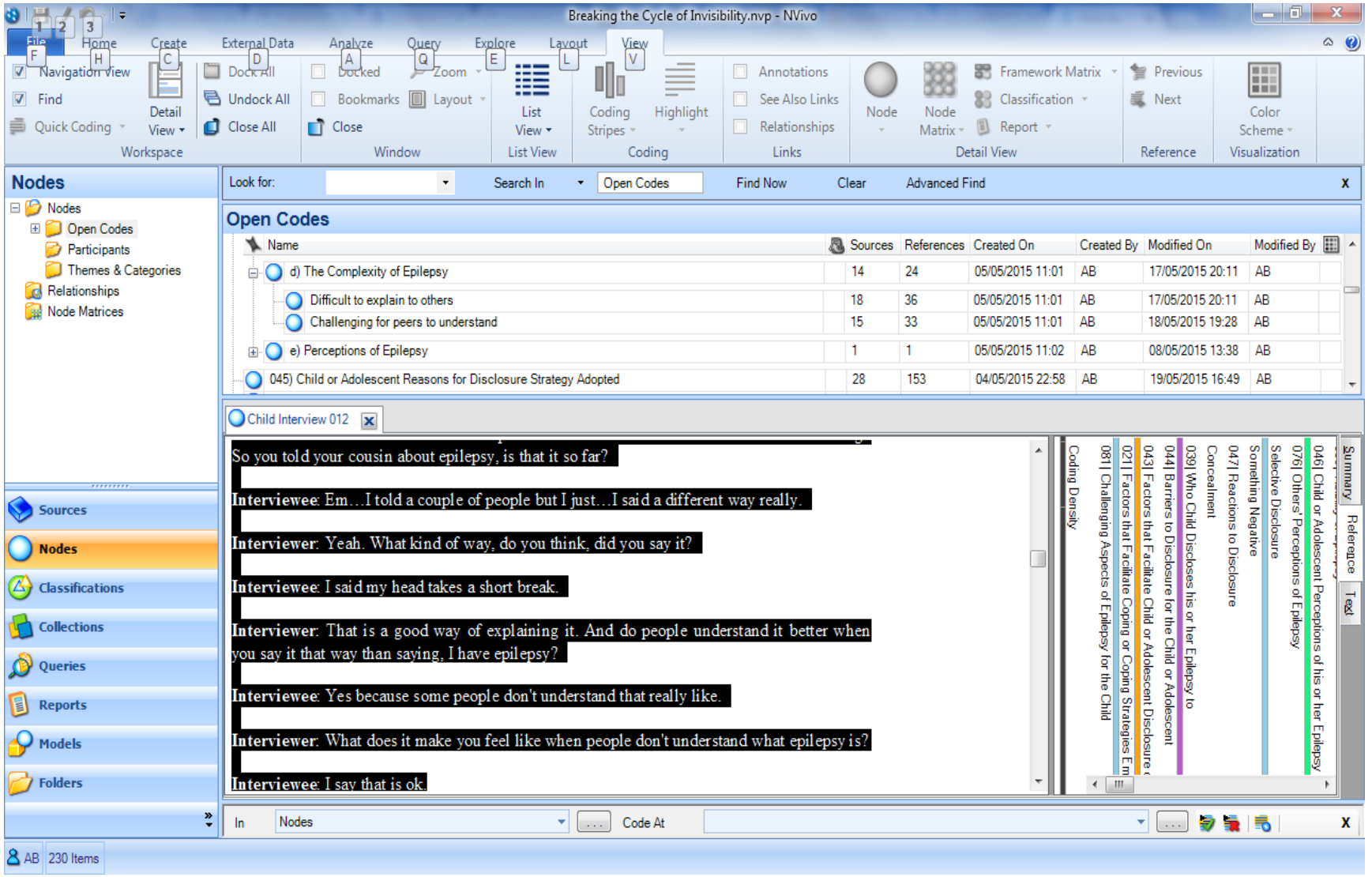
RESEARCHER SIGNATURE:_____

DATE AND TIME:_____

Appendix K: Phase One: Exemplar of Coded Data Extracts

Two examples of coded data extracts are presented below. The first is an excerpt from an interview transcript for Robyn (female, aged 10 years) which was coded manually using the comment function in Microsoft Word. The second is the same excerpt in NVivo v10. Due to several organisational features offered by NVivo (e.g. the ability to view all incidents under any given code), it became the coding platform of choice.




Breaking the Cycle of Invisibility.nvp - NVivo
File
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Analyze
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Explore
Layout
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Navigation View
Find
Quick Coding
Detail View
Dock All
Undock All
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List View
Coding Stripes
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Annotations
See Also Links
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Node Matrix
Framework Matrix
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Find Now
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Advanced Find
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Name
Sources
References
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d) The Complexity of Epilepsy 14 24 05/05/2015 11:01 AB 17/05/2015 20:11 AB
Difficult to explain to others 18 36 05/05/2015 11:01 AB 17/05/2015 20:11 AB
Challenging for peers to understand 15 33 05/05/2015 11:01 AB 18/05/2015 19:28 AB
e) Perceptions of Epilepsy 1 1 05/05/2015 11:02 AB 08/05/2015 13:38 AB
045) Child or Adolescent Reasons for Disclosure Strategy Adopted 28 153 04/05/2015 22:58 AB 19/05/2015 16:49 AB
Child Interview 012
So you told your cousin about epilepsy, is that it so far?
Interviewee: Em…I told a couple of people but I just…I said a different way really.
Interviewer: Yeah. What kind of way, do you think, did you say it?
Interviewee: I said my head takes a short break.
Interviewer: That is a good way of explaining it. And do people understand it better when you say it that way than saying, I have epilepsy?
Interviewee: Yes because some people don't understand that really like.
Interviewer: What does it make you feel like when people don't understand what epilepsy is?
Interviewee: I say that is ok.
Coding Density
081| Challenging Aspects of Epilepsy for the Child
021| Factors that Facilitate Coping or Coping Strategies Em
043| Factors that Facilitate Child or Adolescent Disclosure
044| Barriers to Disclosure for the Child or Adolescent
039| Who Child Discloses his or her Epilepsy to
Concealment
047| Reactions to Disclosure
Something Negative
Selective Disclosure
076| Others' Perceptions of Epilepsy
046| Child or Adolescent Perceptions of his or her Epilepsy
Summary
Reference
Text
Sources
Nodes
Classifications
Collections
Queries
Reports
Models
Folders
In
Nodes
Code At
AB
230 Items

Pseudonym	Gender	Age (years)	Class in School	Age at diagnosis	Seizure Type(s)	Period of Seizure Freedom	Treatment Regime	Family History of Epilepsy	Language Employed around Epilepsy
Claw	Male	7	2nd class (Primary)	6	-Tonic-Clonic -Simple Partial	10 months	*Current:* One AED (Sodium Valproate) *Previous:* One AED (Oxcarbazepine)	No	All typical
Marie	Female	13	1st year (Secondary)	9	-Complex Partial -Absence	2 weeks	*Current:* Three AEDs (Clobazam, Lamotrigine and Zonisamide) *Previous:* Two AEDs (Levetiracetam and one other medication the mother couldn't recall the name of)	No	The child and mother refer to partial seizures as "funny feelings"
Mandz	Female	6	Senior Infants (Primary)	4	-Absence	12 months	*Current:* One AED (Sodium Valproate) *Previous:* N/A	No	All typical
Luke	Male	7	1st class (Primary)	2	Every type	A few hours (absence seizure)	*Current:* Two AEDs (Sodium Valproate and Lamotrigine) *Previous:* N/A	Yes (child's cousin; also the child's brother had febrile seizures)	Seizures referred to as 'fits'
Tom	Male	11	5th class (Primary)	6	-Absence	2 weeks	*Current:* Two AEDs (Lamotrigine and Clobazam) *Previous:* N/A	No	The family never use the term seizures-the phrase 'zoning out' is used to refer to the child's absence seizures

Pseudonym	Gender	Age (years)	Class in School	Age at diagnosis	Seizure Type(s)	Period of Seizure Freedom	Treatment Regime	Family History of Epilepsy	Language Employed around Epilepsy
Paul	Male	13	1st year (Secondary)	10	-Tonic-Clonic -Complex Partial	1 day	*Current:* 2 AEDs (Levetiracetam and Lamotrigine) *Previous:* One AED (Sodium Valproate)	No	All typical
Carl	Male	11	5th class (primary)	10	-Complex Partial -Tonic-Clonic	10 days	*Current:* Three AEDs (Levetiracetam, Sodium Valproate and Oxcarbazepine) *Previous:* N/A	Yes (child's great aunt)	All typical
Taylor	Female	10	4th class (primary)	8	-Tonic-Clonic -Simple Partial	2 months (simple partial seizure)	*Current:* One AED (Lamotrigine) *Previous:* N/A	Yes (child's cousin)	All typical
Jack	Male	9	3rd class (primary)	7	-Tonic-Clonic -Myoclonic -Absences	15 months	*Current:* One AED (Oxcarbazepine) *Previous:* One AED (Sodium Valproate)	No	All typical
Hermione	Female	13	1st year (Secondary)	11	-Tonic-clonic -Eyelid myoclonia -Absences	A few hours (simple partial)	*Current:* Two AEDs (Clobazam and Ethosuximide) *Previous:* Three AEDs (Levetiracetam, Lamotrigine and Carbamazepine)	No	All typical

Pseudonym	Gender	Age (years)	Class in School	Age at diagnosis	Seizure Type(s)	Period of Seizure Freedom	Treatment Regime	Family History of Epilepsy	Language Employed around Epilepsy
Dave	Male	12	6th class (primary)	12	-Tonic-Clonic -Complex Partial -Electrical Status Epilepticus	4 months	*Current:* Three AEDs (Levetiracetam, Clobazam and Sultiame) *Previous:* Three AEDs (Lamotrigine, Sodium Valproate and Carbamazepine)	No	All typical
Ruth	Female	13	6th class (primary)	3	-Complex Partial -Tonic-Clonic	12 hours	*Current:* Three AEDs (Vigabatrin, Oxcarbazepine and one other medication the mother couldn't recall the name of) *Previous:* According to the mother, every type of AED suitable for the child's type of epilepsy has been tried and three surgeries have been undertaken in an attempt to gain seizure control.	No	"S's" or "the 's' word" used to refer to seizures.
Jessie	Female	11	5th class (Primary)	8	-Tonic-Clonic -Absence	5 months	*Current:* One AED (Sodium Valproate) *Previous:* Two AEDs (Carbamazepine and Sultiame)	No	All typical

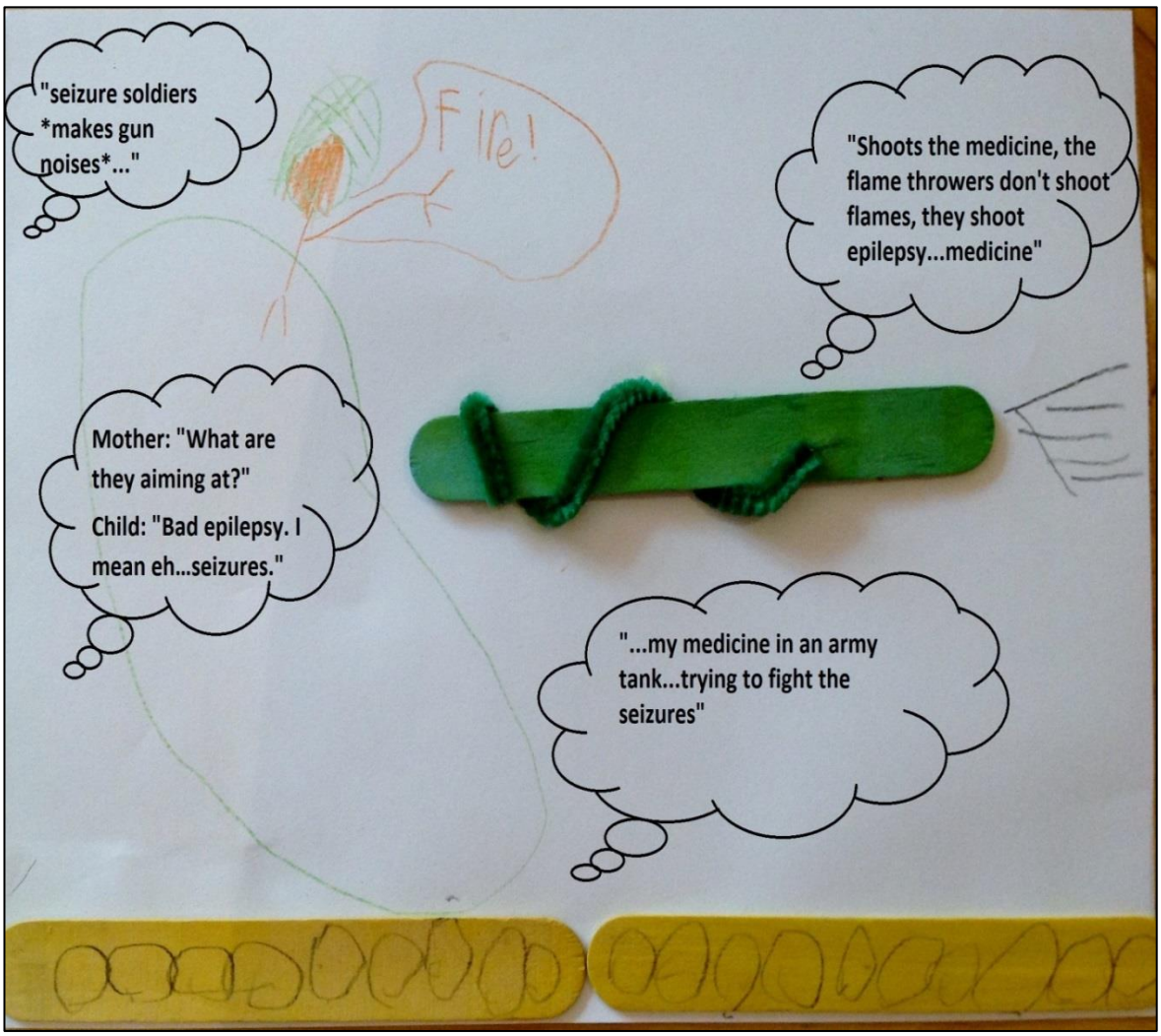
Pseudonym	Gender	Age (years)	Class in School	Age at diagnosis	Seizure Type(s)	Period of Seizure Freedom	Treatment Regime	Family History of Epilepsy	Language Employed around Epilepsy
Hannah	Female	7	Senior Infants (Primary)	4	-Atonic -Myoclonic -Absence -Tonic -Tonic-Clonic	12 hours	*Current:* Two AEDs (Levetiracetam and Lamotrigine) *Previous:* Two AEDs (Clobazam and Sodium Valproate)	No	All typical
Cee Lo	Female	8	1st class (Primary)	4	-Tonic-Clonic -Myoclonic -Absence	During interview	*Current:* Three AEDs (Levetiracetam, Sodium Valproate and Clonazepam) *Previous:* Three AEDs (Clobazam, Zonisamide and Oxcarbazepine)	No	Absences referred to as "wobbly moments"
Selena	Female	11	5th class (Primary)	4	-Simple Partial	3 weeks	*Current:* Three AEDs (Lacosamide, Lamotrigine and Carbamazepine) *Previous:* One AED (Sodium Valproate)	Yes (child's aunt)	Seizures are referred to as "frights"
Anna	Female	15	3rd year (Secondary)	6	-Complex Partial	3 months	*Current:* One AED (Carbamazepine) *Previous:* One AED (Lamotrigine)	No	All typical
Nikki	Female	15	3rd year (Secondary)	12	-Absence -Tonic-Clonic	5 days	*Current:* Two AEDs (Clobazam and Oxcarbazepine) *Previous:* One AED (Sodium Valproate)	Yes (child's cousin)	All typical

Pseudonym	Gender	Age (years)	Class in School	Age at diagnosis	Seizure Type(s)	Period of Seizure Freedom	Treatment Regime	Family History of Epilepsy	Language Employed around Epilepsy
Tadhg	Male	12	6th class (Primary)	6	-Complex Partial	12 hours	*Current:* Four AEDs (Phenobarbital, Clobazam, Carbamazepine and Perampanel) and Vagus Nerve Stimulation *Previous:* Four AEDs (Topiramate, Sodium Valproate, Levetiracetam and Lamotrigine)	No	All typical
Rebecca	Female	15	3rd year (Secondary)	12	-Absence	12 hours	*Current:* One AED (Ethosuximide) *Previous:* One AED (Lamotrigine)	No	All typical
Colm	Male	12	5th class (Primary)	8	-Complex Partial	12 hours	*Current:* Two AEDs (Sodium Valproate and Clobazam) and surgery being considered *Previous:* Six AEDs (Levetiracetam, Zonisamide, Lacosamide, Lamotrigine, Topiramate and Carbamazepine)	No	All typical
Rooney	Male	10	4th class (Primary)	4	-Tonic-clonic -Tonic	4 months	*Current:* One AED (Carbamazepine) *Previous:* N/A	Yes	Seizures referred to as 'fits'
Ryan	Male	9	3rd class (Primary)	8	-Tonic-clonic -Tonic	1 week	*Current:* One AED (Oxcarbazepine) *Previous:* N/A	No	All typical

Pseudonym	Gender	Age (years)	Class in School	Age at diagnosis	Seizure Type(s)	Period of Seizure Freedom	Treatment Regime	Family History of Epilepsy	Language Employed around Epilepsy
Tony	Male	13	6th class (Primary)	6	-Tonic -Atonic -Tonic-Clonic	13 months	*Current:* Two AEDs (Sodium Valproate and Lacosamide) *Previous:* 4 AEDs (Lamotrigine, Sodium Valproate, Sultiame and Phenytoin) and the Modified Atkins Diet	No	All typical
Lucy	Female	7	1st class (Primary)	7	-Absence -Myoclonic -Atonic -Tonic-clonic	During interview	*Current:* Two AEDs (Levetiracetam and Clobazam) *Previous:* One AED (Oxcarbazepine)	Yes	All typical
Audrey	Female	15	3rd year (Secondary)	14	-Complex Partial	8 months	*Current:* One AED (Oxcarbazepine) *Previous:* N/A	Unsure	All typical
Macklemore	Female	14	1st year (Secondary)	12	-Tonic-Clonic -Absence	12 hours (absence)	*Current:* One AED (Lamotrigine) *Previous:* One AED (Sodium Valproate)	Yes (child's grand-mother)	All typical
Robyn	Female	10	3rd class (Primary)	9	-Absence	2 months	*Current:* One AED (Ethosuximide) *Previous:* N/A	No	Never refer to the term seizures-use the terms 'absences' or 'trances' only

Pseudonym	Gender	Age (years)	Class in School	Age at diagnosis	Seizure Type(s)	Period of Seizure Freedom	Treatment Regime	Family History of Epilepsy	Language Employed around Epilepsy
Aoife	Female	16	4th year (Secondary)	6	-Tonic-Clonic	2.5 months	*Current:* No treatment-had been weaning off medication but seizures returned and she has been re-prescribed one AED (Lamotrigine) *Previous:* One AED (Lamotrigine)	Yes (child's great uncle and cousins)	All typical

Appendix M: Phase One: Sample Artwork

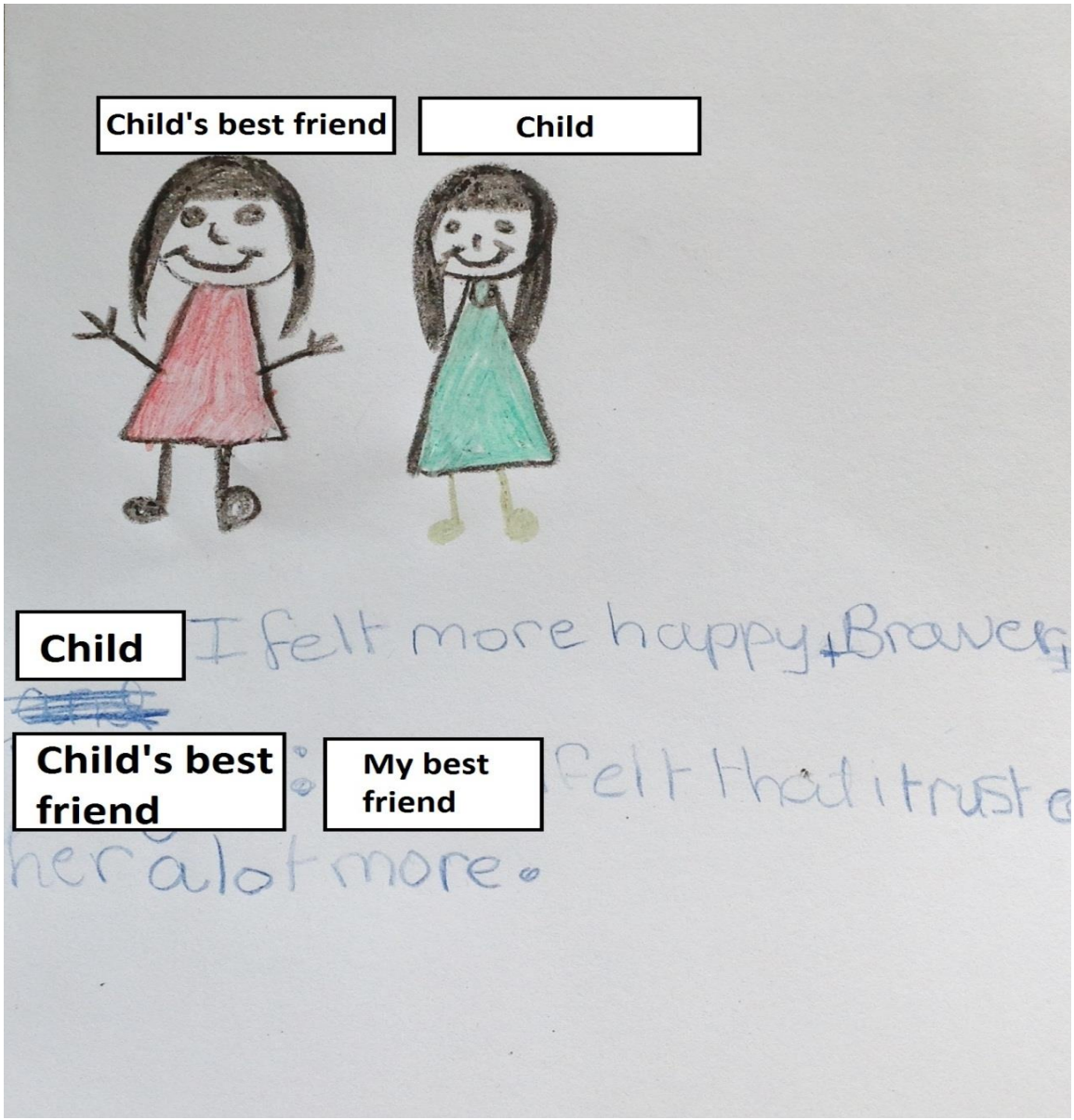


"The war against epilepsy"

- Claw*, Age 7

Claw provided a child-friendly interpretation of his epilepsy via his artwork. In his illustration he depicted a battle, whereby 'seizure soldiers' were attacking his epilepsy and seizures by shooting medicine (Epilim) at them.

*Child-selected pseudonym



"Talking to my best friend about epilepsy"

- Selena*, Age 11

Selena provided an illustration of her experience of talking to her best friend about her epilepsy. She describes how the experience elicited positive feelings for both of them.

*Young person-selected pseudonym

Appendix N.1: Phase Two: Ethical Approval from Dublin City University Research Ethics Committee

Ollscoil Chathair Bhaile Átha Cliath
Dublin City University

DCU

Dr Veronica Lambert
School of Nursing and Human Sciences

10th September 2014

REC Reference: **DCUREC/2014/191**

Proposal Title: **Talking about epilepsy: A collaboration of two studies examining 1) family communication (study A); and 2) the selection of disclosure strategies (study B) in families living with epilepsy**

Applicants: **Dr Veronica Lambert, Ms Stephanie O'Toole, Ms Ailbhe Benson, Professor Pamela Gallagher, Dr Amre Shahwan**

Dear Veronica,

Further to expedited review, the DCU Research Ethics Committee approves this research proposal. Materials used to recruit participants should note that ethical approval for this project has been obtained from the Dublin City University Research Ethics Committee. Should substantial modifications to the research protocol be required at a later stage, a further submission should be made to the REC.

Yours sincerely,

DCU Research & Innovation

Dónal O'Mathúna

Dr. Donal O'Mathuna
Chairperson
DCU Research Ethics Committee

Taighde & Nuálaíocht Tacaíocht
Ollscoil Chathair Bhaile Átha Cliath,
Baile Átha Cliath, Éire

Research & Innovation Support
Dublin City University,
Dublin 9, Ireland

T +353 1 700 8000
F +353 1 700 8002
E research@dcu.ie
www.dcu.ie

Appendix N.2: Phase Two: Ethical Approval from Temple Street Children's University Hospital Research Ethics Committee

Children's University Hospital
TEMPLE STREET, DUBLIN

DEPARTMENT OF RESEARCH
Children's University Hospital
Temple Street, Dublin 1
Tel: +353 1 892 1787
Email: research@cuh.ie Web: www.cuh.ie

Ms Ailbhe Benson
School of Nursing and Human Sciences
DCU
Glasnevin
Dublin 9

21st August 2014

Re: 14.026. Talking about epilepsy

Dear Ms Benson,

Thank you for your response to the Ethics Committee letter dated 18th July 2014. You have successfully addressed the concerns raised by the Committee and therefore the Committee is happy to grant ethics approval for your project.

We wish you every success with your study. The research Office would like to receive a report on completion.

Yours sincerely,

Prof Philip D Mayne
Medical Secretary Ethics Committee
MCRN: 06935

c.c. Department of Research

Appendix N.3: Phase Two: Ethical Approval from Our Lady of Lourdes Hospital, Drogheda

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Regional Manager Consumer Affairs
HSE Dublin North East

Bective Street, Kells
Co. Meath

Tel: +353 (0) 46 9251264
Fax: +353 (0) 46 9251774

Loughtee Business Park
Drumalee, Cavan

Tel: +353 (0) 49 4377343
Fax: +353 (0) 49 4377379
Email: consumeraffairs.hsedne@hse.ie

9th April 2015

Ms Ailbhe Benson
School of Nursing and Human Sciences
Dublin City University
Glasnevin
Dublin 9

Re/ **"Talking about Epilepsy"**
Email correspondence from Ms Stephanie O'Toole dated 23/03/15

Dear Ms Benson

I am in receipt of correspondence from Ms Stephanie O'Toole dated 23rd March 2015 regarding an amendment to the above study.

I wish to advise that I have reviewed same and approval is given for the amendment to the study as outlined.

This will be formally noted at the next Research Ethics Committee meeting.

Yours sincerely

Dr Brendan MacMahon
Chairperson
HSE North East Area
Research Ethics Committee

Copied to/ **Dr Veronica Lambert, Lecturer, Nursing and Human Sciences, Dublin City University**
Ms Fiona Edwards, A/GM, Our Lady of Lourdes Hospital, Drogheda, Co Louth
Ms Emma Gordon, Lead Paediatrician, Our Lady of Lourdes Hospital, Drogheda, Co Louth
Dr Siobhan Gormally, Consultant Paediatrician and Neonatologist, Our Lady of Lourdes Hospital, Drogheda, Co Louth

Appendix N.4: Phase Two: Ethical Approval from St. James's Hospital, Dublin

SJH/AMNCH Research Ethics Committee Secretariat
Claire Hartin Ph: 4142199
email: claire.hartin@amnch.ie

THE ADELAIDE & MEATH HOSPITAL, DUBLIN
INCORPORATING
THE NATIONAL CHILDREN'S HOSPITAL

Ms. Stephanie O'Toole
School of Nursing and Human Sciences
DCU
Glasnevin
Dublin 9

27th March 2015

RE: Talking about Epilepsy

REC Reference: 2015-03 Chairman's Action (20) ***Please quote REC reference on all correspondence***

Dear Ms. O'Toole,

Thank you for your correspondence dated 25th March to SJH/AMNCH Research Ethics Committee in which you requested ethical approval for the above study.

The Chairman, on behalf of the SJH/AMNCH Research Ethics Committee has given ethical approval to this study.

Yours sincerely,

Claire Hartin
Secretary
SJH/AMNCH Research Ethics Committee

Appendix O.1: Phase Two: Child/Young Person Plain Language Statement

Talking about epilepsy:
Would you like to help us with our project?

Our names are Ailbhe and Stephanie and we are students at Dublin City University. We are doing a project on what it is like for young people like you to have epilepsy

What will I do in the project?

We would like you to fill out a questionnaire about what it is like to have epilepsy. We will ask you about your epilepsy and what it is like for you to talk to your parents and people outside of your family, like your friends, teachers and neighbours, about your epilepsy.

How long will this all take?

Probably about 1 hour but you can take your time and you can take as many breaks as you want to. When you are filling out the questionnaire, it is fine if you decide you want to stop at any stage and you do not want to take part any more. Whether you want to take part or not is completely up to you.

Why do we want this information?

We want to know what are the things that make it ok and what are the things that make it difficult to have epilepsy. Then, we can help young people just like you in the future.

What will happen to my answers?

You will not be writing your name anywhere on the questionnaire so no one will know what you have answered. Your answers will be kept locked up safely so that no one else can see them. We will be writing a long essay about what you tell us but we will not mention your name in the essay. There are no right or wrong things to say, we are just really interested in finding out about what it is like to have epilepsy.

Can one of my parents stay with me while I fill in my answers?

Yes, of course, but if you want to you can also fill in your answers by yourself.

What should I do if I do not want to take part?

That is fine. We will respect your wishes. We won't mind at all.

If you have any questions you want to ask us before you fill in your answers, you can ask your parents if it would be ok for you to contact us. We would be very happy to answer any questions you have.


talkingaboutepilepsy@gmail.com

Appendix O.2: Phase Two: Parent Plain Language Statement

Research Study: Talking about Epilepsy

What is this study about?

We are doing this study to find out more about you and your child's experiences of living with epilepsy. We are interested in learning about you and your child's experiences of talking/not talking about epilepsy and the impact of your discussions on your opinions of epilepsy as a condition. We are also interested in hearing about you and your child's experiences of telling/not telling, or talking/not talking, to others (e.g. friends, family members, teachers, etc.) about your child's epilepsy.

Who is conducting this study?

Led by Dr. Veronica Lambert, a team of researchers at the School of Nursing and Human Sciences in Dublin City University (DCU) and Temple Street Children's University Hospital (TSCUH) are conducting two studies in the area of communicating about epilepsy both within and external to the family. Two PhD researchers are currently working on these projects. Ailbhe is focusing on parents' and children's experiences of telling/not telling others about epilepsy, and Stephanie is focusing on parents' and children's experiences of talking about epilepsy within the family. These studies are Medical Research Charities Group (MRCG)/Health Research Board (HRB) funded and were developed in collaboration with the Neurology Department of TSCUH and Epilepsy Ireland - The Irish Epilepsy Association. The studies have received ethical approval from the research ethics committees in TSCUH, DCU and other regional paediatric units.

If I give consent to take part what will we be asked to do?

- The team of researchers has created one questionnaire designed to address the focus of both Ailbhe's and Stephanie's studies. We would like you to complete this questionnaire, either online or in paper form, about being the parent or guardian of a child living with epilepsy.
- Your child/children will also receive an information letter about completing a questionnaire about his/her epilepsy. Please be aware that you are under no obligation to share this information with your child, however doing so implies that you consent for your child to participate. The child information letter will be a simple, easier to read version. If you wish for your child to participate, we would encourage you to discuss the information letter with your child/children.
- If you complete the questionnaire in hard copy form, we would ask you to kindly return the questionnaire using the enclosed stamped addressed envelope.

How long will the process take?

- The questionnaire should take no longer than 1 hour to complete.

What if we do not decide to take part?

- We understand that not all families will have the time to take part in our study, and some families may not be interested. If you choose not to take part in the study, this will in *no way* affect your child's treatment in any of the affiliated hospitals or your participation in any activities/events organised by Epilepsy Ireland in the future.

What will be done with the information collected by us?

- All the information you and your family provides will be de-identifiable (i.e. no one will be able to tell what you specifically answered).
- While completing the questionnaire, you may decide to stop participating and withdraw from the study at any time. However, as we will not be able to identify your data, once you have submitted the questionnaires (by post or online) we will not be able to withdraw you from the study.
- Only the research team and possibly the examiners of our theses will have access to the data and these will be treated in the strictest of confidence at all times.
- All information will be stored in locked filing cabinets and/or on password-protected computers in DCU.
- The information we collect from all the families who complete this questionnaire will be used to write a report on the findings of this research.
- The MRCG/Epilepsy Ireland and HRB who are funding the project will receive annual reports and the findings from the study may be published in journals. Additionally, we will write our theses using information we have gathered from families involved in this research.

How will this study be of benefit to me and my children?

While there may be no immediate benefits to you, and your child/children from taking part in the study, the researchers hope that studies such as these can be used to identify the needs of children living with epilepsy and thus inform and develop new services for families.

Are there any risks or downsides to taking part?

There should be no risks involved in taking part, however if you feel it might help to talk to somebody about any of the issues that came up, we can put you in touch with someone (e.g. your local Community Resource Officer in Epilepsy Ireland) who can advise you on next steps.

Is there anything else I need to know?

If you would like to talk informally with us about any questions or queries you may have about this research, please contact us by email at ***talkingaboutepilepsy@gmail.com*** or by phone –**01-7007997 (Ailbhe)** or **01-7006867 (Stephanie)*.***

Thank you for taking an interest in this research and completing this questionnaire!

If participants have concerns about this study and wish to contact an independent person, please contact:

The Secretary,
Dublin City University Research Ethics Committee,
Care of Research and Innovations Support,
Dublin City University,
Dublin 9.
Tel: 01-7008000

Appendix P: Phase Two: Recruitment Advertisement

Talking about Epilepsy

We are trying to find out what it is like for children living with epilepsy and their parents

Who is involved?

Our names our Ailbhe Benson and Stephanie O'Toole and we are PhD students at DCU. We are doing a project in collaboration with Epilepsy Ireland and we are looking for children (aged 8 – 18 years) with a diagnosis of epilepsy as well as their parents to participate. Due to the nature of the research, we require that children participating have no other significant medical conditions and/or significant learning difficulties.

What will the study involve?

The study will involve children and/or their parents filling out questionnaires. The questionnaires can be completed in hard copy format, online or with the assistance of the researchers (face-to-face or over the telephone).

Why is this study beneficial?

This study will help us to learn more about the challenges (positive and negative) that face children living with epilepsy and their parents. Such information will help us to tackle the negative challenges faced by children living with epilepsy in the future and ultimately it will help us to raise awareness about epilepsy in children.

How do we participate?

If you are interested in knowing more, or you think you and your child would like to participate, please contact us by phone – **01-7006867 (Stephanie) or 01-7007997 (Ailbhe)** - or by email at **talkingaboutepilepsy@gmail.com**. Alternatively, if you would like to complete the questionnaires online, please follow the following links:

Parent Questionnaire: www.bit.ly/epilepsyparent
Child Questionnaire: www.bit.ly/epilepsychild

Although your participation would be highly appreciated, you do not have to take part - it is completely up to you!

Appendix Q.1: Phase Two: 2 week Follow-up Letters/Reminders

Epilepsy Ireland Version

Reminder: "Talking about Epilepsy" Research Study

Dear

Approximately 2 weeks ago, you received correspondence from the 'Talking about Epilepsy' research team requesting your participation in a very important questionnaire about how children living with epilepsy and their parents communicate about epilepsy.

If you have already completed and returned the questionnaires, please accept our sincere thanks and appreciation and disregard this letter. If you have not yet had the chance to complete the questionnaires, we would encourage you to please do so either in hard copy format or online. In order for the results to truly represent the opinions of all families living with epilepsy, it is important that as many questionnaires as possible are completed and returned. Again, we would like to emphasise that your participation is entirely voluntary and anonymous. Therefore, if you do not wish to participate, please disregard this follow-up letter. This will in no way affect your engagements with Epilepsy Ireland.

If by some chance you did not receive the questionnaire or in the event that your questionnaire has been misplaced and you would still like to participate in the study, please contact a member of the research team by phone or by e-mail (talkingaboutepilepsy@gmail.com) and they will mail you out another one. **Alternatively, if you would like to complete these questionnaires either over the telephone or face-to-face with a member of the research team, we would be happy to call you or arrange a meeting at a time and location of your choice in order to do so.** If you have any further queries about the study, or any suggestions as to how we could make the process as easy as possible for you, please do not hesitate to contact Ailbhe (**01-7007997**) or Stephanie (**01-7006867**), who would be happy to answer any questions and receive any suggestions you might have.

Once again, we would like to extend our gratitude for all of your assistance and support-without the input of families living with epilepsy, this research would not be possible.

Kind Regards,

Ailbhe Benson *(PhD student)*

Phone: 01-7007997

Stephanie O' Toole *(PhD student)*

Phone: 01-7006867

Neurology/Paediatric Clinic Version (Template)

Reminder: "Talking about Epilepsy" Research Study

Dear

Approximately 2 weeks ago, you received correspondence from the 'Talking about Epilepsy' research team and I requesting your participation in a very important questionnaire about how children living with epilepsy and their parents communicate about epilepsy.

If you have already completed and returned the questionnaires, please accept our sincere thanks and appreciation and disregard this letter. If you have not yet had the chance to complete the questionnaires, I would encourage you to please do so either in hard copy format or online. In order for the results to truly represent the opinions of all families living with epilepsy, it is important that as many questionnaires as possible are completed and returned. Again, I would like to emphasise that your participation is entirely voluntary and anonymous. Therefore, if you do not wish to participate, please disregard this follow-up letter. This will in no way affect your relationship with us here in Temple Street Children's University Hospital.

If by some chance you did not receive the questionnaire or in the event that your questionnaire has been misplaced and you would still like to participate in the study, please contact a member of the research team by phone or by e-mail (talkingaboutepilepsy@gmail.com) and they will mail you out another one. Alternatively, if you would like to complete these questionnaires either over the telephone or face-to-face with a member of the research team, we would be happy to call you or arrange a meeting at a time and location of your choice in order to do so. If you have any further queries about the study, or any suggestions as to how we could make the process as easy as possible for you, please do not hesitate to contact Ailbhe (**01-7007997**) or Stephanie (**01-7006867**), who would be happy to answer any questions and receive any suggestions you might have.

Once again, we would like to extend our gratitude for all of your assistance and support-without the input of families living with epilepsy, this research would not be possible.

Yours Sincerely,

Dr. Amre Shahwan

Appendix Q.2: Phase Two: 4 week Follow-up Letters/Reminders

Epilepsy Ireland Version

Reminder: "Talking about Epilepsy" Research Study

Dear

Approximately 4 weeks ago, you received correspondence from the 'Talking about Epilepsy' research team requesting your participation in a very important questionnaire about how children living with epilepsy and their parents communicate about epilepsy.

If you have already completed and returned the questionnaires, please accept our sincere thanks and appreciation and disregard this letter. We are writing to you again because of the importance each questionnaire has to the usefulness of this study. If you have not yet had the chance to complete the questionnaires, we would encourage you to please do so either in hard copy format or online. In order for the results to truly represent the opinions of all families living with epilepsy, it is important that as many questionnaires as possible are completed and returned. This research is the first of its kind and is highly important in terms of both: (a) highlighting areas for advancement in paediatric epilepsy care in Ireland; and (b) finding ways to enhance public perceptions of epilepsy. Only through your help can the success of this study be ensured. Again, we would like to emphasise that your participation is entirely voluntary and anonymous. Therefore, if you do not wish to participate, please disregard this follow-up letter. This will in no way affect your engagements with Epilepsy Ireland.

If by some chance you did not receive the questionnaire or in the event that your questionnaire has been misplaced and you would still like to participate in the study, please contact a member of the research team by phone or by e-mail (talkingaboutepilepsy@gmail.com) and they will mail you out another one. **Alternatively, if you would like to complete these questionnaires either over the telephone or face-to-face with a member of the research team, we would be happy to call you or arrange a meeting at a time and location of your choice in order to do so.** If you have any further queries about the study, or any suggestions as to how we could make the process as easy as possible for you, please do not hesitate to contact Ailbhe (**01-7007997**) or Stephanie (**01-7006867**), who would be happy to answer any questions and receive any suggestions you might have.

Once again, we would like to extend our gratitude for all of your assistance and support-without the input of families living with epilepsy, this research would not be possible.

Kind Regards,

Ailbhe Benson *(PhD student)*

Phone: 01-7007997

Stephanie O' Toole *(PhD student)*

Phone: 01-7006867

Neurology/Paediatric Clinic Version (Template)

Reminder: "Talking about Epilepsy" Research Study

Dear

Approximately 4 weeks ago, you received correspondence from the 'Talking about Epilepsy' research team and I requesting your participation in a very important questionnaire about how children living with epilepsy and their parents communicate about epilepsy.

If you have already completed and returned the questionnaires, please accept our sincere thanks and appreciation and disregard this letter. I am writing to you again because of the importance each questionnaire has to the usefulness of this study. If you have not yet had the chance to complete the questionnaires, I would encourage you to please do so either in hard copy format or online. In order for the results to truly represent the opinions of all families living with epilepsy, it is important that as many questionnaires as possible are completed and returned. This research is the first of its kind and is highly important in terms of both: (a) highlighting areas for advancement in paediatric epilepsy care in Ireland; and (b) finding ways to enhance public perceptions of epilepsy. Only through your help can the success of this study be ensured. Again, I would like to emphasise that your participation is entirely voluntary and anonymous. Therefore, if you do not wish to participate, please disregard this follow-up letter. This will in no way affect your relationship with us here in Temple Street Children's University Hospital.

If by some chance you did not receive the questionnaire or in the event that your questionnaire has been misplaced and you would still like to participate in the study, please contact a member of the research team by phone or by e-mail (talkingaboutepilepsy@gmail.com) and they will mail you out another one. Alternatively, if you would like to complete these questionnaires either over the telephone or face-to-face with a member of the research team, we would be happy to call you or arrange a meeting at a time and location of your choice in order to do so. If you have any further queries about the study, or any suggestions as to how we could make the process as easy as possible for you, please do not hesitate to contact Ailbhe (**01-7007997**) or Stephanie (**01-7006867**), who would be happy to answer any questions and receive any suggestions you might have.

Once again, we would like to extend our gratitude for all of your assistance and support-without the input of families living with epilepsy, this research would not be possible.

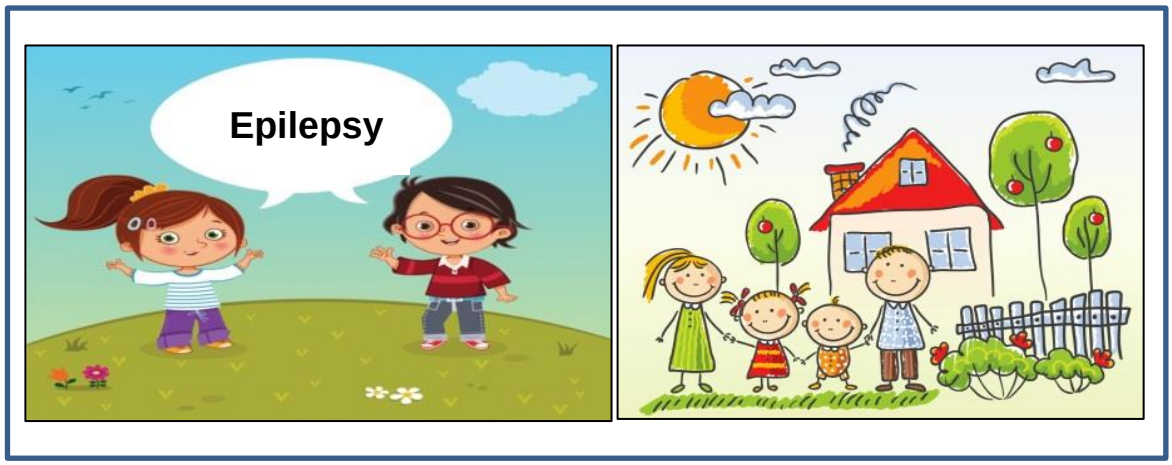
Yours Sincerely,

Dr. Amre Shahwan

Appendix R.1: Phase Two: Child/Young Person Survey Questionnaire

Child/Young Person Questionnaire

Talking about Epilepsy

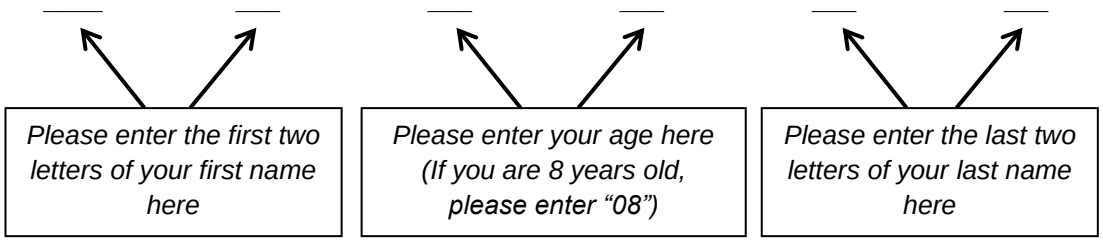


IF YOU WANT TO TAKE PART IN THIS PROJECT PLEASE FILL IN THE ANSWERS BELOW, OTHERWISE THANK YOU FOR YOUR TIME.

Please tick yes/no:

- I am aged 8 – 18 years and have epilepsy. ☐ Yes ☐ No
- I have read the information about the project. ☐ Yes ☐ No
- I agree to take part in the project. ☐ Yes ☐ No
- I am aware that I do not have to take part. ☐ Yes ☐ No
- I am aware that I can stop taking part at any time as long as I stop before sending back the questionnaire to Ailbhe and Stephanie. ☐ Yes ☐ No
- I am aware that Ailbhe and Stephanie may talk about the findings of the project or write about them, but nobody will know what I have answered. ☐ Yes ☐ No

In order to help us to link your and your parent's answers (if they are taking part), please list the following letters/numbers:



*For example, if your name was '**Su**san Smi**th**' and you were **13** years old, you would enter:*

S U 1 3 T H

Demographic Information (Section A)

In this section we would like to ask you a few questions about you and your epilepsy.

A1. What is your age?

____ years

A2. What is your gender?

☐ Female ☐ Male

A3. Please state your ethnicity.

☐ Caucasian/White
☐ Black or African American
☐ Hispanic or Latino
☐ Asian / Pacific Islander
☐ Arab
☐ Multiracial
☐ Would rather not say
☐ Other

If other, please state: _____

A4. What type of seizures do you have or have you had in the past?
(Please tick all relevant to you)

☐ Tonic-clonic seizures
(You fall down; your body stiffens and shakes)

☐ Absence seizures
(You seem to daydream or "switch off" for a few seconds, you might not be aware of where you are or what has happened)

☐ Simple Partial
(You have partial seizures in which you are fully awake, alert and able to communicate during the seizure)

☐ Complex Partial
(You have partial seizures in which you might not be aware of where you are or what has happened and you might stare blankly)

☐ Myoclonic seizures
(Your muscles in your arms, legs or face briefly jerk or twitch, you will usually be awake and able to think clearly)

☐ Atonic seizures
(Drop attacks; you may drop to the ground suddenly without any warning. In some people, only their head suddenly drops)

☐ Tonic seizures
(Your arms or legs make sudden stiffening movements, you are usually aware that this is happening)

☐ Clonic seizures
(Your arms and legs jerk/shake over and over again)

☐ Other, please describe:

A5. Have you ever had seizures when you were with anyone other than your parents or brother/sister?

☐ Yes ☐ No

If you answered yes, please list who has seen you have a seizure:

A6. At what age did you have your first seizure?

Age: _____ (years)

A7. How frequent are your seizures currently?

☐ Daily *(once a day or more)*
☐ Frequently *(several times a week)*
☐ Weekly *(about once a week)*
☐ Monthly *(about once a month)*
☐ Occasionally *(less than monthly)*
☐ Yearly *(about once a year)*
☐ Other, please describe:

A8. When was your last seizure?

A9. Are you currently receiving treatment or taking medication for your epilepsy?

☐ Yes ⇨ Please provide details of what medication(s) you currently use and how often you take them in the box below.

Please provide details of any medication(s) you used to use and how often you used to take them in the box below.

☐ No ⇨ When did you stop using/receiving treatment/taking medication?

(M)	(M)	(Y)	(Y)	(Y)	(Y)

Please provide details of any medication(s) you used to use and how often you used to take them in the box below.

A10. Have you experienced any side effects as a result of treatment or medication?

☐ Yes ☐ No

If you answered yes, please list the side effects experienced:

A11. Have you missed any days of school as a result of your epilepsy?

☐ Yes ☐ No

If you answered yes, please state the number of days within the past year

____ days (roughly)

A12. What county are you currently living in?

A13. Please tell us what you call your epilepsy in your own words.

A.14 At hospital appointments, do you find talking to doctors and nurses (etc.) ok?

☐ Yes ☐ No

Please tell us more:

A15. Where did you complete this questionnaire?

☐ At home ☐ In a healthcare facility

☐ Other, please describe:

A16. Was your parent present as you completed this questionnaire?

☐ Yes ☐ No

A17. Where did you hear about this project?

☐ Epilepsy Ireland ☐ Temple Street Children's University Hospital

☐ Other, please describe:

End of Section A

Section B

Do I tell and talk to others about my epilepsy?

Please read each statement carefully. Indicate how you feel by ticking the box that you most agree with for each statement.

B1. When you can, do you keep your epilepsy a secret from others?

☐ Often ❑ Sometimes ❑ Rarely ❑ Never

B2. How frequently do you talk to people outside your family about your epilepsy?

☐ Often ❑ Sometimes ❑ Rarely ❑ Never

B3. Do any of your friends know that you have epilepsy?

☐ All ❑ Some ❑ Few ❑ None

B4. When people find out you have epilepsy, it is usually because:

☐ You tell them
❑ You have a seizure and then you explain it
❑ You have a seizure and they see it
❑ Someone else tells them about it

B5. How difficult has it been for you to talk to others about what you are going through?

☐ Not at all ❑ A little ❑ Somewhat ❑ Very

B6. How much have you wanted someone to talk to about your experience with epilepsy?

☐ Not at all ❑ A little ❑ Somewhat ❑ A lot

B7. To what degree have you *wanted to keep* your epilepsy a secret?

☐ Not at all ❑ A little ❑ Somewhat ❑ A lot

B8. To what degree have you *actually kept* your epilepsy a secret?

☐ Not at all ❑ A little ❑ Somewhat ❑ A lot

B9. How much have you written about your epilepsy (such as in a diary, journal, letters or online in support groups or on social media i.e. Facebook, Twitter, Tumblr, blogs etc.)?

☐ Not at all ❑ A little ❑ Somewhat ❑ A lot

B10. If you have written about your epilepsy, where have you written about it?

Diary/Journal	☐ Yes	☐ No
Letters	☐ Yes	☐ No
Facebook	☐ Yes	☐ No
Twitter	☐ Yes	☐ No
Epilepsy Support Groups	☐ Yes	☐ No
Tumblr	☐ Yes	☐ No
Blogs	☐ Yes	☐ No

Any other sources ☐ Yes ☐ No

Please write down where else you have written about your epilepsy below:

Who do I tell and talk to about my epilepsy?

B11. Using the scale below, please indicate the degree to which you have talked with each of the following individuals about your experience with epilepsy since your diagnosis: (please mark "0" next to any categories that do not apply to you).

0	1	2	3	4
Not Applicable	Not at all	A little	Somewhat	Very Much

____	Boyfriend or Girlfriend	____	Close male friend(s)
____	Close female friend(s)	____	Male friend(s)
____	Female friend(s)	____	Neighbour(s)
____	Classmates	____	Therapist/Counsellor
____	Other Adults with Epilepsy	____	Doctors
____	Nurses	____	Mother
____	Father	____	Older sisters(s)
____	Older brother(s)	____	Younger sisters(s)
____	Younger brother(s)	____	Co-workers
____	Grandparents	____	Aunts/Uncles
____	Cousins	____	Employers
____	Your friends' parents	____	Your teacher(s)
____	Your principal	____	Your sports club coaches
____	Your sports team members	____	Other Young People with Epilepsy
____	Your child-minder/nanny/au pair	____	Young People with Other Illnesses
____	Young People with something that makes them different		

Other, please list: _____

B12. As far as you are aware, which of the following adults <u>know</u> that you have epilepsy? (Please tick a box for each person listed).

The principal	☐ Yes	☐ No	☐ Not applicable
Your head of year teacher	☐ Yes	☐ No	☐ Not applicable
Your class teachers overall	☐ Yes	☐ No	☐ Not applicable
Your PE teacher	☐ Yes	☐ No	☐ Not applicable
Your sports coaches	☐ Yes	☐ No	☐ Not applicable
Your friends' parents	☐ Yes	☐ No	☐ Not applicable
Your babysitter	☐ Yes	☐ No	☐ Not applicable
Your child-minder/nanny/au pair	☐ Yes	☐ No	☐ Not applicable
Your grandparents	☐ Yes	☐ No	☐ Not applicable
Your aunts/uncles	☐ Yes	☐ No	☐ Not applicable
Your parents' friends	☐ Yes	☐ No	☐ Not applicable
Any other adults	☐ Yes	☐ No	☐ Not applicable

Please write down who this person is in relation to you or what this person does (**not** their name):

B13. As far as you are aware, which of the following children at school or college <u>know</u> that you have epilepsy?

None of the other children know	☐ Yes	☐ No
My best friend only	☐ Yes	☐ No
My few best friends only	☐ Yes	☐ No
Most of the other children in my class only	☐ Yes	☐ No
Most of the other children in the school	☐ Yes	☐ No
Any other children	☐ Yes	☐ No

Please write down who these children are in relation to you (**not** their name):

When do I tell and talk to others about my epilepsy?

In this section, we want to find out in what types of situations you usually tell and talk to others (including friends, classmates, team members and those outside the family) about your epilepsy.

I usually tell and talk to others about my epilepsy when…

B14. I have had a seizure that others have seen (e.g. in school etc.)

☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B15. I have had a seizure that others have not seen (e.g. at home etc.)

☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B16. I feel like I might have a seizure

☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B17. Others see me taking my medication

☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B18. Others ask me questions

☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B19. My medication is causing me difficulties

☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B20. I have a hospital appointment coming up or I have recently had a hospital appointment

☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B21. I cannot take part in an activity because of my epilepsy

☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B22. I miss school because I have had a seizure

☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B23. I need support

☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

I usually tell and talk to others about my epilepsy when…

B24. Epilepsy comes up in conversation
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B25. I am starting a new activity or sport
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B26. I am meeting new people
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B27. My friends are telling me their secrets
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B28. Other, please describe:

What do I tell others when I am talking to them about my epilepsy?

In this section, we are interested in finding out what kind of things you usually tell and talk to others (including friends, classmates, team members and those outside the family) about in relation to your epilepsy.

When I talk to others about my epilepsy, I talk to them about…

B29. What epilepsy is
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B30. The type of epilepsy I have
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B31. What happens when I have a seizure (e.g. what I look like)
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B32. How seizures affect me
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B33. What they should do if I have a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

When I talk to others about my epilepsy, I talk to them about…

B34. My medication

☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B35. The medication side-effects

☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B36. My hospital appointments

☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B37. Things I cannot take part in because of my epilepsy

☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B38. Whether my seizures are controlled or not

☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B39. Whether I will grow out of my epilepsy

☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B40. How I feel about having epilepsy

☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B41. Other, please describe:

Why do I choose to talk to or not talk to others about my epilepsy?

In this section, we are interested in finding out what kind of things make you decide to tell and talk to others (including friends, classmates, team members and those outside the family) about your epilepsy, as well as what kind of things make you decide not to tell and talk to others about your epilepsy.

I tell others about my epilepsy because…

B42. I want them to know I might have a seizure

☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my epilepsy

I tell others about my epilepsy because…

B43. I want them to know what to do if I have a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my epilepsy

B44. I want others to learn about epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my epilepsy

B45. Talking to others about my epilepsy makes me feel better
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my epilepsy

B46. Talking to others about my epilepsy helps me to learn more about epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my epilepsy

B47. It makes me feel more comfortable when others know about my epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my epilepsy

B48. Other, please describe:

I don't tell others about my epilepsy because…

B49. It makes me feel different
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B50. I am worried others will treat me differently
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B51. I am scared of how people will react
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B52. I think people might tease me
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B53. I don't want people to spread it around
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

I don't tell others about my epilepsy because…

B54. Others do not think good things about epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B55. It makes me sad
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B56. My parents think that epilepsy is something we should keep private
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B57. Nobody else I know has epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B58. Others cannot see that I have epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B59. Others do not need to know I have epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B60. My epilepsy is private/secret
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B61. I don't want to seem like I am looking for attention
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B62. Other, please describe:

What helps or hinders me when talking to others about my epilepsy?

In this section, we are interested in finding out what you find helpful or challenging when telling and talking to others (including friends, classmates, team members and those outside the family) about your epilepsy.

Do any of the following things help or make it challenging for me to tell and talk to other people about my epilepsy?

B63. How often I have seizures
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B64. How I feel about epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B65. How much I know about my epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B66. Knowing others with epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B67. How others have reacted when I have told them about my epilepsy in the past
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B68. How much others know about epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B69. If other people have something that makes them different
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B70. Whether other people can see that I have epilepsy (e.g. if I have had seizures in front of them or not)
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B71. How long I have had epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B72. How well I can explain epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B73. How epilepsy makes me feel
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B74. How other people might treat me
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B75. What other people think about epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B76. Whether other people understand epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

Do any of the following things help or make it challenging for me to tell and talk to other people about my epilepsy?

B77. When epilepsy is on TV or on the radio
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B78. When I hear that famous people have epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B79. Other, please describe:

What happens when I talk to others about my epilepsy?

In this section, we are interested in finding out how it makes you feel to tell and talk to others (including friends, classmates, team members and those outside the family) about your epilepsy and how others react when you tell them about your epilepsy.

Before telling others about my epilepsy I feel…

B80. Worried/Nervous
☐ Yes ☐ No ☐ Does not apply, I never tell others about my epilepsy

B81. Embarrassed/Ashamed
☐ Yes ☐ No ☐ Does not apply, I never tell others about my epilepsy

B82. Different
☐ Yes ☐ No ☐ Does not apply, I never tell others about my epilepsy

B83. Afraid
☐ Yes ☐ No ☐ Does not apply, I never tell others about my epilepsy

B84. Uneasy
☐ Yes ☐ No ☐ Does not apply, I never tell others about my epilepsy

B85. Confident
☐ Yes ☐ No ☐ Does not apply, I never tell others about my epilepsy

B86. Hopeful
☐ Yes ☐ No ☐ Does not apply, I never tell others about my epilepsy

Before telling others about my epilepsy I feel…

B87. Brave

☐ Yes ☐ No ☐ Does not apply, I never tell others about my epilepsy

B88. Others, please list:

In the past, when I have told others about my epilepsy they have…

B89. Been kind about it

☐ Yes ☐ No ☐ Does not apply, I have never told others about my epilepsy

B90. Been mean about it

☐ Yes ☐ No ☐ Does not apply, I have never told others about my epilepsy

B91. Asked me questions

☐ Yes ☐ No ☐ Does not apply, I have never told others about my epilepsy

B92. Made me feel better about it

☐ Yes ☐ No ☐ Does not apply, I have never told others about my epilepsy

B93. Found it difficult to understand

☐ Yes ☐ No ☐ Does not apply, I have never told others about my epilepsy

B94. Laughed at or teased me about it

☐ Yes ☐ No ☐ Does not apply, I have never told others about my epilepsy

B95. Treated me differently

☐ Yes ☐ No ☐ Does not apply, I have never told others about my epilepsy

B96. Made me feel left out

☐ Yes ☐ No ☐ Does not apply, I have never told others about my epilepsy

B97. Been scared of me

☐ Yes ☐ No ☐ Does not apply, I have never told others about my epilepsy

B98. Others, please list:

After telling others about my epilepsy when they react well I feel…

B99. Happy

☐ Yes ☐ No ☐ Does not apply, others have never reacted well
☐ Does not apply, I never tell others about my epilepsy

B100. Better

☐ Yes ☐ No ☐ Does not apply, others have never reacted well
☐ Does not apply, I never tell others about my epilepsy

B101. Relieved

☐ Yes ☐ No ☐ Does not apply, others have never reacted well
☐ Does not apply, I never tell others about my epilepsy

B102. Others, please list:

After telling others about my epilepsy when they react poorly I feel…

B103. Embarrassed/Ashamed

☐ Yes ☐ No ☐ Does not apply, others have never reacted poorly
☐ Does not apply, I never tell others about my epilepsy

B104. Different

☐ Yes ☐ No ☐ Does not apply, others have never reacted poorly
☐ Does not apply, I never tell others about my epilepsy

B105. Silly

☐ Yes ☐ No ☐ Does not apply, others have never reacted poorly
☐ Does not apply, I never tell others about my epilepsy

B106. Sad

☐ Yes ☐ No ☐ Does not apply, others have never reacted poorly
☐ Does not apply, I never tell others about my epilepsy

B107. Angry/ Mad

☐ Yes ☐ No ☐ Does not apply, others have never reacted poorly
☐ Does not apply, I never tell others about my epilepsy

B108. Worried

☐ Yes ☐ No ☐ Does not apply, others have never reacted poorly
☐ Does not apply, I never tell others about my epilepsy

After telling others about my epilepsy when they react poorly I feel…

B109. Others, please list:

End of Section B

Section C

When do I talk to my parents about my epilepsy?

In this section, we are interested in what types of situations you talk to your Mum or Dad about your epilepsy.

I usually talk to my Mum or Dad about my epilepsy when…

C1. I have a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C2. I take my medication
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C3. My medication is causing me difficulties
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C4. I have a question about epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C5. I have a hospital appointment coming up or I have recently had a hospital appointment
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C6. I cannot take part in an activity because of my epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C7. I am worried/ upset
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C8. I need support
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

I usually talk to my Mum or Dad about my epilepsy when…

C9. Other, please describe:

When I talk to my Mum or Dad about my epilepsy, what do we talk about?

When I talk to my Mum or Dad about my epilepsy, we talk about…

C10. What epilepsy is
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C11. How I feel about having epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C12. What happens when I have a seizure (e.g. what I look like)
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C13. My medication
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C14. Medication side effects
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C15. My hospital appointments
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C16. Things I cannot take part in because of my epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C17. Whether my seizures are controlled or not
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C18. Whether I will grow out of my epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

When I talk to my Mum or Dad about my epilepsy, we talk about…

C19. Other, please describe:

Why do I choose to talk to my Mum or Dad about my epilepsy?

In this section we are interested in what kinds of things make you decide to talk to your Mum or Dad about your epilepsy, as well as what kinds of things make you decide to not talk to your Mum or Dad about your epilepsy.

I talk to my Mum or Dad about my epilepsy because…

C20. I don't want to feel different
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C21. I want to know what I should do if I have a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C22. It helps me to deal with certain situations
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C23. I want to know a lot about my epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C24. I don't want to keep secrets about my epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C25. Others, please list

I don't talk to my Mum or Dad about my epilepsy because…

C26. I don't want to feel different
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always talk to my Mum or Dad about my epilepsy

C27. I don't want to worry my Mum or Dad
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always talk to my Mum or Dad about my epilepsy

I don't talk to my Mum or Dad about my epilepsy because…

C28. I don't want my Mum or Dad to think I am looking for attention
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always talk to my Mum or Dad about my epilepsy

C29. If I talk to my Mum or Dad they might not let me go to things
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always talk to my Mum or Dad about my epilepsy

C30. My Mum or Dad will make a big deal about it
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always talk to my Mum or Dad about my epilepsy

C31. Other, please describe:

What helps or hinders me when talking to my Mum or Dad about my epilepsy?

In this section we are interested in what you find helpful or challenging when talking to your Mum or Dad about your epilepsy.

Do any of the following things help or make it challenging for me to talk to my Mum or Dad about my epilepsy?

C32. How much I usually talk to my Mum and Dad about things
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

C33. The amount of time that I have had epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

C34. How much I know about my epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

C35. How often I have seizures
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

C36. When epilepsy is on the T.V. or radio
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

C37. How I feel about my epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

Do any of the following things help or make it challenging for me to talk to my Mum or Dad about my epilepsy?

C38. Others, please list:

What happens when I talk to my Mum or Dad about my epilepsy?

In this section, we are interested in finding out how talking to your Mum or Dad about your epilepsy makes you feel.

Talking about my epilepsy with my Mum or Dad makes me feel…

C39. Happy

☐ Yes ☐ No

☐ Does not apply, I never talk to my Mum or Dad about my epilepsy

C40. Sad

☐ Yes ☐ No

☐ Does not apply, I never talk to my Mum or Dad about my epilepsy

C41. Worried

☐ Yes ☐ No

☐ Does not apply, I never talk to my Mum or Dad about my epilepsy

C42. Brave

☐ Yes ☐ No

☐ Does not apply, I never talk to my Mum or Dad about my epilepsy

C43. Embarrassed

☐ Yes ☐ No

☐ Does not apply, I never talk to my Mum or Dad about my epilepsy

C44. Different

☐ Yes ☐ No

☐ Does not apply, I never talk to my Mum or Dad about my epilepsy

C45. Special

☐ Yes ☐ No

☐ Does not apply, I never talk to my Mum or Dad about my epilepsy

C46. Other, please list:

End of Section C

Section D

In this section, we would like to ask you some questions about how you feel about your epilepsy. Each time please tell us how often you have these feelings.

D1. How often do you feel different from other kids because you have epilepsy?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D2. How often do you feel people may not like you if they know you have epilepsy?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D3. How often do you feel other children are uncomfortable with you because of your epilepsy?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D4. How often do you feel people may not want to be friends with you if they know you have epilepsy?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D5. How often do you feel people would not want to go out with you or ask you to parties if they know you have epilepsy?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D6. How often do you feel embarrassed about your epilepsy?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D7. How often do you keep your epilepsy a secret from other kids?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D8. How often do you try to avoid talking to other people about your epilepsy?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D9. How good or bad do you feel it is that you have epilepsy?

☐ Very Good
☐ A Little Good
☐ Not Sure
☐ A Little Bad
☐ Very Bad

D10. How fair is it that you have epilepsy?

☐ Very Fair
☐ A Little Fair
☐ Not Sure
☐ A Little Unfair
☐ Very Unfair

D11. How happy or sad is it for you to have epilepsy?

☐ Very Sad
☐ A Little Sad
☐ Not Sure
☐ A Little Happy
☐ Very Happy

D12. How bad or good do you feel it is to have epilepsy?

☐ Very Good
☐ A Little Good
☐ Not Sure
☐ A Little Bad
☐ Very Bad

D13. How often do you feel that your epilepsy is your fault?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D14. How often do you feel that your epilepsy keeps you from doing things you like to do?

☐ Very Often
☐ Often
☐ Sometimes
☐ Not Often
☐ Never

D15. How often do you feel that you will always be sick?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D16. How often do you feel that your epilepsy keeps you from starting new things?

☐ Very Often
☐ Often
☐ Sometimes
☐ Not Often
☐ Never

D17. How often do you feel different from others because of your epilepsy?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D18. How often do you feel bad because you have epilepsy?

☐ Very Often
☐ Often
☐ Sometimes
☐ Not Often
☐ Never

D19. How often do you feel sad about being sick?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D20. How often do you feel happy even though you have epilepsy?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D21. How often do you feel just as good as other kids your age even though you have epilepsy?

☐ Very Often
☐ Often
☐ Sometimes
☐ Not Often
☐ Never

End of Section D

What Am I Like and People in My Life? (Section E)

In this section, we are interested in what each of you is like, what kind of a person you are like and the people in your life. This is a survey, not a test. There are no right or wrong answers. Since kids are very different from one another, each of you will be putting down something different.

First, let me explain how these questions work. There is a sample question at the top, marked (a). This question talks about two kinds of kids, and we want to know which kids are most like you.

1) So, what I want you to decide first is whether you are more like the kids on the left side who would rather play outdoors, or whether you are more like the kids on the right side who would rather watch T.V. Don't mark anything yet, but first decide which kinds of kids are most like you, and go to that side of the sentence.

2) Now the second thing I want you to think about, now that you have decided which kinds of kids are most like you, is to decide whether that is only sort of true for you, or really true for you. If it's only sort of true, then put an X in the box under Sort of True for me; if it's really true for you, then put an X in that box, under Really True for me.

3) For each sentence, you only check one box. Sometimes it will be on one side of the page, another time it will be on the other side of the page, but you can only check one box for each sentence. **You don't check both sides, just the one side most like you.**

4) Ok, that one was just for practice. **Now we have some more sentences. For each one, just check one box - the one that goes with what is true for you, what you are most like.**

	1 Really true for me	2 Sort of true for me				3 Sort of true for me	4 Really true for me
Sample Sentence							
a.	☐	☐	**Some kids would rather play outdoors in their spare time**	**but**	**Other kids would rather watch T.V.**	☐	☐
	1 Really true for me	2 Sort of true for me				3 Sort of true for me	4 Really true for me
E1.	☐	☐	**Some kids feel that they are very good at their school work**	**but**	**Other kids worry about whether they can do the school work assigned to them**	☐	☐
E2.	☐	☐	**Some kids find it hard to make friends**	**but**	**Other kids find it pretty easy to make friends**	☐	☐
E3.	☐	☐	**Some kids do very well at all kinds of sports**	**but**	**Other kids don't feel that they are very good when it comes to sports**	☐	☐
E4.	☐	☐	**Some kids are happy with the way they look**	**but**	**Other kids are not happy with the way they look**	☐	☐
E5.	☐	☐	**Some kids often do not like the way they behave**	**but**	**Other kids usually like the way they behave**	☐	☐
E6.	☐	☐	**Some kids are often unhappy with themselves**	**but**	**Other kids are pretty pleased with themselves**	☐	☐
E7.	☐	☐	**Some kids feel like they are just as smart as other kids their age**	**but**	**Other kids aren't so sure and wonder if they are as smart**	☐	☐
E8.	☐	☐	**Some kids know how to make classmates like them**	**but**	**Other kids don't know how to make classmates like them**	☐	☐
E9.	☐	☐	**Some kids wish they could be a lot better at Sports**	**but**	**Other kids feel they are good enough at sports**	☐	☐
E10.	☐	☐	**Some kids are happy with their height and weight**	**but**	**Other kids wish their height or weight were different**	☐	☐

	1 Really true for me	2 Sort of true for me				3 Sort of true for me	4 Really true for me
E11.	☐	☐	**Some kids usually do the right thing**	**but**	**Other kids often don't do the right thing**	☐	☐
E12.	☐	☐	**Some kids don't like the way they are leading their life**	**but**	**Other kids do like the way they are leading their life**	☐	☐
E13.	☐	☐	**Some kids are pretty slow in finishing their school work**	**but**	**Other kids can do their school work quickly**	☐	☐
E14.	☐	☐	**Some kids don't have the social skills to make friends**	**but**	**Other kids do have the social skills to make friends**	☐	☐
E15.	☐	☐	**Some kids think they could do well at just about any new sports activity they haven't tried before**	**but**	**Other kids are afraid they might not do well at sports they haven't ever tried**	☐	☐
E16.	☐	☐	**Some kids wish their body was different**	**but**	**Other kids like their body the way it is**	☐	☐
E17.	☐	☐	**Some kids usually act the way they know they are supposed to**	**but**	**Other kids often don't act the way they are supposed to**	☐	☐
E18.	☐	☐	**Some kids are happy with themselves as a Person**	**but**	**Other kids are often not happy with themselves**	☐	☐
E19.	☐	☐	**Some kids often forget what they learn**	**but**	**Other kids can remember things easily**	☐	☐
E20.	☐	☐	**Some kids understand how to get peers to accept them**	**but**	**Other kids don't understand how to get peers to accept them**	☐	☐
E21.	☐	☐	**Some kids feel that they are better than others their age at sports**	**but**	**Other kids don't feel they can play as well**	☐	☐
E22.	☐	☐	**Some kids wish their physical appearance (how they look) was different**	**but**	**Other kids like their physical appearance the way it is**	☐	☐

	1 Really true for me	2 Sort of true for me				3 Sort of true for me	4 Really true for me
E23.	☐	☐	**Some kids usually get in trouble because of things they do**	**but**	**Other kids usually don't do things that get them in trouble**	☐	☐
E24.	☐	☐	**Some kids like the kind of person they are**	**but**	**Other kids often wish they were someone else**	☐	☐
E25.	☐	☐	**Some kids do very well at their classwork**	**but**	**Other kids don't do very well at their classwork**	☐	☐
E26.	☐	☐	**Some kids wish they knew how to make more friends**	**but**	**Other kids know how to make as many friends as they want**	☐	☐
E27.	☐	☐	**In games and sports, some kids usually watch instead of play**	**but**	**Other kids usually play rather than just watch**	☐	☐
E28.	☐	☐	**Some kids wish something about their face or hair looked different**	**but**	**Other kids like their face and hair the way they are**	☐	☐
E29.	☐	☐	**Some kids do things they know they shouldn't do**	**but**	**Other kids hardly ever do things they know they shouldn't do**	☐	☐
E30.	☐	☐	**Some kids are very happy being the way they are**	**but**	**Other kids wish they were different**	☐	☐
E31.	☐	☐	**Some kids have trouble figuring out the answers in school**	**but**	**Other kids almost always can figure out the answers**	☐	☐
E32.	☐	☐	**Some kids know how to become popular**	**but**	**Other kids do not know how to become popular**	☐	☐
E33.	☐	☐	**Some kids don't do well at new outdoor games**	**but**	**Other kids are good at new games right away**	☐	☐
E34.	☐	☐	**Some kids think that they are good looking**	**but**	**Other kids think that they are not very good looking**	☐	☐
E35.	☐	☐	**Some kids behave themselves very well**	**but**	**Other kids often find it hard to behave themselves**	☐	☐

	1 Really true for me	2 Sort of true for me				3 Sort of true for me	4 Really true for me
E36.	☐	☐	**Some kids are not very happy with the way they do a lot of things**	**but**	**Other kids think the way they do things is fine**	☐	☐
E37.	☐	☐	**Some kids with epilepsy say kids won't play with them.**	**but**	**Other kids with epilepsy say other kids always play with them.**	☐	☐
E38.	☐	☐	**Some kids with epilepsy think they are not as good at things as other kids are.**	**but**	**Other kids with epilepsy think they are just as good at things as other kids are.**	☐	☐
E39.	☐	☐	**Some kids with epilepsy don't have many friends.**	**but**	**Other kids with epilepsy have lots of friends.**	☐	☐
E40.	☐	☐	**Some kids with epilepsy feel that other kids treat them differently.**	**but**	**Other kids with epilepsy feel that they are treated the same as everyone.**	☐	☐
E41.	☐	☐	**Some kids with epilepsy feel like they are being picked on.**	**but**	**Other kids with epilepsy don't feel they get picked on.**	☐	☐
E42.	☐	☐	**Some kids always have to think about their epilepsy before doing things.**	**but**	**Other kids don't think about their epilepsy before doing things.**	☐	☐
E43.	☐	☐	**Some kids with epilepsy think their parents are worried that they will hurt themselves.**	**but**	**Other kids with epilepsy don't think their parents are worried about them.**	☐	☐
E44.	☐	☐	**Some kids with epilepsy may not be able to go away to camp or similar places.**	**but**	**Other kids with epilepsy can go away to camp or similar places if they want to.**	☐	☐
E45.	☐	☐	**Some kids worry about what might happen to them if they forget to take their medicine.**	**but**	**Other kids are not worried about what might happen if they forget to take their medicine.**	☐	☐

	1 Really true for me	2 Sort of true for me				3 Sort of true for me	4 Really true for me
E46.	☐	☐	**Some kids worry about getting hurt during a seizure.**	**but**	**Other kids are not worried about getting hurt during a seizure.**	☐	☐
E47.	☐	☐	**Some kids with epilepsy get upset easily.**	**but**	**Other kids with epilepsy do not get upset easily.**	☐	☐
E48.	☐	☐	**Some kids with epilepsy have trouble paying attention at school.**	**but**	**Other kids with epilepsy can concentrate well at school.**	☐	☐
E49.	☐	☐	**Some kids with epilepsy get angry easily.**	**but**	**Other kids with epilepsy do not get angry easily.**	☐	☐
E50.	☐	☐	**Some kids with epilepsy have trouble remembering things they learned at school.**	**but**	**Other kids with epilepsy can easily remember things they learned at school.**	☐	☐
E51.	☐	☐	**Some kids feel they will have to take seizure medicine for the rest of their life.**	**but**	**Other kids feel they could soon stop taking medicine for their seizures.**	☐	☐
E52.	☐	☐	**Some kids feel OK telling people about their epilepsy.**	**but**	**Other kids are nervous telling people about their epilepsy.**	☐	☐
E53.	☐	☐	**Some kids are afraid that their friends will find out they have epilepsy.**	**but**	**Other kids don't mind if their friends find out they have epilepsy.**	☐	☐
E54.	☐	☐	**Some kids with epilepsy feel safe away from home.**	**but**	**Other kids with epilepsy do not feel safe away from home.**	☐	☐
E55.	☐	☐	**Some kids feel embarrassed to have epilepsy.**	**but**	**Other kids are not embarrassed to have epilepsy.**	☐	☐
E56.	☐	☐	**Some kids with epilepsy feel their friends are a bit afraid of them.**	**but**	**Other kids with epilepsy feel their friends are not afraid of them.**	☐	☐

	1 Really true for me	2 Sort of true for me				3 Sort of true for me	4 Really true for me
E57.	☐	☐	**Some kids with epilepsy are treated the same as their brothers and sisters.**	**but**	**Other kids with epilepsy are treated differently than their brothers and sisters.**	☐	☐
E58.	☐	☐	**Some kids live a normal life even though they have seizures.**	**but**	**Other kids can't live a normal life because of their seizures.**	☐	☐
E59.	☐	☐	**Some kids with epilepsy feel their teachers treat them the same as other kids at school.**	**but**	**Other kids with epilepsy feel that their teachers treat them differently from other kids at school.**	☐	☐
E60.	☐	☐	**Some kids do not let their epilepsy slow them down.**	**but**	**Other kids get slowed down by their epilepsy.**	☐	☐
E61.	☐	☐	**Some kids with epilepsy feel comfortable at school.**	**but**	**Other kids with epilepsy feel nervous at school.**	☐	☐
E62.	☐	☐	**Some kids have parents who don't really understand them.**	**but**	**Other kids have parents who really do understand them.**	☐	☐
E63.	☐	☐	**Some kids have classmates who like them the way they are**	**but**	**Other kids have classmates who wish they were different**	☐	☐
E64.	☐	☐	**Some kids have a teacher who helps them if they are upset or have a problem**	**but**	**Other kids don't have a teacher who helps them if they are upset or have a problem**	☐	☐
E65.	☐	☐	**Some kids have a close friend who they can tell problems to**	**but**	**Other kids don't have a close friend who they can tell problems to**	☐	☐
E66.	☐	☐	**Some kids have parents who don't seem to want to hear about their children's problems**	**but**	**Other kids have parents who do want to listen to their children's problems**	☐	☐

	1 Really true for me	2 Sort of true for me				3 Sort of true for me	4 Really true for me
E67.	☐	☐	**Some kids have classmates they can become friendly with**	**but**	**Other kids don't have classmates that they can become friendly with**	☐	☐
E68.	☐	☐	**Some kids don't have a teacher who helps them to do their very best**	**but**	**Other kids do have a teacher who helps them to do their very best**	☐	☐
E69.	☐	☐	**Some kids have a close friend who really understands them**	**but**	**Other kids don't have a close friend who really understands them**	☐	☐
E70.	☐	☐	**Some kids have parents who care about their feelings**	**but**	**Other kids have parents who don't seem to care very much about their feelings**	☐	☐
E71.	☐	☐	**Some kids have classmates who sometimes make fun of them**	**but**	**Other kids don't have classmates who make fun of them**	☐	☐
E72.	☐	☐	**Some kids do have a teacher who cares about them**	**but**	**Other kids don't have a teacher who cares about them**	☐	☐
E73.	☐	☐	**Some kids have a close friend who they can talk to about things that bother them**	**but**	**Other kids don't have a close friend who they can talk to about things that bother them**	☐	☐
E74.	☐	☐	**Some kids have parents who treat their child like a person who really matters**	**but**	**Other kids have parents who don't usually treat their child like a person who matters**	☐	☐
E75.	☐	☐	**Some kids have classmates who pay attention to what they say**	**but**	**Other kids have classmates who usually don't pay attention to what they say**	☐	☐
E76.	☐	☐	**Some kids don't have a teacher who is fair to them**	**but**	**Other kids do have a teacher who is fair to them**	☐	☐

	1 Really true for me	2 Sort of true for me				3 Sort of true for me	4 Really true for me
E77.	☐	☐	**Some kids don't have a close friend who they like to spend time with**	**but**	**Other kids do have a close friend who they like to spend time with**	☐	☐
E78.	☐	☐	**Some kids have parents who like them the way they are**	**but**	**Other kids have parents who wish their children were different**	☐	☐
E79.	☐	☐	**Some kids don't get asked to play in games with classmates very often**	**but**	**Other kids often get asked to play in games by their classmates**	☐	☐
E80.	☐	☐	**Some kids don't have a teacher who cares if they feel bad**	**but**	**Other kids do have a teacher who cares if they feel bad**	☐	☐
E81.	☐	☐	**Some kids don't have a close friend who really listens to what they say**	**but**	**Other kids do have a close friend who really listens to what they say**	☐	☐
E82.	☐	☐	**Some kids have parents who don't act like what their children do is important**	**but**	**Other kids have parents who do act like what their children do is important**	☐	☐
E83.	☐	☐	**Some kids often spend their break being alone**	**but**	**Other kids spend break playing with their classmates**	☐	☐
E84.	☐	☐	**Some kids have a teacher who treats them like a person**	**but**	**Other kids don't have a teacher who treats them like a person**	☐	☐
E85.	☐	☐	**Some kids don't have a close friend who cares about their feelings**	**but**	**Other kids do have a close friend who cares about their feelings**	☐	☐

End of Section E

Section F

We are interested in how you and your parents communicate.
Please tick the box that describes your parents best for the next 23 statements:

F1. My parents often say things like "You'll know better when you grow up."
☐ Strongly Agree
☐ Agree
☐ Neither Agree nor Disagree
☐ Disagree
☐ Strongly Disagree

F2. My parents often say things like "My ideas are right and you should not question them."
☐ Strongly Agree
☐ Agree
☐ Neither Agree nor Disagree
☐ Disagree
☐ Strongly Disagree

F3. My parents often say things like "A child should not argue with adults."
☐ Strongly Agree
☐ Agree
☐ Neither Agree nor Disagree
☐ Disagree
☐ Strongly Disagree

F4. My parents often say things like "There are some things that are just not to be talked about."
☐ Strongly Agree
☐ Agree
☐ Neither Agree nor Disagree
☐ Disagree
☐ Strongly Disagree

F5. When anything really important is involved, my parents expect me to obey without question.
☐ Strongly Agree
☐ Agree
☐ Neither Agree nor Disagree
☐ Disagree
☐ Strongly Disagree

F6. In our home, my parents usually have the last word.
☐ Strongly Agree
☐ Agree
☐ Neither Agree nor Disagree
☐ Disagree
☐ Strongly Disagree

F7. My parents feel that it is important to be the boss.
☐ Strongly Agree
☐ Agree
☐ Neither Agree nor Disagree
☐ Disagree
☐ Strongly Disagree

F8. My parents sometimes become irritated with my views if they are different from theirs.
☐ Strongly Agree
☐ Agree
☐ Neither Agree nor Disagree
☐ Disagree
☐ Strongly Disagree

F9. If my parents don't approve of it, they don't want to know about it.
☐ Strongly Agree
☐ Agree
☐ Neither Agree nor Disagree
☐ Disagree
☐ Strongly Disagree

F10. When I am at home, I am expected to obey my parents' rules.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F11. My parents often ask my opinion when the family is talking about something.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F12. My parents encourage me to challenge their ideas and beliefs.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F13. I usually tell my parents what I am thinking about things.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F14. I can tell my parents almost anything.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F15. I talk to my parents about feelings and emotions.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F16. My parents and I often have long, relaxed conversations about nothing in particular.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F17. I really enjoy talking with my parents, even when we disagree.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F18. My parents often say something like "You should always look at both sides of an issue".

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F19. My parents like to hear my opinion, even when I don't agree with them.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F20. My parents encourage me to express my feelings.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F21. My parents tend to be very open about their emotions.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F22. We often talk as a family about things we have done during the day.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F23. In our family, we often talk about our plans and hopes for the future.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

End of Section F

Section G

We are interested in your visits with the doctors and nurses.

For each of the following 6 statements we would like for you to pick the response that best describes how you feel.

G1. The doctors and nurses explained my epilepsy to me

☐ Less Than I Wanted ☐ Just As Much As I Wanted ☐ More Than I Wanted

G2. The doctors and nurses told me how the medicine worked

☐ Less Than I Wanted ☐ Just As Much As I Wanted ☐ More Than I Wanted

G3. The doctors and nurses told me about possible problems or side effects with the medicine

☐ Less Than I Wanted ☐ Just As Much As I Wanted ☐ More Than I Wanted

G4. The doctors and nurses told me things I can and cannot do because of seizures

☐ Less Than I Wanted ☐ Just As Much As I Wanted ☐ More Than I Wanted

G5. I have had a chance to ask questions about my epilepsy

☐ Less Than I Wanted ☐ Just As Much As I Wanted ☐ More Than I Wanted

G6. The doctors and nurses talked to me about my fears and worries about my epilepsy

☐ Less Than I Wanted ☐ Just As Much As I Wanted ☐ More Than I Wanted

We are interested in the areas where you want or need more information or more help with your seizures.

Please answer each of the next 12 questions with a yes or no

.

At this time…

G7. Would you like more information about your epilepsy?
☐ Yes ☐ No

G8. Would you like more information about your medication?
☐ Yes ☐ No

G9. Would you like more information about possible causes of your epilepsy?
☐ Yes ☐ No

G10. Would you like more information about how to handle future seizures?
☐ Yes ☐ No

G11. Would you like more information about any activities or things you can or cannot do because of your seizures?
☐ Yes ☐ No

G12. Would you like more information about keeping safe during a seizure?
☐ Yes ☐ No

G13. Would you like to talk to someone about your feelings about having epilepsy?
☐ Yes ☐ No

G14. Would you like to talk to someone about how to tell your friends about your epilepsy?
☐ Yes ☐ No

G15. Would you like to talk to someone about any concerns or fears you have about having epilepsy?
☐ Yes ☐ No

G16. Would you like to talk to someone about how your epilepsy might affect your future?
☐ Yes ☐ No

G17. Would you like to talk to other kids your age who also have epilepsy?
☐ Yes ☐ No

G18. Would you like to talk to someone about how to handle seizures at school?
☐ Yes ☐ No

END OF QUESTIONNAIRE

Appendix R.2: Phase Two: Parent Survey Questionnaire

Parent Questionnaire

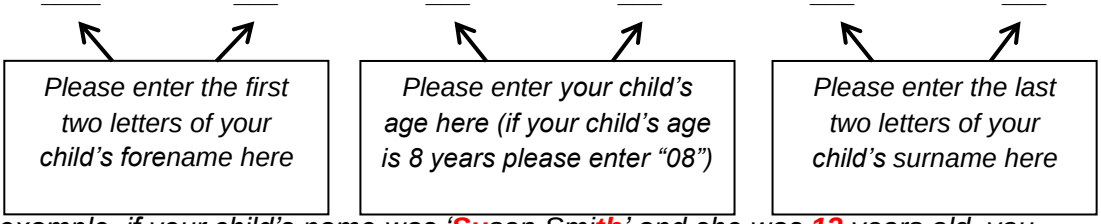
Talking about Epilepsy

IF YOU ARE INTERESTED IN PARTICIPATING IN THIS STUDY PLEASE PROVIDE YOUR CONSENT BELOW, OTHERWISE THANK YOU FOR YOUR TIME AND INTEREST.

Please tick yes/no:

- I am the parent/guardian of a child living with epilepsy aged 8 – 18 years. ☐ Yes ☐ No
- I have read the information in relation to the study. ☐ Yes ☐ No
- I agree to participate in the study. ☐ Yes ☐ No
- I am aware that my participation is voluntary. ☐ Yes ☐ No
- I am aware that I may withdraw before I post back the questionnaire or before I hit the submit button at the end of the questionnaire (online version). ☐ Yes ☐ No
- I am aware that the findings of the study may be reported at a conference or published but as the findings are anonymous nobody will know my specific answers. ☐ Yes ☐ No

In order to help us to link your and your child's answers (if he/she chooses to participate), please provide the following code:



*For example, if your child's name was '**Su**san Smi**th**' and she was **13** years old, you would enter:*

S U 1 3 T H

Please bear in mind when completing the questionnaires, if you or your child have any difficulties or require any assistance, do not hesitate to contact Ailbhe (01-7007997) or Stephanie (01-7006867). We are always happy to help!

Demographic Information (Section A)

In this section we would like to ask you a few questions about yourself and your child.

A1. What is your age?
☐ 25 or under ☐ 26 – 40 ☐ 41 – 55 ☐ 56 or older

A2. What is your gender?
☐ Female ☐ Male

A3. What is your child's age?
____ years

A4. What is your child's gender?
☐ Female ☐ Male

A5. Please specify your ethnicity.
☐ Caucasian/White ☐ Black or African American
☐ Hispanic or Latino ☐ Asian / Pacific Islander
☐ Arab ☐ Multiracial
☐ Would rather not say ☐ Other

If other, please specify: _____

A6. Are you the legal parent/guardian of the child who usually provides the most care to him/her?
☐ Yes ☐ No

A7. Which of the following best describes your relationship to the child?
☐ Biological mother / father ☐ Grandparent
☐ Adoptive mother / father ☐ Aunt / Uncle
☐ Step-mother / Step-father ☐ Other relative / In-law
☐ Partner of child's parent ☐ Unrelated guardian
☐ Foster mother /father

A8. What is the highest level of education you have completed?
☐ Less than Junior Certificate ☐ Honours Bachelor Degree
☐ Junior Certificate ☐ Higher Diploma
☐ Leaving Certificate ☐ Master's Degree
☐ Higher Certificate ☐ Doctoral Degree
☐ Ordinary Bachelor Degree

A9. What type of seizures does your child currently have, or have they had in the past?
(Please tick all relevant to your child)
☐ Tonic-clonic seizures
(Your child loses consciousness, his/her body goes stiff, he/she falls to the floor, his/her limbs jerk)
☐ Absence seizures
(Your child appears to daydream or "switch off" for a few seconds; he/she will experience a lapse in awareness)
☐ Simple Partial
(Your child experiences partial seizures in which he/she is fully awake, alert and able to interact throughout the seizure)

What type of seizures does your child currently have, or have they had in the past?
(Please tick all relevant to your child)

☐ Complex Partial
(Your child experiences partial seizures in which he/she experiences a loss of awareness and may stare blankly)

☐ Myoclonic seizures
(Your child experiences extremely brief shock-like jerks/twitches of a muscle or group of muscles, your child will usually be awake and able to think clearly)

☐ Atonic seizures
(Drop attacks; your child experiences an abrupt loss of muscle tone and may drop to the ground. In some children, only their head suddenly drops)

☐ Tonic seizures
(Your child's arms or legs make sudden stiffening movements, consciousness is usually preserved)

☐ Clonic seizures
(Your child experiences rhythmic jerking movements of the arms and legs)

☐ Other/Unknown, please describe:

A10. Has your child ever had seizures in the company of anyone besides his/her parents or siblings?

☐ Yes ☐ No

If you answered yes, please specify:

A11. Has your child been diagnosed with a specific type of epilepsy?

☐ Yes ☐ No ☐ Unsure

If you answered yes, please specify the diagnosis received:

A12. At what age did your child experience his/her first seizure?

Age: _____ (years)

A13. How frequent are your child's seizures currently?

☐ Daily *(once a day or more)*
☐ Frequently *(several times a week)*
☐ Weekly *(about once a week)*
☐ Monthly *(about once a month)*
☐ Occasionally *(less than monthly)*
☐ Yearly *(about once a year)*
☐ Other, please specify:

A14. When was your child's last seizure?

A15. Is your child currently receiving treatment or taking medication for his/her epilepsy?

☐ Yes ⇨ Please provide details of what medication(s) your child uses and how often your child takes them in the box below.

Please provide details of any medication(s) your child used to use and how often your child took them in the box below.

☐ No ⇨ When did your child cease receiving treatment/taking medication?

(M) (M) (Y) (Y) (Y) (Y)

Please provide details of any medication(s) your child used to use and how often your child took them in the box below.

A16. Has your child experienced any side effects as a result of treatment or medication?

☐ Yes ☐ No

If you answered yes, please list the side effects experienced:

A17. Is there a known cause for your child's epilepsy?

☐ Yes ☐ No

If you answered yes, please specify:

A18. Is there a history of epilepsy in your family?

☐ Yes ☐ No ☐ Unsure

If you answered yes, please specify what family member (if known):

A19. Has your child missed any days of school as a result of his/her epilepsy?

☐ Yes ☐ No

If you answered yes, please specify the number of days within the past year:

____ days (approximately)

A20. What county are you and your child currently living in?

A21. In relation to your child's epilepsy care, how accessible have you found healthcare services to date?

☐ Very easy to access
☐ Somewhat easy to access
☐ Okay to access
☐ Somewhat difficult to access
☐ Very difficult to access

A22. What services does your child currently attend for his/her epilepsy care?

☐ A Neurology Department in a Hospital
☐ A Paediatric/General Clinic in a Hospital
☐ A General Practitioner (GP)
☐ Other, please specify:

A23. Has your child seen a neurologist about his/her epilepsy?

☐ Yes ☐ No

A24. When receiving your child's epilepsy diagnosis, was your experience satisfactory?

☐ Yes ☐ No

Please expand:

A25. At hospital appointments, do you find communicating with health care providers satisfactory?

☐ Yes ☐ No

Please expand:

A26. Please tell us what you call your child's epilepsy in your own words.

A27. Does your child have any other medical conditions?

☐ Yes ☐ No

If you answered yes, please specify:

A28. Where did you complete this questionnaire?

☐ At home ☐ In a healthcare facility

☐ Other, please specify:

A29. Was your child present as you completed this questionnaire?

☐ Yes ☐ No

A30. Where did you hear about this research?

☐ Epilepsy Ireland ☐ Temple Street Children's University Hospital

☐ Other, please specify:

End of Section A

Do I tell others and talk to others about my child's epilepsy? (Section B)

In this section, we are interested in how you communicate about your child's epilepsy with others.

Please read each statement carefully. Indicate how you feel about each statement.

B1. When you can, do you keep your child's epilepsy a secret from others?

☐ Often ☐ Sometimes ❑ Rarely ❑ Never

B2 How frequently do you talk to people about your child's epilepsy?

☐ Often ☐ Sometimes ❑ Rarely ❑ Never

B3. Do any of your friends know that your child has epilepsy?

☐ All ❑ Some ❑ Few ❑ None

B4. When people find out your child has epilepsy, it is usually because:

☐ You tell them

☐ Your child has a seizure and then you explain it

☐ Your child has a seizure and they see it

☐ Someone else tells them about it

B5. How difficult has it been for you to talk to others about what you and your child are going through?

☐ Not at all ☐ A little ☐ Somewhat ❑ Very

B6. How much have you wanted someone to talk to about your experience with your child's epilepsy?

☐ Not at all ☐ A little ☐ Somewhat ❑ A lot

B7. To what degree have you *wanted to keep* your child's epilepsy a secret?

☐ Not at all ☐ A little ☐ Somewhat ❑ A lot

B8. To what degree have you *actually kept* your child's epilepsy a secret?

☐ Not at all ☐ A little ☐ Somewhat ❑ A lot

B9. How much have you written about your child's epilepsy (such as in a diary, journal, letters; or online in support groups or on social media i.e. Facebook, Twitter, Tumblr, blogs etc.)?

☐ Not at all ☐ A little ☐ Somewhat ❑ A lot

B10. If you have written about your child's epilepsy, where have you written about it?

Diary/Journal	☐ Yes	☐ No
Seizure control journals	☐ Yes	☐ No
Letters	☐ Yes	☐ No
Facebook	☐ Yes	☐ No
Twitter	☐ Yes	☐ No
Epilepsy Support Groups	☐ Yes	☐ No
Tumblr	☐ Yes	☐ No
Blogs	☐ Yes	☐ No
Any other sources	☐ Yes	☐ No

Please specify where else you have written about your child's epilepsy below:

B11. Who do I tell and talk to about my child's epilepsy?

Using the scale below, please indicate the degree to which you have talked with each of the following individuals about your experience with epilepsy since your child's diagnosis: (please mark "0" next to any categories that do not apply to you).

0	1	2	3	4
Not Applicable	Not at all	A little	Somewhat	Very Much

____	Partner/Spouse	____	Close male friend(s)
____	Close female friend(s)	____	Male friend(s)
____	Female friend(s)	____	Neighbour(s)
____	Other People with Epilepsy	____	Doctors
____	Nurses	____	Parent(s)
____	Sibling(s)	____	Therapist/Counsellor
____	Co-workers	____	Your child with epilepsy
____	Your other younger child(ren)	____	Your other older child(ren)
____	Your child's friends' parents	____	Your child's teacher(s)
____	Your child's principal	____	Babysitters
____	Nannies/Child-minders/Au pairs	____	Your child's sports club coaches
____	Your employer	____	Your in-laws

____ Other Parents of Children with Epilepsy

____ Parents of Children with Other Chronic Illnesses or Disabilities

Other, please specify: _____

When do I tell and talk to others about my child's epilepsy?

We want to find out in what types of situations and how often you usually tell and talk to others *(including friends, colleagues, your child's teacher and those outside the family)* about your child's epilepsy.

I usually talk to others about my child's epilepsy when…

B12. They have seen my child having a seizure

☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

I usually talk to others about my child's epilepsy when…

B13. I think my child might be at risk of having a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B14. They see my child taking his/her medication
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B15. They ask me questions
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B16. My child has a hospital appointment coming up or has recently had a hospital appointment
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B17. My child's medication is causing difficulties
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B18. My child cannot partake in an activity due to his/her epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B19. My child misses school because he/she has had a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B20. I need support
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B21. I need information
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B22. Epilepsy comes up in conversation
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B23. My child is entering a new environment or starting a new activity
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B24. Others will be responsible for my child
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

I usually talk to others about my child's epilepsy when…

B25. There is a change in my child's behaviour due to his/her epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B26. Others are speaking about their child's difficulties
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B27. Other, please specify;

What do I tell others when I am talking to them about my child's epilepsy?

We are interested in finding out what kind of things you usually tell and talk to others (including friends, colleagues, your child's teacher and those outside the family) about in relation to your child's epilepsy.

When I talk to others about my child's epilepsy, I talk to others about…

B28. What epilepsy is
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B29. The type of epilepsy my child has
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B30. What happens/how my child appears when he/she is having a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B31. How seizures impact on my child
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B32. What to do in the event of my child having a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B33. My child's medication
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B34. Medication side-effects
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

When I talk to others about my child's epilepsy, I talk to others about…

B35. My child's hospital appointments
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B36. Restrictions my child experiences due to his/her epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B37. My child's seizure control (or lack thereof)
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B38. Whether my child will grow out of his/her epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B39. How I feel about my child having epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B40. How my child feels about having epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B41. Other, please specify:

Why do I choose to talk to or not talk to others about my child's epilepsy?

We are interested in finding out what informs your decision whether to tell and talk to others (including friends, colleagues, your child's teacher and those outside the family) about your child's epilepsy or not.

I tell others about my child's epilepsy because…

B42. I want them to be aware that my child may have a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my child's epilepsy

B43. I want them to know what to do in the event of my child having a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my child's epilepsy

B44. I want to ensure others do not overreact if my child has a seizure in front of them
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my child's epilepsy

I tell others about my child's epilepsy because…

B45. I want to raise awareness about epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my child's epilepsy

B46. I want to make sure people are comfortable with my child's epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my child's epilepsy

B47. I want to explain the changes in my child's behaviour
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my child's epilepsy

B48. Talking to others helps me to learn more about epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my child's epilepsy

B49. Talking to others offers me emotional support
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my child's epilepsy

B50. It makes me feel more comfortable when others know about my child's epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my child's epilepsy

B51. Other, please specify:

I don't tell others about my child's epilepsy because…

B52. I am afraid of how others will react
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my child's epilepsy

B53. I am anxious that my child will be discriminated against or excluded
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my child's epilepsy

B54. Other people are misinformed about epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my child's epilepsy

B55. Other people have difficulty understanding epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my child's epilepsy

I don't tell others about my child's epilepsy because…

B56. Epilepsy is rarely spoken about in public
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my child's epilepsy

B57. It makes me upset
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my child's epilepsy

B58. My child does not want others to know about his/her epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my child's epilepsy

B59. My child's epilepsy is not visible (i.e. he/she does not have seizures in public or during the day)
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my child's epilepsy

B60. I do not feel that it is necessary for others to know about my child's epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my child's epilepsy

B61. My child's epilepsy is a private matter
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my child's epilepsy

B62. I do not want to seem attention-seeking
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my child's epilepsy

B63. Other, please specify:

What helps or hinders me when talking to others about my child's epilepsy?

We are interested in finding out what you find helpful or challenging when telling and talking to others (including friends, colleagues, your child's teacher and those outside the family) about your child's epilepsy.

Do any of the following encourage or discourage you to talk about your child's epilepsy with others?

B64. Epilepsy is a medical condition
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

Do any of the following encourage or discourage you to talk about your child's epilepsy with others?

B65. My child's seizures are well controlled
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B66. My child's epilepsy is mild in comparison to others
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B67. My child's epilepsy is not visible to others
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B68. The level of information I have about my child's epilepsy
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B69. The amount of time that has passed since my child's diagnosis
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B70. Portrayals of epilepsy in the media
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B71. My own attitudes towards epilepsy
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B72. Experiences I have had with epilepsy prior to my child's diagnosis
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B73. The reactions from others when I've talked about my child's epilepsy in the past
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B74. Public perceptions of epilepsy
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

Do any of the following encourage or discourage you to talk about your child's epilepsy with others?

B75. My ability to explain epilepsy to others

☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B76. How I feel others will treat/perceive my child

☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B77. How talking about my child's epilepsy to others makes me feel

☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B78. Public understanding about epilepsy

☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B79. Whether my child wants others to know about his/her epilepsy

☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B80. Other, please specify:

What happens when I talk to others about my child's epilepsy?

We are interested in finding out how it makes you feel to tell and talk to others (including friends, colleagues, your child's teacher and those outside the family) about your child's epilepsy and how others react when you tell them about your child's epilepsy.

Before telling others about my child's epilepsy I feel…

B81. Anxious

☐ Yes ☐ No
☐ Does not apply to me, I never tell others about my child's epilepsy

B82. Optimistic

☐ Yes ☐ No
☐ Does not apply to me, I never tell others about my child's epilepsy

Before telling others about my child's epilepsy I feel…

B83. Uncomfortable
☐ Yes ☐ No
☐ Does not apply to me, I never tell others about my child's epilepsy

B84. Pessimistic
☐ Yes ☐ No
☐ Does not apply to me, I never tell others about my child's epilepsy

B85. Confident
☐ Yes ☐ No
☐ Does not apply to me, I never tell others about my child's epilepsy

B86. Fearful
☐ Yes ☐ No
☐ Does not apply to me, I never tell others about my child's epilepsy

B87. Unsure
☐ Yes ☐ No
☐ Does not apply to me, I never tell others about my child's epilepsy

B88. Other, please specify:

In the past, when I have told others about my child's epilepsy others have mostly…

B89. Reacted positively
☐ Yes ☐ No
☐ Does not apply, I have never told others about my child's epilepsy

B90. Asked questions
☐ Yes ☐ No
☐ Does not apply, I have never told others about my child's epilepsy

B91. Reassured me
☐ Yes ☐ No
☐ Does not apply, I have never told others about my child's epilepsy

B92. Had difficulty understanding the condition
☐ Yes ☐ No
☐ Does not apply, I have never told others about my child's epilepsy

B93. Reacted negatively
☐ Yes ☐ No
☐ Does not apply, I have never told others about my child's epilepsy

In the past, when I have told others about my child's epilepsy others have mostly…

B94. Treated my child differently

☐ Yes ☐ No

☐ Does not apply, I have never told others about my child's epilepsy

B95. Excluded or discriminated against my child

☐ Yes ☐ No

☐ Does not apply, I have never told others about my child's epilepsy

B96. Other, please specify:

After telling others about my child's epilepsy, when they react well I feel…

B97. Happy

☐ Yes ☐ No ☐ Does not apply, others have never reacted well

☐ Does not apply, I never tell others about my child's epilepsy

B98. Reassured

☐ Yes ☐ No ☐ Does not apply, others have never reacted well

☐ Does not apply, I never tell others about my child's epilepsy

B99. Relieved

☐ Yes ☐ No ☐ Does not apply, others have never reacted well

☐ Does not apply, I never tell others about my child's epilepsy

B100. Other, please specify:

After telling others about my child's epilepsy, when they react poorly I feel…

B101. Frustrated

☐ Yes ☐ No ☐ Does not apply, others have never reacted poorly

☐ Does not apply, I never tell others about my child's epilepsy

B102. Angered

☐ Yes ☐ No ☐ Does not apply, others have never reacted poorly

☐ Does not apply, I never tell others about my child's epilepsy

B103. Upset

☐ Yes ☐ No ☐ Does not apply, others have never reacted poorly

☐ Does not apply, I never tell others about my child's epilepsy

After telling others about my child's epilepsy, when they react poorly I feel…

B104. Worried

☐ Yes ☐ No ☐ Does not apply, others have never reacted poorly
☐ Does not apply, I never tell others about my child's epilepsy

B105. Other, please specify:

End of Section B

How do I talk to my child about his/her epilepsy? (Section C)

In this section, we are interested in what types of situations and how often you talk to your child about his/her epilepsy.
Please read each statement carefully. Indicate how you feel about each statement.

I usually talk to my child about his/her epilepsy when…

C1. My child has a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C2. My child takes his/her medication
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C3. My child asks me questions
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C4. My child has a hospital appointment coming up or has recently had a hospital appointment
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C5. My child's medication is causing difficulties
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C6. My child cannot partake in an activity due to his/her epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C7. My child is worried/upset
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

I usually talk to my child about his/her epilepsy when…

C8. My child needs support
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C9. Other, please specify:

When I talk to my child about his/her epilepsy, what do we talk about?

When I talk to my child about his/her epilepsy, we talk about…

C10. What epilepsy is
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C11. How my child feels about having epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C12. What happens when my child has a seizure (e.g. how he/she appears)
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C13. My child's medication
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C14. Medication side effects
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C15. My child's hospital appointments
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C16. Restrictions my child experiences due to his/her epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C17. My child's seizure control (or lack thereof)
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C18. Whether my child will grow out of his/her epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

When I talk to my child about his/her epilepsy, we talk about…

C19. Other, please specify:

Why do I choose to talk to my child about his/her epilepsy?

We are interested in what informs your decision whether to talk to your child about his/her epilepsy or not.

I talk to my child about his/her epilepsy because…

C20. I don't want my child to feel different
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C21. I want my child to know what he/she should do in the event of a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C22. It helps my child to deal with certain situations
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C23. It helps me to deal with certain situations
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C24. I want my child to be informed about his/her epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C25. I don't want my child to keep secrets about his/her epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C26. Other, please specify:

I don't talk to my child about his/her epilepsy because…

C27. I don't want to single my child out in comparison to his/her siblings
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always talk to my child about his/her epilepsy

I don't talk to my child about his/her epilepsy because…

C28. I don't want to worry my child
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always talk to my child about his/her epilepsy

C29. I don't want my child to dwell on his/her epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always talk to my child about his/her epilepsy

C30. Other, please specify:

What helps or hinders me when talking to my child about his/her epilepsy?

We are interested in what you find helpful or challenging when talking to your child about his/her epilepsy.

Do any of the following encourage or discourage you to talk to your child about his/her epilepsy?

C31. My child's disposition (i.e. – your child's temperament and nature)
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk to my child about his/her epilepsy

C32. The amount of time my child has had epilepsy
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk to my child about his/her epilepsy

C33. The level of information I have about my child's epilepsy
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk to my child about his/her epilepsy

C34. My child's seizures are well controlled
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk to my child about his/her epilepsy

C35. Portrayals of epilepsy in the media
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk to my child about his/her epilepsy

Do any of the following encourage or discourage you to talk to your child about his/her epilepsy?

C36. My own attitudes towards epilepsy

☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk to my child about his/her epilepsy

C37. Experiences I had with epilepsy prior to my child's diagnosis

☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk to my child about his/her epilepsy

C38. Other, please specify:

What happens when I talk to my child about his/her epilepsy?

We are interested in finding out how talking to your child about his/her epilepsy makes you feel.

Talking about epilepsy with my child makes me feel…

C39. Reassured

☐ Yes ☐ No ☐ Does not apply, I never talk to my child about his/her epilepsy

C40. Optimistic

☐ Yes ☐ No ☐ Does not apply, I never talk to my child about his/her epilepsy

C41. Anxious

☐ Yes ☐ No ☐ Does not apply, I never talk to my child about his/her epilepsy

C42. Uncomfortable

☐ Yes ☐ No ☐ Does not apply, I never talk to my child about his/her epilepsy

C43. Pessimistic

☐ Yes ☐ No ☐ Does not apply, I never talk to my child about his/her epilepsy

C44. Other, please specify:

End of Section C

Section D

In this section we would like to ask you some questions about how you feel about your child's epilepsy
Please indicate how much you *agree or disagree* with each of the following statements.

D1. People, who know that my child has epilepsy, treat him/her differently.
☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D2. It really doesn't matter what I say to people about my child's epilepsy: they usually have their minds made up.
☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D3. My child always has to prove him/herself because of the epilepsy.
☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D4. Because of the epilepsy, my child will have problems in finding a husband or wife
☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D5. In many people's minds, epilepsy attaches a stigma or a label to my child.
☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D6. I know how to recognize side effects or problems from my child's medicine for the epilepsy. *(Please skip if your child is not on medication)*
☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D7. I find myself getting irritable with my child.
☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D8. I cheer up my child when he/she is sad.
☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D9. I enjoy staying home with my child more than going out with my friends.
☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D10. My child talks to me when he/she is afraid.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D11. I am often too tired from dealing with the epilepsy to do the things for fun that I used to do.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D12. I know what to do when the next seizure happens.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D13. We have fewer leisure outings with other families since my child developed the epilepsy.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D14. Handling the behaviour of my child is hard for me.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D15. My child usually feels better after I talk over worries with him/her.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D16. My partner and I disagree about how to handle the epilepsy. (*Please skip if you do not have a partner*)

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D17. I am usually successful when I try to get my child to do something.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D18. Despite my best efforts, I am uncomfortable with how my child and I get along.

☐Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D19. I do a good job of disciplining my child.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D20. I know when to call the doctor about my child's epilepsy.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D21. My child is overly dependent on me.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D22. I am proud of the accomplishments of my child.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D23. Having one child with epilepsy makes it difficult on other children in the family.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D24. Our family activities outside the home are limited because of worry that my child will have a seizure in front of others.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D25. I need to know what my child is doing at all times.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D26. I do a good job of supporting my child in doing things that are hard for him/her.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D27. The only time I am happy is when my child is doing well.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D28. I know when to take my child to the accident and emergency department for the epilepsy.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D29. Our family goes on fewer leisure outings because of my child's epilepsy.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D30. My partner and I disagree about how to discipline my child because of the epilepsy. *(Please skip if you do not have a partner)*

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D31. I usually understand what my child needs from me.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D32. I limit the activities of my child more than our doctor recommends.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D33. I feel confident in my ability to handle my child's epilepsy.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D34. I give more attention to my child than other people in the family.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D35. My child has his/her own feelings and ideas, and it is okay for him/her to tell me about them.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D36. My child is my life's only focus.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D37. I like my child better when he/she does not disturb me.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D38. When I think of myself as a parent of my child, I believe I can handle anything that happens.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D39. My partner and I have less time to spend together because of my child's epilepsy. *(Please skip if you do not have a partner)*

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D40. My partner and I differ about how to tell others about my child's epilepsy. ***(Please skip if you do not have a partner)***

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

End of Section D

Section E

In this section we are interested in how you engage with the people in your life, both within your family and outside it, and how you respond to distressing situations.

Please indicate the extent to which you agree or disagree with the following statements:

E1. When I feel upset, I usually confide in my friends.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

E2. I prefer not to talk about my problems.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

E3. When something unpleasant happens to me, I often look for someone to talk to.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

E4. I typically don't discuss things that upset me.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

E5. When I feel depressed or sad, I tend to keep those feelings to myself.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

E6. I try to find people to talk with about my problems.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

E7. When I am in a bad mood, I talk about it with my friends.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

E8. If I have a bad day, the last thing I want to do is talk about it.

☐ Strongly Disagree
☐ Disagree
☐ Neither Disagree nor Agree
☐ Agree
☐ Strongly Agree

E9. I rarely look for people to talk with when I am having a problem.

☐ Strongly Disagree
☐ Disagree
☐ Neither Disagree nor Agree
☐ Agree
☐ Strongly Agree

E10. When I'm distressed I don't tell anyone.

☐ Strongly Disagree
☐ Disagree
☐ Neither Disagree nor Agree
☐ Agree
☐ Strongly Agree

E11. I usually seek out someone to talk to when I am in a bad mood.

☐ Strongly Disagree
☐ Disagree
☐ Neither Disagree nor Agree
☐ Agree
☐ Strongly Agree

E12. I am willing to tell others my distressing thoughts.

☐ Strongly Disagree
☐ Disagree
☐ Neither Disagree nor Agree
☐ Agree
☐ Strongly Agree

E13. There is a special person who is around when I am in need.

☐ Very Strongly Disagree
☐ Strongly Disagree
☐ Mildly Disagree
☐ Neither Disagree nor Agree
☐ Mildly Agree
☐ Strongly Agree
☐ Very Strongly Agree

E14. There is a special person with whom I can share my joys and sorrows.

☐ Very Strongly Disagree
☐ Strongly Disagree
☐ Mildly Disagree
☐ Neither Disagree nor Agree
☐ Mildly Agree
☐ Strongly Agree
☐ Very Strongly Agree

E15. My family really tries to help me.

☐ Very Strongly Disagree
☐ Strongly Disagree
☐ Mildly Disagree
☐ Neither Disagree nor Agree
☐ Mildly Agree
☐ Strongly Agree
☐ Very Strongly Agree

E16. I get the emotional help and support I need from my family.

☐ Very Strongly Disagree
☐ Strongly Disagree
☐ Mildly Disagree
☐ Neither Disagree nor Agree
☐ Mildly Agree
☐ Strongly Agree
☐ Very Strongly Agree

E17. I have a special person who is a real source of comfort to me.

☐ Very Strongly Disagree
☐ Strongly Disagree
☐ Mildly Disagree
☐ Neither Disagree nor Agree
☐ Mildly Agree
☐ Strongly Agree
☐ Very Strongly Agree

E18. My friends really try to help me.

☐ Very Strongly Disagree
☐ Strongly Disagree
☐ Mildly Disagree
☐ Neither Disagree nor Agree
☐ Mildly Agree
☐ Strongly Agree
☐ Very Strongly Agree

E19. I can count on my friends when things go wrong.

☐ Very Strongly Disagree
☐ Strongly Disagree
☐ Mildly Disagree
☐ Neither Disagree nor Agree
☐ Mildly Agree
☐ Strongly Agree
☐ Very Strongly Agree

E20. I can talk about my problems with my family.

☐ Very Strongly Disagree
☐ Strongly Disagree
☐ Mildly Disagree
☐ Neither Disagree nor Agree
☐ Mildly Agree
☐ Strongly Agree
☐ Very Strongly Agree

E21. I have friends with whom I can share my joys and sorrows.

☐ Very Strongly Disagree
☐ Strongly Disagree
☐ Mildly Disagree
☐ Neither Disagree nor Agree
☐ Mildly Agree
☐ Strongly Agree
☐ Very Strongly Agree

E22. There is a special person in my life who cares about my feelings.

☐ Very Strongly Disagree
☐ Strongly Disagree
☐ Mildly Disagree
☐ Neither Disagree nor Agree
☐ Mildly Agree
☐ Strongly Agree
☐ Very Strongly Agree

E23. My family is willing to help me make decisions.

☐ Very Strongly Disagree
☐ Strongly Disagree
☐ Mildly Disagree
☐ Neither Disagree nor Agree
☐ Mildly Agree
☐ Strongly Agree
☐ Very Strongly Agree

E24. I can talk about my problems with my friends.

☐ Very Strongly Disagree
☐ Strongly Disagree
☐ Mildly Disagree
☐ Neither Disagree nor Agree
☐ Mildly Agree
☐ Strongly Agree
☐ Very Strongly Agree

End of Section E

Section F

In this section we are interested in learning about how you like to parent your child.

In the following statements, please indicate how often you exhibit this behavior with your child.

F1. I encourage my child to talk about his/her troubles.

☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F2. I guide my child by punishment more than by reason.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F3. I know the names of my child's friends.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F4. I find it difficult to discipline my child.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F5. I give praise when my child is good.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F6. I spank when my child is disobedient.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F7. I joke and play with my child.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F8. I withhold scolding and/or criticism even when my child acts contrary to my wishes.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F9. I show sympathy when my child is hurt or frustrated.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F10. I punish by taking privileges away from my child with little if any explanation.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F11. I spoil my child.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F12. I give comfort and understanding when my child is upset.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F13. I yell or shout when my child misbehaves.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F14. I am easy going and relaxed with my child.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F15. I allow my child to annoy someone else.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F16. I tell my child our expectations regarding behavior before the child engages in an activity.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F17. I scold and criticize to make my child improve.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F18. I show patience with my child.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F19. I grab my child when being disobedient.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F20. I state punishments to my child and do not actually do them.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F21. I am responsive to my child's feelings or needs.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F22. I allow my child to give input into family rules.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F23. I argue with my child.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F24. I appear confident about parenting abilities.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F25. I give my child reasons why rules should be obeyed.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F26. I appear to be more concerned with my own feelings than with my child's feelings.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F27. I tell my child that I appreciate what the child tries or accomplishes.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F28. I punish by putting my child off somewhere alone with little if any explanation.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F29. I help my child to understand the impact of behavior by encouraging my child to talk about the consequences of own actions.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F30. I am afraid that disciplining my child for misbehavior will cause the child to not like his/her parent(s).
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F31. I take my child's desires into account before asking the child to do something.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F32. I explode in anger towards my child.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F33. I am aware of problems or concerns about my child in school.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F34. I threaten my child with punishment more often than actually giving it.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F35. I express affection by hugging, kissing, and holding my child.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F36. I ignore my child's misbehavior.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F37. I use physical punishment as a way of disciplining my child.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F38. I carry out discipline after my child misbehaves.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F39. I apologize to my child when making a mistake in parenting.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F40. I tell my child what to do.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F41. I give into my child when the child causes a commotion about something.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F42. I talk it over and reason with my child when the child misbehaves.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F43. I slap my child when the child misbehaves.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F44. I disagree with my child.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F45. I allow my child to interrupt others.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F46. I have warm and intimate times together with my child.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F47. When two children are fighting, I discipline the children first and ask questions later.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F48. I encourage my child to freely express himself/herself even when disagreeing with parent(s).
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F49. I bribe my child with rewards to bring about compliance.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F50. I scold or criticize when my child's behavior doesn't meet my expectations.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F51. I show respect for my child's opinions by encouraging my child to express them.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F52. I set strict well-established rules for my child.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F53. I explain to my child how I feel about the child's good and bad behavior.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F54. I use threats as punishment with little or no justification.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F55. I take into account my child's preferences in making plans for the family.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F56. When my child asks why he/she has to conform, I state: because I said so, or I am your parent and I want you to.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F57. I appear unsure on how to solve my child's misbehavior.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F58. I explain the consequences of the child's behavior.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F59. I demand that my child does things.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F60. I channel my child's misbehavior into a more acceptable activity.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F61. I shove my child when the child is disobedient.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

F62. I emphasize the reasons for rules.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often
☐ Always

End of Section F

The Impact of Epilepsy (Section G)

In this section we would like to ask you some questions about how epilepsy affects your child's and your family's everyday life.

G1. How much extra supervision is needed in your child's daily activities?
☐ None ☐ A little ☐ Some ☐ A lot

G2. Does your child require special precautions in daily activities (such as wearing a helmet)?
☐ Never ☐ Sometimes ☐ Usually ☐ Always

G3. Does the epilepsy influence the freedom of your child to play in the house?

☐ Not at all ☐ A little ☐ Some ☐ A lot

G4. Does epilepsy influence the freedom of your child to play outside?

☐ Not at all ☐ A little ☐ Some ☐ A lot

G5. Does epilepsy influence the freedom of your child to go swimming?

☐ Not at all ☐ A little ☐ Some ☐ A lot

G6. Does epilepsy influence the freedom of your child to participate in sports activities (excluding swimming)?

☐ Not at all ☐ A little ☐ Some ☐ A lot

G7. Does epilepsy influence the freedom of your child in traffic (such as riding a bicycle)?

☐ Not at all ☐ A little ☐ Some ☐ A lot

G8. Does epilepsy influence the freedom of your child to stay elsewhere overnight (with friends or family)?

☐ Not at all ☐ A little ☐ Some ☐ A lot

G9. Does epilepsy influence the freedom of your child to go to parties?

☐ Not at all ☐ A little ☐ Some ☐ A lot

G10. Does epilepsy influence the freedom of your child to participate in physical education?

☐ Not at all ☐ A little ☐ Some ☐ A lot

G11. During the past week, how often did you feel helpless or frightened when your child experienced seizures?

☐ All of the time
☐ Most of the time
☐ Quite often
☐ Some of the time
☐ Once in a while
☐ Hardly any of the time
☐ None of the time

G12. During the past week, how often did your family need to change plans because of your child's epilepsy?

☐ All of the time
☐ Most of the time
☐ Quite often
☐ Some of the time
☐ Once in a while
☐ Hardly any of the time
☐ None of the time

G13. During the past week, how often did you feel frustrated or impatient because your child was irritable due to epilepsy?

☐ All of the time
☐ Most of the time
☐ Quite often
☐ Some of the time
☐ Once in a while
☐ Hardly any of the time
☐ None of the time

G14. During the past week, how often did your child's epilepsy interfere with your job or work around the house?

☐ All of the time
☐ Most of the time
☐ Quite often
☐ Some of the time
☐ Once in a while
☐ Hardly any of the time
☐ None of the time

G15. During the past week, how often did you feel upset because of your child's seizures?

☐ All of the time
☐ Most of the time
☐ Quite often
☐ Some of the time
☐ Once in a while
☐ Hardly any of the time
☐ None of the time

G16. During the past week, how often did you have sleepless nights because of your child's epilepsy?

☐ All of the time
☐ Most of the time
☐ Quite often
☐ Some of the time
☐ Once in a while
☐ Hardly any of the time
☐ None of the time

G17. During the past week, how often were you bothered because your child's epilepsy interfered with family relationships?

☐ All of the time
☐ Most of the time
☐ Quite often
☐ Some of the time
☐ Once in a while
☐ Hardly any of the time
☐ None of the time

G18. During the past week, how often were you awakened during the night because of your child's epilepsy?

☐ All of the time
☐ Most of the time
☐ Quite often
☐ Some of the time
☐ Once in a while
☐ Hardly any of the time
☐ None of the time

G19. During the past week, how often did you feel angry that your child has epilepsy?

☐ All of the time
☐ Most of the time
☐ Quite often
☐ Some of the time
☐ Once in a while
☐ Hardly any of the time
☐ None of the time

G20. During the past week, how worried or concerned were you about your child's performance of normal daily activities?

☐ Very, very worried or concerned
☐ Very worried or concerned
☐ Fairly worried or concerned
☐ Somewhat worried or concerned
☐ A little worried or concerned
☐ Hardly worried or concerned
☐ Not worried or concerned

G21. During the past week, how worried or concerned were you about your child's epilepsy medications and side effects?

☐ Very, very worried or concerned
☐ Very worried or concerned
☐ Fairly worried or concerned
☐ Somewhat worried or concerned
☐ A little worried or concerned
☐ Hardly worried or concerned
☐ Not worried or concerned

G22. During the past week, how worried or concerned were you about being overprotective of your child?

☐ Very, very worried or concerned
☐ Very worried or concerned
☐ Fairly worried or concerned
☐ Somewhat worried or concerned
☐ A little worried or concerned
☐ Hardly worried or concerned
☐ Not worried or concerned

G23. During the past week, how worried or concerned were you about your child being able to lead a normal life?

☐ Very, very worried or concerned
☐ Very worried or concerned
☐ Fairly worried or concerned
☐ Somewhat worried or concerned
☐ A little worried or concerned
☐ Hardly worried or concerned
☐ Not worried or concerned

In this section, we would like to know how you feel your child's epilepsy affects either your child's or your family's everyday life at the present time and during the past 3 months.

How does epilepsy affect the following areas of your child's or your family's everyday life (social consequences, seizures, and treatment)?

G24. Your child's overall health
☐ A lot ☐ Some ☐ A little ☐ Not at all ☐ Does not apply

G25. Your child's relationship with parents
☐ A lot ☐ Some ☐ A little ☐ Not at all ☐ Does not apply

G26. Your child's relationships with siblings
☐ A lot ☐ Some ☐ A little ☐ Not at all ☐ Does not apply

G27. Your relationship with your spouse/partner
☐ A lot ☐ Some ☐ A little ☐ Not at all ☐ Does not apply

G28. Your child's relationships with friends/peers
☐ A lot ☐ Some ☐ A little ☐ Not at all ☐ Does not apply

G29. Your child's acceptability by others
☐ A lot ☐ Some ☐ A little ☐ Not at all ☐ Does not apply

G30. Your child's number of activities
☐ A lot ☐ Some ☐ A little ☐ Not at all ☐ Does not apply

G31. Your child's schooling/academic performance
☐ A lot ☐ Some ☐ A little ☐ Not at all ☐ Does not apply

G32. Your child's self-esteem
☐ A lot ☐ Some ☐ A little ☐ Not at all ☐ Does not apply

G33. Your loss of original hopes for your child
☐ A lot ☐ Some ☐ A little ☐ Not at all ☐ Does not apply

G34. Family activities
☐ A lot ☐ Some ☐ A little ☐ Not at all ☐ Does not apply

End of Section G

Learning about Epilepsy (Section H)

In this section we would like to ask you some questions about learning about epilepsy. We are interested in the areas where you desire more information about your child's epilepsy or need more help in handling the seizures at this time.

At this time…

H1. How much do you need information about seizures?
☐ No Need for Information or Help ☐ Some Need for Information or Help
☐ Strong Need for Information or Help

H2. How much do you need information about treatment of seizures?
☐ No Need for Information or Help ☐ Some Need for Information or Help
☐ Strong Need for Information or Help

H3. How much do you need information about possible causes of seizures?
☐ No Need for Information or Help ☐ Some Need for Information or Help
☐ Strong Need for Information or Help

H4. How much do you need information about handling future seizures?
☐ No Need for Information or Help ☐ Some Need for Information or Help
☐ Strong Need for Information or Help

H5. How much do you need information about any activity restrictions?
☐ No Need for Information or Help ☐ Some Need for Information or Help
☐ Strong Need for Information or Help

H6. How much do you need information about protecting your child from injury?
☐ No Need for Information or Help ☐ Some Need for Information or Help
☐ Strong Need for Information or Help

H7. How much do you need encouragement and support?
☐ No Need for Information or Help ☐ Some Need for Information or Help
☐ Strong Need for Information or Help

H8. How much do you need help in handling responses of others (school personnel, friends, child's peers)?
☐ No Need for Information or Help ☐ Some Need for Information or Help
☐ Strong Need for Information or Help

H9. How much do you need to discuss your concerns and fears about your child's future?
☐ No Need for Information or Help ☐ Some Need for Information or Help
☐ Strong Need for Information or Help

H10. How much do you need to discuss fears about your child's seizures?
☐ No Need for Information or Help ☐ Some Need for Information or Help
☐ Strong Need for Information or Help

H11. How much do you need to discuss concerns about your child's mental health?
☐ No Need for Information or Help ☐ Some Need for Information or Help
☐ Strong Need for Information or Help

H12. How much do you need help with handling your child's response to seizures?
☐ No Need for Information or Help ☐ Some Need for Information or Help
☐ Strong Need for Information or Help

H13. How much do you need for your child to discuss his/her concerns and fears about seizures with other children who have seizures?
☐ No Need for Information or Help ☐ Some Need for Information or Help
☐ Strong Need for Information or Help

H14. How much do you need for your child to receive counselling about the seizures?
☐ No Need for Information or Help ☐ Some Need for Information or Help
☐ Strong Need for Information or Help

We are also interested in learning about your experiences with doctors and nurses related to the care of your child's epilepsy.
Please respond to the following with the response that best describes how you feel.

H15. The doctors/nurses clearly explained the epilepsy to us
☐ Less Than I Wanted ☐ Just As Much As I Wanted
☐ More Than I Wanted

H16. The doctors/nurses clearly described how the medicine worked, and possible side effects of the medicine prescribed
☐ Less Than I Wanted ☐ Just As Much As I Wanted
☐ More Than I Wanted

H17. The doctors/nurses described any problems from the medicine that would need to be reported immediately
☐ Less Than I Wanted ☐ Just As Much As I Wanted
☐ More Than I Wanted

H18. The doctors/nurses described how to give the medication
☐ Less Than I Wanted ☐ Just As Much As I Wanted
☐ More Than I Wanted

H19. The doctors/nurses gave us an opportunity to ask questions about the seizures
☐ Less Than I Wanted ☐ Just As Much As I Wanted
☐ More Than I Wanted

H20. The doctors/nurses clearly explained what to do in the event of a future seizure
☐ Less Than I Wanted ☐ Just As Much As I Wanted
☐ More Than I Wanted

H21. The doctors/nurses addressed our concerns and fears about seizures

☐ Less Than I Wanted ☐ Just As Much As I Wanted
☐ More Than I Wanted

H22. The doctors/nurses explained how to handle the seizures at school

☐ Less Than I Wanted ☐ Just As Much As I Wanted
☐ More Than I Wanted

End of Section H

Your Child's Epilepsy (Section I)

In this section we would like to ask you some questions about your child's seizures. Some of the questions will refer to auras or warnings. An aura or warning is a feeling that a child might experience, such as a tummy ache or fuzzy head which might occur on its own, but suggests that a seizure is likely to follow.

Please answer these questions with reference to the seizures your child has experienced in the past year.

I1. Over the past year, how often have your child's seizures consistently occurred at a particular time of day or night?

☐ Always ☐ Sometimes
☐ Usually ☐ Never or can occur at any time of day or night

I2. Over the past year, when your child has had a seizure, how often has he/she been able to tell you when a seizure was going to occur in time to be able to protect him/herself?

☐ Always ☐ Sometimes
☐ Usually ☐ Never

I3. Over the past year, how often have you child's seizures occurred during sleep?

☐ Always ☐ Sometimes
☐ Usually ☐ Never

I4. Over the past year, how many things that your child wanted to do have been stopped because of seizures?

☐ Almost all things were stopped because of seizures
☐ A lot of things were stopped because of seizures
☐ A few things were stopped because of seizures
☐ Seizures did not stop my child from doing things he or she wanted to do

I5. Has your child passed out (become unconscious or fainted) during seizures over the past year? (If no, mark "Does not or does so for less than 1 minute" and go to the next question. If yes, proceed.)
When your child has passed out during seizures over the past year, how long has it commonly lasted?

☐ Does not or does so for less than 1 minute ☐ Between 2 and 5 minutes
☐ Between 1 and 2 minutes ☐ For more than 5 minutes

I6. Is your child ever confused after seizures? (If no, mark Not confused at all and Go to the next question. If yes, proceed.) Over the past year, how confused has your child commonly been after his/her seizures?

☐ Very confused ☐ Slightly confused
☐ Moderately confused ☐ Not confused at all

I7. During the past year, how often has your child appeared to be sleepy or had a headache after the seizure?

☐ Always ☐ Sometimes
☐ Usually ☐ Never

I8. During the past year, how often has your child wet him/herself during the seizure?

☐ Always ☐ Sometimes
☐ Usually ☐ Never

I9. During the past year, how often has your child bitten his/her tongue or injured him/herself during a seizure?

☐ Always ☐ Sometimes
☐ Usually ☐ Never

I10. In the past year, how long has it usually been before your child could return to what he/she was doing before the seizure?

☐ Immediate return or less than 1 minute ☐ Between 6 minutes and 1 hour
☐ Between 1 and 5 minutes ☐ 1 hour or more

I11. In the past year, how often were you child‘s seizures extremely disruptive (e.g., shouting, wandering, undressing) to others viewing the seizures?

☐ Always ☐ Sometimes
☐ Usually ☐ Never

I12. During the past year because of seizures, how often did your child need to wear a helmet to protect him/herself?

☐ Always ☐ Sometimes
☐ Usually ☐ Never

End of Section I

END OF QUESTIONNAIRE

Appendix S.1: Phase Two: Information on the Pre-Validated Instruments Included in the Child Survey

Child Stigma Scale (CSS; Austin et al., 2004)

The CSS comprises a total of eight items, with item development based on: (i) a literature review; and (ii) unstructured interviews with CWE about their concerns and fears related to having seizures. The developed items capture feelings of differentness, the child's view of others' perceptions and disclosure of the child's epilepsy condition. Children rate how often they feel or act in ways described in the eight items on 5-point Likert type scales ranging from 1 (representative of 'never') to 5 (representative of 'very often'). A higher score reflects greater perceptions of stigma.

This scale has demonstrated high internal consistency with a coefficient alpha of 0.81 (Austin et al., 2004). Empirical support for the predicted relationships between stigma perceptions and key seizure, child and family variables provides evidence for the validity of the scale (Austin et al., 2004).

Although this scale was originally developed for use in children aged 9-14 years, it was successfully adapted for use in a study examining adolescent mental health with participants aged up to 18 years (Moses, 2010).

Child Attitude toward Illness Scale (CATIS; Austin & Huberty, 1993)

The CATIS is a 13-item scale that assesses children's positive and negative feelings towards living with a chronic health condition. Four items are rated on a 5-point scale of bipolar adjectives, while 9 items ask children to rate on a 5-point Likert scale the frequency of their positive or negative feelings towards having a chronic condition (i.e. epilepsy). Higher scores are indicative of children possessing more positive attitudes towards their illness.

This measure has been demonstrated to have good reliability, with internal consistency ranging from α=0.77 to α=0.82 (Austin & Huberty, 1993) and α=0.87 to α=0.89 (Heimlich, Westbrook, Austin, Cramer & Devinksy, 2000). Additionally, test-retest reliability over a 2-week timeframe was 0.80 (Austin & Huberty, 1993). Validity for the one-factor scale structure was established using confirmatory factor analysis. Convergent validity for the scale has also been demonstrated via the confirmation of hypothesised correlations between scores on the scale and scores on the Child Behavior Checklist (Achenbach & Edelbrock, 1983; cited by Austin & Huberty, 1993) and the Piers-Harris Children's Self-Concept Scale (Piers, 1984; cited by Austin & Huberty, 1993).

While the scale was originally developed for use in children aged 8-12 years, it has been successfully used with children ranging in age from 6 to 17 years (Briery & Rabian, 1999; Heimlich et al., 2000).

Self-Perception Profile for Children (SPPC; Harter, 1985)

The SPPC assesses children's global self-worth, in addition to their self-esteem and competence in five specific domains: 1) scholastic competence; 2) social competence; 3) athletic competence; 4) physical appearance; and 5) behavioural conduct. The questionnaire has 36 items divided into 6 items per subscale. Validity for the six-factor structure of the scale

was established using exploratory factor analysis (Harter, 1985). Items on the SPPC are rated on a four-point Likert scale ranging from 1-4, with a score of 1 reflecting the lowest level of perceived competence or adequacy and a score of 4 reflecting the highest level of perceived competence or adequacy. Thus, higher scores on this scale indicate more positive self-perceptions.

This instrument has been shown to have satisfactory psychometric properties with McCullough, Muldoon & Dempster (2009) reporting alpha coefficients for all six subscales as 0.76 (scholastic competence), 0.69 (social acceptance), 0.66 (athletic competence), 0.72 (physical appearance), 0.71 (behavioural conduct) and 0.62 (global self-worth). Additionally, convergent validity for this scale has been demonstrated via the confirmation of a number of hypothesised correlations between the scale and the Self-Description Questionnaires (Marsh, 1988, 1991; cited by Harter, 2012).

While there is also a self-perception profile for adolescents (13-20 years), correspondence with the author and examination of its use in other studies has confirmed that the SPPC is suitable for use with children up to the age of 15 years (McClenahan, Irwing, Stringer, Giles & Wilson, 2003). Thus, rather than employing two separate versions of the scales for children and adolescents, it was decided to retain this version of the scale for both child and adolescent participants in the present study.

Health-Related Quality of Life measure for Children with Epilepsy (CHEQOL-25; Ronen, et al., 2003)

The CHEQOL-25 is a 25-item scale consisting of 5 subscales (each comprising 5 items) measuring the following aspects of CWE's health-related quality of life: Interpersonal/Social Consequences, Worries and Concerns, Intrapersonal/Emotional Issues, Epilepsy My Secret and Quest for Normality. Children are presented with two statements and decide which one is more like them, for instance, "some kids with epilepsy say kids won't play with them BUT other kids with epilepsy say other kids always play with them." Children then decide if the statement is "sort of true" or "really true of them." Responses to items on the CHEQOL are then rated on a 4-point Likert scale ranging from 1-4, with higher scores indicative of CWE's more positive perceptions of HRQoL.

This scale has demonstrated sound psychometric properties with alpha coefficient scores reported as $\geq$0.63 for all subscales. For each individual subscale coefficient alpha scores for children aged 8-15 years were as follows; Interpersonal/Social Consequences=0.84, Worries and Concerns=0.71, Intrapersonal/Emotional Issues=0.73, Epilepsy My Secret=0.70, and Quest for Normality=0.63 (Ronen et al., 2003). Overall, these reliability analyses demonstrate that the scale has good internal consistency. Face and content validity for this scale has been confirmed with all of the items being identified and discussed as HRQoL issues by a sample of CWE and their parents in specifically designed focus groups (Ronen et al., 1999). Construct validity for this scale was demonstrated via the confirmation of a number of hypothesised correlations between the subscales and seizure variables (Ronen et al., 2003).

This scale has been successfully used in populations of CWE aged 8-18 years (Yam et al., 2008)

Social Support Scale for Children and Adolescents (SSSCA; Harter, 1985)

The SSSCA is a 24-item rating scale, with four subscales which assess children's perceptions of social support from four sources (i.e. parents, teachers, classmates, and friends). Similar in format to Ronen et al.'s CHEQOL measure (2003), children are presented with two statements and decide which one is more like them, for instance, "some kids have parents who don't really understand them BUT other kids have parents who really do understand them." They then decide if the statement is "sort of true" or "really true of them", with responses to items again rated on a 4-point Likert scale ranging from 1-4. The main construct Harter purports to measure in the SSSCA is social support in the form of positive regard from others. Examples of topics assessed include the extent to which participants feel they can talk with others about their problems or feelings and the extent to which they feel accepted as they are by others. Higher scores on this scale are indicative of higher levels of perceived social support.

Cronbach's alpha scores for this scale were reported as 0.75 for Parental Support, 0.83 for Close Friend Support, 0.73 for Classmate Support and 0.78 for Teacher Support (Bokhorst, Sumter & Westenberg, 2010). Reliability analyses thus suggest good reliability for the subscales. Construct validity for this scale was demonstrated via the confirmation of a number of hypothesised correlations between the subscales and measures of self-competence and global self-worth (Harter, 2012).

Child Need for Information and Support: Subscale of the Child Report of Psychosocial Care Scale (Austin et al., 1998)

The Child Need for Information and Support subscale of the Child Report of Psychosocial Care Scale comprises 12 items that measure children's need for information and support related to their seizure condition. Six items relate to children's need for information about their seizure condition, medications, seizure causes, seizure management, activities that they can do and keeping safe. Six items relate to children's need for support in relation to talking to someone about their feelings regarding having a seizure condition, telling friends about their condition, talking about fears and concerns, the future and handling seizures at school. Children rate responses on a binary yes/no scale with lower scores reflective of children's need for greater epilepsy-related information and/or support.

The coefficient alpha for the Need for Information subscale was 0.71 at 3 months and 0.80 at 6 months and the coefficient alpha for the Need for Support subscale was 0.87 at 3 months and 0.80 at 6 months (Austin et al., 1998). Construct validity for this subscale was demonstrated via the confirmation of a hypothesised correlation between scores on this subscale and scores on the CATIS, whereby unmet needs amongst CWE were significantly associated with them possessing negative attitudes toward their illness (Austin et al., 1998).

Although this subscale was originally developed for use in CWE age 8-14 years, Valizadeh et al. (2013) successfully employed this scale with a population of children and adolescents with epilepsy aged 10-18 years.

Child Information Received: Subscale of the Child Report of Psychosocial Care Scale (Austin et al., 1998)

The Child Information Received subscale of the Child Report of Psychosocial Care scale measures children's satisfaction with the level of epilepsy-related information received during

their engagements with HCPs. There are six items to which children initially respond on three-point scales (ranging from 1='less than I wanted' to 3='more than I wanted'). For the purposes of analysis, these responses are rescored to reflect binary responses so that a score of 1 denotes the child's dissatisfaction with level of information received (i.e. 'less than I wanted' or 'more than I wanted') and a score of 2 reflects the child's satisfaction with level of information received (i.e. 'just as much as I wanted'). Thus, lower scores on this subscale indicate that a dissatisfactory (inadequate or excessive) level of information was received by the child during his/her interactions with HCPs whilst higher scores on this subscale indicate that a satisfactory level of information was received by the child during his/her engagements with HCPs.

The coefficient alpha for this subscale was 0.75 at 3 months and 0.85 at 6 months (Austin et al., 1998).

Again, despite this subscale being devised with the original intention of capturing the level of satisfaction with information received by CWE aged 8-14 year olds, this subscale has been successfully implemented with a population of children and adolescents with epilepsy aged 10-18 years (Valizadeh et al., 2013).

Appendix S.2: Phase Two: Information on the Pre-Validated Instruments Included in the Parent Survey

Seizure Severity Scale (SSS) (Baker et al., 1991; Austin et al., 2004):

The Seizure Severity Scale was originally a 12-item scale developed to reflect the degree to which seizures disrupt the everyday lives of adults (Baker et al., 1991). This scale has been revised for completion by parents to rate their child's seizure severity (Austin et al., 2004), with the revised version containing 9 items. Items assess intrusiveness, disruptiveness and effects of seizures rated from 1 (never) to 4 (always). Other items measure time of disruption, seizure length and time until resuming normal activities. Higher scores on this scale reflect greater seizure severity.

The coefficient alpha reported for this final 9-item scale was 0.79 (Austin et al., 2004). Convergent validity for this measure has been demonstrated via the confirmation of hypothesised relationships between greater seizure severity and increased child and parent stigma perceptions (Austin et al., 2004).

Parent Stigma Scale (PSS) (Austin et al., 2004):

Items for the PSS were constructed from a literature review and unstructured interviews with parents of CWE and related to how parents perceive others might view their child because of epilepsy (Austin et al., 2004). The PSS is a 5-item scale that uses a 5-point Likert response rating ranging from 1 (strongly disagree) to 5 (strongly agree). To score this scale, the five items are summed and divided by the number of items. Higher scores reflect greater perceptions of stigma associated with their child having epilepsy.

This scale has shown good internal consistency with the coefficient alpha reported as 0.79 and 0.77 for chronic and new-onset samples respectively (Austin et al., 2004). Empirical support for a number of predicted relationships between stigma perceptions and key seizure, child and family variables provides evidence for the convergent validity of the scale (Austin et al., 2004).

Parent Response to Child Illness Scale (PRCI) (Austin et al., 2008):

The PRCI is a 35 item scale with a 5-point Likert response rating; ranging from 1=disagree= to 5=strongly agree. Factors measured include; Child Support (8 items), Family Life/Leisure (10 items), Condition Management (5 items), Child Autonomy (6 items) and Child Discipline (6 items). Higher scores on the Child Support subscale are indicative of greater parental provision of emotional support to the child in relation to his/her health condition. Higher scores on the Family Life/Leisure subscale are reflective of greater family participation in leisure activities. A higher score on the Condition Management subscale is indicative of higher levels of parental confidence in their ability to manage their child's health condition. Higher scores on the Child Autonomy subscale are reflective of more frequent parental encouragement of their child's independence. Finally, a higher score on the Child Discipline subscale is indicative of greater parental confidence in their competence in managing their child's behaviour.

This measure has shown reliability for a seizure sample with Cronbach's alpha coefficients of 0.67 (Child Support), 0.85 (Family Life\Leisure), 0.72 (Condition Management), 0.67 (Child

Autonomy) and 0.70 (Child Discipline) (Austin et al., 2008). Convergent validity was demonstrated for the subscales via the confirmation of predicted correlations between the subscales and scales measuring similar constructs (Austin et al., 2008).

Distress Disclosure Index (DDI) (Kahn and Hessling, 2001):

The DDI is a 12 item scale that measures an individual's tendency and willingness to disclose (versus conceal) personally distressing information to others across time and situations. This measure contains six positive and six negative items. Each of the items is scored on a Likert type scale from 1 (Strongly Disagree) to 5 (Strongly Agree). On this scale higher scores indicate a greater tendency to disclose personal experiences of distress to others and vice versa.

This 12-item scale demonstrated good reliability with the coefficient alpha found to range from 0.92 to 0.95 (Kahn & Hessling, 2001). Exploratory and confirmatory factor analyses of the scale confirmed the existence of one bipolar dimension with frequent concealment of distress represented at one end of the continuum and frequent disclosure of distress represented on the other (Kahn & Hessling, 2001). The DDI has been shown to possess adequate convergent validity (Kahn & Hessling, 2001) and strong predictive validity (Kahn, Lamb, Champion, Eberle & Schoen, 2002).

Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al., 1988):

The MSPSS is a 12-item scale that measures the perceived level of social support an individual experiences from three sources; namely: 1) Significant Other; 2) Family; and 3) Friends. Participants respond on a 7-point Likert rating scale ranging from 1 (Very Strongly Disagree) to 7 (Very Strongly Agree). Higher scores on this scale are indicative of greater perceived social support.

The coefficient alpha for the total scale is 0.85, with reported coefficient alphas for each of the subscales also demonstrating high internal consistency (Significant Other=0.91; Family=0.87; and Friends=0.85) (Zimet et al., 1988). The MSPSS has also shown good test-retest reliability (Zimet et al., 1998). Finally, construct validity has been established for the MSPSS via the confirmation of hypothesised negative correlations between perceived social support and anxiety and depression symptoms (Zimet et al., 1998).

Hague Restrictions in Childhood Epilepsy Scale (HARCES) (Carpay et al., 1997):

The HARCES is a 10 item scale that was developed to quantify parental perceptions of child disability as a result of restrictions imposed in order to reduce the risk of seizure-related injuries. The scale includes two items reflecting global restrictions (i.e. amount of supervision and extra precautions required) and eight items reflecting restrictions to specific activities of daily living (e.g. swimming, staying elsewhere overnight etc.). Items on the HARCES are rated on a 4-point Likert response scale ranging from 1 (most favourable) to 4 (least favourable). Thus, higher scores on this scale are indicative of greater perceived disability as a consequence of the imposed restrictions.

This scale has demonstrated high test-retest reliability after 14 days (r^2=0.93) and 1 year (r^2=0.75) and good internal consistency with a Cronbach's alpha coefficient of 0.89 (Carpay et al., 1997).

Impact of Pediatric Epilepsy on the Family Scale (IPES) (Camfield et al., 2001):

The IPES is an 11 item scale with a 4-point Likert response scale (ranging from 0-3) used to specifically measure the psychosocial impact of paediatric epilepsy on the family. In particular, the scale assesses parents' perceptions regarding the impact of epilepsy on: the child's academic achievement; the child's health; family participation in activities; their relationship with their spouse/partner; the child's relationships with parents, siblings and peers; the child's social activities; the child's self-esteem; and their hopes for their child's future. Higher scores on the IPES are reflective of parents perceiving the child's epilepsy as having a greater impact on the family.

The Cronbach's alpha coefficients reported for this 11 item scale ranged from 0.92- 0.94 indicating high internal consistency (Camfield et al., 2001). The IPES also demonstrated good test-retest reliability and has shown construct validity via the confirmation of a number of predicted correlations between the IPES and other measures based on theory (Camfield et al., 2001).

Parent Need for Information or Help: Subscale of the Parent Report of Psychosocial Care Scale (Austin et al., 1998):

This 14 item subscale of the Parent Report of Psychosocial Care Scale measures parents' need for information and support in relation to their child's condition. Six items relate to parents' need for information about their child's seizure condition, treatment, seizure causes, seizure management and injury prevention; six items relate to parents' need for epilepsy-related help and support (i.e. handling others' responses, their child's response to seizures and discussing concerns/fears); and two items require parents to report on their child's need for epilepsy-related help and support. Parents respond on a 3-point Likert scale ranging from 1 (no need for information/help) to 3 (strong need for information/help), i.e. higher scores are indicative of parents' unmet needs.

The subscales demonstrated high internal consistency with coefficient alpha for the Need for Information subscale reported as 0.92 at 3 months and 0.93 at 6 months, and coefficient alpha for the Need for Help subscale reported as 0.92 at 3 months and 0.94 at 6 months (Austin et al., 1998). Construct validity was demonstrated via the confirmation of a number of hypothesised correlations between the subscales and other measures based on theory, namely the Parent Stigma Scale and Parent Mood Scale (Austin et al., 1998).

Parent Information Received: Subscale of the Parent Report of Psychosocial Care Scale (Austin et al., 1998):

The Parent Information Received subscale of the Parent Report of Psychosocial Care Scale measures parental satisfaction with the level of information received during interactions with HCPs (in particular, doctors and nurses) in relation to their child's epilepsy. There are eight items to which parents initially respond on three-point Likert scales (ranging from 1= 'less than I wanted' to 3='more than I wanted'). For the purposes of analysis, responses are rescored to reflect binary responses so that a score of 1 denotes parental dissatisfaction with level of information received (i.e. 'less than I wanted' or 'more than I wanted') and a score of 2 reflects parental satisfaction with level of information received (i.e. 'just as much as I wanted'). Thus, lower scores on this subscale indicate that a dissatisfactory (inadequate or excessive) level of

information was received by parent during their interactions with HCPs, whilst higher scores on this subscale indicate that a satisfactory level of information was received by parents during their engagements with HCPs.

Austin et al. (1998) reported alpha coefficients for this subscale of 0.83 at 3 months and 0.84 at 6 months.

Appendix T: Phase Two: Capturing Information Related to CWE's and Parents' Disclosure Targets

In capturing information related to children's and parents' disclosure targets specifically, items were drawn from Henderson et al.'s Patient Profile Questionnaire (2002). Furthermore, where CWE were concerned, additional items in relation to disclosure targets were adapted and incorporated from Dyson et al.'s Questionnaire for Young People with Sickle Cell Disorder (2010). Details of the items adapted for use with CWE and parents in the present study are outlined below.

Patient Profile Questionnaire (PPQ; Henderson et al., 2002)

As part of a questionnaire to explore the disease disclosure patterns among breast cancer patients, Henderson et al. (2002) created the Patient Profile Questionnaire (PPQ). The first item on this seven-item questionnaire identifies to whom the patients have disclosed their illness following their diagnosis, asking participants to specify the degree to which they have talked to specific social targets about their illness. Responses are rated on a four-point Likert-type scale with scores ranging from 1 (not at all) to 4 (very much). This item pertaining to disclosure targets was adapted for use with a population of CWE and their parents and incorporated to collect descriptive information regarding the extent to which CWE and their parents spoke to particular individuals in their lives (or not) about the child's epilepsy. Disclosure targets additional to those included in Henderson et al.'s original version of this item (2002) were included for examination in the present study based on the disclosure targets identified by CWE and their parents in the qualitative phase of this study (e.g. teachers, other children or parents of children living with chronic illnesses etc.). Furthermore, the decision was made to also assess the extent to which CWE and their parents spoke to each other and other members of the nuclear family about the child's epilepsy with this item because, in phase one of the study, level of familial communication about epilepsy-related issues was identified as a factor that influenced disclosure decisions.

Questionnaire for Young People with Sickle Cell Disorder (Dyson et al., 2010)

As part of their questionnaire to explore the educational experiences of young people (aged 4-25 years) living with sickle cell disorder, Dyson et al. (2010) included some questions to examine disclosure patterns in relation to reported school experiences (e.g. as far as you are aware, which of the following children at school know that you have sickle cell disorder? Responses include - None, my best friend only, my few best friends, most of children in my class only, most of children in the school; and as far as you are aware, which of the following adults know that you have sickle cell disorder? Responses include – The head teacher, your head of year teacher, your class teachers overall, your P.E. teacher, the school nurse). Similar questions in relation to epilepsy were incorporated in the present study to establish in a very precise manner which children within a school context and which adults in their lives CWE perceived to be aware about their epilepsy diagnosis.

Appendix U: Phase Two: Developing the Epilepsy Disclosure Scale – Youth and Parent Versions

Stage 1: Item Development

One of the intended purposes of the present study was to develop psychometrically sound, valid and reliable scales that would appropriately capture child and parent epilepsy disclosure behaviours, as previously developed scales in this regard lacked sensitivity. In order to quantitatively assess the extent to which CWE and their parents tell and/or talk to others (or not) about the child's epilepsy, the Epilepsy Disclosure Scale (EDS) – youth and parent versions – were developed by adapting and amalgamating items from two pre-existing scales. The specific scales adapted for the measurement of child and parent epilepsy disclosure or concealment behaviours and incorporated into the new EDS – youth and parent versions - developed for the present study included the Disclosure Practices Questionnaire (Westbrook, Silver, Coupey & Shinnar, 1991) and the PPQ (Henderson, Davison, Pennebaker, Gatchel & Baum, 2002). Information regarding these scales, the specific items from these scales adapted for use with CWE and parents in the present study in order to assess child and parent epilepsy disclosure behaviours, and the scale development procedure is outlined below.

The Disclosure Practices Questionnaire (Westbrook et al., 1991; Westbrook, Bauman & Shinnar, 1992)

Based on a review of the literature on self-esteem, disclosure practices and stigma theory in adolescents with epilepsy, Westbrook et al. (1991) developed a set of four questions that were factor analysed for validity (1992) and aimed to examine the management of disclosure and concealment behaviours in adolescents with epilepsy. In particular, the questions: 1) address whether participants engage in concealment strategies surrounding their epilepsy; 2) assess the frequency of participants' disclosure of their epilepsy; 3) examine whether the participants' friends are aware of their epilepsy; and 4) investigate how others become aware of the participants' epilepsy condition. Respondents score the items on a four-point Likert-type scale ranging from 0-3 with higher scores indicative of a greater affinity towards concealment behaviours. For the present study, these four items were included to examine epilepsy disclosure amongst child participants. Additionally, as in the Ryu et al. (2015) study where this measure was adapted for use with mothers of adolescents with epilepsy to assess maternal concealment behaviours, for the purposes of this study, this measure was modified for use in parents to also examine parental epilepsy disclosure. Although Westbrook et al. (1992) identified that this measure had moderate inter-item correlations and acceptable internal consistency, they queried the measure's construct validity and suggested that it may lack the required sensitivity to capture the complexities of epilepsy disclosure and/or concealment decisions. Therefore, as this measure alone is not sufficiently sensitive in capturing CWE's and parents' epilepsy disclosure behaviours, items from the PPQ were also incorporated in the development of the youth and parent versions of the EDS.

Patient Profile Questionnaire (PPQ; Henderson et al., 2002)

As previously mentioned, the PPQ (Henderson et al., 2002) was developed to explore disease disclosure patterns among breast cancer patients. The first item on this seven-item questionnaire identifies who the patients have disclosed their illness to following their diagnosis (see Appendix T). The second item on this questionnaire asks how many individuals live within the home of the diagnosed individual. The final five items on this scale examine

other elements of disclosure and concealment behaviours such as participants' attitudes towards talking to others about their illness, their preferences with regard to concealment versus disclosure of their diagnosed illness and their engagements in written forms of disclosure. For the purpose of this study, with the exception of the second item which was excluded due to its irrelevance in addressing any of the research questions posited at the outset of the study, this questionnaire was modified for use in CWE (using child friendly language and instructions) and their parents to obtain a more comprehensive picture of their disclosure behaviours surrounding epilepsy, and to identify to whom children and their parents disclose the child's epilepsy diagnosis (previously discussed). For the purposes of the youth and parent versions of the EDS, only the five items that captured attitudes towards disclosure, preferences for concealment versus disclosure and engagements with written disclosure were incorporated. These items all required responses on a four-point Likert-type scale, with higher scores reflective of CWE's and parents' greater disposition towards concealment behaviours.

Stage 2: Piloting and Reviewing the newly developed EDS– Youth and Parent Versions:

Piloting the newly developed EDS – youth and parent versions – with six families (comprising CWE aged 7-14 years and one or both of their parents) allowed the research team to assess the construct validity of the newly developed scales, and to discuss and identify problematic items with CWE and parents themselves. On this basis and following discussions with all members of the research team about such items, three of the nine initial items on the scales were dropped from the EDS due to concerns that they either lacked construct validity (i.e. they did not seem to be successfully capturing epilepsy disclosure behaviours but rather other constructs such as coping strategies) or because they posed issues for CWE and/or their parents (e.g. they were being commonly misconstrued or were causing confusion).

Two of the items that were dropped from the EDS came from Henderson et al.'s PPQ (2002), while one item that was dropped was drawn from Westbrook et al.'s Disclosure Practices Questionnaire (1991). The item *"How much have you wanted someone to talk to about your experience with epilepsy/your child's epilepsy?"* (Henderson et al., 2002) was excluded on the basis that a number of children and parents (with whom the questionnaires were piloted) perceived this item as representing their desire and/or need to seek professional help surrounding the epilepsy and/or to speak specifically to a healthcare professional (e.g. a counsellor and/or therapist) about their/or their child's epilepsy as opposed to perceiving it in the more general sense of wishing to speak to any individuals external to the nuclear family about the epilepsy (as the researchers had originally intended for this item to connote). Similarly, an item pertaining to written disclosure (Henderson et al., 2002) was excluded from the final version of the EDS – youth and parent versions - due to the fact that during piloting the majority of children and parents spoke of how they wrote about epilepsy more so for their own personal use (or for medical purposes in instances where parents reported maintaining records of the child's seizures [e.g. seizure control journals]) rather than as a means of disclosure to those outside the immediate family unit. Finally, it was decided to omit the following item from Westbrook's Disclosure Practices Questionnaire (1991) from the final version of the EDS, *"When people find out you have epilepsy it is usually because…"* for two reasons. First, this item represented disclosure management strategies - which as identified in the qualitative phase of the study are highly variable, subject to considerable change throughout the duration of the child's illness and dependent on numerous factors inclusive of clinical characteristics of the child's condition – rather than disclosure behaviours specifically. Second, scoring this item posed difficulties as Westbrook et al. (1992) recommend scoring the disclosure management

strategy of 'indirect telling' highest (thereby suggesting that this disclosure management strategy is most reflective of concealment), followed by unplanned revelations and then voluntary telling. However, in both piloting the questionnaires and from analysis of the qualitative interview data, unplanned revelations emerged as being most indicative of concealment. Hence, the validity of this item in terms of accurately assessing disclosure versus concealment behaviours was called into question. Therefore, these three items were omitted from the final versions of the EDS – youth and parent versions- to ensure that all items on the scales accurately represented children's and parents' epilepsy disclosure behaviours. These items were however retained as individual items in the final versions of the questionnaires to capture valuable information on children's and parents' required supports, coping strategies and disclosure management strategies.

Stage 3: Psychometrically Evaluating the Newly Developed EDS - Youth and Parent Versions

Subsequent to piloting the newly developed scales with six families living with epilepsy, six item versions of the EDS – youth and parent versions – were retained. Items on the EDS specifically aim to capture information related to CWE's and parents' disclosure behaviours (i.e. the extent to which they tell and talk to others (or not) about the child's epilepsy). Items are rated on a 4-point Likert-type response scale, with scores ranging from 0-3. Higher scores reflect greater concealment of the child's epilepsy, whilst lower scores are indicative of more open disclosure behaviours surrounding the child's epilepsy. During the analysis phase of the study, the performance of these newly formulated six-item youth and parent versions of the EDS (i.e. the amalgamation of three items from Westbrook et al.'s Disclosure Practices Questionnaire [1991] and three items from Henderson et al.'s Patient Profile Questionnaire [2002]) were psychometrically evaluated. Factor analyses and reliability analyses were performed in SPSS 22.0 (IBM, 2013) on these final items included in the youth and parent versions of the EDS to explore the factor structure of the scales and to assess their internal consistency (see chapter 8).

Appendix V: Phase One: Feedback Provided to Parent Participants

"TALKING ABOUT EPILEPSY" RESEARCH STUDY: FEEDBACK FOR PARENTS

Between April 2013 and October 2013, two studies exploring how families talk about epilepsy both within and external to the family were conducted by a team of researchers in Dublin City University. These HRB/MRCG funded studies were conducted in collaboration with Temple Street Children's University Hospital and Epilepsy Ireland. In total, 34 families (i.e. - children and young people aged 6 - 16 years living with epilepsy and their parents) were interviewed. The following is a summary of the most relevant findings that emerged.

This study is Epilepsy Ireland/Health Research Board funded and was developed in collaboration with the Neurology Department of Temple Street Children's University Hospital and Epilepsy Ireland - The Irish Epilepsy Association.

WHAT WERE PARENTS' EXPERIENCES OF THE DIAGNOSIS PROCESS?

- The majority of parents found that receiving a diagnosis of epilepsy for their child was a lengthy and burdensome process. However, getting a definitive diagnosis was a relief to many.
- Parents' reported that the quality of communication with doctors varied. Some parents felt that their doctor was not direct with them with a number of parents reporting receiving insufficient information at the time of diagnosis. However, receiving adequate information and support improved parents' overall experience of their child's diagnosis.
- The importance of the doctor communicating directly with the child and taking an interest in them was highlighted by a number of families.
- A number of parents reported difficulties in accessing a neurologist; some even relayed experiences of showing extreme perseverance in order to access specialist services.
- Many families mentioned that the support of a clinical nurse specialist was crucial in their coming to terms with the diagnosis.

WHAT IS IT LIKE FOR PARENTS AND CHILDREN TO TALK ABOUT EPILEPSY WITHIN THE FAMILY?

- Families adopt a range of communication strategies around epilepsy. The extent to which epilepsy is spoken about within the family varies considerably. Many parents adopt an open policy when discussing epilepsy with their children. A number of families identified specific barriers in relation to speaking about epilepsy within the home. From parents' perspectives such barriers included not wanting to cause worry, not wanting child to dwell on epilepsy, parents feeling uninformed about their child's epilepsy, parental difficulty in answering epilepsy-related questions and unwillingness of the child to talk about epilepsy. From children and young people's perspectives, such barriers included not wanting to cause worry, not wanting to seem attention-seeking and minimizing perceived hyper-vigilance and activity restrictions.
- While there are many challenges to family communication, families mentioned a number of factors that enabled them to talk more freely about epilepsy including children feeling that their parents were informed about epilepsy, and parents creating an environment where talking about epilepsy was a part of normal life.
- The topics that parents and children discussed when talking about epilepsy were varied and often dependent on the child's age and the severity of their epilepsy. In many families, discussions circled upon seizure freedom and the likelihood of the child growing out of his/her epilepsy. A number of parents expressed that at times such discussions presented difficulty for them.

WHAT IS IT LIKE FOR CHILDREN/YOUNG PEOPLE AND THEIR PARENTS TO LIVE WITH EPILEPSY EVERY DAY?

- The ways in which families perceived epilepsy varied considerably. Several families compared their child's epilepsy to other conditions which they perceived to have a greater negative impact on the child, this facilitated coping and enabled them to view epilepsy as a manageable condition. In contrast, for some families, receiving a diagnosis of epilepsy was fraught with concern and deemed to have a greater negative impact in comparison to other ailments/illnesses.
- A large proportion of parents reported that they did not allow epilepsy to impact on activities that their child was involved in and strove to normalise the child's epilepsy. However, a number of children and young people were still aware of the restrictions imposed on them due to their epilepsy, in particular parental desire for supervision emerged as a salient issue. Similarly, many of the teenage participants expressed concern over restrictions that their peer groups may impose on them due to their epilepsy. Some of the main restrictions children and young people reported experiencing included restrictions in terms of sports, swimming, sleepovers, and discos. Furthermore, a number of the teenage participants expressed awareness of future restrictions they may face in relation to driving, drinking alcohol and career choices.
- When asked about living with epilepsy, a large proportion of participants (children/young people and parents) spoke about medication. For some of the families, the side-effects of medication presented an even greater challenge than seizures themselves. In addition, many children and young people expressed concern over the fact that taking medication resulted in visibility of their epilepsy to peers. A number of parents expressed concern over medication adherence, with some children/young people not taking medication due to either side-effects or worry that this would result in revelation of their epilepsy to others. Parents were fearful of how this would impact on their child's level of seizure control.
- Epilepsy affected a number of children and young people's education. Parents and children/young people reported that issues arose particularly due to fatigue, medication-associated difficulties with concentration and poor attendance. However, a number of parents strove to ensure that their child was keeping up with schoolwork by working with them at home. When disclosing the child's epilepsy diagnosis to the school, several families reported positive encounters. Positive reactions comprised mainly of teachers proactively learning about epilepsy and educating others (other teachers and students) about the condition.
- Unfortunately, a large proportion of families had much more negative experiences with schools. Families relayed that some teachers and principal teachers had no desire to educate themselves and/or others about the child's epilepsy; this issue poses a number of health and safety hazards. In addition, some schools imposed unnecessary restrictions on the child only further exacerbating feelings of differentness and promoting social exclusion.
- Another issue pertaining to schooling that emerged was that the transition from primary school to secondary school was a considerable source of stress for parents and presented a challenge for many families. In particular, state examination periods presented specific difficulties for a number of young people and parents.
- Some parents perceived support groups as particularly beneficial in coming to terms with their child's diagnosis of epilepsy. However, many parents expressed dismay at the lack of child-specific support groups available.

WHAT IS IT LIKE FOR PARENTS AND CHILDREN TO TELL OTHERS OUTSIDE THE IMMEDIATE FAMILY ABOUT THE CHILD'S EPILEPSY DIAGNOSIS?

- Parents and children/young people adopted a variety of strategies when communicating about the diagnosis of epilepsy to others, ranging from total concealment (i.e. - actively working to keep the diagnosis a secret) to full and open disclosure (i.e. - disclosing to anyone and everyone).
- Some parents and children/young people opted to disclose the child's epilepsy diagnosis for preventative reasons (i.e. - telling others in the hope of minimising epilepsy-related stigma and/or avoiding any anticipatory risk of detection).
- A number of families spoke about being selective about who they told and what aspects of the epilepsy they discussed with others.
- A number of specific challenges pertaining to telling others about the child's epilepsy diagnosis emerged for both parents and children/young people living with epilepsy. Notable reasons for parental concealment or selective disclosure around their child's epilepsy included: 1) seeking normalcy for the child; 2) the invisibility of epilepsy; 3) reactions to disclosure (anticipated and actual negative reactions); 4) public perceptions of epilepsy; 5) coming to terms with the diagnosis; and 6) parents' private dispositions.

- Specific challenges to epilepsy disclosure for children were: 1) the reactions of others (anticipated and actual negative reactions); 2) feelings of differentness; 3) the invisibility of epilepsy; 4) difficulty understanding and explaining epilepsy to others; 5) lack of ability by peers to understand epilepsy; 6) children's negative perceptions of epilepsy; 7) parental tendency towards privacy; and 8) others' perceptions of epilepsy.

- While many families expressed that there were challenges associated with telling others about the epilepsy, a number of families identified factors that enabled them to be open about epilepsy with others. For parents these factors included: 1) some seizure characteristics (e.g. nocturnal seizures and/or well controlled epilepsy); 2) getting used to disclosing the child's epilepsy; 3) positive previous reactions to disclosure; 4) positive parental perceptions about epilepsy; 5) identifying with others who have something that makes their child "different" too; 6) improving public perceptions about epilepsy; and 7) enhanced feelings of safety for the child.

- Factors that enabled children to tell others about their epilepsy included: 1) the child having positive perceptions about his/her epilepsy; 2) the child being proud of his/her knowledge about epilepsy; 3) parents normalising epilepsy; 4) children feeling informed about epilepsy; 5) positive reactions from others; 6) parents framing epilepsy positively; 7) identifying with others who have something that makes them "different" too; and 8) media coverage of epilepsy.

GOING FORWARD - WHAT NEEDS TO BE DONE?

We have gained a wealth of valuable information from our interviews with children/young people living with epilepsy and their parents, some of which could be used to inform the development of improved services for families living with epilepsy in the future.

- **Firstly, there is a need for greater accessibility to neurology services, a less drawn out diagnosis process, the provision of more comprehensive information and support at the time of diagnosis and more open communication channels between children/young people, their parents and doctors. A primary objective of the National Epilepsy Care Programme is to enhance the care of individuals with the condition through the provision of quality care to people with epilepsy by experts in epilepsy nursing. The benefits of epilepsy clinical nurse specialists have been reinforced by accounts provided by families in these studies.**

- **Secondly, a number of recommendations for schools in facilitating a safe and welcoming environment for children living with epilepsy can be made. These include teacher conscientiousness about the consequences of epilepsy on child learning and the education of all school staff about epilepsy and seizure first aid. In particular, emphasis needs to be placed on creating a school environment that is free of stigma, exclusion and over-restriction.**

- **Thirdly, while many parents perceived epilepsy support groups as extremely beneficial, a number remarked that there is a distinct need for child-specific support groups. However, parents conveyed that if such support groups were to exist they would be most effective if tailored in terms of child/young person age and seizure severity.**

- **Finally, a large proportion of interviewed families highlighted society's lack of understanding of epilepsy. Efforts should be made to further enhance public knowledge and awareness about epilepsy and to eliminate misconceptions about epilepsy, thus reducing epilepsy-related stigma. In doing so, epilepsy will be brought out of the shadows which in turn will create a platform for epilepsy to be spoken about more openly.**

We feel that the implentation of these recommendations could substantially improve the lives of families living with epilepsy in Ireland. In order to further investigate issues such as those highlighted in these findings, the researchers intend to look at these issues across a wider population of families living with epilepsy using questionnaires. The findings from these questionnaires will inform the development of interventions to improve the quality of life of children living with epilepsy and their parents.

We would like to take this opportunity to thank you for your participation in this study. The information you have provided has been invaluable and we really appreciate your input. If you have any further queries please do not hesitate to contact us.

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Appendix W: Phase Two: Reliability Analyses

Child Measures	Cronbach's α
Epilepsy Disclosure Scale (Youth Version)	
Total Scale (6 Items)	0.83
Child Stigma Scale	
Total Scale (8 Items)	0.92
Child Attitudes Towards Illness Scale	
Total Scale (13 Items)	0.86
Self-Perception Profile for Children Scale	
Scholastic Competence Subscale (6 Items)	0.93
Social Competence Subscale (6 Items)	0.87
Athletic Competence Subscale (6 Items)	0.92
Physical Appearance Subscale (6 Items)	0.92
Behavioral Conduct Subscale (6 Items)	0.84
Global Self-Worth Subscale (6 Items)	0.93
Total Scale (36 Items)	0.95
Health-Related Quality of Life measure for Children with Epilepsy	
Interpersonal/Social Consequences Subscale (5 Items)	0.89
Worries and Concerns Subscale (5 Items)	0.77
Intrapersonal/Emotional Issues Subscale (5 Items)	0.77
Epilepsy: My Secret Subscale (5 Items)	0.76
Quest for Normality Subscale (5 Items)	0.71
Total Scale (25 Items)	0.93
Social Support Scale for Children and Adolescents	
Parental Support Subscale (6 Items)	0.81
Classmate Support Subscale (6 Items)	0.81
Teacher Support Subscale (6 Items)	0.81
Close Friend Support Subscale (6 Items)	0.94
Total Scale (24 Items)	0.90
Child Need for Information and Support: Subscale of the Child Report of Psychosocial Care Scale	
Need for Information Subscale (6 Items)	0.76
Need for Support Subscale (6 Items)	0.83
Total Scale (12 Items)	0.83
Child Information Received: Subscale of the Child Report of Psychosocial Care Scale	
Total Scale (6 Items)	0.65

Parent Measures	Cronbach's α
Epilepsy Disclosure Scale (Parent Version)	
Total Scale (6 Items)	0.74
Parent Stigma Scale	
Total Scale (5 Items)	0.79
Parent Response to Child Illness Scale	
Child Support Subscale (8 Items)	0.68
Family Life/Leisure Subscale (10 Items)	0.86
Condition Management Subscale (6 Items)	0.54
Child Autonomy Subscale (6 Items)	0.64
Child Discipline Subscale (5 Items)	0.70
Total Scale (35 Items)	0.86
Distress Disclosure Index	
Total Scale (12 Items)	0.91
Multidimensional Scale of Perceived Social Support	
Significant Other Subscale (4 Items)	0.92
Family Subscale (4 Items)	0.92
Friends Subscale (4 Items)	0.95
Total Scale (12 Items)	0.94
Hague Restrictions in Childhood Epilepsy Scale	
Total Scale (10 Items)	0.91
Impact of Pediatric Epilepsy Scale	
Total Scale (11 Items)	0.91
Parent Need for Information and Support: Subscale of the Parent Report of Psychosocial Care Scale	
Need for Information Subscale (6 Items)	0.88
Need Support Subscale (8 Items)	0.89
Total Scale (14 Items)	0.91
Parent Information Received: Subscale of the Parent Report of Psychosocial Care Scale	
Total Scale (8 Items)	0.89
Seizure Severity Scale	
Total Scale (9 Items)	0.79

Appendix X: Phase Two: Testing Normality Assumptions in order to decide whether to Perform Parametric or Non-Parametric Analyses on Data

1. *Child-Reported Demographic and Clinical Data*

Demographic/Clinical Variables (Child-Reported)	Skewness Statistic	Normality Assumed	Analysis to be Performed
Child Age			
Years	-0.35	Yes	Pearson's Correlation
Primary versus Secondary School Aged	-0.60	Yes	Independent t-test
Child Gender	-0.13	Yes	Independent t-test
Child Seizure Type(s)/Activity			
Tonic-Clonic	-0.05	Yes	Independent t-test
Absence	0.73	Yes	Independent t-test
Simple Partial	-1.74	No	Mann Whitney U
Complex Partial	-1.23	No	Mann Whitney U
Myoclonic	-1.38	No	Mann Whitney U
Atonic	-4.58	No	Mann Whitney U
Tonic	-2.99	No	Mann Whitney U
Clonic	-2.56	No	Mann Whitney U
Child's Seizure Characteristics			
Multiple Seizure Types versus One Seizure Type	0.14	Yes	Independent t-test
Disruptive versus more Benign Seizure Types	0.52	Yes	Independent t-test
Seizure Frequency	-0.84	Yes	Pearson's Correlation
A History of having Seizures in the Presence of Others	1.89	No	Mann Whitney U
Experience of Medication Side Effects	0.70	Yes	Independent t-test
Age at Onset of the Epilepsy	-0.28	Yes	Pearson's Correlation
Time Since Diagnosis	0.85	Yes	Pearson's Correlation

2. *Parent-Reported Demographic and Clinical Data*

Demographic/Clinical Variables (Parent-Reported)	Skewness Statistic	Normality Assumed	Analysis to be Performed
Parent Age	-0.97	Yes	Pearson's Correlation
Parent Gender	3.05	No	Mann Whitney U
Parent Level of Education	0.53	Yes	Pearson's Correlation
Child Age			
Years	-0.22	Yes	Pearson's Correlation
Primary versus Secondary School Aged	-0.36	Yes	Independent t-test
Child Gender	0.09	Yes	Independent t-test
Child Seizure Type(s)/Activity			
Tonic-Clonic	0.29	Yes	Independent t-test
Absence	0.35	Yes	Independent t-test
Simple Partial	-1.37	No	Mann Whitney U
Complex Partial	-0.66	Yes	Independent t-test
Myoclonic	-1.37	No	Mann Whitney U
Atonic	-2.32	No	Mann Whitney U
Tonic	-2.13	No	Mann Whitney U
Clonic	-1.37	No	Mann Whitney U
Child's Seizure Characteristics			
Multiple Seizure Types versus One Seizure Type	0.61	Yes	Independent t-test
Disruptive versus more Benign Seizure Types	1.09	No	Mann Whitney U
Seizure Frequency	-0.88	Yes	Pearson's Correlation
A History of the Child having Seizures in the Presence of Others	1.58	No	Mann Whitney U
Child Experience of Medication Side Effects	1.01	No	Mann Whitney U
Family History of Epilepsy	0.13	Yes	Independent t-test
Child Age at Illness Onset	-0.12	Yes	Pearson's Correlation
Child Time Since Diagnosis	-1.14	No	Spearman's Correlation
Seizure Severity Scale	0.06	Yes	Pearson's Correlation

3. Child-Reported Disclosure, Psychosocial and Illness Attitude Data

Disclosure/Psychosocial/Illness Attitude Variables (Child-Reported)	Skewness Statistic	Normality Assumed	Analysis to be Performed
Epilepsy Disclosure Scale (Youth Version)	0.43	Yes	Pearson's Correlation
Child Stigma Scale	0.71	Yes	Pearson's Correlation
Child Attitudes Towards Illness Scale	-0.06	Yes	Pearson's Correlation
Self-Perception Profile for Children Scale			
Scholastic Competence	0.19	Yes	Pearson's Correlation
Social Competence	-0.49	Yes	Pearson's Correlation
Athletic Competence	-0.42	Yes	Pearson's Correlation
Physical Appearance	-0.39	Yes	Pearson's Correlation
Behavioral Conduct	-0.33	Yes	Pearson's Correlation
Global Self-Worth	-0.79	Yes	Pearson's Correlation
Total Scale Score	-0.48	Yes	Pearson's Correlation
Quality of Life Measure for Children with Epilepsy			
Interpersonal Social Consequences	-1.17	No	Spearman's Correlation
Worries and Concerns	0.05	Yes	Pearson's Correlation
Intrapersonal/Emotional Issues	-0.14	Yes	Pearson's Correlation
Epilepsy: My Secret	-0.16	Yes	Pearson's Correlation
Quest for Normality	-0.65	Yes	Pearson's Correlation
Total Scale Score	-0.31	Yes	Pearson's Correlation
Children and Adolescents' Perceived Social Support Scale			
Parental Support	-1.58	No	Spearman's Correlation
Classmate Support	-1.04	No	Spearman's Correlation
Teacher Support	-0.60	Yes	Pearson's Correlation
Close Friend Support	-1.71	No	Spearman's Correlation
Total Scale Score	-0.84	Yes	Pearson's Correlation
Level of Epilepsy-related Communication with Parents			
Level of Epilepsy-related Communication with Mother	-1.69	No	Spearman's Correlation
Level of Epilepsy-related Communication with Father	-1.21	No	Spearman's Correlation
Total Level of Epilepsy-related Communication with Parents	-1.23	No	Spearman's Correlation
Child Need for Information and Support Scale			
Need for Information	0.28	Yes	Pearson's Correlation
Need for Support	-0.66	Yes	Pearson's Correlation
Total Scale Score	-0.09	Yes	Pearson's Correlation
Child Satisfaction with Level of Epilepsy-related Information Received Scale	-0.67	Yes	Pearson's Correlation

4. *Parent-Reported Disclosure, Psychosocial and Illness Attitude Data (Full Sample)*

Disclosure/Psychosocial/Illness Attitude Variables (Parent-Reported)	Skewness Statistic	Normality Assumed	Analysis to be Performed
Epilepsy Disclosure Scale (Parent Version)	0.97	Yes	Pearson's Correlation
Parent Stigma Scale	0.32	Yes	Pearson's Correlation
Parent Response to Child Illness Scale			
Child Support	-0.15	Yes	Pearson's Correlation
Family Life and Leisure	-0.68	Yes	Pearson's Correlation
Condition Management	-0.31	Yes	Pearson's Correlation
Child Autonomy	-0.59	Yes	Pearson's Correlation
Child Discipline	-0.52	Yes	Pearson's Correlation
Total Scale Score	-0.20	Yes	Pearson's Correlation
Distress Disclosure Index	-0.45	Yes	Pearson's Correlation
Multidimensional Perceived Social Support Scale			
Significant Other	-0.89	Yes	Pearson's Correlation
Family	-1.20	No	Spearman's Correlation
Friends	-1.06	No	Spearman's Correlation
Total Scale Score	-0.85	Yes	Pearson's Correlation
Level of Epilepsy-related Communication with Child	-1.07	No	Spearman's Correlation
Hague Restrictions in Childhood Epilepsy Scale	0.82	Yes	Pearson's Correlation
Impact of Pediatric Epilepsy Scale	0.69	Yes	Pearson's Correlation
Parent Need for Information and Support Scale			
Need for Information	1.08	No	Spearman's Correlation
Need for Support	0.29	Yes	Pearson's Correlation
Total Scale Score	0.71	Yes	Pearson's Correlation
Parent Satisfaction with Level of Epilepsy-related Information Received Scale	-0.79	Yes	Pearson's Correlation

5. *Parent-Reported Disclosure, Psychosocial and Illness Attitude Data (Sample for whom Dyadic Data were Available)*

Disclosure/Psychosocial/Illness Attitude Variables (Parent-Reported)	Skewness Statistic	Normality Assumed	Analysis to be Performed
Epilepsy Disclosure Scale (Parent Version)	0.72	Yes	Pearson's Correlation
Parent Stigma Scale	0.63	Yes	Pearson's Correlation
Parent Response to Child Illness Scale			
Child Support	-0.33	Yes	Pearson's Correlation
Family Life and Leisure	-1.02	No	Spearman's Correlation
Condition Management	-0.70	Yes	Pearson's Correlation
Child Autonomy	-0.53	Yes	Pearson's Correlation
Child Discipline	-0.55	Yes	Pearson's Correlation
Total Scale Score	-0.31	Yes	Pearson's Correlation
Distress Disclosure Index	-0.45	Yes	Pearson's Correlation
Multidimensional Perceived Social Support Scale			
Significant Other	-0.87	Yes	Pearson's Correlation
Family	-1.10	No	Spearman's Correlation
Friends	-0.92	Yes	Pearson's Correlation
Total Scale Score	-0.98	Yes	Pearson's Correlation
Level of Epilepsy-related Communication with Child	-1.42	No	Spearman's Correlation
Hague Restrictions in Childhood Epilepsy Scale	1.03	No	Spearman's Correlation
Impact of Pediatric Epilepsy Scale	0.94	Yes	Pearson's Correlation
Parent Need for Information and Support Scale			
Need for Information	0.82	Yes	Pearson's Correlation
Need for Support	0.47	Yes	Pearson's Correlation
Total Scale Score	0.67	Yes	Pearson's Correlation
Parent Satisfaction with Level of Epilepsy-related Information Received Scale	-0.95	Yes	Pearson's Correlation
Seizure Severity Scale (Parent Reported)	0.32	Yes	Pearson's Correlation

Appendix Y.1: Phase Two: Child/Young Person Resource List

Child/Young Person Resource List

Thank you so much for taking part in our project! We really appreciate you filling in our questionnaire. If you want to contact us or to find out more about the study, please feel free to contact us by email, if you have your parents' permission:
talkingaboutepilepsy@gmail.com

In case any of the questions made you feel upset in any way, please talk to your parents or feel free to ring the following helplines or look at the following websites with your parents' permission.

- Epilepsy Ireland
  www.epilepsy.ie

  Tel: 01-4557500

- Reach Out
  www.reachout.com

- Headstrong

  www.headstrong.ie

Appendix Y.2: Phase Two: Parent Resource List

Parent Resource List

Many thanks again for participating in our research. Your time and contributions are really appreciated. If you wish to contact us or are interested in the findings of the study, please feel free to contact Stephanie on 01-7006867 or Ailbhe on 01-7007997. Alternatively, you can contact us by e-mail: **talkingaboutepilepsy@gmail.com**

In case any of the questions have adversely affected you in any way, please feel free to ring the following helplines or consult the following websites.

- Epilepsy Ireland
  www.epilepsy.ie

  Tel: 01-4557500

- Parent-line
  www.parentline.ie

  Tel: 1890927277

- Aware
  www.aware.ie

  Tel: 1890 303302

We have asked your child to talk to you in case any of the questions made him/her feel upset in any way. Additionally, below is a list of child-friendly resources that you can refer your child to if he/she needs any further support.

- Epilepsy Ireland
  www.epilepsy.ie

  Tel: 01-4557500

- Reach Out
  www.reachout.com

- Headstrong
  www.headstrong.ie

Appendix Z: Phase Two: Parents for whom Dyadic Data were available: Parent Demographics and Parent-Reported Demographic/Seizure Characteristics for their CWE (N=47)

Demographic/Seizure Characteristics	**N**	
Parent Gender		
Male	5	10.6%
Female	42	89.4%
Parent Age		
26-40 years	11	23.4%
41-55 years	35	74.5%
56 years or older	1	2.1%
Parent Ethnicity		
Caucasian/White Irish	47	100%
Geographic Location		
Living in Dublin	15	31.9%
Living outside Dublin[10]	29	61.7%
Unspecified	3	6.4%
Parent Level of Education		
Less than Junior Certificate	1	2.1%
Junior Certificate	5	10.6%
Leaving Certificate	11	23.4%
Higher Certificate	11	23.4%
Ordinary Bachelor Degree	4	8.5%
Honours Bachelor Degree	5	10.6%
Higher Diploma	5	10.6%
Master's Degree	3	6.4%
Doctoral Degree	1	2.1%
Unspecified	1	2.1%
Child Age		
Mean	47	13.19 years (*S.D.*=2.82)
Range	47	8-18 years
Primary School Aged (8-12 years)	17	36.2%
Secondary School Aged (13-18 years)	30	63.8%
Child Gender		
Male	22	46.8%
Female	25	53.2%
Child Age at Onset (Years)		
Mean	45	8.97 years (*S.D.*=3.68)
Range	45	0.67-16 years
Time Since Diagnosis (Years)		
Mean	45	4.25 years (*S.D.*=3.00)
Range	45	0-12 years
Child's Seizure Type(s)/Activity		
Tonic-Clonic	25	53.2%
Absence	30	63.8%
Simple Partial	10	21.3%
Complex Partial	15	31.9%
Myoclonic	11	23.4%
Atonic	3	6.4%
Tonic	7	14.9%
Clonic	11	23.4%
Electrical Status Epilepticus during Sleep (ESES)	1	2.1%

[10] Inclusive of the following counties in the Republic of Ireland: Carlow, Clare, Cork, Donegal, Galway, Kerry, Kildare, Laois, Limerick, Louth, Mayo, Meath, Sligo, Waterford, Westmeath.

Demographic/Seizure Characteristics	N	
One versus Multiple Seizure Types Experienced by Child		
One Seizure Type Only	16	34.0%
Multiple Seizure Types	30	63.8%
Visual Disruptiveness of Child's Seizure Types		
Disruptive Seizure Types	32	68.1%
More Benign Seizure Types	15	31.9%
Child's Seizure Frequency		
Daily Seizures (once a day or more)	5	10.6%
Frequent Seizures (several times a week)	2	4.3%
Weekly Seizures (about once a week)	3	6.4%
Monthly Seizures (about once a month)	1	2.1%
Occasional Seizures (less than monthly)	11	23.4%
Yearly Seizures (about once a year)	6	12.8%
Rare Seizures or Seizure Free (less than yearly/seizure free)	15	31.9%
Unspecified	4	8.5%
Seizure Severity Scale Scores		
Mean	36	16.33 (*S.D.*=5.18)
Range	36	9-26
Child's Seizure Visibility (Have had Seizures in the Presence of Others External to the Nuclear Family)		
Yes	42	89.4%
No	5	10.6%
A History of the Child Missing School due to Epilepsy		
Yes	31	66.0%
No	13	27.7%
Unspecified	3	6.4%
Child Receiving Treatment/Taking Medication at Time of Survey		
Yes	44	93.6%
No	3	6.4%
Type of Medication Therapy		
Monotherapy (1 AED only)	25	53.2%
Polytherapy (≥2 AEDS)	18	38.3%
Unspecified	1	2.1%
Child Experience of Medication Side Effects		
Yes	31	66.0%
No	13	27.7%
Unspecified	3	6.4%
Family History of Epilepsy		
Yes	14	29.8%
No	27	57.4%
Unsure	5	10.6%
Unspecified	1	2.1%

Research Dissemination

Publications

Benson, A., O'Toole, S., Lambert, V., Gallagher, P., Shahwan, A. & Austin, J.K. (2016). The stigma experiences and perceptions of families living with epilepsy: Implications for epilepsy-related communication within and external to the family unit. *Patient Education and Counseling*. Advance online publication. doi: 10.1016/j.pec.2016.06.009

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O'Toole, S., **Benson, A.,** Lambert, V., Gallagher, P., Shahwan, A., & Austin, J. K. (2015). Family communication in the context of pediatric epilepsy: A systematic review. *Epilepsy & Behavior*, *51*, 225-239.

Lambert, V., Gallagher, P., O'Toole, S., & **Benson, A.** (2014). Stigmatising feelings and disclosure apprehension among children with epilepsy. *Nursing Children and Young People*, *26*(6), 22-26.

Conference Proceedings

Benson, A., O'Toole, S., Lambert V., Gallagher P., Shahwan, A. & Austin, J.K. (2015). *The lived stigma experiences of families living with epilepsy: Implications for familial engagement in dialogue surrounding the condition.* International Conference on Communication in Healthcare (ICCH), New Orleans, U.S., October 25th-28th 2015 *(oral presentation)*.

O'Toole S., **Benson, A.,** Lambert V., Gallagher, P., Shahwan A. & Austin, J.K. (2015). *Feeling under-informed: Parental challenges when communicating about epilepsy*. International Conference on Communication in Healthcare (ICCH), New Orleans, U.S., October 25th-28th 2015 *(oral presentation)*.

Benson, A., O'Toole, S., Lambert, V., Gallagher, P., Shahwan, A. & Austin, J.K. (2015). *Concealable stigmatized identity revelations: Familial experiences of telling or not telling other about a child's epilepsy diagnosis*. 21st Qualitative Health Research (QHR) Conference, Toronto, Canada, October 19th-21st 2015 *(oral presentation)*.

Benson, A., O'Toole, S., Lambert, V., Gallagher, P., Shahwan, A. & Austin, J.K. (2015). *The stigma experiences of children living with epilepsy and their parents: A hidden condition.* 21st Qualitative Health Research (QHR) Conference, Toronto, Canada, October 19th-21st 2015 *(oral presentation).*

O'Toole, S., **Benson, A.,** Lambert, V., Gallagher, P., Shahwan, A. & Austin, J.K. (2015). *Familial interactions about epilepsy: The perspectives of children living with epilepsy and their parents.* 21st Qualitative Health Research (QHR) Conference, Toronto, Canada, October 19th-21st 2015 *(oral presentation).*

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<u>Media Coverage</u>

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