

DUBLIN CITY UNIVERSITY

MERGING THE PERSON AND THE ILLNESS

THE LIVED EXPERIENCE OF EMERGING ADULTS WITH CHILDHOOD ONSET CHRONIC ILLNESS

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DEDICATION

To Ellen and Ryan, anything can be achieved if you put your mind to it ~

Never give up

We shall not cease from exploration, and the end of all our exploring will be to arrive where we started and know the place for the first time.

T. S. Eliot

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SUMMARY OF CHAPTERS

Chapter one provides an overview of the study, the aims and objectives of the study and the rationale for choosing this study.

Chapter two examined the relevant literature related to the phenomena of both emerging adulthood and childhood chronic illness. The literature related to emerging adulthood, wellness and living with illness in the digital world are critically discussed. The burden of chronic illness, adherence and non-adherence to treatment and what it means to live with a chronic illness for emerging adults are explored. The findings indicate that the research in this area is predominantly based on an empirical psychological framework. Therefore, based on the findings of the literature review, the need for an alternative approach to explore the emerging adults' experience of childhood chronic illness is recommended.

Chapter three examines the study's underlying philosophical assumptions and methodological approach. The ontological and epistemological positions are outlined and discussed on how as a researcher I moved from the research question towards an interpretive inquiry. The challenges of how to navigate the terrain of the lived experience to access participants stories and the decision to employ van Manen's lifeworld existentials as a theoretical framework for this study are discussed.

Chapter four presents a detailed account of the methodological features employed in this study: an interpretive paradigm that employed hermeneutic phenomenology. The hermeneutical phenomenological approach employed was based on the philosophical perspective of Martin Heidegger and the more contemporary Max van Manen. In particular, van Manen's (1990) notion of lifeworld was used to explore the lived experience.

Chapter five describes the research process used to conduct this study. The recruitment strategy, ethical issues, and the study setting are presented. van Manen's (1990) method of analysis which informed the approach used in this study will also be briefly outlined. How the data were managed, methodological rigour and ethical issues are detailed.

Chapter six 'the journey of thinking' describes the technique used to analyse the data from the study. An overview of the methods applied in hermeneutic phenomenology research followed by my rationale for choosing van Manen's lifeworld approach is discussed.

Chapter seven ‘unending stories’ presents the findings in relation to the existing literature. The application of van Manen four lifeworld existentials offered a means to identify, describe and interpret the lived experience of emerging adults who have grown up with chronic illness. The themes that emerged in this study were embedded in the participants’ stories of growing up and living with a childhood chronic illness. While the meanings of the stories were often difficult to ascertain, van Manen’s process of analysis aided the process of understanding the experience of living with chronic illness. This doctoral thesis was guided by the research question ‘what is the lived experience of emerging adults growing up with childhood chronic illness?’

Chapter eight considers the implications of this study as a whole. I revisit the methodological approach hermeneutic phenomenology used in this study. I discuss the contribution of this thesis to our understanding of the lived experience of emerging adults with COCI. Study limitations and directions for further research development are presented. The findings and conclusions of this study are discussed throughout the chapter.

DEFINITIONS/TERMS

Chronic illness In this study the term ‘chronic illness’ refers to conditions that require ongoing monitoring and management to prevent or minimize mortality, morbidity and disability (Wedgewood 2008).

Emerging adulthood Arnett (2000, 2001) proposed the term “emerging adulthood” to describe the developmental period between the ages of 18 to 25 years which is characterised by frequent change and exploration in the areas of life such as work, living arrangements, interpersonal relationships, education, and worldviews.

The World Health Organization defines **adolescent** as the second phase of life from 10-20 years and defines a category of youth as 10-25 years (World Health Organization 1993).

“A child is any human being below the age of eighteen years, unless under the law applicable to the child, majority is attained earlier” Convention on the Rights of the Child”, United Nations (1989). However, the RCN Adolescent Health Forum 2004 suggests that all adolescents – including those with learning disabilities or special needs – should be supported to leave children’s services by the age of 18 or 19 (p.6).

ABSTRACT

Chronic illness is emerging as major health problem in the developing and developed world. The increased prevalence of childhood chronic conditions such as asthma and diabetes coupled with the successful management of childhood onset disease has altered the landscape of chronic illness among young people. The purpose of this study is to explore the lived experiences of emerging adults who have grown up and live with chronic illness since childhood. The health of emerging adults (18 to 25 years) has received far less attention in the literature compared to adolescence. Yet they seem to fare worse than adolescents in many areas including adherence to treatment and are more likely to have social, emotional and behavioural problems than their healthy counterparts. Despite being considered a separate developmental group in recent years, emerging adults tend to be grouped with adolescents and are often not studied as a separate group in the nursing and healthcare literature. The paucity of research on this particular developmental group living with chronic illness will hinder policy makers in the future planning of chronic illness care. Exploring the lived experience of this specific age group, emerging adults, from a qualitative philosophical and developmental perspective is critical because of the challenges young people face moving to adulthood with illness.

To explore the lived experience of this particular developmental group I needed to adopt an approach that allowed me to create an appropriate recruitment strategy and data collection tools with emerging adults. van Manen's hermeneutic phenomenological approach provided the methodology for studying of the lived experience of 15 emerging adults aged between 18 and 25 years living in Ireland who had a self-reported chronic illness since childhood. Drawing on the philosophy of van Manen's lifeworld existentials the lived experiences findings were revealed in eight emergent themes: *Transitioning to the adult world with illness*, *Living with unanswered questions*, *Visibility of chronic illness*, *Fitting in: the desire for normalcy*, *Developing a sense of self*, *Hopefulness*, *Sense of connectedness with peers* and *the overarching theme of Merging the person and the illness*. Emerging adults struggle to achieve a sense of identity which is often sabotaged by illness. The findings of this study conclude that a *Sense of connectedness with peers* can aid emerging adults' journeys towards developing their sense of identity.

CHAPTER 1: INTRODUCTION

Adjustment to one's illness during childhood sets the stage for later adjustment in adulthood
(Patterson 1988)

Chapter one begins with an overview this study followed by the aims and objectives and a summary of the chapters. van Manen (1990) contends that phenomenology has no standard set of rules for conducting an effective study. Researchers rely on the fundamental principles outlined in the phenomenological methodology coupled with an understanding of qualitative research practices and principles, and clear reasoning. A clear outline of decisions has been provided throughout the dissertation. The overview of the study is intended to provide justification for some research design decisions made in the course of the inquiry. The overall organisation of the dissertation is intended to move from broad and general terms to more and more specific and finer detail.

1.1 OVERVIEW OF THE STUDY

This thesis is set against the background of changes in contemporary Western societies and reflects both global healthcare trends in chronic illness and changing definitions of adulthood. Chronic illness causes significant morbidity and mortality, resulting in poorer quality of life for many people both globally and in Ireland. The World Health Organisation report (2007) prevalence rates of chronic illness among adolescents as high as 15% with over 90% of these young people now surviving into adulthood (Michaud, Suris and Viner 2007). Chronic illness is set to be the main cause of death by 2020 (Pai and Ostendorf 2011; Michaud, Suris & Viner 2007; Blum 1995). This places a considerable burden on both the population and health services and is set to rise with population growth and lifestyle risk factors by approximately 40% in 2020 (Institute of Public Health in Ireland 2010). Societal and policy changes over the last decade have led to an altered landscape of childhood chronic illness. Increased prevalence of childhood chronic conditions such as asthma and diabetes (Kepreotes *et al.* 2010; Perrin *et al.* 2007) coupled with the successful management of childhood chronic disease has meant that many young people with previous lethal diseases are now living with their illness successfully into adulthood. The management of chronic illness can be a major challenge for young adults as they enter a time of physiological changes accompanied by important individuation and socialisation processes. The purpose of this thesis is to explore

the experiences of young people living with childhood onset chronic illness as they transition to adulthood.

In undertaking this study I explored my own ideas and orientations towards the subject of childhood chronic illness. I was cognisant that for any understanding to emerge, self-reflection and self-understanding would aid the process of attempting to understand what influences my interpretations. Following a long career in paediatric nursing and the influence of having a chronic illness since childhood, asthma, I acknowledge and bring to the forefront my own pre-understandings and possible biases toward the experience of living with childhood chronic illness. Gadamer (1989, p. 277) argues that individuals prejudices make up the ‘historical reality’ of and individual far more than his judgments. Furthermore as a paediatric nurse I was interested not only child development but also in how in particular identity development unfolds for children as they move towards adulthood. The literature acknowledges that this is a critical developmental period for young people but also that it is shaped by historical and social circumstances (Schwartz *et al.* 2012). How growing up and transitioning this critical period to adulthood with a childhood chronic illness influences their lives needs to be explored? Just as developing a sense of identity has become increasingly important for young people, it may be more challenging to navigate with illness. This is their time to ready themselves to become individuals that expected to contribute to society by fulfilling adult roles including managing their chronic illness. As the researcher in this doctoral study, I sought to sensitize my current theoretical understandings of the developmental phase or emerging adulthood from which I could examine the literature and interrogate the data.

Since developmental psychologist Jeffrey Arnett’s landmark study in 2000 there has been increasing interest in the study of emerging adults as a separate developmental group. The theory of emerging adulthood identifies emerging adults aged 18 to 25 years Park *et al.* (2006) highlight two contextual influences that shape this period, delayed transition to adulthood with its responsibilities and weakening of the safety net normally present in childhood. Vulnerable populations such as those with illness can suffer from changes in support leaving them to navigate to adulthood healthcare with less supports (Osgood *et al.* 2005). Emerging adults seem to fare worse than other developmental groups in many areas

including poor illness management (Scal et al. 2008; Park 2005) and are more likely to have social, emotional and behavioural problems than their healthy counterparts (Pallindino *et al.* 2013; Maslow *et al.* 2011; Geddes *et al.* 2006; Huurre and Aro 2002).

There is a growing need to develop a model of care based on needs of young people moving into adulthood. Current adult-orientated models of care are not suitably translated to young people growing up with chronic illness. Changes in chronic illness strategies both in Ireland, Chronic Illness Framework 2008 and the UK Improving Health Together: A Policy for Chronic Illness 2011 have begun to incorporate the concept of “wellness” focusing on maximising the potential of the individual with chronic illness. Watson (2005, 2011) argues for research to be carried out on views of young people who have already transferred to the adult health service to better inform the transition process. Accurate information regarding the lived experiences of emerging adults with a childhood chronic illness and how they integrate it into their lives is clearly necessary to facilitate new models of chronic illness. Exploring the lived experience of this specific age group, emerging adults, from a qualitative philosophical perspective is critical because of the challenges both developmentally and emotionally young people face moving to adulthood with illness (Snelgrove 2012).

The overall aim of the thesis was to explore the lived experiences of emerging adults with childhood onset chronic illness and to advance the meanings participants offer towards the realms of practice. To find the lived experience I sought an approach that allowed me to create an appropriate recruitment strategy and data collection tools with emerging adults. van Manen's (2003) hermeneutic phenomenological research provides the methodology approach for the study. Emerging adults aged between 18 and 25 years living in Ireland who had a self-reported chronic illness since childhood needing regular care were invited to participate.

In designing this research study I was cognisant that the choice of methodology must compliment the aims of the research and fulfil personal aspirations and academic objectives. Given this, I chose to explore the lived experiences of emerging adults with childhood chronic illness from philosophical and developmental perspective. Thus a qualitative methodology was deemed appropriate for this study judging from the nature of the research

problem (living with childhood chronic illness) and the philosophical and theoretical orientations of phenomenology drawing on the philosophy of lifeworld as described by van Manen. As the researcher I wanted the phenomenon to unfold naturally with no predetermined strategy. Within an interpretive paradigm I sought to explore the lived experience of the participants. Hermeneutic phenomenology was employed to seek meaning from the lived experiences of participants in this study. Hermeneutic phenomenology is an ideal method for experiential work within an interpretive paradigm. The over-riding concern remained that the research design was both relevant to the research question and rigorous in its approach.

1.2 THE AIMS OF THE STUDY

The aim of this study is to explore the lived experience of emerging adults aged 18 to 25yrs living with a self-reported chronic illness since childhood in Ireland.

The study will address the following research question:

What is the lived experience of emerging adults growing up and living with a childhood chronic illness?

1.3 OBJECTIVES

1. To explore the lived experience of emerging adults growing up and living with a chronic illness since childhood.
3. To explore the meanings emerging adults offer of their experience living with chronic illness since childhood.

1.4 RATIONALE FOR THE STUDY

1.3.1 CHILDHOOD CHRONIC ILLNESS: THE CURRENT STATE OF AFFAIRS

The successful management of childhood onset disease has meant that many young people with previous lethal diseases are now living with their illness successfully into adulthood. This coupled with the increased prevalence of childhood chronic conditions such as asthma

and diabetes has altered the landscape of chronic illness among young people (Kepreotes *et al.* 2010; Perrin *et al.* 2007). While diseases of the early 20th century like polio and rheumatic fever have almost been eliminated there has been an increase in chronic conditions such as asthma and diabetes. For instance the growth of conditions like diabetes type 2 as a result of rising obesity levels among children is a major concern across Europe (Pomerleau, Knai and Nolte 2008). The WHO report (2007) prevalence rates of chronic illness among adolescents as high as 15% and over 90% of these young people will survive into adulthood (Pai and Ostendorf 2011; Blum 1995). It is estimated that there are 532,000 people aged between eighteen and twenty eight years living in Ireland which accounts for almost 12% of the current population (Central Statistics Office 2011). Figures have shown that 11.4% males and 12.1% females aged between 16 and 24 years have a reported chronic illness (Central Statistics Office 2010). The government responded with the publication of The Chronic Illness Framework 2008 as part of the Transformation Strategy (HSE 2008). The purpose of the framework is to minimise and manage the impact of chronic illness on individuals and the population. The framework specifically addresses those with a chronic illness stating “every effort must be made to ensure that they are facilitated to live their lives in a way that maximizes their health and social well-being in a supportive environment” (Health Services Executive 2008, p.6). However with the success of health care in extending the lives of young people with chronic illness come the challenges associated with this developmental period. More recently in Ireland the Health Service Executive (HSE) recognised the trends in health care problems that are emerging in modern society publishing *Healthy Ireland: A framework for improved health and wellbeing 2013 – 2025*. This publication acknowledges that an alternative approach is need to tackle the significant challenges we face otherwise we will face an unhealthy and costly future. The goal of Healthy Ireland, is to bring together organisations such as Government Departments, public bodies, businesses, employers, sports and voluntary groups, communities and families to create coherent health care policy that promotes health and wellbeing.

1.3.2 CHILDHOOD CHRONIC ILLNESS AND DEVELOPMENTAL CHALLENGES

For some young people there is a struggle to achieve their authentic identity which can be sabotaged by external forces like illness. Young adults with chronic illness are often concurrently transitioning to emerging adulthood (18 to 25 years) (Arnett 2006) and their

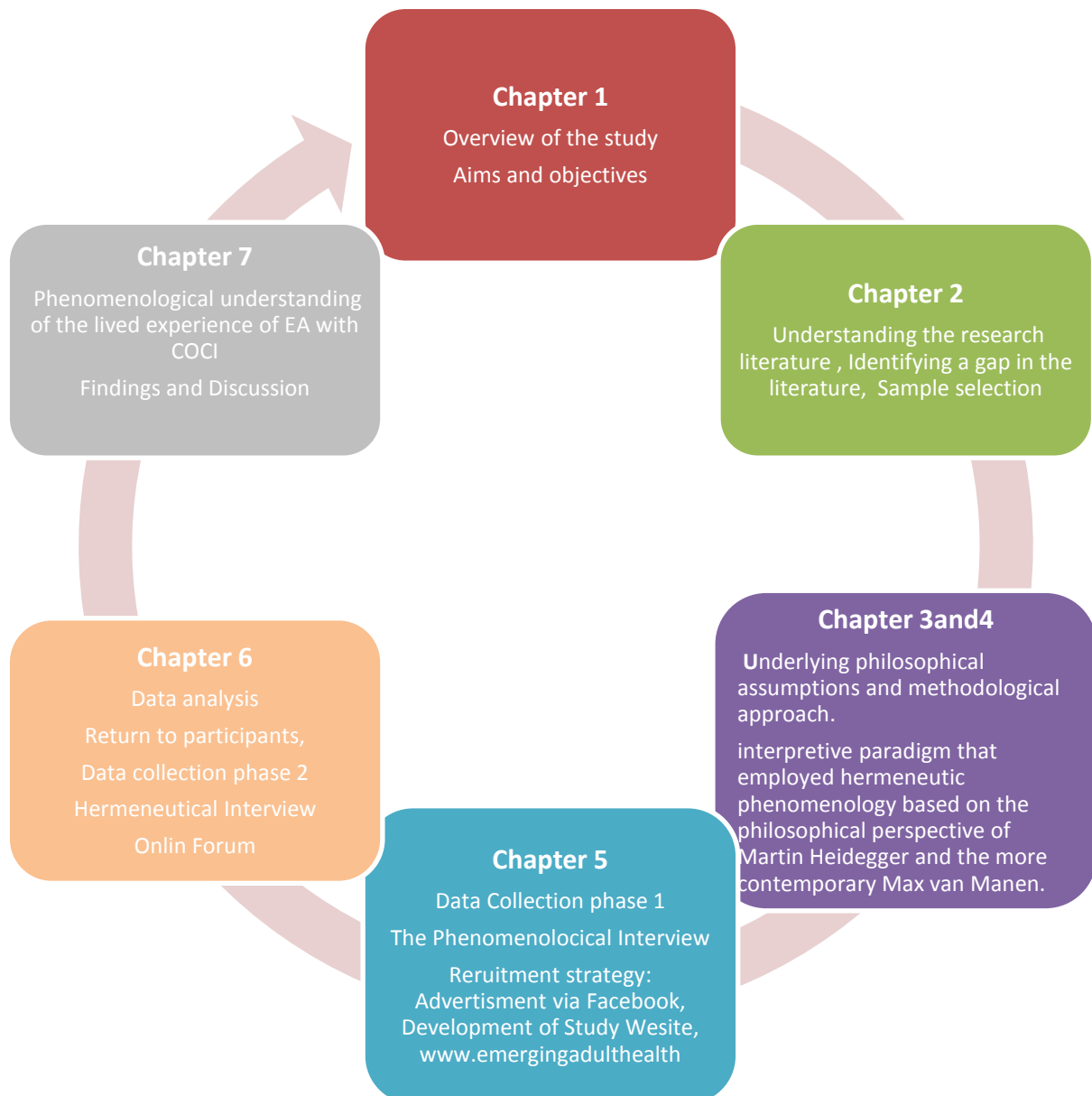
transfer to adult health services. The young adult period often falls outside of both child and adult health care. A body of research on aspects of living with chronic illness has accumulated from a range of disciplines in young people. In recent years longitudinal studies examining the outcomes of young people with chronic illness (Pallindino *et al.* 2013; Maslow *et al.* 2011; Huurre and Aro 2002) have reported significant challenges both socially and psychologically with this group. Issues such as low self-esteem, depression, reduced life satisfaction and increased risk of poorer educational and vocational outcomes are evident in these studies. In addition both emerging adults with chronic illness and without appear to engage in similar risky behaviours.

Arnett (2004) argues that emerging adulthood is a critical phase in an individual's development as they explore personal and professional avenues to which they will commit in later in adult life. In recent years a limited number of studies have emerged exploring the experiences of emerging adults in healthcare particularly in relation to diabetic care (Palladino *et al.* 2013; Peters and Laffel 2011; Luyckx *et al.* 2008). The focus of much of the research on this population with chronic illness has been the ability to successfully manage the transition from the child setting to adult services and adherence or non-adherence to treatment. Few studies have focused explicitly on what it means for emerging adults living with childhood chronic illness and their experience of growing up with a chronic illness (Christian and Auria 1997; Eiser 1993).

It is essential that we understand the commonalities and diversities of emerging adulthood as one phenomenon and chronic illness as another and how they interact at different stages in the young adult's biography. Social scientists have professed for some time now that there is a prolonged transition to adulthood compared to a half a century ago (Arnett 2004; Mortimer and Shanahan 2003). This has left young adults in a 'demographic limbo' (Furstenberg 2006) Over the past decade studies have identified adolescence as a period of high risk behaviour (Modi *et al.* 2008; Peveler *et al.* 2005; Bryden *et al.* 2003) whereas compared to emerging adulthood is not. Entering adulthood is a time where young people develop more autonomy and responsibility for managing their illness. However this period is often fraught with adjustment and coping difficulties (Annunziato *et al.* 2011; Scal *et al.* 2008). It is often a time that they develop the skills and behaviours managing of their illness that they will need for

the future. Several studies highlight deficiencies in the care of young adults with chronic illness (Suris *et al.* 2009; Scal *et al.* 2008; Wedgewood 2007; Hogan *et al.* 2006). Suris *et al.* (2009) argues for a developmentally appropriate, knowledgeable coordinated care for young adults to prevent long term sequelae of their disease process. The paucity of research with this particular age group they argue will hinder policy makers in the future planning for chronic illness care. The views and experiences of young adults who have grown up with a childhood chronic illness and had contact with the health services and healthcare professionals can assist service providers to shape services for young people with chronic illness and in the longer term to help improve the quality of their lives from a developmental stance. A significant gap exists in the comprehensive body of research on emerging adults with chronic illness that is present in the adult and paediatric literature. Exploring this specific age group, emerging adults, from a qualitative perspective is critical because of the challenges both developmentally and emotionally young people face emerging into adulthood (Snelgrove 2012). This introductory chapter concludes with Figure 1.0 which illustrates the structure used to present the thesis in the proceeding chapters.

Figure 1.0 Thesis map



CHAPTER TWO: LITERATURE REVIEW

It is human to have a long childhood; it is civilized to have an even longer childhood.

Erik Erikson (1902-1994)

This chapter follows on from chapter one which provided an overview of the study that included the rationale for the study and the aims and objectives of the topic under investigation. In this chapter, I initially review the foundational work in emerging adulthood drawing on work from Jeffrey Arnett (2000, 2004, 2006) and others (Schwartz *et al.* 2009, 2013; Luyckx *et al.* 2011; Tanner 2006). Emerging adulthood is proposed as a new theory of development that focuses on a distinct period from late teens to middle or late twenties (Arnett 2000). The aim of this review is to present a theoretical overview of Arnett's theory of emerging adulthood and critical analysis of relevant literature in relation emerging adulthood and childhood chronic illness. The aim was to sensitize my current theoretical understandings of this developmental phase, examine the relevant literature and interrogate the review findings. This chapter goes on to present a critical review specifically examining the literature in relation to childhood onset chronic illness (COCI) from an Irish and International perspective. I critique the literature in relation to the study of chronic illness as a separate entity and the recent policy move towards living well with illness. In this study the term 'chronic illness' refers to conditions that require on-going monitoring and management to prevent or minimize mortality, morbidity and disability (Wedgewood 2008). Since the theory emerging adulthood is a relatively new concept and the age range can vary greatly for the term adolescence, studies were explored using the term 'young people' and 'adolescents'. Only a few chronic illness studies were found that specifically address the term 'emerging adulthood' (Palladino *et al.* 2013; Snelgrove 2012; Reiss 2012; Peters and Laffel 2011). However a number of studies use the term young adults and adolescents that identify the age range of Arnett's Emerging Adulthood (18 to 25 years) and are discussed within this review. Table 2.0 identifies a range of longitudinal studies that address this age group with chronic illness. This review indicates that the research in this area is predominantly based on an empirical psychological framework. Therefore, based on the findings of the literature review, the need for an alternative approach to explore the emerging adults lived experience of childhood chronic illness is recommended.

2.1 THE APPROACH OF THE LITERATURE REVIEW

The literature was reviewed intermittently throughout the full course of this study using electronic databases, such as CINAHL, MEDLINE, Blackwell Synergy, SwetsWise, SpringerLink, PsychINFO, PsycARTICLES, Science Direct, BMJ Journals, SAGE journals, and Web of Science. A search of the literature was performed using the terms ‘chronic illness’ AND ‘childhood’ AND ‘emerging adulthood’ OR ‘young people’. Only articles in the English language were accessed. A search of the Cochrane Library’s Reviews of relevant areas was also conducted. In addition, manual searching of relevant textbooks, journals, and “grey literature” was performed. Key nursing Professional Doctoral theses and PhD theses were studied, which specifically focused on various aspects of the experience of childhood chronic illness. Government policy and publications were sourced from UK and Ireland from both statutory and voluntary organizations related to chronic illness and social media. The search was limited to papers published in English between 1990 and 2014. Reference works software was used to collate, summarise, categorise, store and retrieve the output from the searches described above. A matrix of published articles was developed under the headings: childhood chronic illness, emerging adulthood, young peoples’ experiences chronic illness, psychosocial outcomes living with childhood chronic illness, adherence and non-adherence to treatment in young people.

2.2 INTRODUCTION

The profound nature of changes to young adult’s lives over the last 50 years in the developed world has led to the development of a Theory of Emerging Adulthood. Arnett’s landmark study of 300 young adults in the United States in 2000 led to the recognition of this separate developmental group, emerging adulthood. Since then there has been increasing interest in the study of this group. However the term ‘emerging adulthood’ is still only recognised within academia. Prolonged or delayed transition to adulthood are features of this period of development. The theory of emerging adulthood is not without controversy. In a recent article Côté (2014) argues that the variations during this period can be attributed to other more convincing notions. Others argue that Arnetts’ formulations could limit enquiry (Dulmen 2013). However Arnett *et al.* (2011) contend that experiences of emerging adults vary according to context such as social and historical background that there may not be one but

many different emerging adulthoods. This enquiry will support and describe this variation by exploring emerging adults living with childhood onset chronic illness. Emerging adults living with chronic illness are a unique group that require attention. This theory provides a framework for investigating, describing and analysing these changes (Arnett 2006) particularly with those that live with illness. The exact age range varies in the developmental literature however Arnett labelled the period 18 to 25 years as “emerging adulthood”.

2. 3 THEORY OF EMERGING ADULTHOOD

Over the last century developmental theorists have argued when early adulthood actually begins. Traditional developmental theorist Erikson (1950, 1968) identified the period immediately after adolescence as young adulthood. However more recently contemporary developmental theorists have contended that adulthood does not follow adolescence (Arnett 2000). Instead Arnett proposed that adulthood starts in the late twenties, early thirties (2000). Arnett (2000, 2004, 2006) was the first to label the period 18 to 25 years as ‘emerging adulthood’ within industrialised countries. Emerging adulthood, not to be confused with adolescence is considered a transitional period, and it should be studied as a separate period of life. Arnett based his theory of emerging adulthood on interviews and demographic information with young adults carried out over several years in the United States (US) and revealed a period of time where emerging adults explore issues such as identity, relationships, values and beliefs. Both Erikson and Arnett’s theories must be viewed in the context of time and space in which they were developed. Erikson developed and refined his theory of psychosocial development in the 1950’s and 1960’s against a background of individuals of that time. Although he did address the phenomenon of “prolonged adolescence” Erikson addressed it mainly in relation to what happened before in adolescence and after in adulthood (Erikson 1968). Arnett’s theory however focused on the importance of emerging adulthood and what happens in this period.

Figure 2.0 Arnett describes five main features of this period

1. It is the age of identity explorations, of trying out various possibilities,
 2. It is the age of instability.
 3. It is the most self-focused age of life.
 4. It is the age of feeling in-between, in transition, neither adolescent nor adult.
 5. It is the age of possibilities when people have an opportunity to transform their lives.
- (Arnett 2000)

2.4 AGE OF IDENTITY EXPLORATION

Erikson (1950, 1968) proposed in his life-span theory that each period of the life course has a central challenge and that in adolescence it was an identity crisis. Erikson described the age of identity exploration occurring in adolescent period where adolescents focus on forming an identity, especially with respect to love and work (Erikson 1968). However this may have been correct in the 1950s when young people tended to live at home with their parents until their late teens and early twenties when they married. Since then vast social changes have occurred in the Industrialised world that have altered the shape of families within society today. In the US the median age for marriage in the 1960s was 20.3 for women and 22.8 for men by the year 2000 this had risen to 25 years for women and 27 years for men (Arnett 2006). Delayed marriage is only one indicator of social change, uptake in university education for this age group markedly increased in tandem with this change¹. In Ireland a period of great social change occurred, although somewhat later beginning in the 1970s with young people marrying later and a sharp rise in the uptake of third level education (Department of Education and Skills 2010). Thus reinforcing the suggestion that life expectations and lifestyles have changed.

In the late 1980s, both psychologists and sociologists began to observe that the transition between adolescence and young adulthood had altered and challenged Erikson's life span theory. Susan Littwin, author of *The Postponed Generation: Why American Youth Are*

¹ The average age at which women marry increased from 24.7 years in 1980 to 31 years in 2005 (Central Statistics Office 2007) and a sharp rise in participation in 3rd level education among this age group which has grown from 20% in 1980 to 55% in 2004 and is currently estimated to be over 65% in Ireland.

Growing Up Later, argued that young people were taking longer to adopt adult responsibilities than previous generations. This thinking led to Arnett's study (2000, 2004, 2006, 2011) and the re classification of the third decade of life, a new developmental stage from age 18 to the mid or late 20s, now known as emerging adulthood. This transitional phase of development bridges adolescence period and adulthood. He argues that it is no longer acceptable to group this population with adults as they are unlikely to be married or have children or be in full time employment (Tanner, Arnett and Leis 2009). Equally this period is not just an extension of adolescence as emerging adults will have more freedom from parental rules and more independent decision making. Emerging adults advanced cognitive ability allows for their consideration of future "possible identities" that they hope to achieve or not achieve (Oyserman and James 2011). Erikson (1950, 1968) contended that each stage of development is characterised by a task that had to be achieved in order to move successfully on to the next stage. For instance he claims that the task of the adolescent is to find their identity, as an individual, separate from their family and a member of the wider society. Arnett (2000) however contends that the age of identity exploration happens later in emerging adulthood, when the emerging adult considers various possibilities, particularly in regard to relationships and work. While identity exploration may begin in adolescence the greater part of it now takes place in emerging adulthood (Luyckx *et al.* 2008).

Identity is often considered an ambiguous term with diverse assumptions about what identity is (Buckingham 2008). Derived from the Latin root *idem*, meaning "the same" (Oxford English Dictionary. OED 3rd Edition, November 2010) the term infers both similarity and difference. Much of the debate around identity derives from the tensions between these. While an individual is a product of their unique personal biography on one level this varies for a number of reasons and motivations according to the situation or context the individual find themselves in. Nonetheless individuals also seek multiple identifications with others, on the basis of their social, cultural, and biological characteristics. In seeking the lived experience of emerging adults with COCI this study employed a developmental approach which explores how young people develop their sense of identity as they move toward adulthood.

Some young people may struggle with this stage of identifying their social roles in society and learning to master life successfully. Being allowed to make decisions and learning from wrong decisions is an important part of the process of identity development. This may be a struggle to achieve over time for emerging adults particularly when they face barriers like illness. Emerging adults with COCI may struggle with achieving their sense of identity which may be sabotaged by their illness. Emerging adults who fail to create their own true identity can become confused about their role in the world. In Goffman's (1959) influential work on identity in the *Presentation of Self in Everyday Life* he describes the renowned 'front stage' and 'back stage' dichotomy where he likens the interactions in everyday life to theatre with actors playing a variety of roles. In the front stage we often present our idealised self to others whereas the back stage is where the "impression fostered by the performance is knowingly contraindicated as a matter of course" (Goffman 1959, p.112). The back stage is where the work takes place so that we can present our idealised self (Hogan 2010). This process is evolving for emerging adults who are focusing on forming an identity, especially with respect to relationships and work (Erikson 1968). Identity exploration is an important developmental stage for emerging adults with illness who may be learning to take over the management of their illness from parental control.

2.4.1 IDENTITY DEVELOPMENT IN EMERGING ADULTHOOD

Weissberg-Benchell, Wolpert and Anderson (2007) contend that developing a strong sense of identity can influence chronic illness management and outcomes by promoting resilience. If this is true then health research needs to consider identity development in emerging adults with illness. Based on the work of Erikson (1968), Luyckx et al (2008) identified five interrelated dimensions to identity development in emerging adulthood.

Exploration in breadth - signifies the degree to which young people explore their options and alternatives before making decisions (e.g. considering different degrees by reading university prospectus before making a selection).

Commitment making - signifies the degree to which young people make decisions about identity-relevant issues.

Exploration in depth - involves in-depth exploration of any decision making to examine its suitability or 'fit' with self (e.g. discussing college options with friends and family).

Identification with commitment - signifies the degree to which young people identify and commit to the decision they have made.

Ruminative exploration - signifies the degree to which young people can struggle with moving beyond the exploration phase to decision making due to issue that include an overload of choices.

While it is acknowledged that not all young people will complete each of these phases in a succinct manner (Erikson 1968), those living with chronic illness may be impeded by illness-specific demands. Making college choices, work and life decision making may be restricted by their illness and interfere with their choices and possibilities. Seiffge-Krenke (2001) found that the management of diabetes was a major concern for adolescents that it impeded exploration of identity alternatives. While a growing number of studies over the last decade exploring emerging adults from psychology (Luyckx 2011; Schwartz 2011; Tanner *et al.* 2009; Arnett 2000, 2004, 2006) have acknowledged identity exploration and formation during this period, healthcare research for this population is scant. Few studies have investigated the experiences of emerging adults with chronic illness (Snelgrove 2012; Hilton *et al.* 2009; Luyckx *et al.* 2008; Taylor 2008; Seiffge-Krenke 2001) and only in recent years have linked identity development and adjustment in emerging adults with a chronic illness (Luyckx *et al.* 2008).

However much debate has emerged in recent years examining whether developing a sense of identity can lead to positive emotional and psychological development. While Schwartz, Klimstra *et al.* (2011) argue that identity precedes emotional adjustment, Luyckx (2008, 2011) suggests the association is mutual. Luyckx *et al.* (2008) examined whether identity development was affected in emerging adults with Type 1 Diabetes and argued that clinicians need to consider identity development in emerging adults with diabetes. This they argued was because harnessing identity development could help as a resource in coping with and adjusting to diabetes. Schwartz *et al.* (2013) concurs with this arguing that the study of identity in its various forms to identify specific constructs can be used to promote well-being

and wellness in emerging adults and facilitate a successful transition to adulthood. Seminal literature suggests that adults with chronic illness may experience disruptions to their sense of self (e.g. Charmaz 1983, 1995; Bury 1982). However young adults with chronic illness are only emerging into adulthood and have to contend with the developmental issues and coping with their disease management. Seth Schwartz has written extensively on identity in emerging adulthood, he contends that future research should explore meanings and understandings for emerging adults with chronic illness because of the link with adapting to illness (Schwartz *et al.* 2013; Stanton, Revenson and Tennen 2007).

2.5 AGE OF SELF-FOCUS

In her 1986 textbook *The Postponed Generation: Why American Youth Are Growing Up Later*, Littwin considered this age self-focus age to be a developmental problem where young people often displayed a narcissistic sense of entitlement. However Arnett (2000, 2004) contends that while emerging adulthood is the most self-focused age it is a feature of the development process and is temporal in nature. It is often a time of life where there is least structure, and young people are bound by less restrictions or obligations to others. It is also a time of independent decision making and taking responsibility about their daily lives. While adolescents may be considered more egocentric than other stages of development emerging adults are focused on pursuing issues of self-interest like their education, careers and relationships. In the words of Arnett, “they ponder these concepts and think, yes, but not yet.” However difficulties can arise if there is discrepancy between expectations of the young person during this period and reality. While young adults may be involved in more independent decision making during this stage it is an emerging skill and often requires opportunities for applying new knowledge, practicing decision making skills and learning from mistakes (Reiss 2012). While there are increasing numbers of emerging adults with chronic illness transitioning to adult services, the paediatric community has been slow to introduce developmentally sensitive transition programmes. The US report that less than 15% of paediatric practices offer transition education material to adolescents moving to the adult service (McManus *et al.* 2008). A developmental approach was developed by the American Academy of Paediatrics (AAP) which includes an eight step transition process and has a focus on social and emotional functioning of the young person. Reiss (2012) urges that both health professionals and parents, guide emerging adults with chronic illness towards self-

efficacy and the final step of individuation, and independence. A developmental approach fundamentally includes listening to the views of emerging adults who have grown up with illness and already transitioned to adult services.

2.6 AGE OF INSTABILITY

Arnett (2000, 2004) study of emerging adulthood highlights issues such as their desire for independence, yet also a fear of independence. Previously Erikson (1968) identified the risk of isolation that can peak during this young adult period just after adolescence. Young adults are coping with their freedom from parental supervision which also brings concerns that can be quite daunting. Young adults may be transitioning geographically, economically, and emotionally away from the parental home and experiencing less structure in their daily routine. This can add to the burden of having a chronic illness and how they incorporate into their life context. Risk behaviour has been well documented in adolescence and in recent years, in emerging adulthood (Zimmermann and Sieverding 2010; Schwartz 2010, 2009; Arnett 1992). In Swedish studies comparing the quality of life in adolescents and young adults with epilepsy, the young adults experienced lower self-esteem, internalized more and had poorer sense of coherence compared to the adolescent group (Gauffin, Landtblom and Råty 2010; Råty 2003). Issues such as binge drinking, unprotected sex and impaired driving have tended to be most prevalent in emerging adulthood (Arnett 2005; Schwartz 2009). Furthermore studies suggest that young people with chronic illness are more likely to have social, emotional and behavioural problems than their healthy counterparts (Pallindino *et al.* 2013; Maslow *et al.* 2011; Geddes *et al.* 2006; Huurre and Aro 2002).

Young people with asthma have been shown to display higher levels of anxiety and stress and a lower self-reported quality of life than their matched healthy controls (Chen *et al.* 2007; Gillaspie *et al.* 2002). Early studies on the psychosocial adjustment of young adults with renal disease, highlighted lower educational performance and higher levels of unemployment (Reynolds *et al.* 1993) which could be possible reasons for increased anxiety levels. McDonogh *et al.* (2005) postulates that this may be due to lower expectations by parents and educators. Common experiences for children with chronic illness include school absenteeism, restricted participation in sport and social occasions with their friends (Gannoni and Shute

2009). Even more alarming is the evidence that suggests children with chronic illness are at greater risk of serious health abuse including substance abuse (Gillaspy *et al.* 2002).

Further research is warranted to explore this understudied area and how childhood chronic illness can affect issues like educational performance and its consequences, relationship building and intimacy for this group. Using data from a US National Longitudinal Study of Adolescent Health Maslow *et al.* (2011) report on social, education and vocational outcomes in young adults growing up with childhood chronic illness. They found that young adults aged 24 to 32 years succeed socially but are at risk of poor educational and vocational outcomes. Early research concerned with the psychosocial impact of chronic illness in young people appears to take this 'deficit centred' approach (Drotar 1981), assuming that the child would inevitably show emotional and behavioural deficits. However current theoretical approaches emphasise a more multi-dimensional response to chronic illness as opposed to a simple cause-effect model which may be inadequate in describing the range of outcomes for young people.

2.7 AGE OF FEELING IN-BETWEEN

Arnett describes an age of feeling in-between, in transition, neither adolescent nor adult. A number of surveys in the US (Arnett 2001, 2004, 2007) and other developed countries (Mayseless and Scharf 2003) examined what it means to be an adult and found evidence of this feeling of in-betweenness. Young adults were asked if they felt they had reached adulthood and did not reply with a yes or no but rather 'in some ways yes, in some ways no' answer (Arnett 2001). In addition Tanner and Lynn (2006, 2009) contend that those who attend third level education may retain a sense of in-betweenness as they have more responsibility than they did as adolescents but not as much as they will as adults. In addition those emerging adults with chronic illness will likely remain dependent on their families for longer than those without illness. It is during this period that those emerging adults with chronic illness are required to transition to adult services. As previously discussed (Section 2.5.1) several studies identify a sharp decline in adherence to treatment during this developmental stage (Annunziato *et al.* 2007; Watson 2000 Kipps *et al.* 2002). Osgood *et al.* (2010) proposed an extension to age limits for young people's transitioning to the adult health service until well into adulthood, consistent with theory of emerging adulthood. As Arnett

(2006) explains young people are taking “a longer road to adulthood” therefore policy and service including health service will have to tailor to the current needs of this population. Emerging adults living with chronic illness are not just transitioning to adulthood but also to adult healthcare.

2.7.1 INBETWEENNESS AND CHILDHOOD CHRONIC ILLNESS

The complex co-existence between 'living a life' and 'living an illness' has been identified in the literature (Whittemore and Dixon 2008). Those with chronic illness have to live with illness in a world of health. Not only do they have to live with their illness they also are required to manage their illness and often explain their illness to others. Those who have examined the relationship of illness and health and living with chronic illness have tended to focus on adult onset chronic illness (Radley 2009; Taylor and Bury 2007; Pierret 2003; Bury 1991; Charmaz 1983, 1991, 1995, 2002). However adults diagnosed with chronic illness have moved from being healthy to living with an illness. Whereas emerging adults with childhood onset chronic illness may have always ‘lived’ with their illness. In her seminal work, Charmaz (1983, 1991) talks about how adults with chronic illness have lost “previously taken-for-granted aspects of self” (p.172). Radley (2004) outlines problems with the retention and loss not just of ‘self’ but of a ‘way of life’ that adults face when they are diagnosed with chronic illness. While this is significant in understanding the experiences of adults with chronic illness it may not ring true for young adults who have grown up with a chronic illness and may never have known what it is like to live without illness. Coping strategies and adjustment may differ greatly in children with chronic illness (Compas *et al.* 2012; Petersen, Schmidt and Bullinger 2006). Moreover children are often taught about their illness by their parents, not only how to manage it but also how to communicate about it to friends and family.

The management of any chronic illness during a time of rapid growth and physiological changes, accompanied by important individuation and socialisation processes, constitutes a major challenge for young people (Suris *et al.* 2008, 2009; Michaud, Suris and Viner 2004). Some patients achieve a level of acceptance of the chronic illness while for others the obstacles of everyday life make this movement towards acceptance difficult. A growing body

of research on aspects of living with chronic illness has accumulated from a range of disciplines in young people. Psychological and psychosocial studies have highlighted problems that include loss and disruption to everyday life as a consequence of having chronic illness. Psychologists (Stam *et al.* 2006; Eiser 1993) have tended to lean towards documenting processes of cognition and emotion associated with chronic illness. Whereas the sociologists focus has been on the patterns of behaviour, coping styles, social expectations, and cultural rules related to having a chronic illness (Kiviruusu, Huurre and Aro 2007; Pierret 2003; Gerhardt 1990). Living with a chronic illness can lead to a variety of adjustments and consequences for everyday life in individuals. Indeed many studies over the last two decades have associated long-term psychological and psychosocial effects associated with chronic illness among children and adolescents (Kiviruusu, Huurre and Aro 2007; Huurre and Aro 2002; Patterson and Blum 1996; Wolman *et al.* 1994). The developmental literature acknowledges that as the young person's autonomy increases, behaviour that might have previously been regulated by others (e.g. parents) is now increasingly regulated by the young person themselves (Tanner, Lynn and Arnett 2009; Tanner 2005). Therefore as the young person moves towards adulthood they begin to take over the decisions about their illness and their management of it. Much of the nursing literature on chronic illness for this age group has concentrated on their transition to adult services (Rapley and Davidson 2010; Visentin, Koch and Kralik 2006; Rosen 2004; Rosen *et al.* 2003; Fleming *et al.* 2002; Reiss and Gibson 2002) and quality of life issues (Taylor, Gibson and Franck 2008; Mandzuk and McMillan 2005).

2.7.2 HEALTHCARE TRANSITION AND CHILDHOOD CHRONIC ILLNESS

The concept of healthcare transition first emerged in the 1980's (Reiss 2012). Yet the literature continues to highlight problems for young people moving into adulthood with illness (Reiss 2012). Over a decade ago Reiss and Gibson (2002) examined the transition literature over a 20 year period covering a range of illness and found that adolescents often failed to attend clinic appointments. There are similar findings of infrequent attendance in the medical literature (Garvey, Markowitz and Laffel 2012; Holmes-Walker *et al.* 2007a; Johnston *et al.* 2006). This was associated with an increase in disease specific complications for young people (Cadario *et al.* 2009; Holmes-Walker *et al.* 2007a). Much of the nursing literature has revealed a gap between paediatric and adult service (Steinbeck *et al.* 2008)

with young people feeling ill prepared and lacking in understanding of the consequences of poor compliance on transitioning to adult services (Hogan *et al.* 2006). Overall there is general agreement in the literature across all disciplines that transition still appears to be *ad hoc* with little support for young adults (Wedgewood 2007). While there is a gap in research examining emerging adults' experience of living with chronic illness some studies across several disciplines highlight less than ideal outcomes for young adults living with chronic illness. The literature highlights many problems for young people who are 'living a life' and 'living an illness' (Whittemore and Dixon 2008) particularly in a world of health. Where the gap emerges seems to be in exploring the lived experience of those that have grown up with chronic illness and transitioned to adulthood with their illness. Exploring the lived experiences allows researchers to explore the experience of participants -as-they-live-through-it, their actions, relations and situations are explored through their stories. This in turn will uncover a sense of meaning of the phenomenon of childhood chronic illness which will aid out understanding of healthcare transition for this vulnerable group.

2.8 AGE OF POSSIBILITIES

The final stage of Arnett's Theory of Emerging Adulthood includes the *age of possibility*. Emerging adulthood is often a time for reflecting on future plans for work and relationships and figuring out who one is and where one's life is headed. Young people are availing of entering third level education more so now than in previous decades. Moreover emerging technologies have provided many young people with a wide array of life options, many of which their parents and grandparents could never have imagined (Coyne *et al.* 2013; Schwartz *et al.* 2013). Emerging adults living with chronic illness may have different experiences reflecting on future possibilities due to the limitations of their illness. Research is scant in the area of transition to adulthood with illness however Palladino *et al.* (2013) conducted a large longitudinal study with emerging adults with diabetes and without (n=229) and found that those with illness had a lower life purpose over time compared to those without illness. As previously discussed a number of longitudinal studies have identified lower graduation rates, higher unemployment and lower incomes in emerging adults with a variety of chronic illnesses (Maslow *et al.* 2011) which may account for lower life purpose. Much of the literature exploring how successfully young people transition to adulthood with illness highlights a major concern with non-adherence to treatment.

2.9 NON-ADHERENCE AS ILLNESS MANAGEMENT AMONG EMERGING ADULTS

The terms compliance and adherence are often used interchangeably in the literature however ‘adherence’, is increasingly being used. It comes from the Latin word adherence which means to cling to, keep close, or remain constant (Aronson 2007). The term “adherence” is often preferred within health care, because “compliance” suggests that the patient is passively following the health professional's orders and that treatment is not based on a therapeutic alliance between the patient and the health professional (Osterberg and Blaschke 2005). The WHO defines adherence to treatment as “the extent to which a person’s behaviour-taking medication, following a diet, and/or executing lifestyle changes-corresponds with agreed recommendations from a healthcare provider” (2003, p.17). Regardless of the term used, it is clear that the full benefit of the many effective medications available for chronic illness will be achieved only if patients follow their prescribed treatment regimens reasonably closely. The World Health Organisation (WHO) report *Adherence to long-term therapies: evidence for action 2003* found that an average of 50% of patients failing to follow their prescribed treatment by health professionals in the developed world. Non adherence rates in adolescents appear even higher with cystic fibrosis adolescents self-reporting non adherence rates of 60% and higher (Bregnballe 2011; Rand-Giovannetti *et al.* 2010). Several studies in recent years have found that adolescents with diabetes tend to ignore the potential consequences of failing to adhere to their medication (Birt *et al.* 2014; McDonagh and Gleeson 2011; Rosina, Crisp and Steinbeck 2003; Guthrie *et al.* 2003). The consequences of poor or non-adherence are not only poorer health outcomes and even death but also increased health care costs (Brown and Bussell 2011). There is little doubt that non-adherence is a major stumbling block in chronic illness management in the children and adult populations. However this seems to be exacerbated during the developmental period of emerging adulthood where young people are exploring their identity, who they are and who they will become. Significant declines in adherence have been observed in chronic illness populations during this period of transition to adulthood (Shemesh *et al.* 2011; Annunziato *et al.* 2011; Annunziato *et al.* 2007; Watson 2005).

Despite the many extensive reports and studies in recent years adherence rates have not improved (Desai and Choudhry 2013; Kang 2013; Brown and Bussell 2011; Pai and

Ostendorf 2011; Huang *et al.* 2011; Cadario *et al.* 2009; Geddes *et al.* 2006; Visentin *et al.* 2006). Studies on non-adherence have tended to assess variables such as readiness for transition to adult service, knowledge of disease, family support and skill acquisition or have been too cure focused which has attracted criticism. Moreover the research results tend to be reported with dichotomous variables (adherence versus non-adherence) whereas adherence can vary along a continuum with patients sometimes taking more than the prescribed amount of medication (Osterberg and Blaschke 2005). In the WHO 2003 report on adherence they conceptualised adherence as a multidimensional phenomenon. It contends that patients are not solely responsible for following treatment and that there are other factors that affect patient's capacity to adhere to treatment e.g. patient related factors and socio economic factors. Adherence rates may not be improving because health professionals do not view adherence as a dynamic process influenced by several factors. More and more young people are surviving childhood chronic illness and transitioning into adulthood. Despite this recognition, no specific models or guidelines were found to assist health professionals and young people with their adherence to treatment of chronic illness (Pai and Ostendorf 2011; Osterberg and Blaschke 2005; Stark *et al.* 2003). The use of structured transition programs to assist the transition of young people with diabetes from paediatric to adult care remains sporadic. A recent survey of the International Society for Paediatric and Adolescent Diabetes found that only 50% of respondents received structured transition programs (de Beaufort *et al.* 2010). With the lack of adequately trained healthcare professionals capable of providing developmentally appropriate care for young emerging adults with chronic illness it must be a priority now to find ways to develop strategies to promote adherence (Reiss and Gibson 2005).

Non-adherence to treatment has become a critical issue in population health since it was originally reported by Sacket *et al.* in nineteen seventy five, both from the perspective of poor health outcomes and increased health care costs. Non-adherence is costing EU governments an estimated €125 billion annually and contributing to the premature deaths of nearly 200,000 Europeans a year (European Council Policy 2010). The WHO has advised that “increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatment” (WHO 2003; p.13). There is little doubt that, compared to childhood, there are greater problems in chronic conditions during adolescence and early adulthood such as diabetes management (Hanna *et*

al. 2013; Rasmussen *et al.* 2007) and asthma management (Gabe, Bury and Ramsay 2002; Simon 2013; Cole *et al.* 2013). Several longitudinal studies (see Table 3.0) from the United States (US) and the United Kingdom (UK) have shown an increase in complications from late adolescence and young adulthood into adulthood (Palladino *et al.* 2013; Maslow *et al.* 2012; Maslow *et al.* 2011; Geddes *et al.* 2006; Peveler *et al.* 2005) associated with poor illness management among in this population. Poor illness management is related to increased risk of ongoing complications and premature mortality. Understanding the issues that influence chronic illness management is critical in order to appropriately assist those within this particular developmental group of emerging adulthood with the challenges related to managing their illness. A better understanding of what influences young adults' adherence or non-adherence with treatment and how they integrate their illness into their lives is warranted. A review of literature on young adults' adherence to treatment revealed a gap in qualitative studies that identify common concerns for those transitioning to adult services (Pai and Ostendorf 2011). A recent Irish publication *A Report on Patient Non-Adherence in Ireland* (Al-Lawati 2014) highlighted the importance of healthcare professionals as key in influencing patients to adhere to medication and considers that new innovations may be required to demonstrate a significant effect in improving adherence. Eliciting the experiences of young adults with chronic illness during this phase of identity exploration may assist health professionals to understand the complexity of non-adherence. By beginning the process of dialogue with this population who have lived through the transition from childhood to adulthood may lead to more effective models of care that promote adherence.

2.10 EMERGING ADULT PERSPECTIVES

Recent trends in the nursing literature place a new emphasis on the person and those with chronic illness are no longer considered to be passive recipients of care but rather the principle decision makers in their care. This has led to an increase in the research exploring the experience of those that live with chronic illness as the best source of information to guide practice in the future (Koch *et al.* 2004; Forsner *et al.* 2005). Thus over the last two decades studies have emerged examining the views and narratives of those living with in chronic illness (Gannoni 2010; Savage and Callery 2007; Coyne 2006; Charmaz 2002; Bury 2001). Traditionally this research has been dominated by the views and perspectives of parents (Klok *et al.* 2011; Peterson-Sweeney *et al.* 2003, 2007; Dickson and Dignam 2002), siblings (Kepreotes *et al.* 2010; Guite *et al.* 2004) and healthcare professionals (Beresford and

Sloper 2003). However there is growing awareness over the past twenty years since the United Nations Convention on the Rights of the Child² (UNCRC) 1998 contends that young peoples' perspectives should be sought in matters that affect them. (Kilkelly and Savage 2013; Kilkelly and Donnelly 2011; Coad and Coad 2008; Boylan 2004; Sloper and Lightfoot 2003).

Emerging from the UNCRC are studies examining the views and narratives of children and young people in healthcare (Kilkelly and Savage 2013; Lambert, Glacken and McCarron 2013; Kilkelly and Donnelly 2011; Boylan 2004). Apart from the obligation to listen to young people's views in healthcare levied by the UNCRC, it is also hoped that by involving young people in developing health service, better management of illness can be achieved. Few studies specifically explore the experiences of emerging adults living with chronic illness since childhood. Dovey-Pearce *et al.* (2005) conducted focus group interviews with young people (N=19) 16 to 25 years with diabetes and described the need for providing developmentally appropriate healthcare. A lack of user involvement has been apparent in service planning and developing chronic illness models which may account for the gaps in care (Peters and Laffel 2011). An exploration of the needs of this complex and unique population may help researchers recognise their needs and allow them to better match any approach with a young person's life circumstances.

2.11 EMERGING ADULTS AND THE DIGITAL AGE

Any study exploring the lived experience of emerging adults must acknowledge how much of their lives have altered with the digital age. In a study of adolescence Strasburger, Jordan and Donnerstein (2010) report that young people spend on average more than seven hours per day using some form of modern media. Since the cost of home computers dropped dramatically over the last decade, access to technology has rocketed with most basic mobile phones now including broadband technology bringing digital literacy to wider audiences. The Broadband Commission (2012) reported that by the end of 2011 almost 2.3 billion people were using the

² United Nations Convention on the Rights of the Child (CRC) 1989 ratified by Ireland on 28 September 1992 a blueprint for the care of children defined as everyone under the age of 18 years setting out a standard of treatment to which all children are entitled.

internet accounting for approximately one third of the world population. Current studies exploring the experiences of young people have tended to ignore media influences (Strasburger 2009). Exceptions occur in disciplines such as education where research has begun to explore the role of digital media in the learning, interactions and communication of university students (Yee and Timmis 2013). Hendry *et al.* (2011) explored the integration of digital media in a drop-in centre for homeless young people for deepening relationships between youth and adults finding that it helped to strengthen relationships between the youth and the drop-in staff. Nursing research has yet to embrace how emerging technologies can influence healthcare particularly their role in communication and interactions. Industries such as food and drink (Montgomery 2009) and tobacco (Freeman 2012) have harnessed digital media technologies such as Web 2.0 technology to communicate to young people whereas healthcare has been slow to embrace it. O'Reilly (2005) defines Web 2.0 technology as “the network as platform, spanning all connected devices” (p.17). Described as social software, it has the ability to connect people in order to share their knowledge and information. Both Blogging and Online forums feature in Web 2.0 technology with the emergence of the discussion and chat functionality for users.

While research has begun to emerge on the effects of technology on young people has concentrated on the harmful media effects (Hinduja and Patchin 2010; O’Keeffe and Clarke-Pearson 2011) the prosocial aspects of modern media is limited (Lenhart 2010). Studies have shown that modern media can not only provide current information on safe health practices (Collins Elliot and Mui 2009; Lenhart 2010) for young people but importantly foster a connectedness among like-minded people (Valkenberg 2009). However digital media has become an important source of information and misinformation for young people. The potential for modern media to play a beneficial role in the lives of young people with chronic illness has not been realised. As new views and shifting perspectives of chronic illness emerge and government strategies for dealing with chronic illness widen their focus to include wellness and well-being new ways to communicate with emerging adults must be embraced. Health professionals and health policy needs to appreciate the fact that young people living with chronic illness since their childhood have grown up in a digital age of communication and consider resources that can facilitate some of their needs.

The current generation of children are growing up with new channels of communicating and sharing knowledge. They have been exposed to the full spectrum of technology more than any other demographic group. In the US the Pew Internet and American Life Project (2010) revealed that highest population of internet users (93%) consistently remains both the 12 to 17 years and the 18 to 29 years demographic groups (Rainie 2010). A UK report concurs with this, finding that 15 to 25 year olds were 25% more likely to be online than any other demographic group (www.comscore.com). Web 2.0 social media sites such as Facebook and Twitter have become one of the most common activities of young people today with 22% of teenagers logging on more than 10 times a day (O’Keeffe and Clarke-Pearson 2011).

Ireland is no exception with over 65.6% of the population reporting to be internet users in 2010 compared to 20.9% in 2000. The preferred choice for younger demographic groups to access the internet are mobile devices (phones, tablets and netbooks) with 77% of Irish Internet users using mobile devices compared to a global average of 69%. Much of the activity happening on social media sites includes connecting with friends, communicating with the wider community and exchanging ideas (O’Keeffe and Clarke-Pearson 2011). Among university students Timmis (2012) found that online conversations offered mutual support and help with both studying and social topics. In addition young people can access health information easily and anonymously with increasingly available health resources online. Indeed young people with illness particularly chronic illness have more opportunities to connect with other people with similar conditions via social media (Lenhart *et al.* 2010). Social media holds the potential to influence how emerging adults live with chronic illness. Whether it can reduce any isolating effects that may occur from living with illness needs investigation.

2.12 CHRONIC ILLNESS: A NON CATEGORIAL VIEW

A non-categorical view of child health and health problems was first proposed by Stein and Jessop in 1982. This broader view that is not disease specific and that is concerned with the total life experience of children with chronic illness and their families, offers a conceptual framework to view childhood chronic illness. In seminal work Stein and Jessop in (1982) argue that whilst there will always be disease-specific issues among this population, neglecting the commonalities across illness will not allow health professionals to generalize

from past experience. Not taking away from the need for individualised treatment plans for patients there is a need to examine the whole person as opposed to the disease. Young people with chronic illness face common experiences and problems growing up with illness rather than just the particular characteristics of a specific disease (Eiser 1997). Childhood chronic illness can disrupt the lives of children limiting their role in school, recreation, and vocational pursuit.

The body of research on chronic illness has evolved over the last two decades. Indeed the study of chronic illness as a separate theoretical entity unto itself is still relatively new. Many of the studies concerned with chronic illness limit their inquiries into distinct disease categories. More recently studies are linking their findings with those that might be relevant to other chronic diseases. This move towards exploring chronic illness with a diverse sample of illness should provide a broader range from which to distill the essence of the phenomenon of chronic illness. Young adults with a variety of chronic illnesses can have very different views and experiences about their illness due to length and frequency of hospitalisations, urgency of decisions and certainty or uncertainty about their illness. Despite the fact that there is an acknowledgment in the literature that a 'best practice' approach to chronic illness includes non-categorical management (Mokkink *et al.* 2008) there is little evidence that management has moved beyond a disease specific approach. Adaption studies (Bishop 2005; Stanton, Revenson and Tennen 2007; Parker *et al.* 2003; Jacobson *et al.* 1997) also concur with a multidimensional approach to chronic illness but argue that there is little evidence that this theoretical development has been translated into clinical practice. Yet over two decades ago Stein and Jessop (1989) called for a paradigm shift in research theory when examining the psychological, social, rehabilitative and preventive issues raised by chronic illness in young people.

Several models of chronic illness management (Chronic Illness Model, Innovative Care for Chronic Conditions Framework, Public Health Model, Continuity of Care Model) have been developed in recent years however few studies describe their effectiveness. While they do take a multidimensional approach to the complex problem of chronic illness the complex developmental issues for emerging adults living with their illness from childhood into adulthood are missed. In Ireland a new Model of Paediatric Healthcare takes account of

international trends (National Paediatric Hospital Development Board 2010) highlighting the need for a structures approach to transitional care for young people moving to adult healthcare with illness. However a framework has yet to be developed for this transitional process in Ireland.

2.13 LIVING WELL WITH CHRONIC ILLNESS

It is well recognised that chronic illness is a major concern for individuals as it can limit the quality of their lives. In addition it represents a large portion of healthcare spending for governments in recent decades which has the potential to reach a crisis point particularly in the recent economic downturn. In tandem with efforts to consider the economic cost is the move towards enhancing the quality of life for those with chronic illness to live well with their illness. In the US a committee set up by the Institute of Medicine (IOM) (2012) produced a report *Living Well with Chronic Illness: A Call for Public Health Action*. This was an effort to address the physical, social and psychological needs of individuals and the population as a whole to live well regardless of the illness or the individual's current health status. The committee made several recommendations including the design and implementation of new innovative approaches to promote living well with chronic illness. The ultimate aim of this report is to improve efforts to better understand the burden of those living with chronic illness. In recent years in Ireland chronic illness strategies have incorporated the concept of "wellness" focusing on maximising the potential of the individual with chronic illness (Chronic Illness Framework, HSE 2008; A Framework for Improved Health and Wellbeing 2013 – 2025). Indeed the current nursing paradigm acknowledges that health is not opposed to illness rather it encompasses wellness and illness (Ellefsen 2012). As the current emphasis in chronic illness encourages wellness and living well with illness it becomes important for health professionals to engage with young people to promote healthier lives. Greater efforts to understand issues such non-compliance with treatment and illness behaviour among those living with chronic illness. Sociologists have for some time now highlighted the importance of social networks for people living with illness (Cockerham 2000, 2007; Young 2004). Cockerham (2007) describes social networks as the relationships people make in their day to day interactions and exchange of information. They involve the social world of the person and can include family friends and co-workers. Previous work has examined the role of connectedness to social networks and found increased healthy lifestyle choices and use of preventative health care (DiMatteo 2004; Gallant 2003). Direct links

between social networks and compliance to treatment were found (DiMatteo 2004). Social networks or relationships may provide practical and emotional support and connect individuals to relevant information all of which may increase the likelihood of adhering to treatment. Less is known however about the role of social media as a form connectedness in illness management.

Healthcare is still largely built around an acute, episodic model of care that is ill-equipped to meet the requirements of those with chronic health problems. While new models of healthcare delivery that can achieve better coordination of services have valid appeal, the evidence of the value of different approaches remains uncertain (Ouwens *et al.* 2005). The literature does reveal that the challenges posed by chronic disease cannot be addressed by a universal model of care (Rosen *et al.* 2003) and needs to take account of societal changes and be developmentally conscious if they are to be beneficial. What may be viable for adults diagnosed with chronic illness in adulthood may be impossible in young people growing up with illness when the two differ in critical aspects like development. Each group must find its own model of care.

2.14 INTERNATIONAL PERSPECTIVES

Over the last decade several longitudinal studies have identified that young adults' experiences of living with childhood-onset chronic illness seem to be at risk of poorer educational and vocational outcomes. *Table 2.0* below summarises a range relevant longitudinal studies from both the US and Europe that portray a variety of concerns for young people living with chronic illness. In the United States (US) studies show poorer academic achievement (Martinez and Ercikan 2009) and that less than one-fifth of young adults with childhood-onset chronic illness graduate from college and the average income of these adults is significantly lower than those without chronic illness (Maslow *et al.* 2011). This demonstrates a need to understand the mechanisms that underlie these differences and thereby inform the development of future interventions. Maslow *et al.* (2011) analysis of the US National Longitudinal Study of Adolescent Health confirm this increased risk of poor educational and vocational outcomes among adolescents with chronic illness compared to those without a chronic illness. This significant study of young adults aged between 18 and 28 years (n= 13,236) reported that compared with healthy young adults, those with chronic illness were significantly less likely to graduate high school, ever have had employment, or

currently have employment and were more likely to receive public assistance. The authors argue for the need to pursue efforts to support children growing up with chronic illness to become successful adults.

While much of the literature does concur that young people with a chronic illness are at risk for academic failure leading to income and employment difficulties, the literature shows conflicting evidence of social success. Maslow (2011) found no difference in the social lives including relationships and marriage of young adults with chronic illness. However in the nursing literature a number of Australian studies provide valuable insight into the psychosocial concerns of young people as they move from paediatric to adult focused health services (Steinbeck, Masterson and Sturrock 2007; Steinbeck and Brodie 2006). In a survey Steinbeck, Masterson and Sturrock (2007) aspects of life disruptions were identified by participants that included social life, interaction with friends and peers, school, university, work, freedom and a reminder of mortality. These studies acknowledge the unique developmental and health care needs of this population but point to the often ill-equipped facilities available to deal with the complex developmental needs of young people with chronic illness.

Finnish and Canadian large population based studies indicate poor social outcomes for young adults with epilepsy. In a Canadian study of young people with epilepsy Camfield and Camfield (2007) found that the influence of epilepsy on social outcome is greater than found in other childhood chronic disease control groups with increased rates of social problems in adulthood. They call for research to address these adverse outcomes. A number of population based studies from Finland have investigated young adults views of the psychosocial effects of chronic illness compared to their healthy peers (Kiviruusu, Huurre and Aro 2007; Huurre and Aro 2000, 2002). Kiviruusu, Huurre and Aro (2007) and report that chronically ill males were less often married or cohabiting than healthy control males in their study. In a small qualitative study, young Australian adults with cystic fibrosis reported that the transition process for the child to adult setting had potential effects not only on their psychosocial, psychological but also their physical well-being (Brumfield and Lansbury 2004). A UK study examined medical records of young students aged 18-24 years living away from home with diabetes over a 10 year period (1994-2004) and found that their care was often suboptimal

with poor dietary habits and that greater support was needed for this group (Geddes *et al.* 2006). Several of the UK initiatives have highlighted the need to develop services and facilities designed for young people within the health services (Report of the Age Appropriate Care Working Group, National Steering Group for Specialist Children's Services; *Think transition: developing the essential link between paediatric and adult care*, Royal College of Physicians of Edinburgh 2008). While in the UK, strategies are being developed to advance a comprehensive programme or model of care for young adults with chronic illness, the evidence to guide these strategies is often lacking. The dearth of knowledge on those that have lived with childhood chronic illness and their transition to adulthood and all that it entails will inhibit the development of effective programmes and facilities. NICE (2004) strongly suggested that further research is needed to investigate young people's experiences of transition from paediatric to adult services.

Table 2.0 Relevant longitudinal studies

Authors	Study	Findings
Pallindino et al. 2013	Longitudinal study compared emerging adults with Diabetes Mellitus (DM) and without DM	Both groups adopted similar risky behaviour DM was associated with reduced life satisfaction and life purpose Disturbed sleep in males
Maslow et al. 2011(US)	Longitudinal study	Most young adults growing up with a chronic illness graduate high school and have employment. However, these young adults are significantly less likely than their healthy peers to achieve important educational and vocational milestones.
Maslow et al. 2011(US)	Longitudinal study	Young adults growing up with chronic illness succeed socially, but are at increased risk of poorer educational and vocational outcomes.
Geddes et al. 2006 (UK).	A UK study examined medical records of young students aged 18-24 years living away from home with diabetes over a 10 year period (1994-2004)	Care was often suboptimal with poor dietary habits and that greater support was needed for this group
Steinbeck, Brodie and Towns (2006) (Australia)	Data were collected between August 2004 and October 2005 through face-to-face interviews with over 200 clinicians in 68 clinical services in tertiary paediatric hospitals in New South Wales n= 4200	Results indicate that the transition process remains variable as indicated by few defined transition policies and a lack of formal links with adult services
Huurre and Aro 2002 (Finland)	Long-term psychosocial effects of persistent chronic illness. A follow-up study of Finnish adolescents aged 16 to 32 years	Results indicated that young adults with chronic illness limiting their daily life reported more depression and lower self-esteem than those with non-limiting chronic illness or healthy controls.
Miauto., Narrin and, Michaud (2003) (Switzerland)	Chronic illness, life style and emotional health in adolescence: Results of a cross-sectional survey on the health of 15-20-year-olds in Switzerland	The burden of their illness had important psychological consequence. Experimental behaviours are not rarer in adolescents with a chronic condition and might be explained by a need to test their limits both in terms of consumption and behaviour.

2.15 IRISH PERSPECTIVES

Efforts to manage health care transitions for children with chronic illness to adult services are often complicated by the diversity of the country's health care delivery. Differences in paediatric and adult health care services can be challenging. In Ireland support and care for young adults with chronic illness in the community is often provided on an ad-hoc basis. Support provided at home is often limited and therefore patients often require more hospitalization. There is currently no national child health system for the collection and analysis of data in relation to child health information which impacts on the data for childhood chronic illness. However the Health Service Executive (HSE) are currently establishing a group to review a system whereby information relating to child health and well-being can be integrated and shared effectively (Department of Children and Youth Affairs 2013). This must be a priority for the current government with chronic illness being the main definite cause of rising health care costs and economic losses. The Department of Health and Children, Ireland (DOHC 2008) reported that 77% of service activity and expenditure in the healthcare system is caused by chronic illness. The report called for national and international initiatives to tackle chronic illness to reduce the burden on the healthcare system (DOHC, 2008). The report reflects chronic illness in the older adult population predominantly with the needs of young people with chronic remaining underreported. With the impact that chronic illness has on the Irish economy it makes sense for not only accurate data to be collected but also funding to be made available for less ad hoc and more effective transitional programmes for young people growing up with chronic illness and moving into adulthood.

Much of the international research to date has highlighted a shift in the health care experiences of young people as they enter adult life with illness (Maslow *et al.* 2011; Steinbeck and Brodie 2006; Geddes *et al.* 2006). However limited evidence in the literature was found exploring the experiences of young adults with childhood onset chronic illness in Ireland. Al-Yateem (2012) study explored the experiences of young people in Ireland with Cystic Fibrosis before and after their transition to adult care, and the factors that contributed to and hindered their experience. Findings suggest that young people want a range of interventions to reduce the negative feelings associated with transition (e.g. distress, anxiety, uncertainty), including an approach to care that focuses on young adults. However Savage and Callery (2007) study of Irish children with chronic illness (cystic fibrosis) found

that children were often marginalised in their dealings with healthcare professionals and there was a low level of participation of children and young people in healthcare in Ireland. More recently data taken from the National Longitudinal Study of Children, *Growing Up in Ireland*, with a sample size of 8,570 children, produced evidence of a negative impact on the child's emotional and social state among 9-year old children with chronic illness (Williams *et al.* 2011). How children fare during their childhood with a chronic illness in Ireland and whether they develop long-term repercussions when they reach adulthood warrants investigation.

Driven by the WHO *Innovative Care for Chronic Conditions: Building Blocks for Action* (2002) enhancing the quality of life for those with chronic illness to live well with their illness is becoming the focus of attention in recent years. Chronic illness strategies both in the UK and Ireland have acknowledged this shift in thinking and incorporated the concept of “wellness” focusing on maximising the potential of the individual with chronic illness (Chronic Illness Framework, HSE 2008; Improving Health Together: A Policy for Chronic Illness, 2011). In Ireland progress has been made with the development of the eHealth Strategy 2013 which will benefit the healthcare system with what information and communication technology has to offer. The aim of the strategy is to bring improved population wellbeing. eHealth tools will play a significant role in improving the health of European citizens whether they are used behind the scenes by healthcare professionals, or directly by patients (European Commission 2011).

2.16 CONCLUDING COMMENTS

The theory of emerging adulthood is a new distinct period of life stage. It refers to a stage in life when individuals concentrate on issues related to their identity and have the freedom to focus on their own self-development. The changing face of society with an increasing proportion of single young people and changes in family patterns is likely to lead to new social issues. Park *et al.* (2006) highlight two contextual influences that can shape this period: delayed transition to adulthood with its responsibilities and weakening of the safety net normally present in childhood. Vulnerable populations such as those with illness can suffer from changes in support leaving them to navigate to adulthood healthcare with less supports (Osgood *et al.* 2010). Few studies specifically explore this group of emerging adults in

relation to their experiences living with chronic illness since childhood (Snelgrove 2012; Taylor *et al.* 2008). In a doctoral study Snelgrove (2012) identified that achieving a desired identity is the main challenge for young people with illness. However how they establish their sense of identity as they move into adulthood with illness remains unexplored. Thus a developmental approach was deemed appropriate to uncover the experiences of this population. Arnett (2004) argues for the continuing scholarship examining the nature of life and paths of development for emerging adults. By failing to study this distinct group, researchers miss the unique personal needs of individuals immediately post adolescents. During this period lifelong patterns of behaviours are developed which will be critical to the health of the young adults with chronic illness. This may be the window of opportunity health care professionals have to influence that behaviour. There is little doubt that in order for health professionals to create developmentally sensitive transition programmes they will need to gain insight into this group by exploring their experiences. This review of the literature presented a theoretical overview of Arnett's theory of emerging adulthood and critical analysis of relevant literature in relation emerging adulthood and childhood chronic illness. The aim was to sensitize my current theoretical understandings of this developmental phase and from which I could examine the literature and age group and interrogate the data. While this review examined the developmental literature particularly in relation to how young people lives have changed and the emergence of the term *emerging adulthood* it also covered how the current generation are growing up with new channels of communicating and sharing knowledge.

Social media is becoming the preferred method of communicating health promotion and education because of its ability to reach wide audiences. Other disciplines have harnessed social media to capture the attention of young adults including the film, music industry and politics with success. To date studies examining the effectiveness of social media as a channel for communication health education and promotion have been limited (Korda and Itani 2013). However the evidence suggests its increasing popularity. Without doubt the sense of connectedness that social media provides for young adults should facilitate a new and improved method of communicating health promotion and education between health professionals and those who live with chronic illness. Emerging adults are a particularly appropriate group as social media has become the 'norm' for them as a means of communicating with like-minded people. However the power and reach of the virtual world

is growing and changing constantly and health professionals will need to keep abreast of the emerging technologies as they change. Web 2.0 technology is evolving on a daily basis. Harnessing new technological strategies as they emerge may put health professionals in a unique position to support emerging adults with chronic illness.

There is general agreement in the literature that the paucity of evidence lies in the need to explore the experiences of young people with chronic illness (Wedgewood *et al.* 2008; Steinbeck *et al.* 2007; Beresford and Sloper 2003) particularly those that have already transitioned to adulthood. There is a need to better understand how the care given to young people with chronic illness could be translated into delayed or impeded entry into adulthood (Szelag 2011; Aujoulat *et al.* 2006). Evidence suggests that current adult-orientated models of care are not suitably translated to young people growing up with chronic illness. Following on from both the UK and Irish government's recently published frameworks in both the UK *Transition: Getting It Right for Young People. Improving the Transition of Young People with Long Term Conditions from Children's to Adult Health Services* (DOH 2006) and Ireland *Chronic Illness Framework* (HSE 2008) and the growing need to develop a model of care based on needs of young people, further study is needed. Watson (2005) argues for research to be carried out on viewpoint of young people who have already transferred to better inform the transition process.

Over three decades ago Corbin and Strauss (1987, 1998) argued not only for the adolescent's voice in the study of chronic illness but also how the illness unfolds for them over their childhood. While it is acknowledged that experience and maturation can influence their perspectives nevertheless emerging adults are experts in what it is like to live with their chronic illness. This information is vital if researchers are to develop specific strategies to help both paediatric and adult providers care for the transition needs of this vulnerable population with chronic illness particularly in Ireland where transitional care remains ad hoc. The exclusion of emerging adults in samples covering the complete adult spectrum may mask the issues that arise in the transitional period between adolescence and adulthood. The current study aims to redress this neglect by using a qualitative approach to explore the 'lived experience' while focusing specifically on this important developmental period of young adulthood. The concept of "lived experience" holds specific methodological significance. The

notion of “lived experience,” as described by (Dilthey 1985; Husserl 1970; Merleau Ponty 1962, 1968;) and the more contemporary proponents (vanManen 2004), declares the intent to explore the pre-reflective stories offered by participants. The call for the views and perspectives of young people with chronic illness (Wedgewood *et al.* 2008; Steinbeck *et al.* 2007; Lightfoot and Sloper 2001) in the literature are warranted. However exploring their experiences of the phenomenon of childhood chronic illness as they have lived through it offers the possibility of deeper and original insight.

There is little doubt that the study of emerging adults is in its infancy. Developmental psychologists contend that this is a vulnerable age and the evidence presented in chapter two and three clearly illustrate that many problems arise with adherence to treatment and transitioning to adult healthcare. While recent reports on longitudinal studies examining the outcomes of young people with chronic illness (Palladino *et al.* 2013; Maslow *et al.* 2012; Maslow 2011; Geddes *et al.* 2006; Huurre and Aro 2002) offer valuable information particularly in recent years the views of emerging adults were sought. However the gap lies in seeking the lived experiences of this group who have grown up with illness. If we fail to explore the experiences of emerging adults living with childhood chronic illness we may not ask the right questions in large longitudinal studies. Moreover it has become increasingly obvious that healthcare spend is not synonymous with improved healthcare, therefore future policy needs to adopt a developmentally appropriate approach with this particular group. The extensive literature exploring transition to adult healthcare contends that this group who have transitioned to adult service are well placed to offer valuable insight into what it is like to live with childhood chronic illness. The following section presents the methodology thinking of this doctoral study. It includes chapters presenting the theoretical framework and philosophical underpinnings and methodological approach of this study.

CHAPTER 3: EPISTEMOLOGICAL PERSPECTIVES

3.1 INTRODUCTION

Following on from the literature review presented in Chapter 2 this chapter describes the study's underlying philosophical assumptions and methodological approach. My ontological and epistemological positions are discussed how I moved from the research question towards an interpretive inquiry. Finally I acknowledge the challenges in navigating the terrain of the 'lived experience' and describe the decision to employ van Manen's lifeworld existentials as a theoretical framework for this study. In addition philosophical underpinnings of hermeneutic phenomenology to uncover the lived experience are described. Researchers need to be clear about which philosophical and research traditions they are following. A phenomenological method is considered "sound" if it links appropriately to a phenomenological philosophy and if its claims about method are justified and consistent. Table 3.0 outlines the methodology section of this thesis which is divided into three chapters.

Table 3.0 Structure of the methodology section

PHILOSOPHICAL and RESEARCH TRADITIONS		LOCATION
Paradigm: Research perspective and philosophy Ontological/Epistemological position	Interpretivism	Chapter 3
Theoretical framework	Van Manen's lifeworld existentials	
Methodology	Hermeneutic phenomenology	Chapter 4
Research Approach/Methods	In depth interviews Online Discussion Forum	Chapter 5
Data Analysis	Van Manen approach –The three strand approach included the Holistic, Selective and Detailed reading of the data; followed by the existential investigation of the phenomena (van Manen (1990) and the Hermeneutic Cycle (Heidegger 1962)	Chapter 6

3.2 PARADIGM: RESEARCH PERSPECTIVE AND PHILOSOPHY

Research design is often referred to as “a framework for the generation of evidence that is suited both to a certain set of criteria (for evaluating research) and to the research questions in which the investigator is interested” (Bryman 2003, p.31). Research studies are guided by the choice of methodology, which in turn is driven by research paradigms concerning the nature of reality (ontology), how the knowledge about reality is understood (epistemology) and the role of values (axiology). Ontology and epistemology are branches of philosophy that try to explain the existence of knowledge. This chapter reflects on the ontological, epistemological, methodological and axiological assumptions informing the decision to utilise phenomenology in relation to the research questions. As a researcher I moved from the research question to interpretive inquiry by addressing a range of issues related to where I as the researcher was located. It is important to share how I came to this position. My ontological position is presented in this chapter which informed the way in which knowledge was created for my inquiry (its epistemology) that then led me to the most appropriate methodology, that is, how I intended to deal with data and myself as a researcher. Koch (1999) argues that researchers need to examine and articulate their ontological and epistemological position before commencement of an interpretive inquiry. While undertaking research involves constantly making decisions (Bryman 2012) developing the conceptual framework forces you to be explicit about what you think you are doing and what your own values are. It also helps you to be selective and to decide what are the important features of the phenomenon under study and hence, what data you are going to collect and analyse.

3.3 ONTOLOGY

Ontology, is the philosophical discipline that asks "what is?" and "what does it mean to be" (Heidegger, 1996). It researches the fundamental questions of being, meaning that it studies the nature of reality. Ontological assumptions form one of the most important building blocks of our worldview that are so fundamental that we rarely question them. Ontology is the study of being and is concerned with questions such as what kinds of entities exist. There is much debate over the years regarding whether knowledge for instance is experienced exactly the same by all human beings, because it exists separate to us (realists) or whether we construct it in our consciousness and it is unique for each of us (relativism). Crotty (1998) depicts the world that exists regardless of whether we are conscious of it that only becomes meaningful

when we begin to make sense of it. Constructivism is based on a relativist ontology (Lincoln, Lynham and Guba 2011; Guba and Lincoln 1994). It is based on the notion that the truth about ‘what is what’ (ontology) is socially negotiated (relativism). Indeed this ontological stance contends that knowledge cannot exist without individuals to construct it. Individuals will construct their world in a unique way, depending on their background and issues such as social influences. Traditional medical science is based largely on the objectivist or realist approach that sees knowledge as existing separately to individuals. Knowledge is therefore discovered rather than created by the individual and there is only one universal truth. This conflicts with this researchers world view that every participant is individual, and will approach their illness in their own way, and construct meaning that is unique to them (Silva 2012; Waters 2010; Guba and Lincoln 1989).

3.4 EPISTEMOLOGY

Maxwell (2004b) defines the term epistemology as the relationship between the knower and the known, referring to how we know. Crotty (1998) describes it as a way of looking at the world and making sense of it. It is distinguished from ontology (what exists, and the nature of reality) and axiology (values), as well as methodology. There is a need to identify, and justify our epistemological stance in research. Bryman (2004) argues that the choice of a particular epistemological base leads to a preference for a particular method on the grounds of its suitability. Possible epistemological stances include objectivism, constructionism and subjectivism. Objectivism holds the view that knowledge is reached through reason, understanding the world abstractly and logically (Crotty 1998). Knowledge or truth exists regardless of whether human are aware of it.

Constructivism, opposes this view maintaining that knowing is a process of actively interpreting and constructing individual knowledge (Crotty 1998, Jonassen 1991). Crotty (1998: p.9) articulates this epistemological stance as ‘meaning is not discovered but constructed’. Meanings thus can vary for people even if they experience the same phenomenon. Therefore is easy to understand why constructivism is preferred in qualitative research. The post-modern epistemological stance subjectivism can be confused with constructivism. However meaning is imposed on an object rather than meaning coming for the interaction between the subject and the object. Subjectivism asserts that all knowledge is

purely a matter of perspective starting with ideas, or knowledge of the individual mind without reference to reality. Indeed the epistemological subjectivist considers knowledge to be no more than a matter of personal opinion. The subject under study chronic illness is a relatively new concept largely due to the coming together of the discipline of medicine and the sociology of chronic illness (Radley 2009). The shift towards the view that chronic illness means living with illness in a world of health means that we need to understand illness in the context of the person's life and from their point of view. Bury (1991) talked about those that live with chronic illness being aware of their illness and their past experience and future possibilities. When illness is constructed in an objectivist way, context is notably absent, and gaps in inter-subjectivity follow. Failing to bridge this gap, will lead to chronic illness being removed from the context of thought, feeling and perception.

As the constructivist epistemology contends that object truth is not waiting to be found rather it is constructed from our engagement with reality. Meanings are constructed by humans as they engage with the world they are interpreting (Crotty 1998). Similarly in this study the researcher and the participants created the findings together through their interpretation of the knowledge. Therefore this researcher's epistemological stance is in the constructivist view of human knowledge. This influenced both the research topic and the methodology employed in this study.

While Crotty's knowledge framework appears to clearly distinguish between three epistemological positions identified above, it is important to identify that there are strong and weak versions within each position (Feast and Melles 2010). However Crotty argues that researchers must remain consistent in their chosen epistemological stance. For instance constructionist research must apply all meanings, scientific and non-scientific on an equal basis – they are all constructions, and none is truly objective or generalisable. Feast and Melles (2010) argue that being epistemologically aware requires that at each point in the research process we recognize that we make a variety of assumptions about human knowledge, that include the realities encountered in the human world and the interpretability of our findings. My epistemological position regarding this study can be formulated as follows: a) data are contained within the experiences of emerging adults growing up with a

childhood chronic illness and b) because of this I engaged with the participants in collecting this data.

3.5 RESEARCH PARADIGM

While constructivism, means that individuals are active in making and structuring knowledge (Spivey 1997) when brought into interpretive research, constructivism implies that any “discovery” of meaning of human action involves a conceptual framework in the minds of the researchers and participants (Schwandt 2001; Guba and Lincoln 1989). Interpretivism is based on the view that there are fundamental differences between the natural world and the social world (Bryman and Bell 2007). It emerged as a contraindication to positivism where a particular action produces a given result. Interpretivism acknowledges that social actors do not uniformly react to stimuli. Rather, they interpret the world in which they live and act on the basis of these interpretations. The aim of interpretivism is to understand the subjective experiences of those being studied, how they think and feel and how they act within the world they live in. The core assumption is that social actors generate meaningful constructs of the social world in which they operate. Interpretivism has evolved out of hermeneutics and phenomenology and the view of the fundamental differences between the natural (objective’ knowledge) and social sciences (subjective’ experience). Indeed Crotty (1998) contends that many thinkers would argue that findings of natural science are themselves social constructions and interpretations.

Interpretivism has influenced a whole field of research illuminating people’s everyday life experiences. This has helped researchers to understand social life from the point of view of those being studied, using methods such as unstructured interviews and personal documents or diaries. As a qualitative research paradigm interpretivism can be useful for researchers where gaining insight into the subjective experience is valued (Schwandt 2001). This study of childhood chronic illness moves away from the disciplined eye of medicine to the holistic *insider view* of illness (Neuman 2002). Taking this stance means acknowledging that living with chronic illness involves understanding it from the individuals’ viewpoint in the context of their lives. Radley (2004 p.138) argues that the “experience is woven into the person’s biography- age, point in the lifecourse, achievement of life-goals, the needs of others” and it takes its meaning in terms of how it may affect the rest of their lives. Thus to understand the

experience of emerging adults who have been previously difficult to engage in research, meant that I needed to create appropriate recruitment strategy and data collection tools. Researchers using an interpretive approach deem that the social world consist of and is constructed through meanings which can be captured in the stories told by participants. However the aim is not just to uncover meanings but also to develop new understandings of the phenomenon (living with childhood chronic illness).

Phenomenological methodologies rely on descriptions of experiences by participants to develop understanding of the meaning of human action in everyday life (Schwandt 2001; Van Manen 1990). While interpretivism contends that reality is socially constructed it argues that the goal of the researcher is to understand and therefore interpret what meanings people give to that reality. Weber termed the goal of interpretivist research *verstehen*, or “understanding.” Understanding or *verstehen* is a precondition to true interpretation. Gadamer (1975) states that *verstehen* stems from the hermeneutical philosophy. He acknowledges that interpretations are subjective and that they contain the biases and prejudices of the researcher. Additionally, we do not interpret objectively as our values and prejudgements condition our interpretations and cannot be easily put aside. Thus, understanding requires engaging with one’s prejudices and biases in the interpretation of data (see *Section 5.8 Exploring my own history*). Furthermore, it is through the act of interpretation that understanding comes (Gadamer 2008).

3.6 VAN MANEN’S LIFEWORLD EXISTENTIALS AS A THEORETICAL FRAMEWORK

Navigating the terrain of the lived experience can present difficulties in staying true to the lived experiences of participants and achieving a level of abstraction from the data in order to uncover the essential meanings of the lived experience that the participants present (Rich et al. 2013). van Manen’s four lifeworld existentials offers an interpretive a lens through which to explore the lived experience, navigate the data collected and uncover the essences of lived experience. van Manen contends that peoples’ thoughts and experiences are deeply embedded in their lifeworld (Munhall 2007). When a persons’ well-being is disturbed by illness they become acutely aware of the dimensions of their lifeworld. Through the application of van Manen’s four lifeworld existentials as a theoretical coding framework, I

present the means through which I have identified, described and interpreted the various facets contributing to the composition of the lived experience of the emerging adults within this study.

The idea of the lifeworld is essentially the world of lived experience. The everyday world in which we live and experience naturally through daily interactions and activities (van Manen, 2002). Lavery (2003) describes lifeworld and world of lived experience as what we experience before we have begun to label or conceptualise it. In this study the process of gathering data of the lived experience from the participants meant allowing a fluid interview process between the researcher and the participant, whichever method is used. This allows the process of data gathering to remain as true to the lived experiences of the emerging adults as possible (Lavery 2003). However this can present researchers with challenges of navigating quite disparate interview data, in order to uncover common themes and essences of the lived experience of living with chronic illness. In working within the particular hermeneutic phenomenological tradition I draw on van Manen's lifeworld existentials Spatiality (lived space, felt space), Corporeality (lived body), Temporality (lived time) and Rationality (lived other) as a theoretical framework to explore possible interpretations of the phenomena under investigation, the lived experience of childhood chronic illness.

3.7 CONCLUDING COMMENTS

This study was conceptualised within the interpretive paradigm. The goal of this research was to not only understand the human phenomenon of childhood chronic illness (living with childhood chronic illness) but also to develop that understanding nursing knowledge with practical value. In order to uncover the lived experience of this developmental group, emerging adults a collaborative approach was required. In an attempt to understand the experiences of *what it is like to live with a childhood chronic illness* the philosophy of hermeneutic phenomenology, the science of interpreting human meaning and experience (Gadamer 1976) was employed. The aim of applying hermeneutic interpretive phenomenology was that practical acts of living with childhood onset chronic illness, accessed through "narratives" with the participants would reveal meaning.

The goal of the study fits with the philosophy and strategy of the interpretive research paradigm. While it is recognized that interpretivist paradigm does not allow for solutions to

specific problems as positivism would, it has a role in problem solving in a broader sense, like finding the lived experience of this previously difficult to engage group. Hermeneutic phenomenology ensures the engagement of the participants in creating the knowledge needed for any change in practice. Employing van Manen's lifeworld existentials as a theoretical framework offered a lens through which to developing a deeper insight and understanding of the lived experience of emerging adults living with childhood chronic illness since childhood. Such an approach will contribute to the body of knowledge on determining core constructs in future longitudinal studies.

CHAPTER 4 RESEARCH THEORY AND METHODOLOGY

“Phenomenology is a low-hovering, in-dwelling, meditative philosophy that glories in the concreteness of person-world relations and accords lived experience, with all its indeterminacy and ambiguity, primacy over the known.” Wertz (2005, p.175)

4.1 INTRODUCTION

In this chapter, I describe the qualitative interpretive paradigm that I employed using hermeneutic phenomenology and discuss the rationale for choosing this approach for this study. In this chapter the work of Martin Heidegger and in particular the more contemporary van Manen are explored. van Manen (1990) method of analysis which informed the approach used in this study will also be briefly outlined. Following on from the previous chapter which provided the ontological and epistemological rationale for this doctoral study, this chapter acknowledges the importance of identifying what type of knowledge and knowledge process the researcher is going to create in order to match the methodology with the epistemological stance. Creswell (2007) describes qualitative research as “an intricate fabric composed of many threads, many colours, different textures and various blends of material” (p.35). This implies a certain degree of creativity and complexity involved in weaving one’s own ‘fabric’ in qualitative research.

For this doctoral study I intend to explore the experiences of emerging adults living with childhood onset chronic illness. This presented an array of complexities and challenges with recruitment and retention often associated with qualitative research (Namageyo-Funa 2014; Renert, Russell-Mayhew and Arthur 2013). However qualitative researchers are intrigued with the complexity of social interactions as expressed in daily life and with the meanings the participants themselves attribute to these interactions (Marshall and Rossman 2010). The research process that included a novel recruitment strategy, ethical issues, and the study setting are discussed. The research provided an approach that was appropriate and realisable for both recruitment and data collection with the particular demographic group in this study, emerging adults. The aim was to to engage emerging adults in this study and uncover their lived experience living with chronic illness. How the data was managed, methodological rigour and ethical issues are detailed.

4.3 PHENOMENOLOGY AND NURSING

The aim of nursing research is to build new knowledge base that strengthens the growth of the discipline (Mackey 2005). In doing this, nursing has used a wide range of methodologies from human, social and natural science to answer relevant questions (Streubert and Carpenter 1995). Phenomenology has been a popular approach used in the pursuit of nursing knowledge in recent decades because of its desire for understanding and meaning (Benner's middle range theory of novice to expert (Benner 1984) and Watson's theory of caring first published in 1985 (Watson 2012). It encourages research in the natural setting and acknowledges knowledge that is embedded in experience.

However there have been criticisms in the literature on the use of phenomenology as a methodology in the nursing studies. Crotty (1996) argued that often nursing phenomenological research seek to describe the experiences of individuals as opposed to pursuing the essence of the phenomenon, the original intention of phenomenology. Giorgi (2000b) concurs with this, declaring that there are many poor examples of the application of phenomenology nursing studies again that focus of the descriptions of participant experiences rather than the phenomena or concept itself. Indeed some criticise phenomenology for allowing exploration of the experience but not offering a way to identify the phenomenon common to individuals (Mayoh and Onwuegbuzie 2013; Langridge and Ahern 2003).

Table 4.0 Description of Methodology

Method	Key points of method	Strength of method	Limitation of method
Hermeneutic Phenomenology	Interpretive ethos Emphasis on experience Deepening understandings Uncovering meaning	Encourages research in the natural setting Produces explicit understanding of the situation under investigation Philosophy of action - radicalizes thinking and the action that flows from it" (van Manen 1984, p.2)	Sometimes criticized for not offering a way to identify the phenomenon common to participants (Mayoh and Onwuegbuzie 2013)

4.4 APPROACHES TO PHENOMENOLOGY

Phenomenology is evolving as a methodology that is not only a research approach it is fundamentally a philosophy. Phenomenology is often divided into two main streams in the literature: descriptive phenomenology drawing on the work of Husserl (1859-1938) and interpretive hermeneutic phenomenology drawing on Heidegger (1989-1976) and more recently van Manen. A major criticism of Husserl's thought is the issue of bracketing (Heidegger 1996, 2000). Bracketing assumes that the researcher can, and should, separate knowledge from experience. Heidegger a pupil of Husserl's challenged this assumption. Heidegger claimed that a person cannot be separated from the world, known as a Being-in-the-World. Meaning is co-developed through our shared human experiences. Heidegger believed it was not possible to bracket experiences, but rather, through reflection, we should be aware of our assumptions and worldviews.

In more recent years contemporary phenomenologists have agreed that cultural and social context is important in the understanding of phenomena like the illness experience (Benner 2000; Caelli 2000). Whereas traditional phenomenologists Husserl and Heidegger were critical of the effect of culture on phenomenon under study (Caelli 2000). Within the nursing field Benner and Caelli recognised this change in philosophical thinking, that researchers cannot think "aculturally" Caelli 2000, p.371). While Crotty (1996) argues that nursing research should not claim that they are influenced by the traditional phenomenologists if they are using contemporary phenomenology approaches, Caelli argues that both approaches have value for nursing knowledge where understanding the lived experience is paramount. Hence this study is inspired by the writings of Martin Heidegger and the more contemporary van Manen.

Hermeneutic phenomenology, sees the person holistically, as a being always fully engaged with the world. The lives of people are influenced by the world they grow up in, the world they live in, the choices they make and actions. The combination of interpretative (hermeneutic) and descriptive (phenomenological) elements is summed up by van Manen "phenomenological text is descriptive in the sense that it names something and hermeneutic text is interpretative in the sense that it mediates' (1997, p. 26). Description may fall short and not elucidate the participants lived experience The meanings of lived experience often remain hidden or veiled (van Manen 2010) therefore requiring interpretation of the data in

order to accomplish the goal of the study Understanding is based on the interpretation of the phenomena rather than the description of phenomena.

4.5 HERMENEUTICAL PHENOMENOLOGY

A hermeneutical phenomenological methodology will be employed in this study. The aim is to uncover the lived experience of childhood chronic illness and the meanings emerging adults attribute to their experience, which is rooted in hermeneutic phenomenology. Heidegger's main interest was to raise the issue of 'being', that is, to make sense of our capacity and to make sense of things. Heidegger spoke of 'authentic existence' which can only come into being when individuals arrive at the realisation of who they are and grasp the fact that each human being is a distinctive entity. In the Heideggerian tradition the person is self-knowing, self-interpreting and understands a situation directly according to the meaning it has for them (Levin 1999). This will allow me as the researcher to explore not only the meaning of experiences participants offer give but the context of those experiences or events that have shaped the young adults life. As a methodology, hermeneutical phenomenology reflects the interpretative quality of the research question that underpins the study (Heidegger 1962). This provided a perspective for understanding the experiences of emerging adults living with chronic illness and a lens to view the data. To explore their authentic lives and not only what is for them 'to be' but the process of 'becoming' is valuable in understanding.

4.6 BEING AND TIME

Heidegger notion that time belongs to humans, not objects, is well documented. He refers to *Dasien* a German word for existance which literally means translates as being there (Harman 2007, 2013). Heidegger believed that it was impossible to separate oneself from the world, this he called Being-in-the-World and that we exist within our own personal and social context (Pascal 2010). Our experiences past, present and future shape our existence as human beings. Indeed an understanding of Heidegger's thinking later interpreted by Watts (2001) that we can never start anew we are always what we were before and what we are now in order to become what we strive for in the future.

Heidegger's fundamental concerns were humanistic, locating the individual within the context of their life-worlds. The application of hermeneutic phenomenology for this doctoral research is relevant as it explored the lived experience of young adults growing up with childhood chronic illness. Their past and present experiences have shaped their lives thus far and will shape future life living with their illness. This forms the basis of an interpretive, or hermeneutic, approach to phenomenology. Thus phenomenology was applied both as a research method and a philosophy that can illuminate the experiences that emerging adults had growing up and living with their childhood illness and how illness has shaped them as human beings. Just as Heidegger was concerned with the question of Being (Heidegger 1962), this study was concerned with Being an emerging adult with a childhood onset chronic illness. How they experienced their past as a child, their present life as emerging adults and how they see their future life as adults living with their chronic illness. I was primarily concerned with the experiences my participants had and the meanings they attributed to their experiences of living with illness within the context of their life-worlds.

4.7 VAN MANEN AS A CONTEMPORARY PHENOMENOLOGIST

This study was influenced twofold by the contemporary writings of van Manen. Firstly he contends that peoples' thoughts and experiences are deeply embedded in their lifeworld (Munhall 2007). When a person's well-being is disturbed by illness they become acutely aware of the dimensions of their lifeworld. Chronic illness can change their sense of space, body and time as their priorities change. Even though the participants have grown up with illness their priorities can change as they move into adulthood. At the moment when our wellness is disturbed then we discover, as it were, our own body. Therefore understanding the lived experience of emerging adults growing up with chronic illness involves exploring their lifeworld from spatial, corporeal, temporal and rational perspective. van Manen (1990, 1997) urges that these perspectives occupy the lives of all human beings irrespective of "their historical, culture or social situatedness" (p.101).

Secondly phenomenology is not a mere descriptive methodology. van Manen (1990) describes phenomenology as a philosophy of action that is concerned with deepening thoughts, that "radicalizes thinking and acting that flows from it" (p.2). Phenomenology

offers researchers a unique style of knowing that van Manen describes a 'pedagogic thoughtfulness and pedagogic tact'. Phenomenologist researchers must act sensitively towards their participants to explore what it is like to be in their world. In this instance the phenomenologist researcher wants to find the lived experience of emerging adults who have grown up with chronic illness. Thus van Manen's four lifeworld existentials offered an interpretive a lens to explore the lived experience and navigate data and uncover the essences of lived experience. However to do this researchers' must firstly explore their own history and pre- understandings of the phenomenon under study. *Section 5.1 Exploring my Own History* offers a personal view of my lived experience and the decision process taken in choosing this methodological approach.

van Manen (1990) argues that phenomenology research projects that pursue questions that seek deeper meaning, such as this study, require the act of being more thoughtful and more tactful in a particular situations. This study seeks meaning and understanding of the lived experiences of emerging adults growing up with chronic illness. There is no closure or solution rather the reader is invited to continue with their own thinking. However the new knowledge that emerges from our phenomenological understanding can influence how we act, as van Manen described with tact and thoughtfulness. This data collected from this study provides the opportunity to act with the knowledge gleaned from the phenomenological understandings of the participants lived experience. Phenomenology has been criticized for lacking effectiveness and practically usefulness. Heidegger warned that phenomenology "never makes things easier, but only more difficult" (2000, p. 12).

"Nothing comes" of philosophy; "you can't do anything with it." These two turns of phrase, which are especially current among teachers and researchers in the sciences, express observations that have their indisputable correctness [It] consists in the prejudice that one can evaluate philosophy according to everyday standards that one would otherwise employ to judge the utility of bicycles or the effectiveness of mineral baths. (2000, p. 13).

However van Manen (2007) argues that does not mean that phenomenology cannot have practical value.

Participants in this study offered different perspectives and experiences and constructed different interpretations of what it is like live with a childhood chronic illness. The dialogue, and increased understanding of the phenomena being studied that resulted, can be the foundation for improved practice for nurses and inform healthcare policy particularly in relation to transition to adult healthcare. The goal of phenomenology is to seek an understanding of the meaning of lived experience as it becomes a part of the individuals' consciousness (Groenwald 2004; Lindseth and Norberg 2004). It is not merely introspective (the process of looking under the surface at current experiences) but retrospective (looking back at past experiences). van Manen (1997) describes the ultimate aim of phenomenological research "to become more fully who we are" (p.12). By gaining understanding of the experiences of emerging adults living with chronic illness as they have lived it through reflective dialogue interactions with me, the researcher, it is both introspective and retrospective. I ask my participants who have grown up with a childhood chronic illness to *remember*, to tell me their *experience* and how they *feel* about living with illness. The phenomenology aim was to seek meaning from the lived experiences of participants in this study. The over-riding concern remained that the research design was both relevant to the research question and rigorous in its approach.

Table 4.1 Elements of the methodological approach in my doctoral research using Hermeneutic Phenomenology.

Hermeneutic Phenomenology
Exploratory, explanatory or descriptive
Focus on "How?" and "Why?"
Interpretive
Collaborative
Researchers' own values and beliefs explicit

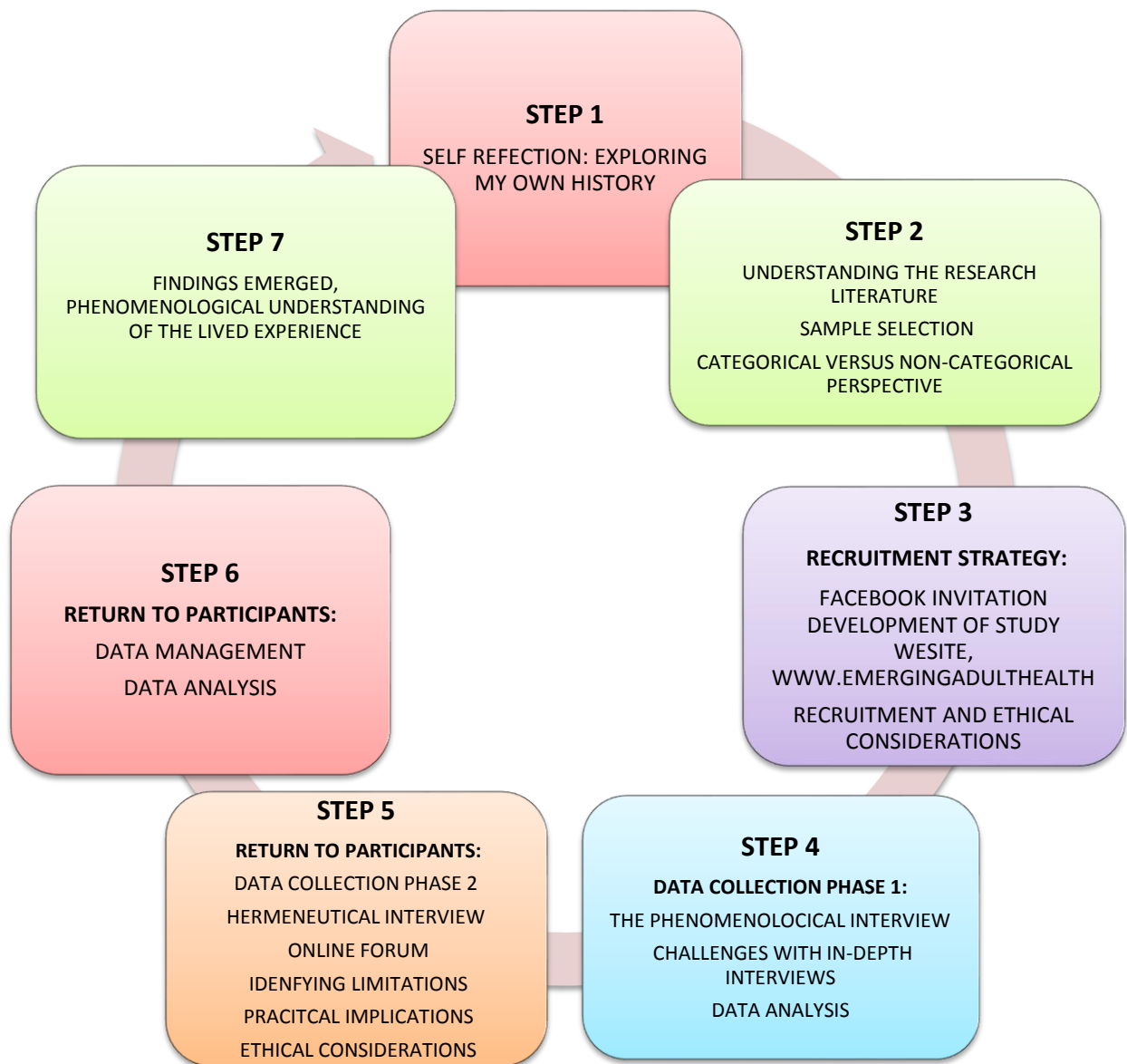
4.8 CONCLUDING COMMENTS

This chapter describes the methodological features of the study. An interpretive paradigm that employed hermeneutic phenomenology was described. The hermeneutical phenomenological approach employed was based on the philosophical perspective of Martin Heidegger and the more contemporary Max van Manen. In particular, van Manen's (1990) notion of lifeworld was used to explore the lived experience. He contends that peoples' thoughts and experiences are deeply embedded in their lifeworld (Munhall 2007). When a persons' well-being is disturbed by illness they become acutely aware of the dimensions of their lifeworld from spatial, corporeal, temporal and rational perspective. Employing hermeneutic phenomenology served the aim of the study to with engage emerging adults who have grown up with chronic illness and explore their lived experiences of living with illness and to develop phenomenological understandings into practical nursing knowledge.

CHAPTER 5 RESEARCH PROCESS

This chapter describes the research process used to conduct this study. This comprised of series of steps moving in a cyclical fashion but incorporated some back and forth movement congruent with phenomenology shown in *Figure 5.0 Research process used to conduct this study*. The research process in this study begins with self-reflection acknowledging that any understanding involves self-understanding as we attempt to understand what influences our interpretations. Therefore I examine my own pre-understandings and possible biases toward the experience of living with childhood chronic illness. Emerging adults in this study were seen as equals or actors in their own right (Bergold and Thomas 2012) and not as the problem that required a solution. The recruitment strategy presented here incorporated more than one tool in participant recruitment due to the particular needs of the target population. It was felt that traditional methods of recruitment such as mailing, newspaper advertisement and canvassing relevant locations such as clinics were possibly not going to capture the attention of this particular developmental group. Therefore sample recruitment was carried out via a social networking site, Facebook. Data was collected using both face to face in-depth interviews conducted by the researcher and an online forum. The online forum yielded benefits that included: greater access to participants, allowed participants time to reflect on their experiences growing up and living with chronic illness, provided an alternative medium in reflective writing and a medium familiar to emerging adults. The relevant ethical issues that researchers need to consider when using online medium for data collection are discussed in detail in this chapter. They informed the guidelines I used in this study. How data was managed and analysed and methodological rigour area also discussed.

Figure 5.0 Research process used to conduct this study



5.1 SELF REFLECTION: EXPLORING MY OWN HISTORY

The research process in this study begins with self-reflection. While it is acknowledged that the choice of methodology must compliment the aims of the research it should also fulfill personal aspirations and academic objectives. In phenomenology one must explore one's own ideas and orientations towards the subject. Hermeneutic phenomenologists attempt to understand the meaning from something. Moran (2002, p. 277) describes this hermeneutical understanding as:

“we grasp and interpret objects in terms of a fore-having, a ‘fore-sight’ (Vorsicht) and a ‘pre-grasp’ or ‘fore-conception’ (Vorgriff) of the thing. The relation between these advance expectations and future confirmations and disconfirmations constitutes the essence of understanding as interpreting (Auslegung).

Therefore any understanding involves self-understanding as we attempt to understand what influences our interpretations. In completing this study I examine my own pre-understandings and possible biases toward the experience of living with childhood chronic illness. Gadamer (1989, p. 277) argues that individuals prejudices make up the ‘historical reality’ of and individual far more than his judgments. An example of this possible bias occurred as the participants related their experiences of being labeled with their illness. I felt a connection with the emerging adults that stemmed from my own experience of being labeled an ‘asthmatic’ at school. This experience could have contributed to some bias in my study. However, my label as ‘sick’ or ‘asthmatic’ may have proved more of a strength than a liability. Self-disclosing my illness to the participants raised the possibility that they view me as a compassionate listener thus enabling me to draw out detailed narratives from participants and convey a sense of “emotional credibility, vulnerability, and honesty” that has been valued in creative social science work (Ellingson 2009, p. 154). While there is criticism in the literature regarding researchers’ self-disclosure with participants (Karnieli-Miller, Strier and Pessach 2009) if it is carried out to exploit or manipulate participants. However in this case the motive was a commitment to the re-distribution of power with participants in data collecting. *Appendix 9* reflects excerpts from the blog research tool set up to record my Reflections of researching the lived experience at www.emergingadulthealth.blogspot.ie.

5.2 UNDERSTANDING THE RELEVANT LITERATURE

Even with moves towards a holistic view of health and illness there is general agreement in the literature that chronic illness continues to cause significant morbidity and mortality, and can result in poorer quality of life for many young people. In Ireland this places a considerable burden on both the population and health services and is set to rise with population growth and lifestyle risk factors. The Institute of Public Health in Ireland report a rise in chronic illness of around 40% by 2020 (Balanda, Barron and Fahy 2010). Vulnerable populations such as those with illness can suffer from changes in support leaving them to navigate to adulthood healthcare with less supports (Osgood *et al.* 2005). Emerging adults seem to fare worse than other developmental groups in many areas including maladaptive behaviours and poor illness management that can lead to on-going complications (Scal *et al.* 2008; Park and Irwin 2008). This there is a need to better understand how the care given to young people with chronic illness could be translated into delayed or impeded entry into adulthood (Aujoulat *et al.* 2006).

Beginning with a critical examination of the literature in relation to the lived experience of growing up and living with childhood chronic illness, I identified a gap in qualitative studies exploring the experiences of emerging adults who have grown up and live with a childhood onset chronic illness. While longitudinal studies have provided information that is vital for health professionals to better understand this group, further investigation from a qualitative perspective is needed. A paucity of evidence lies in the need to elicit the experiences of young people with chronic illness (Wedgewood *et al.* 2008; Steinbeck *et al.* 2007; Beresford 2003). Watson (2005) argues for research to be carried out on viewpoints of young people who have already transferred to better inform the transition process. Accurate information regarding the ability of emerging adults living with a chronic illness since childhood and how they integrate it into their lives is clearly necessary to facilitate new models of chronic illness. The gap identified in the literature review supports the aim and purpose of this study outlined in Chapter 1.

5.3 SAMPLE SELECTION

A purposive sampling strategy was used to select participants who had experienced the specific phenomena concerned and provide a rich and in-depth description of their experience

of having a childhood chronic illness. This type of sampling permits the selection of participants whose qualities or experiences permit an understanding of the phenomena in question, and are therefore valuable. Eligibility was confirmed using a definition of chronic illness which refers to conditions that require on-going monitoring and management to prevent or minimize mortality, morbidity and disability (Wedgewood 2008) and will be based on self-identification of having a chronic illness since childhood. This is the strength of purposive sampling. In a phenomenological study two principal criteria exist for eligibility, having experienced the phenomenon, and willingness to talk about that experience to the researcher (Thomas and Pollio 2002). The inclusion criteria for this study were:

1. Emerging adults aged between 18 and 25 years living in Ireland with a childhood chronic illness and needing regular care were the selected population in the study. Researchers completing doctoral studies often do not have the luxury of continuing the sort of open-ended research that saturation requires. This researcher was guided by research on sample size in phenomenology (Creswell (2000) five to 25; Morse (2000) at least six). However I was also cognizant of fact that the study is large enough to ensure that the data is defensible. LoBondo-Wood and Haber (1998) argue that results based on a small sample (under 10) tend to be unstable so for this reason a sample of 15 young adults will be invited to participate in the study. However the researcher remained aware of data saturation, and the issues that affect it, in relation to the study. Morse (2010) argues that doctoral students carrying out qualitative research should have an understanding of the concept of saturation so that they can make properly informed decisions about guiding the fieldwork and eventually closing the analysis.
2. This study examined chronic illness from a non-categorical stance however generic mild conditions such as seasonal allergies or mild asthma may not have the same effects as more severe conditions and may weaken the detected effects of chronic illness on young adult outcomes. A diverse sample would provide a broader range from which to distill the essence of the phenomenon of chronic illness. Therefore in this study participants were drawn from a mixed population and not a single illness type.

5.4 CATEGORICAL VERSUS NON-CATEGORICAL PERSPECTIVE

Much of the research examining children's experiences (Amer 2008; Angstrom, Norberg and Jansson 2008; Savage and Callery 2007; Reid et al. 2004; Sartain, Clarke and Heyman 2000) and adolescents (Ivey, Wright and Dashiff 2009; Taylor, Gibson and Franck 2008; Huus and Enskar 2007; Beaune and Forrest 2004) experiences and perceptions of living with chronic illness have found commonalities in themes to lessen the burden of chronic illness. In addition changes in nursing paradigms have shifted the focus to the young person with an illness rather than the illness itself. Therefore this study will explore from a non-categorical approach and not from disease specific illness.

Young adults with a variety of chronic illnesses may have very different experiences about their illness due to length and frequency of hospitalisations, urgency of decisions and certainty or uncertainty about their illness. The body of research on chronic illness has evolved over the last two decades. Indeed the study of chronic illness as a separate theoretical entity unto itself is still relatively new. Much of the studies concerned with chronic illness limited their inquiries into distinct disease categories (Kiviruusu, Huurre, Aro 2007; Badlan 2006; Geddes *et al.* 2006; Gabe, Bury and Ramsay 2002). However over three decades ago Stein and Jessop (1882) argued for a change in direction to a broader view of chronic illness so that researchers can explore commonalities such as characteristics, attitudes, behaviors and experiences living with childhood chronic illness. This they argued would not only facilitate building the empirical knowledge but also aid service planning and delivery. More recently studies are linking their findings with those that might be relevant to other chronic diseases (Taylor *et al.* 2008). This move towards exploring chronic illness with a diverse sample of illness should provide a broader range from which to distill the essence of the phenomenon of chronic illness. The inclusion of several conditions will enable the examination of data from this non-categorical perspective. Based on the literature and my knowledge of this particular population, emerging adults I developed a recruitment strategy. The aim was to incorporate participant friendly tools to capture the attention of participants into the recruitment strategy. Cognisant that emerging adults with chronic illness are a vulnerable group in society I explored recruitment tools with a collaborative approach.

5.5 RECRUITMENT STRATEGY

Web 2.0 social media tools such as Twitter, Facebook, Flickr and Blogger are now integrated into the daily lives of young adults. Therefore researchers should consider using these new methods in order to capture their attention and engage with them via a medium with which they are familiar and spend increasing amounts of time. Further Namageyo-Funa *et al.* (2014) maintains that researchers should incorporate more than one tool in their participant recruitment and that they should be familiar with their target population. Traditional methods of recruitment such as mailing, newspaper advertisement and canvassing relevant locations such as clinics were possibly not going to capture the attention of this particular developmental group. Much of the available research into chronic illness experience seems to have been done on populations accessed through outpatient clinics (Stam *et al.* 2006; Thorne *et al.* 2004). This may suggest that convenience rather than theoretical or demographic interests play a role in determining the samples that are most commonly represented in the research literature. Moreover as the evidence suggested in *Section 2.7.1 Inbetweenness and Childhood Onset Chronic Illness*, emerging adults with chronic illness often have infrequent or indeed complete lack of follow up care following their transfer to the adult setting. Therefore there is a high probability that they are not represented in research studies on chronic illness. The recruitment strategy therefore included advertisement via social media and development of a study website.

5.5.1 FACEBOOK STUDY INVITATION

Sample recruitment was carried out via a social networking site, Facebook (<http://www.facebook.com>). The motive for choosing this form of recruitment was twofold. Internet access is higher amongst young people (16–24 years) (DeBell 2006) and social networking applications such as Facebook are increasingly being used to recruit participants for experimental, survey, interview and ethnographic studies (Fisher *et al.* 2010). Within the field of health the Internet has been increasingly used to facilitate health research (Baernholdt and Clarke, 2006; Kralik *et al.* 2006) in particular psychology and medicine. However nursing has been slower to embrace the Internet as a tool for either research or sample recruitment. Facebook and other social networking sites could provide nurse researchers with a great opportunity to recruit study participants.

Thus sample recruitment strategy begun with an advertisement placed on the social networking site, Facebook (See Appendix 2). The advertisement included a clear indication that it was a request to participate in the study from the researcher and that participation is entirely voluntary. The advertisement campaign in Facebook involved the following steps:

1. Setting up an account with www.facebook.com.
2. Following this I logged into the Facebook website and clicked on the Create Ad tab.
3. The advertisement was created using the information in Appendix 2
4. Within the Ad Manager tab I chose the spend limit (no more than 10 eur per day) and the chose the target audience of young adults between 18 and 25years living in Ireland for the advertisement.
5. The Ad Manager tab allowed me to check activity on the advertisement and view how many people clicked through into the advertisement see below. The ad resulted in 421,181 impressions with a reach of 100,379. Of the young adults reached 131 young adults clicked on the advertisement (0.031% click through rate). 23 young adults made contact via email however some of the participants were not eligible for this study and 15 young adults were finally recruited to the study.

Young people who fit the criteria were redirected from the Facebook advertisement to the secure study website www.emergingadulthealth.com set up by the researcher. The website contained details of the study and what was involved for participants. Social networking sites such as Facebook offers an innovative way for researchers to recruit participants for research studies. Moreover participants could view the study website and details of the project and access a biography of the researcher. Fisher *et al.* (2010) urge that this can level the playing field between the researcher and participant where the researcher is no longer behind the one-way mirror. The motive for choosing this form of online recruitment is twofold. Firstly more than half of young people use social media sites with most logging on daily (Balfe, Doyle and Conroy 2012) with Facebook being the dominant social media site at the time of this study and secondly Internet access is higher amongst young people (16–24 years) (DeBell, 2006). Social networking applications such as Facebook are increasingly being used to recruit participants for experimental, survey, interview and ethnographic studies (Fisher *et al.* 2010).

5.5.2 STUDY WEBSITE

Secondly a study website www.emergingadulthealth.com was developed to provide study information for possible study participants. The aim of the study website was to establish legitimacy for potential participants to consider taking part in the study. James and Busher (2006) argue that engaging in web based research, researchers need to consider different ways to build trust and rapport. As a strategy of visibility, the study website included the following:

- **Meet the researcher:**
- Biographical sketch of the researcher
- Photo of the researcher
- **Study information:**
- Details of the research project
- Confidentiality: Identities of participants treated as confidential and used only for research purposes
- Voluntary: Participation was voluntary and participants had the right to leave at any point during the study.
- The likely time commitment from participants

Participants in this study appeared to value this experience. Participants noted:

“I like the idea of seeing if it was legit first and what was involved I read the info on the study too just to make sure I was eligible [P2; 2013]

“It was easy to follow from the advert just clicked into the link and I got all the information without asking a question” [P15; 2013]

This strategy of visibility further promoted collaboration between the researcher and the participants where this less powerful group in society had the opportunity to explore the aims and objective of the study before making any commitment. Following the recruitment phase of the study, 15 emerging adults aged between 18 and 25 years with a childhood chronic illness living in Ireland and needing regular care were invited to participate in the study. Kvale (1996, p.165) argued that when researchers consider the common question of how many participants to include in a study the simple answer is to “interview so many subject

that you find out what you need to know”. Englander (2012) contends that realistically researchers should consider that the number is not relevant in qualitative research as that is a quantitative concern. The aim in phenomenology research is not to produce research that is representative of the population (van Manen 2007). Indeed much of the foundational research in the field of nursing has been conducted with small numbers of subjects.

5.6 RECRUITMENT AND ETHICAL CONSIDERATIONS

At each step of the recruitment and data collecting phase researchers are responsible to protect the participants of the study. Lo Biondo-Wood and Haber (2013) identified three basic ethical principles to guide all research studies that include: respect for persons, beneficence, and justice. The principle of respect for persons signifies that persons had the right to self-determination and the freedom to participate, or not to participate in research (Lo Biondo-Wood and Haber 2013; Burns and Grove 2001). Beneficence is described as an obligation to do no harm and maximise the possible benefits for participants of research study (Lo Biondo-Wood and Haber 2013). The principle of justice implies that human beings should be treated fairly during research studies (Lo Biondo-Wood and Haber 2013). These principles were upheld throughout all stages of this doctoral research project. Ethical approval was sought and granted from the university Research Ethics Committee³. Pseudonyms were assigned to each participant prior to the interview phase and participant numbers for the online phase of data gathering. Care was taken to ensure that those participants who logged onto the study website but did not wish to take part in the study could easily exit the web page. Once participants gave their verbal and written consent to participate in the study they were invited to join the online forum as authors. Only the researcher and the moderator had an administration role on the online forum.

5.7 DATA COLLECTION 1: THE PHENOMENOLOGICAL INTERVIEW

The interview is considered the main method of data collection in qualitative research as it provides a situation where: participants’ descriptions of experiences can be explored (Kvale and Brinkmann 2009; Kvale 1983, 1994) and it fosters interaction and it allows feedback (Mason 2010; Meho 2006). Phenomenological researchers tend to choose the interview due to their interest in seeking the meaning of a phenomenon as it is lived by participants. I was

³ See Appendix 4 Informed consent form.

influenced by Englander (2012) who argues that phenomenology researchers need to be clear in their research process that data collection and data analysis are both seen as part of a single, unified process.

The first stage of data collection included a phenomenological interview which was conducted at a time and place convenient to the participants. Interviews took place in a range of places including cafes, the participant's college library and in some cases the home of the participant. However there were challenges in sourcing a suitable location for interviews which are discussed in *Section 5.7.1 Challenges with in-depth interviews*. The study relied on participants to recall their experiences past and present. Hermeneutics is concerned with identifying, describing and interpreting experience (Morse 1991; Benner 1985). Interviews took between 60 and 90 minutes with each participant. As the interviewer I asked the participants for a description of a situation in which they had experienced the phenomenon. This is vital in phenomenology where the aim is to uncover the meaning of the phenomenon (Englander 2012). Participants were encouraged to reveal their experiences and recollected moments of what it is like live with a childhood chronic illness. Unlike other qualitative methodologies, phenomenology is not concerned with opinions or views of the phenomenon (Adams 2014). When participants veered towards offering their viewpoint on the phenomenon, I encouraged stories and accounts of specific moments to maintain the intent of the interview. This dialogue, and increased understanding of the phenomena being studied that results, can be the foundation for improved practice for nurses. The goal of phenomenology is to seek an understanding of the meaning of lived experience as it becomes a part of the individual's consciousness (Groenwald 2004; Holloway 1997, Kvale 1996). It is not merely introspective (the process of looking under the surface at current experiences) but retrospective (looking back at past experiences). van Manen (1997) describes the ultimate aim of phenomenological research "to become more fully who we are" (p.12). By gaining understanding of the experiences of emerging adults living with chronic illness as they have lived it through reflective dialogue interactions with me, the researcher, it is both introspective and retrospective. I asked my participants who have grown up with a childhood chronic illness to *recall* and to tell me their *stories* about living with illness.

In this research I presented myself as the interviewer/listener and asked participants to give accounts of their experience of having childhood chronic illness. Rarely in phenomenological

studies do we ask the phenomenological question *What is the lived experience....?* Instead we use probing questions to encourage the participant to elaborate on the details to achieve clarity and to stay close to the lived experience. In this study field notes were used to record emotional responses and the conditions of the data collection. Interviews began with open-ended questions, such as “Can you describe a time, particularly one that stands out for you, because it reminds you of what it means to live with chronic illness?” Further probing took the form of “Describe what that means to you?” or “What has that been that been like for you?” Ironside *et al.* (2003) recommend this type of questioning in hermeneutic phenomenology to keep the participants engaged in their stories without directing them to particular aspects or events. These interviews were audiotaped and transcribed verbatim for analysis (see Appendix 12 Example of Interview Transcripts). This resulted in a series of recollected events described by the participants.

The skill of the interviewer can effect on the quality of data collected (Morse 2008). Therefore in addition to having an interest in the topic area, this researcher gained both training and experience in such as reflection, clarification and listening skills. In addition I attended qualitative creative interview technique workshops with both David Morgan and Vanessa May (Qualitative Summer School, Dublin City University May 2011) during the course of this doctoral study. This experience was invaluable in providing insights for the skill of interviewing. These skills are valuable in phenomenological research (Patton 2005; Seidman 2012). Life experience and maturation can influence people’s views and perspectives over time. The participants were asked to take the researcher on a journey back in time and picture in their minds what it was like growing up with chronic illness from earliest memories to current experiences. Interviews were audio-taped and data was transcribed verbatim by the researcher. Since this study employed a non-invasive approach to data collection it was anticipated that there would no negative implications for participants. However should any participant have displayed signs of discomfort or distress following an interview or during the online forum the researcher was guided by the research on ethical issues in relation to in-depth interviewing (Appendix 6) (Johnson 2002; Boyce and Neale 2006). Participants in this study were informed that should they withdraw from the study they will have a right to require that any data pertaining to themselves, including any recordings, transcriptions and online postings could be removed and deleted at their request.

5.7.1 CHALLENGES WITH IN-DEPTH INTERVIEWS

Interviews offer the researcher an opportunity to explore the lived experience of participants by enabling them to narrate their experiences and understandings. Despite their popularity in phenomenology research, challenges exist that include cost, time, access to research participants (Denzin and Lincoln 2005; Patton 2002, 2005; Gubrium and Holstein 2002; Strauss and Corbin 1998; Kvale 1996), issues of power (Nunkoosing 2005) and sensitive subject matter (Schulman-Green *et al.* 2009) that can be demanding for both researchers and participants. Moreover Nunkoosing (2005; p.705) argues that the problem with interviews “is assuming that what is talked can be an exact replication of what is lived and experienced”. Researching the lived experience requires more than telling stories the researcher must also address how the stories are told. Traditional methods like interviews can sometimes fall short of providing full expression to the lived experience. Another problem can be that emerging adults with illness may not feel confident enough to discuss their experiences or may not have the capacity due to their illness. Nurses should consider alternative data gathering techniques in order to give a voice to the more vulnerable. How else will their stories be told?

Therefore following the in-depth interviews I reflected on the methodological issues around interviewing. In this study the two main challenges with interviewing participants included: suitable location and time to reflect. Participants were less likely to take part in the study if the location was not convenient. In addition access to locations for interviews with emerging adults, became limited. Many of the participants lived in their family home and did not want to be interviewed where their parents or siblings may be present. Some opted for public areas such as a café which proved difficult. In a study Namageyo-Funa *et al.* (2014) reported challenges in conducting qualitative research in public areas and highlighted issues such as noise and opening times for the research. I was reluctant to hold interviews in my workplace office in case it adversely affected the researcher-participant relationship needed for the phenomenological approach of this study.

Moreover the literature contends that online resources could provide an environment for research participants’ that safeguards against possible embarrassment when discussing potentially delicate issues or experiences (Im and Chee 2008; Kramish *et al.* 2001). While

participants in this study seemed to talk freely about their experiences a number of them contacted me following the interviews by email with stories they had omitted during the interview or considered later. I considered using online resources as this could facilitate the participants with a space to talk freely about their experiences growing up with illness, reduce the issues with finding location and provide an environment to allow participants to speak more freely about their experiences.

5.8 RETURNING TO THE PARTICIPANTS - THE HERMENEUTIC INTERVIEW

Returning to the participants to clarify meanings was invaluable in the data analysis phase of the study. Siedman (2012) describes a series of three interviews that characterizes the phenomenological approach originally proposed by Schuman (1981). Three separate interviews are encouraged each ascertaining different aspects that include: life history, details of experiences and finally reflections on meanings. The online forum provided access to return to the participants with ease and at their convenience to clarify understandings from participants and replaced the second and third interview with participants. Returning to the participants to clarify meaning and understanding is often termed the hermeneutic interview. Following my experiences with the phenomenological interview I chose to use an online forum to gather data in the hermeneutic interview. As this research study focused on the meaning of the lived experience of emerging adults, collecting data in naturalistic settings where context is essential as opposed to contrived situations was important. The Internet has become so ensconced in daily life that the line between online and offline communication has blurred. Indeed researchers have argued that methodologies should capture participants lives both online and offline (Boyd 2008). With over 2.7 billion Internet users in the world (www.internetworldstats.com/stats.htm accessed 22/08/2013) new modes of communicating with research participants need to be explored. In the last decade new technologies have begun to challenge researchers to consider the Internet and in particular Web 2.0 technology because of the interactive and collaborative capability as a medium for qualitative research.

The phenomenological research approach facilitates exploration of a phenomenon within its context using a variety of data sources. This offered an opportunity to gain insight into the topic (Baxter 2008; Creswell 2003). Creswell (1998) asserts that the process of data collection and analysis is fundamental to a phenomenological approach; first, the researcher

explores experiences as told by the participants and identifies significant statements; the statements are then advanced into meanings, which are then clustered into common themes. While the phenomenological interview allowed participants in this study to fully expand on their experiences, the online forum (Hermeneutic interview) provided an opportunity for individuals that have had a similar experience to share ideas with the researcher (Creswell 1998). Onwuegbuzie *et al.* (2010) urges that postmodern interviews and focus groups be extended to include ground-breaking media such as social networking tools. Young people who use social media routinely share personal information and stories in cyberspace, these individuals might be more comfortable participating in research via the Internet. Using innovative approaches such as this online forum as a method of data collection can move nursing research towards a period of methodological innovation, in which qualitative research goes beyond the traditional ways of collecting data. Phenomenological understanding is more likely to come through prolonged interaction. In this study the online forum allowed participants to construct their own experiences using dialogue which offered them more control of the flow of the interaction (Bowker and Tuffin 2004).

Moreover the age profile of the participants of this study are the highest proportion of Internet users. Similar to other EU countries Ireland reports that 16 to 34 years olds account for over 80% internet users (Central Statistics Office 2008). However it is vital that researchers select a medium that fits with the research goals and not slavishly adapt current qualitative methods of data collections (Clarke 2000). The aim was to choose methods that exploited the functionality of the chosen medium while minimizing any limitations. By embracing new online mediums for collecting data, researchers must acknowledge the strengths, limitations and any associated ethical issues of privacy and confidentiality.

Table 5.0 Strengths of In-Depth Interviews versus Online Forum

	Appropriate for	Strength of Method
Interviews	Eliciting individual experiences opinions, feelings Elicits in-depth responses, with nuances and contradictions	Gets at interpretive perspective, i.e. the connections and relationships a person sees between particular events, phenomena, and beliefs Elicits information on participants experiences and perspectives in a short time
Online forum	Identifying and eliciting group norms Addressing sensitive topics Populations familiar with the online environment Discovering variety within a population Group dynamic can stimulates conversations, reactions	Convenient for participants Naturalistic stories in participants own language Effective accounts in participants own language Convenient for verifying data/understandings/interpretations of the participant experiences Provides comfortable environment for participants to discuss private thoughts and experiences Greater access to participants from wider geographical area Participants have greater control over the flow of the interaction (Bowker and Tuffin 2004)

An online forum was set up using Google docs. The participants, who met the criteria detailed in *Section 5.3 Sample selection* had had taken part in the in depth interviews, were invited to register with the online forum for a period of four months. Two participants who were unable to attend for interviews but had been recruited and consented to the study joined the forum phase of the study. An online consent form was set up using Google Docs for these two participants who consented to take part in the online forum. A secure online forum site that only the participants could log into using their usernames and passwords was set up. The participants were asked to register on the forum site using their assigned pseudonym to maintain anonymity. In total 15 participants took part in the online forum. Discussion topics such as ‘Tell me about a time when’ were posted on the forum every 3 to 4 weeks. Over a period of four months the participants discussed their experiences sometimes engaging with each other by reflecting back on a previous participants posting. The aim was to return to the participants to clarify meanings and was invaluable in the data analysis phase of the study as discussed above. There were lulls in the online conversation for a variety of reasons and are discussed in more detail in *Section 5.8.2 Online forum and practical implications*. Online forums allow participants to construct their own experiences using dialogue which allows them more control of the flow of the interaction (Bowker and Tuffin, 2004). The forum was not be led by any one participant and the researcher was conscious to minimise any steps

involved in logging in to the forum. Ground rules were established emphasizing issues of privacy and respect for other participants (Appendix 7). Participants were asked to post their response directly to the forum. The following section describes potential limitations and practical implications of using the online forum in our study.

5.8.1 IDENTIFYING POTENTIAL LIMITATIONS TO USING AN ONLINE MEDIUM IN QUALITATIVE RESEARCH

Certainly there are potential limitations to using an online medium in qualitative research. A lack of non-verbal cues, possible breaches of security issues, technological limitations and potential for offending remarks by participants are acknowledged in the literature as potential problems for researchers (Im and Chee 2006, 2012; Rodham and Gavin 2006; Clarke 2000). However the forum was checked daily throughout the study by the researcher and a moderator was available for advice. While subtle visual and non-verbal cues are missing on the online environment, there is potential benefit to providing a sheltered setting for participants to discuss private thoughts and feelings particularly in the area of chronic illness (Im and Chee 2012; Kramish *et al.* 2001). In addition peer-related experiences can also be explored within the online forum as the participants interact with each other. The forum provides a setting where participants are comfortable with self-disclosure, and where the group dynamics and synergies help participants understand why they hold the views they hold about growing up with chronic illness. It also provided an opportunity for participants' to relate to one another's experience.

Wow, your stories are all so heart-warming because they're all so relatable in one way or another even if they're all very different illnesses [P5: 2013: 2].

Linked to this is the possibility of 'flaming' messages where participants may post offending or insulting comments. Clarke (2000) argues that this requires text-based conflict management however Rodham and Gavin (2006) found that when it occurred in their research the support the participants offered each other meant that they carried on despite of the intrusion. As this research involved a closed private forum with invited and consenting participants it was felt that 'flaming' was unlikely to occur and in this study there was no evidence of flaming among participant responses.

5.8.2 ONLINE FORUM AND PRACTICAL IMPLICATIONS

While it is acknowledged that online forums have become increasingly popular in recent years as a medium for electronic data collection little is known about the practicalities of online forums in qualitative research. Im and Chee (2006, 2012) examined the practical issues related to an online forum for data collection in a cancer care study. While a high response and retention rate by participants was reported in their study they found that participants did not come to the study website that often and some participants read postings but did not engage in the discussion. Known as “lurking” this is not unusual in forums. In the UK Forrester Research (2009) suggest that 68% of 18 to 24 year olds read posts on forums and blogs but only 38% will actually comment. Similarly in an Irish study evaluated an online peer support forum and found that some participants observed the interactions on the forum without engaging in them. Both Horgan, McCarthy and Sweeney (2013) and Klemm (2012) suggest that online forums be moderated closely by researchers to improve frequency and relevance of postings to the site. Further other studies found additional problems with participants often forgetting their passwords and usernames. Thus researchers need to moderate their forums and provide technical support to participants who contact them. Thus a ‘critical friend’ employed in this study had a technology background and was able to take on the role of moderator and assist the researcher with any complex technical issues. In research studies a ‘critical friend’ tends to share a commitment to the inquiry while offer continuing support throughout the research process (Foulger 2010).

Some participants had problems accessing computers but developments in mobile phone technology provided the solution. Participants were advised during the data collection phase that they could use smart phone technology to access the forum via Google Drive application with many mobile phones now including 3G technology.

Participant 2: ‘I haven’t had access to my PC for a few days so haven’t posted my discussion yet but will do so in next few days’

Participant 9: ‘.left my computer in college is it possible to access the forum from my phone and if so can you tell my how and give the link thanks’

Access to the Internet on a mobile handheld device is becoming more commonplace. 55% of mobile phone owners now report that their phone is a smartphone (O’Keeffe and Clarke-

Pearson 2011). According to Pew Research Center's Internet and American Life Project (2013) one in four teenagers in the US access the Internet using their mobile phone and not other devices such as a desktop or laptop computer (Madden *et al.* 2013). Furthermore in Ireland the use of mobile phones for Internet use in children is above the European average (46% vs. 31%) (O'Neill, Grehan and Ólafsson 2011). By providing access via smart phone technology response rates to the online forum improved in this study with emerging adults.

5.9 DATA COLLECTION AND ETHICAL CONSIDERATIONS

Data was collected using both face to face in-depth interviews conducted by the researcher and an online forum therefore I was guided by the current research and a number ethical guidelines concerning these specific ethical considerations. They include the research on ethical issues in relation to in-depth interviewing as outlined in *Appendix 6 In-depth interviews and ethical considerations* and *Appendix 8 Guidelines for ethical practice in the online research forum in this study* (Im and Chee 2012; Rodham and Gavin 2006). In addition I followed guidelines published by An Bord Altranais 2007 *Guidance to Nurses and Midwives Regarding Ethical Conduct of Nursing and Midwifery Research*. The procedures for minimising any risk during interviewing participants, and ensuring that clear procedures are in place in case of any emergency for this study were detailed in the ethical application for this study and are outlined below:

1. Not to give personal details (e.g. home address or phone number) to participants.
2. Where possible, schedule research activities during the day or early evening.
3. Where possible, carry out research in venues where other people are around (e.g. on-campus; at the person's workplace; volunteer organisation's centre, etc.).
4. Ensure safety to and from the venue
5. Put details of where the researcher is going into a sealed envelope (to maintain participant confidentiality), and on the outside of the envelope put (1) expected time of arrival, (2) time you expect to finish, and (3) time you expect to be home. Give this to someone you can trust and are able to contact easily. Call this person before entering this venue; call again when leaving venue; and let them know you have arrived home safely. Ensure that you collect the envelope from them as soon as practicable afterwards. The envelope should only be opened by your contact person in the event of an emergency.
6. Keep a fully charged mobile phone (An Bord Altranais 2007).

Using Internet mediums for collecting data is in its infancy and in the absence of universally accepted ethical guidelines for qualitative researchers it is incumbent for researchers to consider both safety and ethical implications of using the internet to collect qualitative research data (Rodham and Gavin 2006). Kinkus (2002) referred to four areas of security in Internet data confidentiality, integrity, authentication and availability (see Appendix 8 for detail). Specific Internet ethical guidelines highlighted in the literature (Im and Chee 2006, 2012; Rodham and Gavin 2006; Clarke 2000) were used as a benchmark to guide this study. These guidelines supplemented rather than replacing the ethical guidelines of the institute (Dublin City University) and the profession (An Bord Altranais). *The Report of the Working Party on Conducting Research on the Internet: Guidelines for ethical practice in psychological research online* published by The British Psychological Society (2007) highlight 10 relevant ethical issues that researchers need to consider when using online medium for data collection. They informed the guidelines used in this study.

Kinkus (2002) referred to four areas of security in Internet data confidentiality, integrity, authentication and availability:

Confidentiality refers to whether the information can be accessed by unauthorized individuals. The data collected from the online forum were protected in the same manner as all other data (Interview transcripts). All computerised data and information was stored in a computer accessed only via a coded password. The data and participant information was stored for the duration of the study, i.e. until the work is fully reported and disseminated in the form of the doctoral thesis and will be deleted/destroyed accordingly. The online forum in this study did not have public access and was accessed by participants using a username and password. Participants were asked to register on the forum site and use a pseudonym to maintain their anonymity. Participants who agreed to take part in the study were invited to join the online forum by the researcher and pseudonyms of participants were assigned by the researcher. Participants often use the same pseudonyms as their individual identities across many online environments (Hudson and Bruckman 2005) therefore to protect participants these were assigned by the researcher in the form of P1, P2 and so on. The researcher discussed the boundaries of confidentiality and anonymity with each of the participants and obtained their agreement that no information will be revealed that can be attributed to a specific individual, institute or allow identification of a participant.

Integrity refers to whether the information on the forum can be protected from interference. Im and Chee (2006) found both potential viral infection and hacking attempts in their study using online forums with cancer patients. Thus the priority in this study was to ensure that software including the firewall was installed and regularly updated.

Authentication refers to whether participants are who they say they are within the forum. While this issue has been raised frequently in the literature researchers argue that the in-depth nature of qualitative research requires an understanding of the topic that would be difficult to preserve beyond initial encounters (Im and Chee 2012; Mann and Stewart 2005). In addition keeping the forum private with only those who were invited and had consented to take part in the research may help to eradicate the problem in this study.

Availability raises the issue that resources must be made available to authorized parties. All participants would need access to the Internet and be able to navigate the Internet. It is important for researchers using online mediums to collect data to be aware of current trends in online activities. 77 per cent of Irish internet users now use mobile devices (phones,

tablets and netbooks) as the preferred choice for younger demographic groups to access the internet, compared to a global average of 69 per cent (<http://www.socialbakers.com>). Ensuring access to the online forum via a smart phone was a priority in this study. In a recent Irish study evaluating an online peer support forum Horgan, McCarthy and Sweeney (2013) urged that smart phone access using applications should improve retention for participants. The following table illustrates the guidelines for ethical practice in the online research forum in this study.

Table 5.1 Guidelines for ethical practice in the online research forum in this study.

Verifying Identity	- the forum is private with only those invited and consented to take part in the research.
2. Public/Private space	– continuously aware of perceived risks to Internet research acknowledging the changing nature of internet technology.
3. Informed Consent	– participant autonomy was protected by using the process of informed consent. The study website contained full detailed description of the study and contact number/email of the researcher was available should participants have any questions.
4. Level of Control	- a balance between moderating the site on a daily basis to avoid any confusion for participants and facilitating a non-intrusive environment was maintained.
5. Withdrawal	– participants had the right to withdraw at any point during this study and without incurring any penalty.
6. Debriefing	– since the study employs a non-invasive approach to data collection it was anticipated that there would be no negative implications for participants. However if any participant display signs of discomfort or distress during the online forum process the researcher offered participants the opportunity to discuss spend time debriefing as close to the incident as possible. The researcher was sensitive to the fact that the interview could have raised uncomfortable issues/feelings for the participants and therefore observed participants closely throughout the data collection process.
7. Deception	- <i>Authentication</i> refers to whether participants are who they say they are within the forum. While this issue been raised frequently in the literature researchers argue that the in-depth nature of qualitative research requires an understanding of the topic that would be difficult to preserve beyond initial encounters (Im and Chee 2013; Mann and Stewart 2005).
8. Monitoring	-ground rules were established with participants at the beginning of the study. Careful monitoring of online interactions.
9. Protection	- forum was checked daily by the researcher and the moderator was available for advice.
10. Data protection	- regular updating internet security software including the firewall installation which was regularly updated.

5.10 DATA MANAGEMENT – ONLINE FORUM POSTS

Within the online forum the posts are multimedia texts presented in chronological order. Participants could add hyperlinks however the researcher focused only on the written textual aspects of the posts. In order to manage the data, the researcher will convert the posts into text files so that they can be easily imported into the version of Microsoft Word for analysis. While the absence of non-verbal cues is lost in online data collection (Hewson *et al.* 2003: Rodham and Gavin 2006) new computer jargon such as ‘smiley’s’ can be defined and incorporated into the coding process as non- verbal cues from participants. In addition Rodham and Gavin (2006) argue that the automatic transcription of data with online forums increases the accuracy of the data by reducing human error and therefore increasing validity of any findings. Once themes were identified in the phenomenological interview I was able returned to the participants to follow up with this interpretive process in the hermeneutic interview which in this case was conducted as an online forum. This led to the discovery of essential themes and understandings described in the following chapter.

The purpose of the data analysis was to identify the relational themes and patterns present in the data that uncover the meanings common to the lived experience of chronic illness among young adults. In place of a reflexive journal a blog was set up and maintained by the researcher as a research tool [www.emergingadulthealth.blogspot.ie] This enabled the researcher to describe and interpret the experiences throughout the study (Koch 1996, 2009) in order to appreciate how the research reached the findings or conclusions of the study. Use of blogging is emerging as a research tool for qualitative research during fieldwork. The benefits include encouraging the researcher to write regularly engaging with the data and encouraging regular feedback not only from limited scholarly circles but the wider public audience (Saka 2008). [Reflexive journal blog:

Transcribing:

I am finding the transcribing process very arduous work however I realise I am developing familiarity with the data I might not have otherwise had. I start transcribing the interviews the same day that the interview had taken place, and although a slow tedious process, it does help with recalling my participants body language used, tone of voice, pauses and periods of silence to be recorded on the data sheet.

Posted by Siobhan MacDermott at 02:38

I was also cognisant of voice, expression and listening in interviews with participants and the translation of their style into a written text. The oral style and written form should have harmony and be representative of the interviewees' "habitual modes of expression" (Kvale 2008, p. 133). I transcribed each audible sound such as, "Um," "Ah," and "soft laugh;" the frequently stated expression "you know," and times of silence in the interview as, (pause). I regarded these transcriptions as "the truth."

5.11 DATA ANALYSIS

The methodology of phenomenology requires a cyclical process known as the Hermeneutic Cycle that involves going back and forth between the parts and the whole text until meaning occurs, free from inner contradictions (Kvale 2008; Koch 1999) described in detail in Chapter 7. This study involved a series of "back and forth," encounters that invariably moved me as the researcher more deeply, and with emerging clarity, into the lived experience presented by the participants. There was a continuous cycle of listening to data, reading the literature and writing. Themes were identified and developed across the participant narratives. The final data analysis stage involved a three strand approach that included the reading process (holistic, selective and detailed reading of the data), followed by the existential investigation of the phenomena (van Manen 1990) and the Hermeneutic Cycle. Themes emerged from this study incorporating phenomenological understanding of the lived experience describing the universal essence of the phenomenon. See Chapter 7 for a detailed discussion.

5.12 METHODOLOGICAL RIGOUR

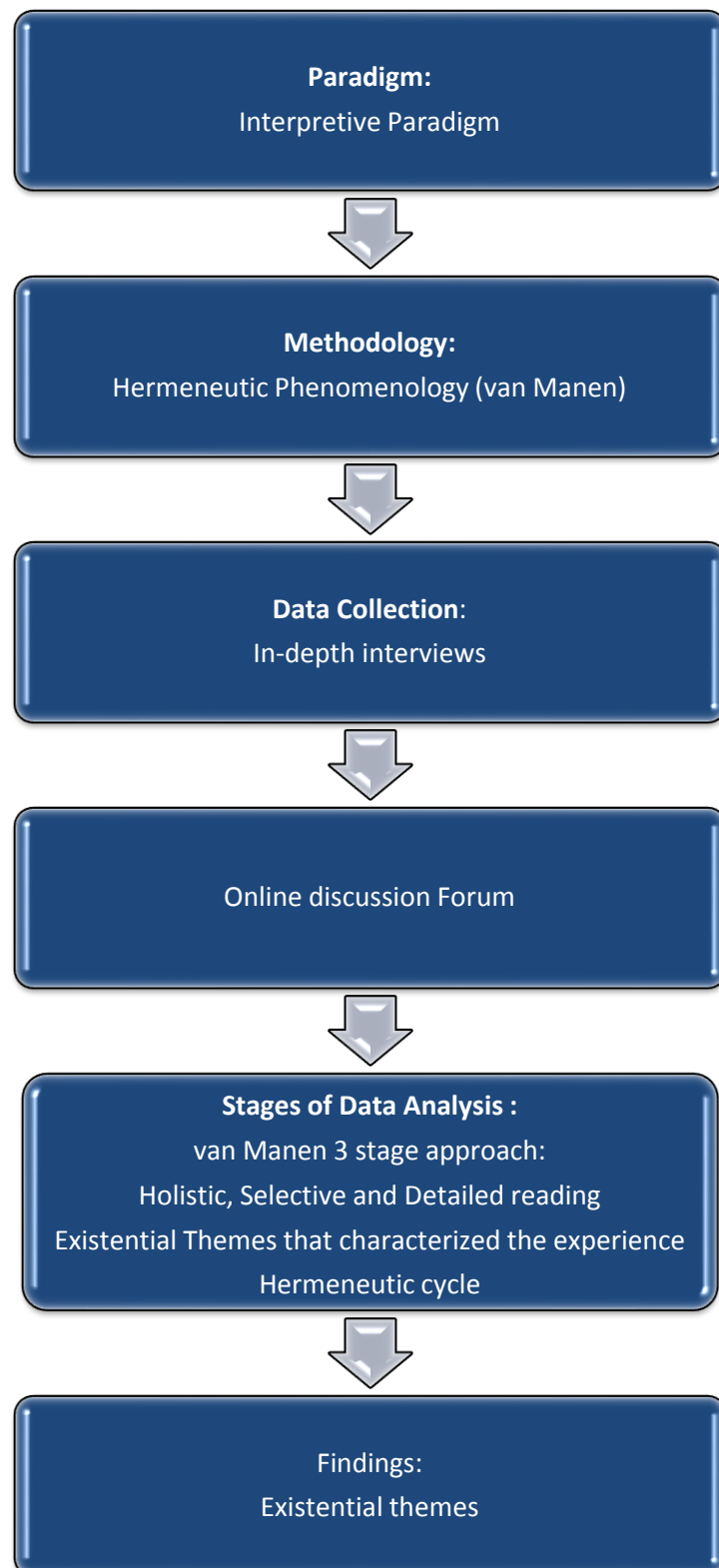
To ensure the robustness of a study, qualitative researchers need to be explicit about the decisions throughout (Tobin and Begley 2004). While terms of validity, reliability and generalisability are associated more with the positivist paradigm, emerging terms such as trustworthiness, confirmability and credibility (Sandelowski 1986) are associated with naturalistic inquiry. However there is a lack of consensus about expressions of rigour in interpretive phenomenological studies (Maggs-Rapport 2001) and specifically in nursing interpretive phenomenological studies (deWitt and Ploeg 2006). There is debate about whether the criterion of credibility is suited to the ‘deeper’ meanings associated with interpretive phenomenology (deWitt and Ploeg 2006; van Manen 1997b). deWitt and Ploeg (2006) argues that the reader in interpretive phenomenology is not just charged with recognising the experience of the phenomenon but also to ‘feel’ the experiences which credibility fails to encapture. van Manen calls this the epiphany where the researcher grasps the experience. Moreover the criterion of ‘confirmability’ as an expression of neutrality and free from bias in qualitative research is controversial in interpretive phenomenology which is not neutral or value free (Morse *et al.* 2002). This has implications for the legitimacy of knowledge within disciplines and in this case nursing. deWitt and Ploeg (2006) proposed a new framework specific to interpretive phenomenological nursing research that include terms like balanced integration, openness, concreteness, resonance and actualization. This framework has provided a means to articulate the expression of rigour specific to this study. The decision trail is weaved throughout this interpretive phenomenological study and is summarized in Appendix 10.

5.13 CONCLUDING COMMENTS

The research process used to conduct this study comprised of series of steps moving in a cyclical fashion but incorporated some back and forth movement congruent with phenomenology. Participants in this study were seen as equals or actors in their own right (Bergold and Thomas 2012) and not as the problem that required a solution. To summarize, a purposive sampling strategy was used to select participants who would provide an in-depth description of their experience of growing up and living with chronic illness since childhood. A combination of methods was used to elicit data. Data was collected using both face to face in-depth interviews (Laverty 2003; van Teijlingen and Ireland 2003) conducted by the

researcher and an online forum (Im and Chee 2008). In this study the online forum yielded benefits that included: greater access to participants, allowed participants time to reflect on their experiences growing up and living with chronic illness, provided an alternative medium in reflective writing and a medium familiar to emerging adults. Online forums can aid researchers to access previously difficult to engage participants and provide an environment for greater disclosure of personal information (Bowker and Tuffin, 2004). Participants may be able to express themselves better in writing than talking and while the opposite could be true, providing a combination of methods can overcome this. van Manen's (1990) phenomenological approach to qualitative research methodology in education is based on "textual reflection on the lived experiences and practical actions of everyday life with the intent to increase one's thoughtfulness and practical resourcefulness or tact" (p. 4). Therefore the practice of reflective writing is central to phenomenological research. By illuminating the lived phenomena, we reflect on experiences already past. Writing offers the opportunity to externalise the internal. It can distance us from the immediate life experience thus and creating a reflective cognitive stance. Providing an online data collection method enabled participants in this study to be relatively unselfconscious in their narratives because of the 'hidden from view' nature of the online forum. Bradley (2005) highlights the feeling of empowerment that young people experience by the "different boundaries offered by the communication that happens online.....and the fact that the communication happens in a peer community" (p.63). With traditional techniques such as the interview the researcher relies on the participants' willingness to talk openly to the researcher. In addition I was motivated by Im and Chee (2003) study which reported high retention rates with online forums. As the researcher I could check and verify understandings at various stages of the study to confirm my understanding of the information collected (Lincoln and Guba 1985; Enosh and Buchbinder 2005). This supported the interpretive approach of hermeneutic phenomenology. How the data was analysed using van Manen's approach will be discussed in detail in the upcoming chapter.

Figure 5.1 Overview of the research approach adopted in this research study.



CHAPTER 6 DATA ANALYSIS: A JOURNEY OF THINKING

“To exhibit the perfect uselessness of knowing the answer to the wrong question.”

— Ursula K. Le Guin, *The Left Hand of Darkness*

6.1 INTRODUCTION

This chapter describes the technique used to analyse the data from the study. While hermeneutic phenomenology provides philosophical foundation for investigating the lived experiences it is often criticised for not providing clarity for data analysis. An overview of the methods applied in phenomenology research followed by my rationale for choosing van Manen’s approach is discussed. In undertaking this analysis I have kept in the foreground of my thinking van Manen’s words “*Qualitative writing ...requires that we be attentive to other voices, to subtle significations in the way things and others speak to us. In part, this is achieved through contact with the words of others. These words need to touch us, guide us, stir us*” (2006, p.713). The process of engaging in a hermeneutic phenomenological study is a journey of ‘thinking’ that not only involves immersing yourself in the data but also a cyclical process of reading, writing and dialogue (Smythe *et al.* 2008). While working with data can mean a process of reducing and synthesizing words, Smythe *et al.* (2008) warn against losing the story and thus losing the meaning. Indeed the interpretive process urged in phenomenological studies involves a ‘thinking’ experience or as Heidegger puts it an experience of being-lost-in-thought (Heidegger 1962). Understanding comes from the thinking and re thinking the experiences that the participants share. I present the process I adopted to analyse the data which included a thinking phase and an interpretive phase which often ran concurrently. I paid particular attention not to develop themes or findings as if to quantify the data, rather I aimed to present meanings and understandings as they appeared significant to me in the data. The following section reviews methods used in hermeneutic phenomenology studies and presents the interpretative process used in this study including the rationale for choosing this approach.

6.2 OVERVIEW OF INTERPRETIVE METHODS

There are several divergent approaches to data analysis within the different schools of phenomenology⁴. Interpretative phenomenology emerged from the work of hermeneutic philosophers (including Heidegger, Gadamer and Ricoeur) Heidegger (1962, p.37). urges “the meaning of phenomenological description as a method lies in interpretation”. Interpretation is not seen as an additional step in the process of analysis rather it is an inevitable part of what Heidegger terms being-in-the-world. While Heidegger’s hermeneutic phenomenology provides philosophical foundation for investigating the lived experiences, Gadamer (1998) and Ricoeur (1981) developed Heidegger’s ideas further thus providing more clarity in the interpretive process. Phenomenologists using the Dutch approach (Utrecht) such as van Manen’s (1990) combine characteristics of descriptive and interpretive phenomenology. According to Van Manen, thematic aspects of experience can be uncovered or isolated from participants’ descriptions of the experience by three methods that include the:

1. Holistic approach - researchers view the text as a whole and try to capture its meanings.
2. Selective or highlighting approach - researchers highlight or pull out statements or phrases that seem essential to the experience under study.
3. Detailed or line by line approach - researchers analyze every sentence in addition to identifying specific themes from the participants’ descriptions.

This hermeneutic phenomenology school of thought advocates that the researcher cannot remove themselves from the phenomena and therefore becomes part of it. Pre conceived knowledge is not bracketed rather it is brought to the forefront and acknowledged. This notion appealed to me for two reasons: I had a visceral sense of what it is like to live with a childhood illness as I had asthma for most of my life and had a career in nursing spanning over 20 years as previously discussed had afforded me vast experiences caring for young people with chronic illness. Casting aside pre conceived knowledge would be unattainable.

⁴ Differences lie in the division between ‘descriptive’ and ‘interpretive’ methods. Phenomenology studies from the Duquesne school of phenomenology include the research of Colaizzi (1978) and Giorgi (1985), all of whom are based on Husserl’s philosophy.

As previously addressed I engaged in writing up my own phenomenological understandings of this experience which was completed prior to data collection. I was conscious that my preconceived understanding would impede or 'blind' my interpretation of the data (van Manen and Adams 2010). van Manen's interpretive approach to data analysis which urges researchers to acknowledging any prior assumptions so that you can set them aside was favoured. If I did not remain open to the understandings and meanings that emerged I would not have heard them in the data.

While there are increasing numbers of hermeneutic phenomenology studies within the field of nursing, few describe with any detail the process of analysis. Aside from a few studies that describe the interpretive process of hermeneutic phenomenology in their studies (Garrett 2010; Merrill and Grassley 2008; Crist and Tanner 2003; Benner, Tanner and Chesla 1996) analysis or interpretive process of this methodology is sparse in the literature. While the hermeneutic phenomenology approach does not include a standard process of steps to gather and analyze data, several authors have offered guidelines that will enable phenomenologists to engage with the interpretive process (Crist and Tanner 2003; Van Manen 1990; Giorgi 1985; Colaizzi 1978). van Manen offers us a process to understand the lived experience that include four lifeworld existentials of lived body, lived space, lived time and lived human relations. It is through our body that we experience the world around us. Employed in a number of nursing studies (Garrett 2010; Merrill and Grassley 2008; Eggenberger and Nelms 2007) van Manen approach four lifeworld existentials provides a useful way to navigate the lived experience.

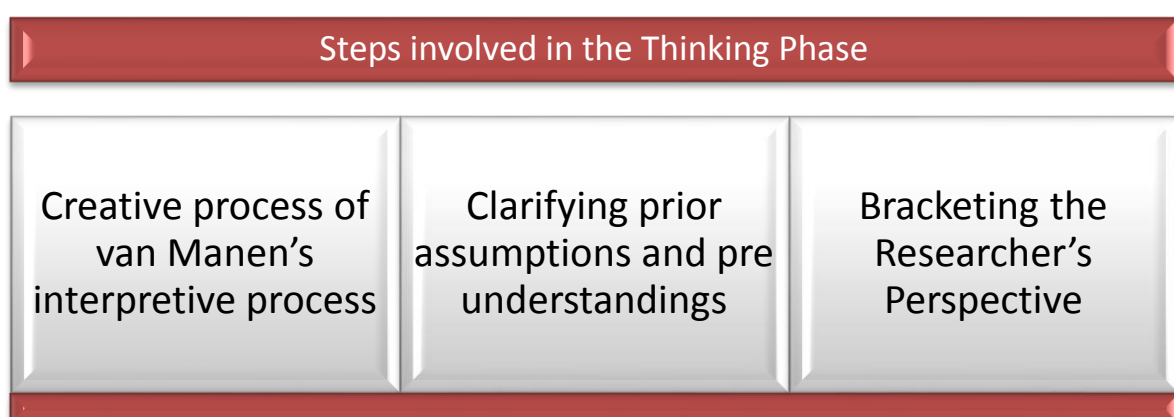
Whatever method of analysis is chosen, the key for researchers is to present the complexity of the lived world being described. However this can be challenging for researchers who seek to articulate the experiences offered to them by participants. For example in phenomenological research we observe body language and voice intonation in interviews however communicating this in the findings can be this can be a difficult task. In order to increase understanding, phenomenology research sometimes looks to creative processes to understand experiences particularly in nursing (Norlyk *et al.* 2011; van Manen 1990). van Manen (1990) articulates "To write phenomenologically is to write poetically" (p.132). He argues that in order for researchers to engage in the interpretive process we need to consider other means to

help us to question or reflect on data. Creative processes such as poetry and literature can be useful in encouraging our thinking beyond its natural limits and promote the ‘openness’ encouraged in exploring the lived experience. A number of phenomenological nursing studies in recent years (Haahr, Kirkevold, Hall and Ostergaard 2011; Norlyk et al. 2011) have begun to utilise creative processes to explore the lived experience of patients. The following section examines the hermeneutic interpretive phenomenological method for analysis as described by van Manen which has been adopted in this study. It describes a creative process (Derrida Writing’s) to improve the researchers’ ability to be open with the data and see beyond any limitations incurred from over 20 years of nursing experience.

6.3 CHOOSING VAN MANEN’S INTERPRETIVE APPROACH – THE THINKING PHASE

This section describes van Manen’s (1990, 2006) interpretive process used in this study. The overall process is illustrated in Figure 7.3 An Overview of the Process of Data Analysis and involves a ‘thinking’ phase and an ‘interpretive’ phase. The thinking phase was enhanced by the creative process (encouraged by van Manen 1990) that included, the importance of establishing pre understanding and issues relating to bracketing.

Figure 6.0 Steps involved in the Thinking Phase



6.3.1 CREATIVE PROCESS OF VAN MANEN'S INTERPRETIVE PROCESS

Creative processes such as art and literature can offer an important lens from which to view interpretive phenomenology. It is particularly suited to this study of emerging adults growing up with chronic illness to offer insight in to participants' experiences and avoid pre-conceived notions. A number of phenomenological studies have acknowledged the use of creative processes in understanding the lived experience of patients (Norlyk et al. 2011; Giorgi 2009; Dahlberg, Todres and Galvin 2009; Lindseth and Norberg 2004; van Manen 1990). However few articulate the process with any detail. Norlyk et al. (2011) argue that creative processes can be a valuable contribution to understanding patient experiences which can be difficult to give a voice to. In their theoretical paper Norlyk et al. (2011) examined the use of creative processes in phenomenology research and found they were a valuable in adding new dimensions to understand the lived experience of patients. The paper highlights Danish philosopher Logstrup's use of sense-based impressions to elaborate patients lived experiences. How do we as individuals sense phenomena (sense of powerlessness, sense of loneliness), it stresses the emotional experience so that we can understand the words. Writing, can distance us from the lifeworld of the individual leading to generalisations. van Manen (1990) suggests that when description is supported by expression (including a work of art, or text) a more compelling sense of interpretation is achieved.

The approach I chose for this study advocated by van Manen, advises qualitative researchers to keep in mind that creative processes such as poetry and literature which can assist researchers to reflect more deeply and consider what may not have occurred to us naturally. The aim of phenomenology is to deliver a piece of writing that illuminates the meaning of human phenomena. The creative process encouraged by van Manen (1991) aids phenomenological researchers to capture and articulate those experiences. Vedder (2002, pp.206-207), draws on Gadamer's writings, describing the use of metaphors to create meaning *"In metaphor it is thus not about describing what is on hand in an empirical reality, but rather about making visible in a being something that was not previously seen...The poem produces the image...a coming to be of an expression and a coming to be of being."* The aim of using creative processes in analysing the data in this study is to encourage reflective thinking so that *"the phenomenologist directs the gaze toward the regions where meaning originates, wells up, percolates through the porous membranes of past sedimentations—and*

then infuses us, permeates us, infects us, touches us, stirs us, exercises a formative affect" (van Manen 2006 p.12). My interest in philosophy and the writings of Derrida drew me towards van Manen's approach to the interpretive process. This I felt would enable me to gain insights in the thinking phase of the study as I attempted to explore the essential meaning of the experience of living with a chronic illness since childhood. Creative process such as literature offered an important lens from which to carry out interpretive phenomenology. Derrida's writings on naming (*On the Name*)⁵ and LeGuin (*She Unnames Them*)⁶ particularly suited this sample of participants, emerging adults and their developmental issues related to identity. They offered the opportunity in this study to gain a deeper understanding of my participants' experiences particularly with their sense of identity.

van Manen (1999) addresses the issue of 'naming' in phenomenology. He points out that nick names demonstrate a familiarity with the person, it "indicates our special relation to something or someone" (van Manen 1999: p.17). He talks about the power of 'unnaming' as illustrated in LeGuin's (1987) short story *She Unnames Them*. LeGuin found the experience of unname animals in her story, powerful, she felt closer to them and had a better sense of presence. She could touch them feel them smell them and get a better sense of who they were without their names. For LeGuin the process of unname the animals removed an invisible barrier.

"When things get unnamed we can no longer ignore the hidden contours of the phenomena that words tend to hide like blankets in the snow" (Derrida 1995).

To understand the lived experience of people we need to put aside, make clear the way so that nothing is standing between us and the participants. van Manen's interpretive approach supported this notion of leaving aside what we know, unname things and going down new path, that is interpretive phenomenological inquiry. In doing so we can explore the lived experience and our ways of 'being in the world'. I considered the writing's of Derrida in particular during the interpretive process of this study. During difficult times immersed in the data and the struggle to understand I found readings from Derrida's book *On the Name* useful. For instance Derrida talks about how we often reduce significant events to a name

⁵ Jacques Derrida, *On the Name*, ed., Thomas Dutoit, Stanford: Stanford University Press, 1995.

⁶ Ursula K. Le Guin, Marion E. Cluff, *She Unnames Them*, Enstar Press, 1995.

like, 9/11 (Borradori 2003). He argues that by reducing this important event to a date can demonstrate our lack of understanding about its meaning. “*Namely, the fact that we perhaps have no concept and no meaning available to us to name in any other way this ‘thing’ that has just happened*” Borradori 2003; Derrida 1995; p.85). Why do we try to reduce complex events to such a simple term? Is it that the event is so complex we cannot capture it properly? This challenged my thinking in two ways. I reflected on the fact that participants in this study often described being named or labelled “epileptic”, “asthmatic” or “sick”. As emerging adults they were transitioning into adulthood exploring their own identities with this added burden of being labelled. The literature reveals a culture with fairly widespread use of labelling patients (Reed *et al.* 2011) ‘the asthmatic’ the diabetic’ and so on. I considered un-naming especially useful considering my pre understandings of chronic illness in young people following a long career in nursing. van Manen (1999) urges us to go beyond the objectifying effects of naming the things in our world with labels that distance us from the experience of illness and its meaning. Indeed naming or labelling an individual as ‘the sick person’ attaches premature interpretations. Un-naming what was familiar to me during those times of thinking, reading writing, talking and re writing offered ways to set aside my previous understanding so that new meanings could emerge.

6.3.2 CLARIFYING PRIOR ASSUMPTIONS AND PRE UNDERSTANDINGS

By bringing together our ways of knowing (epistemology) and ways of being (ontology) we can limit any preconceptions or concrete views we may have which can interfere with any new understandings. Heidegger talks at length about our *disclosure of fore-structure* of understanding (cited in Gadamer 1975, 1989). He explains that it is in our nature as humans to always have pre suppositions. All of our understandings are based on previous experiences or encounters, what Heidegger terms as *for-having*, *for-sight* and *for-conceptions* (cited in Gadamer 1975, 1989). What helps us abandon our preconceived understandings in interpretive hermeneutic phenomenology is our acknowledgement of this *for-structure of understanding*. The nature of the work of health professionals which can be unpredictable and fast paced means that they can develop *fore-structure of understanding* based on ‘popular conceptions’ (McManus Holroyd 2007). As a health professional for many years I was cognizant of this phenomenon in nursing. It may be due to pressure to conform or the busy environment that health professionals often find themselves in, that leads them to popular or

convenient understandings. The aim of interpretative phenomenology is to prevent the usual habit of thought which can distract from finding meaning in the data. To prevent attaching early limited meanings to the data as it emerged in this study, the Hermeneutic Cycle as described by Heidegger and Gadamer (Gadamer 1975,1989) was employed in the interpretive process. This involved examining any ‘popular conceptions’ as they arose during the interpretive process and moving between understanding of the traditional and the emergent. A circular motion ‘back and forth’ between the whole and the parts of the data, involves a process of de-constructing and re-constructing the text leading to shared understanding. Gadamer (1975) refers to this as ‘universality’ that understanding is possible there is a merging or connection of human consciousness between the participant and the researcher. Flood (2010) recognizes this as ‘co-constitutionality’ where meanings are a fusion of both the participants and the researcher meaning.

6.3.3 BRACKETING THE RESEARCHER’S PERSPECTIVE

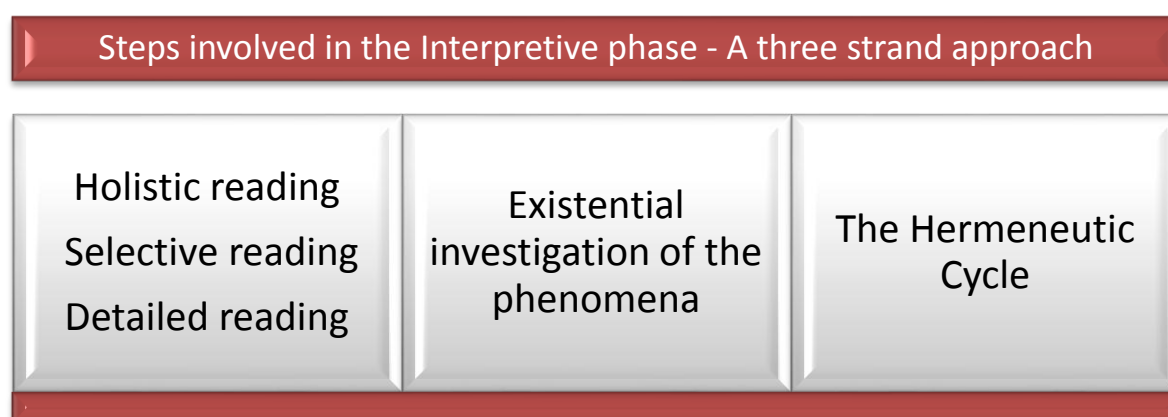
Bracketing the researcher’s perspective is a process used to reduce or prevent any early understandings. The aim was to acknowledge any prior assumptions, bringing to forefront any pre conceived knowledge. This was not bracketing of pre conceived knowledge in the Husserl tradition rather knowledge was brought to the forefront and acknowledged (see *Section 4.4 Approaches to phenomenology*). Casting aside pre conceived knowledge would be unattainable. The aim of this study, as with any phenomenology study, is to gain understanding. Understanding or *Verstehen* Schwandt (1999) argues involves a to-and-fro’ motion between the person and the target of the understanding. Both Heidegger and later Gadamer contend the any understanding involves self-understanding. The hermeneutic view is that understanding begins with acknowledgement of the interpreter’s fore projections as discussed above. For understanding to take place, the researcher who has lived in the world and has developed their own pre understandings must reflect for a period on those pre-understandings, by making them explicit. This helped to clarify meanings interpreted from the data in this study. Openness was sought during this ‘thinking phase’ by using creative processes, clarifying any prior assumptions, bracketing my perspectives and finally reflecting on my own history and life experience related to illness (*Section 5.1 Self Reflection: Exploring my own history*). This allowed me to consider my own established views of childhood chronic illness.

Health professionals are often situated within a certain dominant perspective of illness (McManus Holroyd 2007) influenced by a scientific or traditional medical management view of illness. However in recent years there have been efforts to explore the illness experience from the patients' perspectives which involves a change in perspective. If health professionals limit their inquiry, influenced by their pre understandings, they will fail to add light to a phenomenon or move beyond what McManus Holroyd (2007) call clinical literalism (facts, truth and clinical detail). Writing my own worldviews and reflections about childhood chronic illness in a reflective blog and what could influence meaning and understanding aided the interpretation process. This included personal reflections and questions asked by my supervisor and provided some influential context that contributed to the formation of my views.

6.4 VAN MANEN'S PHENOMENOLOGICAL DATA ANALYSIS: THE INTERPRETIVE STAGE

Data analysis involved a hermeneutic interpretation of the data from the interviews and the online fora guided by van Manen's (1997) framework for phenomenological analysis. This involved three concurrent strands as indicated in *Figure 7.3 An Overview of the Process of Data Analysis*. The initial phase included a three step approach holistic reading, selective reading and detailed reading of the data (Figure 7.2). The results of this approach were then clustered together and written up in an electronic document. Following this van Manen's (1990) four existential themes were employed to explore the world lived of emerging adults with childhood chronic illness: Spatiality (lived space, felt space), Corporeality (lived body), Temporality (lived time), Rationality (lived other). The third concurrent phase included the Hermeneutic Cycle as described by Heidegger and Gadamer (Gadamer 1975, 1989) which was used to aid understanding throughout the interpretive process.

Figure 6.1 Steps involved in the interpretive phase - A three strand approach.



6.4.1 HOLISTIC, SELECTIVE AND DETAILED READING OF THE DATA

This phase involved a reflective process to (a) identify meaningful words and phrases (words and phrases participants emphasised, repeated or lingered on), (b) to identify thematic patterns (emergent themes that ‘stood out’ within and across the transcripts, field notes and reflective journal entries) and (c) to identify overall meanings (4-5 sentence summaries of each participant’s experience of living with chronic illness since childhood). The initial phase offered the opportunity to read and re read the data repeatedly. Holistic reading involved reading the transcripts and field notes to gain initial impressions of the data. Selective reading where the researcher returns to the data on several more occasions to pick out key phrases and words that relate to the researcher question and finally the detailed reading where the researcher employs line by line detailed strategy of words phrases and observations. During this part of the analysis I was conscious of being open to new insights I spent time with the data both listening to the recordings and reading the data and allowed myself to dwell (van Manen 1990) so new impressions could emerge. This was facilitated by the creative processes used in the thinking stage. Danish philosopher Logstrup (Norlyk *et al.* 2010) emphasises the importance of such hesitation in data analysis as it stirs something creative inside us that can enable us to see new analogies. A total of 315 transcript pages were analysed for detailed and selective codes, using the research question as a guide.

6.4.2 EXISTENTIAL INVESTIGATION OF THE PHENOMENA

The second phase included an existential investigation of the phenomena. Themes and corresponding subthemes were identified during the interpretive process and are

representative of the narrative stories told by each participants of the study. The author discussed essential themes with the supervisor over the course of the study. Phenomenology of praxis as identified by van Manen guided the interpretive process and the identification of themes and subthemes. van Manen (1990) outlined four existential themes that aid phenomenologists to explore peoples experience in the world lived: Spatiality (lived space, felt space), Corporeality (lived body), Temporality (lived time) and Rationality (lived other). Van Manen's four fundamental existentials describe the way human beings experience the world and are described in (Table 6.1).

Table 6.0 Existential themes (van Manen 1990)

EXISTENTIAL THEMES (van Manen 1990)		DETAILS
Spatiality	Lived space	How as humans we feel in different spaces, content (home) versus uncomfortable (out of comfort zone), how day to day life is experienced by people.
Corporeality	Lived body	Being physically present in the world, physically presence can reveal or conceal aspects of persons, what is visible on the outside may not be congruent with inside.
Temporality	Lived time	A persons way of being in the world includes the influences of past, present and future, hope for future offers a perspective losing hope may lead to despair.
Relationality or communality	Lived human relations	How as humans we relate to one another within an interpersonal space and how this can change through interactions with each other.

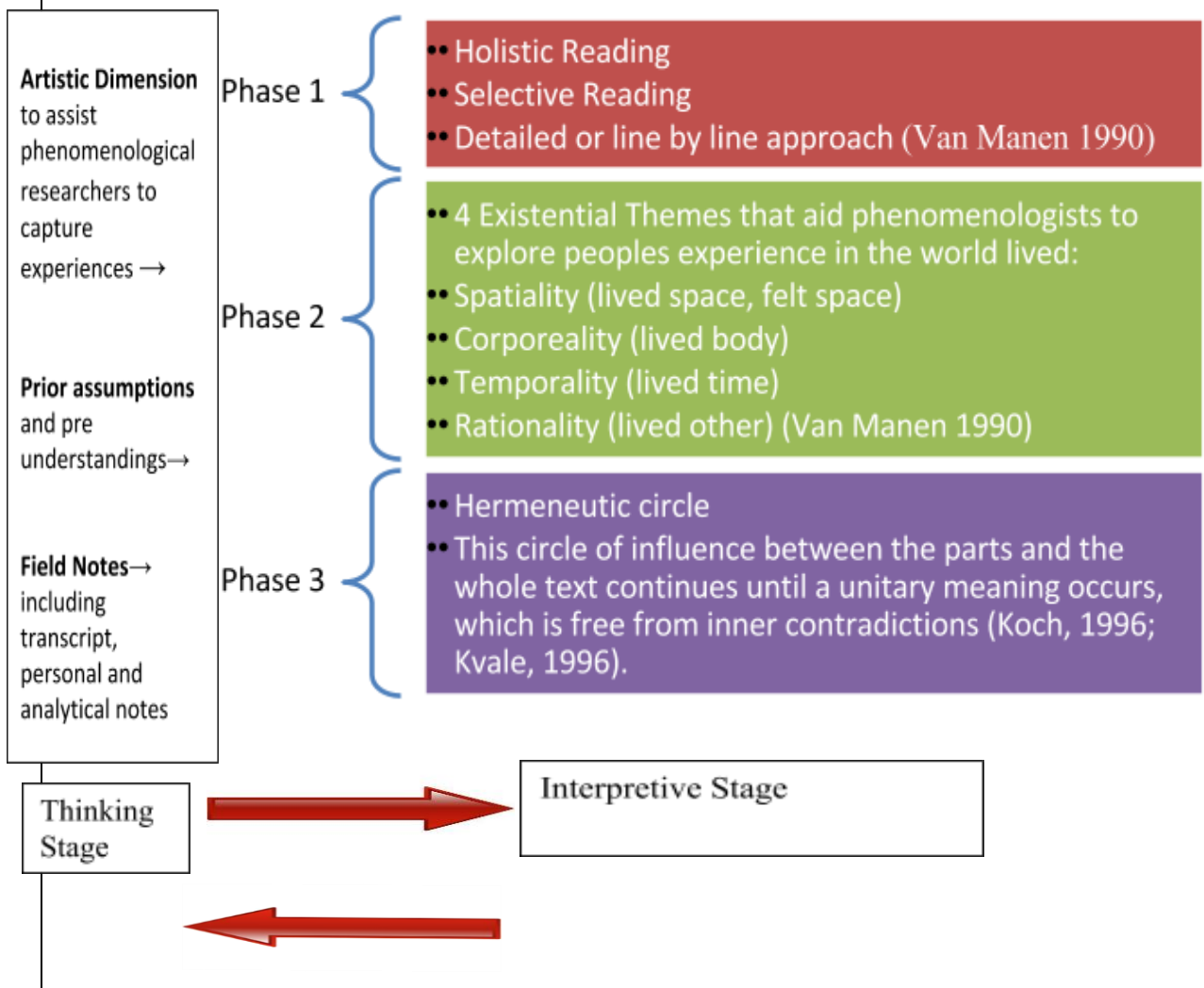
6.4.3 THE HERMENEUTIC CYCLE: BALANCING THE RESEARCH CONTEXT BY CONSIDERING PARTS AND WHOLE:

Thirdly in hermeneutic phenomenology, interpretation of meaning is characterised by a hermeneutic circle, a Gadamerian (1975) metaphor borrowed from Heidegger (1962) and adopted by van Manen (1997a). Heidegger viewed the hermeneutic cycle as a process to

situate our own *priori* understanding. Gadamer later reconceptualised the hermeneutic circle as an iterative process through which reality is explored and an agreement is reached that represents a new understanding. The Hermeneutic Circle is the relationship between the researcher and the data. van Manen suggested that a final feature of conducting research on the lived experience is “balancing the research context by considering parts and whole” (1990, p.31). For instance, in posing the question “What is the lived experience of emerging adults with childhood chronic illness?” I was continually mindful of balancing the overall whole text and individual parts of the text that contributed to the total work and how they relate to each other. This circle of influence between the parts and the whole text continued until meaning occurs, free from inner contradictions (Koch 1999; Kvale 1996). I used this process to guide my analysis, realizing that initial readings of the data offered only partial understanding of the phenomenon. I could gain much more clarity, when contextualizing further understandings with the whole text. By alternating this between the parts and the whole of the text, I gradually gained more clarity and depth of the understanding of the possible meaning embedded in the text.

The analysis of data from the interview and online forum, yielded emerging themes which were then challenged and extended using the literature related to chronic illness, the developmental literature in relation to emerging adulthood and hermeneutic philosophical texts. The purpose of exploring this literature during the analysis was to illuminate the richness and complexity of the experience of childhood chronic illness as it is lived (Ironside 2006) and how that interpretation is to be communicated. Closing the hermeneutic circle, I returned to the whole text which had gained new meaning, and thus understanding. The challenge for researchers is to convey the story in writing in such a way that others can understand it. Refection 6B illustrates the process involved in data analysis during the course of this study (Figure 6.3).

Figure 6.2 An Overview of the Process of Data Analysis



6.7 CONCLUDING COMMENTS

The chosen method of data analysis was not always clear at the beginning but slowly evolved and developed over time. I learned and adjusted many things along the way. As illustrated in throughout this thesis specific decisions were made and action steps were taken as my understanding of the phenomenon of childhood chronic illness emerged. For example using the writings from Derrida allowed me to explore meanings offered by the participants about their experiences of living with childhood chronic illness and to uncover meaning I may not have previously appreciated. The three strand approach adopted in this study enabled me to interpret the experiences of my participants with an open stance. To prevent being blinded by pre understandings and lifetime habits following a long career in nursing I engaged activities that acknowledged prior assumptions (Bracketing interview) in order to clear the way for new thinking. The aim was not to suspend previously held beliefs in the Husserl tradition but to allow an openness towards the data as it emerged. Jones (1975) challenged us to “extend our understanding of bracketing beyond the suspension of belief to a cultivation of doubt” to open one’s self to the phenomenon (p. 304). The creative process’ facilitated by the writings of Derrida allowed me to find new ways of seeing, new ways of engaging with the process of reflecting on their experiences.

The challenge in this study was to allow themes to reveal themselves to me rather than discovering them. Participants had offered me their experiences like a gift for my interpretation and I felt the responsibility honouring their lived experience with illness. Therefore this took time and required a certain intimacy with the content of the data. I listened to each interview recording and read the forum postings observing for nuances, the tone of voice, the humour and the frustrations. There was a continuous cycle of listening to data, reading the literature and writing. This interpretive process took a longer timeframe than I had originally anticipated. Themes were identified and developed across the participant narratives. This process took time like Heidegger’s notion of time, clocks, watches and calendars need to be discarded before recognising the freedom to really explore the concealed content of the ‘Dasein’ of the phenomenon that I was trying to uncover. During this doctoral study I attended workshops with both Elizabeth Smythe and Roxanne Vandermause whose preference for philosophical hermeneutics and expertise in interpretive phenomenological approach is renowned. From their teachings I remained continuously conscious of the

question 'What is the phenomenon, really?' The following chapter identifies and discusses the findings of this study. The aim was to connect my understanding of the experiences of my participants and their meanings with my own past experiences to provide the 'thisness' of new emerging insight and understanding and convey their story.

CHAPTER 7 FINDINGS: UNENDING STORIES

All of us have to learn how to invent our lives, make them up, imagine them. We need to be taught these skills; we need guides to show us how. If we don't, our lives get made up for us by other people.

Ursula K. LeGuin, *The Wave in the Mind*

7.1 INTRODUCTION

In this chapter I present the findings of the study. In the nursing literature, Smythe *et al.* (2008) argue that to arrive at findings means to point the reader in the direction of our thinking. Taking this view I invite the reader to explore my understandings rather than present generalisable statements. My aim is to let the data (participants experiences) speak through new understandings. The ‘journey of thinking’ presented in the previous chapter does not end here in the findings chapter but rather it invites the reader to continue with their own thinking. I do not wish to offer closure within the findings. Similar to the phenomena of chronic illness which is often unpredictable and uncertain there is not attempt to give a sense of resolution to this study rather I sought to write the participants unending stories (Defenbaugh 2008).

Navigating the terrain of the lived experience can present difficulties in staying true to the experiences of participants and achieving a level of abstraction from the data in order to uncover the essential meanings of the lived experience that the participants present (Rich *et al.* 2013). van Manen’s four lifeworld existentials offers an interpretive lens through which to explore the lived experience, navigate the data collected and uncover the essences of lived experience. Peoples’ thoughts and experiences are deeply embedded in their lifeworld (Munhall 2007). When a persons’ well-being is disturbed by illness they become acutely aware of the dimensions of their lifeworld. Chronic illness can change their sense of space, body and time as their priorities change. Even though the participants have grown up with illness their priorities can change as they move into adulthood. At the moment when our wellness is disturbed then we discover, as it were, our own body. Therefore understanding the lived experience of emerging adults growing up with chronic illness involves exploring their lifeworld from spatial, corporeal, temporal and rational perspective. van Manen (1990,

1997) urges that these perspectives occupy the lives of all human beings irrespective of “their historical, culture or social situatedness” (p.101).

This study explores a specific developmental group, emerging adults, therefore Arnett’s theory of emerging adulthood sheds light on important features of this developmental period. This theory has provided an additional model to examine the stories offered by participants, in light of the profound changes that occur in emerging adulthood. The lived experiences across interviews and the online forum with participants are shown in eight over-arching themes: *Transitioning to the adult world with illness*, *Living with unanswered questions*, *Visibility of chronic illness*, *Fitting in: the desire for normalcy*, *Developing a sense of self*, *Hopefulness: Hope for future life*, *Sense of connectedness with peers* and *Merging the person and the illness*. Early themes emerged from the in-depth interviews (see *Section 5.7 The Phenomenological Interview*). Participants recalled their experiences and stories past and present. Later themes of Hopefulness: Hope for future life, Sense of connectedness with peers and Merging the person and the illness emerged from interpreting the data from both the interview data and the online forum (see *Section 5.8 The Hermeneutic Interview*). Hermeneutics is concerned with identifying, describing and interpreting experience (Morse 1991; Benner 1985). The online forum (Hermeneutic interview) provided an opportunity for individuals that have had a similar experience to share with the researcher (Creswell 1998). Onwuegbuzie *et al.* (2010) urges that postmodern interviews and focus groups be extended to include ground-breaking media such as social networking tools. Young people who use social media routinely share personal information and stories in cyberspace, these individuals might be more comfortable participating in research via the Internet. Participants were encouraged to reveal their experiences and recollected moments of what it is like live with a childhood chronic illness. Unlike other qualitative methodologies, phenomenology is not concerned with opinions or views of the phenomenon (Adams 2014). The themes are presented in this chapter with data and discussion excerpts. The interview data excerpts are coded with pseudonyms (see *Section 5.6 Recruitment and ethical considerations*). The online forum excerpts are coded with P1, P2 and so on, so that participants would not be identified (see *Section 5.9 Data collection and ethical considerations*).

van Manen's (1990) four existential life world themes provided a guide for existential investigation of the phenomena (See section 6.4.2 Existential investigation of the phenomena). Themes and corresponding subthemes were identified during the interpretive process and are representative of the narrative stories told by each participants of the study. van Manen's four fundamental existentials describe the way human beings experience the world and are described in (Table 6.1). Together they present the participants' unique lived experiences of growing up and living with childhood chronic illness since childhood. Developing a sense of identity as perceived by the participants collectively, was revealed in the eight essential themes. This overarching theme of identity fits with Arnett's stages of emerging adulthood in particular the *Age of identity exploration*. However the other stages of emerging adulthood Age of instability, Age of self-focus, Age of possibilities, Age of Instability and the Age of feeling in-between featured within the data that emerged. Participant stories revealed how connectedness helped participants' redefine their sense of identity in life in *Merging the person and the illness*. This helped to explain the link or relationship between the themes created from the data. The themes are aligned with van Manen's existential life world themes and represent the phenomenological understanding of the lived experience of the participants in this study.

Using a phenomenological approach prevented the researcher from making primitive contact with the concreteness of lived reality (van Manen 1997) by endeavouring to bracket or reduce pre understandings of childhood chronic illness. In order to interpret these stories I attempted to suspend any beliefs built up over a number of years nursing chronically young people in favour of the participants' experience. Themes were found to align with van Manen's 'lifeworld' theoretical framework described in Chapter 3. Findings from this study reveal insight into the lived experience of emerging adults with childhood onset chronic illness (COCI) which informs Arnett's theory of emerging adulthood (Arnett 2000). Themes were identified from the data that emerged from both interviews and the online forum and were representative of the narrative stories shared by the participants. Table 7.2 outlines the participant information including pseudonyms. Emergent themes were not the same across all participant stories but rather represented "an understanding that we have something that matters significantly, something that we wish to turn the reader towards (Smythe 2007). van Manen (1990) outlined four existential life world themes that aid phenomenologists to explore peoples' experience in the world lived: Spatiality (lived space, felt space),

Corporeality (lived body), Temporality (lived time) and Rationality (lived other). They describe the way human beings experience the world. While each lifeworld emphasizes different aspects of the lifeworld they also overlap. For instance the subtheme ‘Concealing illness’ is discussed under lived space but also under the existential theme, lived relations.

Table 7.0 van Manen (1990) four existential life world themes aligned with study emergent themes and Arnett stages of Emerging Adulthood

van Manen(1990) four existential life world themes	Emergent themes	Subthemes	Arnett Theory of Emerging Adulthood (1990)
Spatiality (lived space, felt space)	Transitioning to the adult world with illness and	Stepping out of a comfort zone Concealing illness	Age of Instability
	Living with unanswered questions		
Corporeality (lived body)	Visibility of chronic illness		Age of Self-focus.
	Fitting in: the desire for normalcy		
Temporality (lived time)	Developing a sense of self	Taking control back	Age of Instability
	Hopefulness: Hope for future life		Age of Possibilities.
Rationality (lived other)	Sense of connectedness with peers		Age of feeling in-between.
Overall pattern/theme	Merging the person and the illness		Age of Identity exploration

Table 7.1 Participant Information

	Participant pseudonyms	Condition	Age	Currently at college	Currently employed	Contributed to Interview/ Online Forum
	Celene	Asthma	25	Yes		Both
	Ciara	Epilepsy				Online forum
	Emma	Diabetes mellitus	22	Yes		Both
	Jill	Cystic Fibrosis	20	Yes		Both
	Ellen	Epilepsy	23	Yes		Both
	Heather	Cleft lip and palette /Asthma	24	Yes		Both
	Jane	Asthma	22	Yes		Both
	Lisa	Asthma	19	Yes		Interview
	Linda	Diabetes mellitus	20	Yes		Both
	Libby	Asthma	18	Yes		Both
	Rachael	Diabetes mellitus	21	Yes		Both
	Sinead	Diabetes mellitus	19	Yes		Both
	David	Epilepsy	22	No	Fulltime	Online forum
	Mark	Epilepsy	20	Yes	Partime	Online forum
	Greg	Cystic Fibrosis	24	No	Fulltime	Both

7.2 SPATIALITY (LIVED SPACE, FELT SPACE)

This existential theme refers to how as humans we feel in different spaces, content (home) versus uncomfortable (out of comfort zone) and how day to day life is experienced by people. Different things can affect how we feel in different spaces. We may feel safe in certain spaces at a certain times which can change over time or perspective. Lived space or felt space (van Manen) encompasses two themes in this study: *Transitioning to the adult world with illness* and *Living with unanswered questions*.

7.2.1 TRANSITIONING TO THE ADULT WORLD WITH ILLNESS

Participant narratives described their experiences growing up with their illness from childhood into adulthood. Issues highlighted by participants transitioning to the adult world with illness include the subthemes ‘moving out of their comfort zone’ and ‘concealing their illness’. They described a journey of accepting they had an illness as a child when they were informed by their parents or health care professionals, to rejecting their illness when it became irritating or isolated them among their friends to taking some control back as they entered emerging adulthood.

7.2.1.1 STEPPING OUT OF A COMFORT ZONE

This subtheme emerged as participants described feelings of moving out of their comfort zone. There were various life events that triggered participants feeling of moving away from familiar environments that included changing schools, starting university and getting a job. In the dimension of spatiality many participants referred to how they felt about their life in the various physical spaces like college and home. Within their own physically defined spaces, participants had the opportunity to withdraw to their ‘inner space’. In a hermeneutic phenomenology study Guimond-Plourde (2009) explored stress coping as an existential phenomenon in healthy adolescents. She argues that within this “inner space” that one can retreat, consider what is facing them and return ready to face the world. It is within a person’s “inner space” that previously learned values and beliefs may aid their ability to confront the world. For participants of this study moving from the physical space of home or school to college often meant retreating to their “inner space” to learn how to ‘be’ in their new world.

Heather who had cleft lip repair told a story about working as part time waitress while in college. How that experience exposed her to ‘looks’ and ‘stares’ from strangers. This appeared to make her feel self-conscious. Stepping outside her comfort zone had meant that she was no longer protected by friends and family:

You get the odd adult staring or that but more so the kids and you might feel they are talking to their parents about it or something like that. Because I remember as a part time job I was a waitress in a hotel and I remember one day I was doing a wedding and was feeling a little bit conscious of what I looked like, that day. Maybe I felt a bit embarrassed because I got some looks from some of the guests there like one of them was looking and caught my eye and she just looked and then looked away quickly as if I had caught her. I felt so self-conscious, I blushed. That was my first job and I remember feeling oh crap they don't know me that's why they are looking I realised I was in the big bad world now. It is fine when you have your own group of people, they know who you are but then you branch out then, go out and things like that you feel a little bit out of your comfort zone. But you just get on with it [Heather: 2012:1]

Heather's experience is what Sartre (1956) in his seminal work has described as the negative consequence of the objectified look. A look or glance from someone can be experienced as affirmative, critical, subjective or objective. Now immersed in the adult world Heather felt ‘conscious’ and ‘embarrassed’ by a look or stare she received. van Manen (1998) describes how the person with visible illness may consider their body as conspicuous. Celene and Sinead recall their stories when they were younger of having to explain their illness. It was uncomfortable to be ‘looked at’ or to be singled out, conspicuous due to the illness.

Yes you have to take your nebuliser and you have a mask on and then there's the shaking. 'I didn't know you had cancer,' was what my youngest cousin said to me one day at a family function in our house because that was the only illness she seemed to know, cancer. I was like, 'I don't have cancer, I am fine.' She was pointing to my nebuliser that I had in my hand. And then I raised my shaking hand I felt really uncomfortable because no one likes being stared at and feeling like a specimen and when you know why they are staring kind of like having the nebuliser, it is not a good feeling. I remember the way she looked at me strangely maybe because my hand was shaking I don't know but I don't think she believed me I think she thought it was cancer [Celene: 2012:1]

I was giving myself insulin in school one day a few girls complained that I was shooting up into my veins and there was blood everywhere of course there wasn't any blood and its sub dermal not into a vein I tried explaining that to them but they weren't listening they were a making a big drama out of it, one of them was retching it was fake though I knew that. After that I had to give myself insulin in the toilet so I

didn't upset them it was awful I hated the fact that I had to remove myself just because they complained it was so unfair [Sinead 2012:1]

Both Celene and Sinead later described within the forum how they would reflect on these glances and looks and try to minimise them in their mind. *I kinda accepted that they needed to look at me first and they would see my illness then after they could see me, its not nice but you learn to deal with it doesn't bother me as much now [Sinead:2012:1]*. While acknowledging the uncomfortable nature of the objectified look these participants over time learned how to manage any negative consequence. Within their “inner space” they used their values and beliefs to deal with the outside world. Guimiond-Plourde (2009) considers that this activity can be related to personal growth. Other participants had a more difficult time David described feeling angry with his ‘well’ friends and the injustice of not being well and being able to complete the same tasks as them *“I wanted to be treated like I didn't have it sometimes I hate the look you get when they find out you have epilepsy it's the pits it never changes cos its always there it never leaves you, if it does there's someone always there to remind you of it again [David 2013: 2]*. Ellen [2012:1] explains that disapproving looks can sometime be ‘others’ lack of understanding. As a diabetic she knew sometimes she appeared to be intoxicated:

I was on the bus on my way into an exam. I got off, I feel like I am going to be sick, I didn't get sick, I passed out at the side of the road in Blank [Location name removed]. So some woman walking her kid to school with the dog, the dog ran over and she was like, 'oh look a person.' She came over and she thought I was drunk and passed out. But then I told her I was a diabetic and could she call my dad. Her attitude changed totally she was like 'I am so sorry I thought you were drunk' then she said 'you shouldn't be out on your own like this'. I was so irritated I couldn't wait for my dad to come but I do rely on my friends a lot of the time they know what to do. At times like that I do get scared a bit.

Arnett's (2000) theory of emerging adulthood addresses the issues of self-focus whereby young people focus on themselves in order to develop the skills for daily living. It is during this period that they learn who they are and what they want from life. The goal being to become increasingly self-sufficient. However young people growing up with chronic illness face competing demands of transitioning emerging adulthood. One of the common threads across the participant stories in the following themes was their desire to maintain close friendships with a group of friends that knew about their illness. This may have been a

conscious effort that they developed in their “inner space” from existing or developing reference points. Stares and disapproving looks could be minimised by keeping a close group of friends around them who knew about their illness. Whether it offers protection as they moved from their childhood (comfort zone) to adulthood (unknown territory) needs further exploration.

7.2.1.2 CONCEALING ILLNESS

The importance of developing friendships during the emerging adult period is well recognised (Tanner et al. 2008; Arnett *et al.* 2007; Roisman et al. 2004). Arnett (2007) and Demir (2010) highlight links between emerging adult psychological adjustment and friendships. The ability to develop friendships lays a foundation for future relationships in both work and romantic relationships. Over the years participants in this study developed friendships with people that knew about their condition and that appeared to offer some protection for the participants. That protection seemed to be against the exposure of the outside adult world. As they moved towards adulthood they had more contact with new people and unfamiliar environments. This seemed to expose them to sometimes unpleasant or dangerous experiences. When they were younger their close friends seem to provide a safety net for them but now it was no longer there. One participant explained how her friends would shield her from ‘others’.

I had two very good friends and we had our own little really tight knit group that I had made. And the start of the year they were just put sitting beside me as it happened and we got on like a house on fire. The first time they saw me checking my bloods they asked a load of questions I remember they were just interested in how it all works and what I can eat and if it hurts. Then that was it they just started talking about something else like it was nothing much. Thinking back they were so cool we are still friends today they never freaked out about it. Then after that we were kept together because my teacher was just like, ok everyone else is freaking out so I'll leave her with her two friends and let them just get on with life or whatever so when anyone asked me anything my pals would jump in and answer them so I didn't have to explain it. [Rachael: 2012: 1].

They (friends) didn't quite understand but my mum explained to their mums and their mums explained to them so through the grapevine they got the information. And then as I could articulate what was going on they kind of learned from me or whatever. We are still best friends to this day and they have insulin in their fridges at home just in case I run out. It is pretty good from that perspective there have been times though like this one time me and my friends were in this girls house we were watching a

movie and stuffing our faces with sweets and she didn't know about my diabetes and I didn't want to explain it all then my friends were like no you can't eat that what are you doing you will die. The girl was like what is going on here I remember feeling I can never get away from it, my close friends are good though like they were just trying to protect me [Linda: 2012: 1].

Participants seemed to rely on their close friends. Often participants referred to their friends as protectors particularly when they were hiding their condition or the treatment required.

I tried to be as discrete as possible, and this one day I was sitting with the desk covering my lap or whatever and trying to disguise my stomach. I was trying to give myself insulin and my friends were standing around me like shielding me a bit like a human wall. I just didn't want anyone to see it because then there's a load of questions so it was easier to just hide it. I was in sweat because I was worried my friends wanted to head outside because it was break. One girl walked by and looked in but my friends told her to 'get lost'. God knows what that girl thought my friends were guarding me I suppose [Emma 2013].

Rachael's narrative relates an experience later in college life. She was out with her college friends and without the 'safety net' of her close school friends. She felt pressured to drink alcohol as everyone else was and not participating would draw attention to the reason. She did not feel ready to inform her new group of friends of her illness. This experience highlighted a sense of vulnerability for Rachael and she felt exposed without a safety net of her 'old friends' who would know what to do if she became ill.

If I am out with my really close group of friends from primary or secondary school it is no problem, they know exactly what is going on, they always make sure I have a chipper at the end of the night to make sure no hypos in the middle of the night... But I was out with my college friends this night, they didn't have a notion so it was all on me so I said I wouldn't drink but because I was out with my new friends from college I did drink. I said no first but then there was the questions why don't you drink? I didn't want to say I am diabetic I just wanted to be me not the one with diabetes. I could easily miscalculate my own limitations for the night and I didn't have that safety net with the girls where they would make sure nothing bad happens. I ended up so concerned about passing out, going to hospital and I immediately started panicking. I had no one to rely on if something happened. I felt vulnerable. Like I could die or something It was the first real time it occurred to me that my old friends were not there anymore I had no protection. So I called it quits for the night. So it is limiting in that sense but largely it is all right. [Rachael: 2012].

Transitioning to the adult world with illness can be precarious for young emerging adults. They described experiences of stepping out of the comfort zone where they were protected by family and friends. Moving away from the 'human wall' and the 'safety net' is challenging for emerging adults with illness with competing life demands. The overwhelming changes during this period may distract from managing their disease. Emerging adulthood is a socially, culturally embedded phenomenon (Tanner and Arnett 2009). Equally chronic illness is a separate phenomenon and both can influence the person's lifeworld. Having a chronic illness while emerging to adulthood presented challenges for the participants of this study. Losing the safety net, forging new friendships (with 'unsensitised' others) and revealing their illness or treatments were concerns for them. Emerging adulthood is a distinctly a self-focused time of life. Arnett's theory highlights self-focus specifically as the freest time for emerging adults to contemplate their future but not be held accountable. However in the recent *European Foundation for the Improvement of Living and Working* report Goffe (2014) confirms that this group spend more time alone than any other group under the age of 40. This is worrying for emerging adults with illness who may then find that losing the 'safety net' isolates them even more from friends and relationships.

Concealing their illness was interpreted as developing a sense of identity that is hindered by illness. During this period of self-focus, emerging adults have the psychological space to consider questions like "who am I? What I am doing with my life? " These questions are at the heart of identity and how participants will pursue opportunities in relationships, education and work, and that will promote their self-knowledge (Schwartz et al. 2013). In addition this is the time when emerging adults consider the future and possible future identities (what they might become in adult life) (Oyserman and James 2011). However emerging adults in this study identify challenges separating their illness from their identity due to the visibility of the illness or the treatment. This struggle to achieve a sense of identity which is sabotaged by illness is identified in the literature and deliberated in Chapter 2. This finding concurs with this struggle that emerging adults have as they attempt to develop their sense of identity.

7.2.2 LIVING WITH UNANSWERED QUESTIONS.

Participants described experiences of living in the unknown. They made attempts to get information or questions answered but felt that they were ‘fobbed off’ by parents and health professionals. They describe being told ‘we will cross that bridge when we come to it’. There were particular ‘taboo subjects’ such as having babies, and life expectancy. It appeared to them that there was no one to voice those concerns to. “No one will hear me” [Rachael: 2012:1]. Imagining future life and motherhood was a strong feeling among girls in the group. Some had tried to bring the subject up with parents and some with friends but felt they were not heard. Rachael (2012:1) story describes her experiences:

I have questions like can I have kids? like will I be able to have kids? and will it affect my diabetes?. It has cropped up in my head from time to time, but then I think what if I ask a question and get no answer. I asked my mam one day when we were driving somewhere I think she was just dropping me off to the bus and I said do you think I will have problems having kids. I mean I think back and it came from nowhere to her but not for me I was thinking so much about it and other things. But anyway she freaked ‘what are you talking about you are only 19 years old for gods sake what are you thinking like that for’. I was thinking great well that is going to stay in my head for the next few months while you don't answer any of my questions. It is difficult because I have always had that kind of a, you know if I have a question about diabetes relating to my actual life. When she calmed down a bit I just got a very wishy washy answer of ‘oh no we will cross that bridge when we come to it’ blah blah. It kind of messes things up a little bit. But by that same token I don't plan on having any kids any time soon. I remember thinking let me out of the car before she explodes I was raging I brought it up then [Rachael, 2012:1].

Living with unknowns was ‘frustrating’ created anxiety for them. Most of the female participants appear to pose their questions to their mothers. Even though they were irritated by the lack of information and clarity in answers they did appear to acknowledge their mothers’ reluctance to answer was out of concern or fear for the future of their daughter. [*I ask my mam things mostly because she controlled it for so long and went to all my appointments but she doesn't give a straight answer I think she doesn't want me thinking about these things*]

It is more that I just get really frustrated with the lack of answers so I don't bother with it anymore. If I ask that question I am just going to get a, ah it will be grand or don't ask that question, that is a bad question to ask now. So I just sit and let myself stew until I am about 30 and then start asking about babies [Rachael, 2012:1].

It seemed also that particular subjects like ‘motherhood’ were taboo subjects among friends and boyfriends. Emma’s story expressed similar feelings of frustration at her struggle to be heard.

And heaven forbid if I mentioned to my boyfriend one day he would be like, 'oh my God you are thinking of babies, get away from me, I need to get away from this girl.' But largely it is a taboo subject. I did bring it up one day with my friends though and they were like [makes a disapproving facial expression]. We were just chatting away about things like the future like travelling getting married all that and I said 'I wonder if I can have kids if I am able to or I will be able to have kids with having diabetes'. It kind of changed the way the conversation was going it was upbeat and then it was awkward no one said anything really so I changed the subject. I was like 'I love the name (name omitted), I really want to name my son ----.' And then it just got into a big argument about names so it kind of degenerated away from my actual question. It was so frustrating why is it that you can't talk about some things like that or people get funny about it [Emma, 2012:1].

For most participants the move to adult hospitals allowed them to attend appointments without their parents. This enabled participants to ask some questions:

Yes I can talk about quite a bit more because my mum doesn't have to be there now. That took a while to convince her not to come to my appointments with me. The last one she was at she was such a pain. My mum doesn't like hearing anything, you know... that is why I have mostly go by myself. But I had some questions that I didn't really want to ask with my mother in the room and stuff like that. But she was sitting there talking away to the doctor saying 'everything is fine shes's fine' to him. So I said 'well I want to know about the long term effect of the meds like are there other side effects that I will get later on?' She was back straight away 'but you already know that.' Which means she already knows that and she doesn't want to listen to anybody else say it again. And I'd be like, I am completely in the dark here, thanks mum. I am getting a lot more questions answered now without her there [Ellen, 2013:1].

Being in the dark with unanswered questions is concerning for emerging adults with illness with risk of social isolation and uncertainty about their future. van Manen (1998) seminal work on *Modalities of body experience in illness and health* contends that when illness occurs there is a break in the relationship with the body. Often it is the symptoms that cause the disruption and sudden awareness of the body. He contends that it is often only a reassuring explanation that is required to satisfy individuals and to help them to resume or rebuild an unbroken relation with the body and thus with the world. Moreover emerging adulthood is a vulnerable age where uncertainty about the future could affect psychological well-being

(Arnett 2000). van Manen (1998) explains that the power of explanation can be amazing. Self-esteem can be increased by providing educational support (Gannoni and Shute 2010) for young people with illness. While initially these stories offer a simple phenomenological understanding that emerging adults with chronic illness are not receiving information they need or want. Explanation can heal and offer reassurance enabling individuals to go about their daily lives. Most of us have experienced anxiety over symptoms like pain or swelling during our lives and once we are reassured by our medical practitioner we forget about it. The body returns to its body in “its “natural” taken-for-granted or silent modality” (Van Manen 1998; p 7). However if individuals with illness are not reassured or offered explanation they may remain in a state of anxiety or confusion. The new freedoms associated with emerging adulthood, highlighted extensively in the developmental psychology literature, come with new responsibilities to self-manage illness. Reiss (2012) urges that health professionals and parents’ guide emerging adults with chronic illness towards self-efficacy and the final step of individuation, and independence. Evidence from this study shows that emerging adults are not receiving the information needed to make informed decisions. While emerging adults may be increasingly involved in more independent decisions making during this period it is an emerging skill and requires opportunities for applying new knowledge, practicing decision making skills and learning from mistakes (Reiss 2012).

Young people are concerned about what their future holds and the literature acknowledges that parental involvement can help them be more optimistic about the future. The developmental literature maintains that there is a prolonged transition to adulthood and the end of dependency on parents (Côté and Bynner 2008) in recent years. The literature on transition to adulthood health services highlights that young people feel ill prepared (Steinbeck, Brodie and Towns 2008) and lack in understanding about the consequences of non-adherence to treatment (Hogan *et al.* 2006). The experiences of the participants in this study confirm that young people are being left in the dark when it comes to questions regarding their future. Once they have made the transition to adult health services and are not being accompanied by parents they begin to get the information they require. While policy-makers have recognised the need to ensure a smoother transition between children and adult services, transition to adult health care is still considered to be *ad hoc* (Rapley and Davidson 2010; Wedgewood 2007). Despite the introduction of holistic, individualised, and person-centred care issues with transition and non-adherence remain. If emerging adults are to negotiate the transfer of their health care from child to adult services successfully they need

to be informed. Future models of care need to incorporate developmentally appropriate education and support so that they are not in the dark.

7.3 CORPOREALITY (LIVED BODY)

Being physically present in the world, physical presence can reveal or conceal aspects of persons, what is visible on the outside may not be congruent with inside. Munhall (2007) refers to this as body intelligence. Indeed when individuals are healthy they may not have reason to take notice of their corporeal being. However the unpredictability of chronic illness and symptoms of illness can have a profound effect on the lived body. Participants narrated experiences of growing up with chronic illness through their lived body. The themes identified in this existential were participant experiences of the *visibility of chronic illness* and their *desire for normalcy*.

7.3.1 VISIBILITY OF CHRONIC ILLNESS

Illness is often invisible. A number of narratives from participants addressed the issue of visibility. Most of the participants had an ‘invisible’ chronic illness with no outward signs of illness. Three participants had an illness (eczema, cleft palate) with outward visible signs. However often the illness is not visible but the treatment is and that alerts ‘others’ to ask questions. Goffman’s (1963, 2009) seminal work on stigma and illness refers to this as ‘unsensitised’ others? Much has been written in the literature about visibility and illness (Hoppe 2010; Taylor 2005; Joachim and Acorn 2000; Charmaz 1991) however for emerging adults transitioning significant life events like college, employment and relationships needs attention. Emerging adult experiences in this study reflected their frustration with ‘others’ who were not aware of their illness and made demands on them that were often difficult to fulfill. In an autoethnography study, Moore (2013) documents her own lived experience with Ulcerative Colitis. She questions whether the invisible nature of the illness is a blessing or a curse and whether she would wish for a sign visible to others. Hoppe (2010) argues that the visibility of a chronic condition does not necessarily lead to stigmatization, but that people can shape strategically how they are perceived. Nonetheless emerging adulthood is a vulnerable time where individuals are learning to negotiate entering adulthood. In a Web-based survey, Roosta et al. (2010) study found a direct link between emerging adults with visible skin disorders and limited healthy psychosocial development to the stigma these disorders create. There are a number of psychosocial adjustments during the emerging

adulthood that can be confounded by illness. *I definitely relate to the feelings of wanting to be “normal”-- I can’t even remember the number of times I’ve felt weird because I had to be nebulised with friends around, it felt so uncomfortable! [Jill: 2013:1].*

Several participants talked about the ‘visibility’ of their illness and how that impacted on their introduction to new groups of people. This appeared to have two effects on participants. Their desire to move into adulthood without the label of illness was often sabotaged by visible signs of the illness or the illness ‘flare up’. This forced participants to ‘come clean’ to new groups of friends.

Celene recalled an experience when she was at college and she became ill. Her new friends were not aware of her illness *“I was feeling bad my breathing was getting worse I didn’t want to tell them so I hid it as best I could but then I think they thought I was being odd you can’t win”*[Celene 2012:1]. She described an internal conflict with on some level needing to inform them (friends) for their support but on the other hand preferring that they didn’t know. I considered participants desire to conceal their illness and not want to be identified as ‘having an illness’. Reflecting on Le Guin’s short story *She Unnames Them* on unnamming I think that by unnamming the animals in the story the narrator tries to maintain a sense of equality among them. While we may think that there is nothing in names as they are just collection of letters (voices) they offer a psychological meaning, for example the name "rabbit" does not give the same effect as when we hear the name "lion". Lion is more frightening. Equally names such as ‘illness’, or specifically ‘asthmatic’ or ‘diabetic’ are not just words they conjure up an image and meaning to something. Le Guin (1985) explains *“They seemed far closer than when their names had stood between myself and them like a clear barrier: so close that my fear of them and their fear of me became one same fear”*. This was the effect I desired to assist me in uncovering the meanings in the data. However I also considered that the naming of their illness was a barrier to new relationships. Labelling or naming them with their specific illness appears to put some distance between them and ‘others’. Is this what they feared in revealing their illness to new ‘others’. Le Guin found that after removing the animals names, things became so indistinguishable from one another there was a need to smell one another’s smells, to feel or rub of one another’s scales, fur, feather, or skin to create a sense of presence. Does unnamming or concealing of the illness make them

more like ‘others’ and support their desire for normalcy and ‘fitting in’, an essential theme discussed later in this chapter.

7.3.2 FITTING IN: THE DESIRE FOR NORMALCY

A study by Balfe (2009) addresses the issue of normalcy for emerging adults with Diabetes Mellitus, “although we know that students are concerned about being normal, we do not have a strong idea of what normalcy means for these young people” (p. 129). The desire for normalcy for participants in this study centred around issues of not being able to participate in activities such as sport or attend sleepovers with friends. Celene tells a story of being frustrated at always being the friend who attended everyone else sports events but the reverse was not possible as she was unable to play sports because of her asthma. Her desire was to play sport and to have people cheer her on as she played. Playing sport represented normality for her in that moment.

Because well as a kid I wanted to be normal. Like when I was small I remember being at one of my friends matches she was one of my really athletic friends and was running around and playing camogie and I was in the audience for the match. I was sitting there wishing I was them wishing I could be the one playing sport and not in the stand watching them I wanted to be the one people were cheering on but I knew I never would be I remember thinking I would love to have everyone come and see me play and I was feeling it was so unfair I am always the one cheering everyone on I will never have a match for them to come and watch me [Celene:2012:1].

Equally some participants tried taking part in sporting activities but were failed by their illness.

Well I'd be happy for them and if there was lull or they didn't have anything I'd be like, gosh I wish I could do that. Then I'd remember why I couldn't do it and I'd get grouchy. In school I would try to take part but then I'd have to kind of take myself out of it when they got the ball or something exciting was happening. But it was kind of like a cycle for every game the same thing would happen [Greg 2013:1]

I was point guard so I was like everywhere and anywhere. And then I got an asthma attack. I just felt everything getting much tighter and much tighter but I kept going then and I had the ball, I couldn't breath and all and I had to go off basically crying and not being able to breath. And it was probably the most embarrassing thing ever [Jane 2012:1].

Three female participants Celene, Jean and Libby told stories of their unsuccessful attempts at attending friends' sleepovers. Time and time again their illness interfered with them staying over at their friends house and parents would have to pick them up early or the experience was ruined by being ill. For other participants activities such as driving prevented their feeling of 'fitting in'. David aged 20 years with epilepsy highlighted this.

Look you just want to be seen as normal not as the epileptic I hate that word people use it like a label how dare they really I am not 'the epileptic' I remember when my younger brother got his first driving lesson I was so mad I wanted to drive more than him I was into cars he wasn't that bothered and there he was younger than me and he gets to drive. I remember feeling it was so unfair its not just about taking your meds it affects your life all of it [David 2013:2]

For these emerging adults a lack of normality appears to permeate their sense of identity. Their stories of the situations where the illness sabotaged their need for normalcy seem to have a direct effect on their sense of identity among friends and friends. "You are always known the sick one among your friends" [Lisa 2013:2] and David's comment "I am not 'the epileptic' ". Having an illness robbed the participants of aspects of 'growing up type' activities that included sports, sleepovers and driving. Other participants referred to socialising opportunities where they attempted to 'fit in' with their peers. Lisa a 19 year old college student has lived with asthma since childhood talks about her experience of missing out on early week of college. Her desire for normalcy forced her to attend college for Freshers' week⁷ even though she was ill. She did not want to miss out on new friendships

I was in [College] for fresher's week, forced myself to come in, I was sick but I came in anyway because I did not want to miss fresher's week. I was so in my head, I am not missing it. But then I missed the second week because I had to stay at home for the week....that was horrible because I felt so excluded. Even though nobody had made friends but I was at home thinking, everybody has made friends. I will come in and I will have no friends. It made me really paranoid, I thought everybody had made friends [2012:1].

Then next time I remember was when going to my first disco. I remember my parents being concerned that the flashing lights would bring on a seizure. I kept trying to reassure them that I would find a safe place to go if that happened. I think I wanted to ignore the fact that flashing lights could bring on a seizure. The first hour of that disco I was petrified that I was going to have a seizure and that everyone would see it. I couldn't relax I didn't want anyone to know how I was feeling that I was scared I

⁷ Freshers' week is known in United Kingdom and Ireland as University orientation week... During this period, students participate in a wide range of social activities, including live music and other performances, sports challenges, stunts, and open-air markets.

had made a mistake going to it and I was feeling guilty about my parents telling me not to go but then then I just got used to and I started to forgot about it. As it turned out I didn't have any seizures at the disco and knew then that this was going to be ok. I remembered feeling relieved as I didn't want to be different and not be able to go out with my friends [Ellen 2012:1].

Most of the participants relayed stories of risky behaviours. Linda, a 20 year old girl with Type 1 Diabetes mellitus described her experience of being out with college friends and drinking too much alcohol causing her to collapse.

They were doing shots, and I just said to hell with it, it was Halloween last year, doing mad things and afterwards I kept saying, 'I feel low, I feel low.' And they were like, 'you are not, it is just the drink.' And I was like, 'no honestly I feel low.' And then I ended up fainting, hitting my head off the banister on the bar and they didn't believe me [Linda 2012:1]

There was one night I was cajoled and coerced into drinking half a naggin of vodka so I was completely light weight and ended up in hospital getting my stomach pumping and all sorts of stuff because the diabetes was out of control I mean I knew it would happen, of course it was going to happen, but what do you do. You 19 and in college that's what everyone does its legal for the first time too. You are out with your mates and they are all having fun and drinking and the pressure is on and if you don't drink you think it will spoil it for them too and a big part of it was you have to try stuff when you are young. I would never get caught out like that now. I would just say no [Rachael 2012:1]

As with many of the participants both of these participants felt some need or desire to take part in what their friends were doing despite knowing the risks to their health. The literature has been clear in its argument that emerging adults with illness have similar behaviours to those of their peers without illness in respect to risky behaviours (Luyckx, Goossens, van Damme and Moons 2011; Luyckx et al. 2008; Jessor et al. 2003). Arnett (2007b) argues that emerging adults 'try out' adult roles which can involve adopting risky behaviours, as part of exploring their identities. A study by Raskin-White et al. (2006) found that emerging adults going to college had significantly higher frequency of alcohol use and heavy episodic drinking during the period from high school to emerging adulthood. They argue that interventions need prosocial involvement to prevent increases in risky behaviour in emerging adulthood. Due to their desire for normalcy (to fit in with their peers) and the need to explore their identities, emerging adults with illness may adopt risky behaviours such a binge drinking, smoking or

non-adherence to their treatment detrimental to their health. For emerging adults with chronic illness this could have severe damaging effects on their future illness pattern and place them at risk for long-term complications.

7.4 TEMPORALITY (LIVED TIME)

Temporality refers to subjective time and a person's temporality of existence (Haahr et al. 2010). A person's way of being in the world includes the influences of past, present and future. Thus a person's temporal landscape is subjective time versus clock time. Heidegger explains that happening is Dasein's (being) understanding of the relationship between the past events, and also that the past makes possible the understanding of the present (see *Section 5.5 Being and Time*, p. 77). Therefore how we understand our past influences our understanding of the present. Heidegger's text *Being and Time* (1966)⁸ refers to the experience of time as the relationship to the past as both an entity and a way of understanding the present. Our relationship to the past has a dualism: the past can be seen as something external, like a series of events or experiences, but, also that the past is also "how I am myself". This relationship to the past allows an individual to engage with the past as a thing, an entity, but also gives the subject (consciousness, Dasein) a way of understanding and being in the present moment and situation. These proved to be important readings for the study of the lived experience of the participants in this study who had grown up with illness and were influenced by those experiences.

A person's hope for future offers a perspective and therefore losing hope may lead to despair. Living with a chronic illness can alter a person's perspective of their 'lived time'. Equally our perceptions can change over time or as we grow up and our previous experience can influence how we feel about the future. For instance having positive experiences about our healthcare as a child may have positive influence on our approach to healthcare as an adult (Tuohy *et al.* 2013). Participants shared stories of how they changed their perspective about their illness over time. They made choices as to what meaning they would ascribe to past events and this would influence how they live with illness. They spoke of their determination

⁸ Heidegger, Martin. 1962. *Being and Time*. Translated by John MacQuarrie and Edward Robinson. New York: Harper and Row Publishers Inc..

that the illness was not going to ‘rule their lives’, that accepting the illness ‘liberated them from the feeling that it was a burden’. This helped their process of redefining who they are and who they are going to become in life, their sense of identity. While participants relayed stories of uncertainty and fear of the future it was mainly a story of hope that prevailed in their experiences. Emergent themes include: *Developing a sense of self* and *Hope for future life*.

7.4.2 DEVELOPING A SENSE OF SELF

Arnett’s (2000, 2004) theory of emerging adulthood highlights issues such as their desire for independence, yet also a fear of independence. It is often during this stage of development that emerging adults are often transitioning geographically, economically, and emotionally away from the parental home. Emerging adults with chronic illness face the competing demands of this stage of development and taking control of their illness management. Arnett refers to this as the *Age of In-between*. Emerging adults may not have fully developed the skills to take over illness management. In addition it is a period marked by feelings of imperiousness where they often reject parental control, which can limit their receptiveness to treatment adherence. A subtheme *taking control back* emerged in the data as participants recalled their experiences of having little or no control over the management of their illness.

8.4.2.1 TAKING CONTROL BACK

Participants recalled their journey towards gaining more control over their lives. Their parents (in general the mothers) had control over how their illness was managed for most of their lives and had difficulty relinquishing that to their emerging adults children. Rachael’s analogy of her mother being the ‘puppet master’ shows how controlling she felt her mother was in relation to illness management. The participants appeared to recognise that parental motives were due to concerns over their health since they were children but that this had ‘chased them their whole lives’.

My mum had total control, she counted out how much carbs I was allowed to eat in a day and measured out how it was going to be given and when to take insulin and how much insulin. She was like the puppet master of my dietary requirements I couldn’t breathe there was so much control so when I started to get the reins so I could manage it myself I wasn’t letting go. Every now and then she will check up on me that I am doing everything right which irritates me but its great not having her breathing down my neck like before [Rachael, 2012:1]

I don't know, she mollycoddles me...I was always the sickly one, I was always the littlest. I was very skinny, dangerously underweight for a long time actually and because I was always sick my mum was actually afraid I would die when I was four or five. I have no recollection of this but she tells everyone a story about this particular time I was in hospital and they were concerned for me I was in Intensive care this time, this particular morning they were trying something to stabilise me and the nurse were running around and this made her panic more I was very, very sick and then the doctor asked to speak to my dad and mam and she thought Oh god I am going to die she never forgets that and is always telling people I have heard that so many times but I don't recall it I was too young So she has kind of got an extra incentive to be extra concerned about me. It has kind of been chasing me for my whole life and I did a course and now they (Parents) are kind of, ok you have got a bit more sense now. And I am like, I have had this sense since I was 17 but I am going to accept that you are leaving me be now. I am slowly, slowly taking full control of my own existence [Ciara 2013: 1].

Their stories of slowly gaining control of their lives fits with Arnetts' Age of feeling in between. Many emerging adults often feel they are ready to take responsibility for themselves, yet still do not totally feel like an adult. Tanner (2010) argues that the foundation laid in childhood and adolescence will dictate how well an adolescent makes the transition into adulthood to become fully independent individuals. This is largely depended not only on parental and society support but critically on giving the right level of support needed. The majority of the participants of this study struggled with the level of parental control in relation to their illness management. The participants talked of slowly gaining control of their lives but they were aware of parental concern "*I was always sick my mum was actually afraid I would die*" and their own previous lack of ability to take control "*you have got a bit more sense now*". If what Tanner says is true, then emerging adults with chronic illness have an impeded transition to independent adulthood. Indeed growing up with chronic illness may mean that emerging adults face challenges becoming independent and meeting developmental tasks. Emerging adults in this study appear to value taking control over their lives that they have waited so long for. Learning to self-manage illness is central to successful transition to adult health care. The literature on self-care highlights a need to develop successful programs based on understanding developmental issues for this age group (Bender 2006; Sawyer and Aroni 2005).

7.4.1 HOPE FOR FUTURE LIFE: AGE OF POSSIBILITIES

Emerging adulthood is a time for reflecting on future plans for work and relationships and figuring out who one is and where one's life is headed (Schwartz, Luyckx, and Vignoles, 2011). However those living with chronic illness have an added burden in the construction of their own identity and in considering their future. The illness may not only sabotage efforts to fit in, seek normalcy and figure out their identity but can also interfere with future plans. While the illness made great demands on their lives their desire to 'live' their lives was clear from their desire for normalcy and to redefine their lives as young adults. All of the participants displayed feelings of hope for the future to some degree as they embarked on their lives as young adults.

With regards to accepting my illness, I think the feeling that it led to was overall positive. I had been essentially fighting my own body, which naturally was something I couldn't win. After I accepted it and got into a proper routine... I generally felt a lot more optimistic and more in control of my life. Has that been the same for anyone else?[P1 2013: 2].

The process of looking forward to future 'time' involved the participants reflecting on past times. Remembering their lived experience of growing up with chronic illness, frustration and anxiety at missed opportunities and missed 'growing up type' experiences (sports, sleepovers, driving). However as emerging adults the participants were now selecting the 'meaning' they were giving to those experiences. In the online forum they described their experiences with each other of re-thinking past experiences growing up with illness. The new meaning they ascribed to those experiences included embracing the illness, accepting it, winning, gaining control. The meanings were of hopefulness. This allowed them to look to the future possibilities.

I became so negative and wrapped up in the 'why me' mentality. This lasted for... 8 years? It's only this year that I've finally accepted my illness as a part of me. And I no longer see it as a punishment or a curse, I actually embrace it and like to see it as something that's been given to me because maybe, had it been given to someone else, they might not be able to handle it at all. So its made me stronger I look to the future with that feeling 'bring it on' I remember looking at a friend of mine struggling with something that really wouldn't cost me a thought she was panicking worrying all that kind of thing and I remember thinking god 'you have no idea don't worry about small things like that there's a world out there' so I think having CF made me appreciate things, life. [P4 2013:2]

Growing up I have learned it is something which is very manageable and I am lucky it isn't worse. I don't take chances any more just sticking to my diet and that has made me feel better. The last time I was hospitalised I talked with the nurse there and she chatted about how she sees a lot of older diabetics that regret not taking better care of themselves, they had a lot of complications I remember thinking 'oh crap if I am not careful I will end up like that it was a wake- up call for sure' I want to live, be healthy I want a future I suppose like everyone I remember she said 'its up to you what happens in the future you have choices so make the right ones' I've grown to accept it as part of my daily routine and eating properly and regular exercise keep me in shape and my sugar levels down.. all in all a win win! [P9 2013:2]

In seminal work, psychologist, Snyder (1991) describes hope as “an alternative variable denoting an individual’s belief that a favourable outcome is possible and the individual’s ability to visualise how that outcome will come about”. Even though the illness has sabotaged some of their experiences growing up, all the participants relayed some future planning and possibilities. In Arnett’s influential work on emerging adulthood (2004) *Emerging adulthood: The winding road from the late teens through the twenties*⁹ optimism reigns in what he describes as the *Age of possibilities*. Most emerging adults aspire to having a better life than their parents did. Arnett's research shows that emerging adults want a lot out of life (a good well paid job, meaningful relationships with a partner). Even those who have had previous struggles or challenges contend that they will do well in life. This optimism was shown among participants of this study who had grown up with the challenge of chronic illness. While Arnett warns that emerging adults may be setting themselves up for disappointment if they expect too much from their future life, findings from this study show that those living with illness had faced disappointments and challenges and learned how to give meaning to those experiences that are positive.

I'm keeping positive and hopeful, believing that this will work and help improve my health rather on focusing on the bad. So basically the same as P1 and P12 in terms of accepting my illness after being properly educated about it I suppose. “I think a lot of people with chronic illnesses might go through a phase of not accepting it, in order to finally accept it. [P6, 2013]”

⁹ Arnett, J. J. (2004). *Emerging adulthood: The winding road from the late teens through the twenties*. New York: Oxford University Press.

More than any other stage of development, emerging adulthood is the age of possibilities greater opportunities and where anything seems possible. The feeling of hopefulness for future life conveyed by participants of this study fit with Arnett's theory. However it also demonstrated that growing up with chronic illness typically led to a positive attitude that may help emerging adults face any future disappointments or challenges. Van Manen asserts that "The past changes under the pressures and influences of the present" (2006, p.104). However it is the influence or meaning attributed to past events that changes, as events in the past cannot actually change.

7.5 RELATIONALITY (LIVED HUMAN RELATIONS)

The final phase of van Manen's lifeworld existentials is that of lived human relations. It refers to the space we share with others including physical contact and impressions (van Manen 1990, 1997). It involves how individuals relate to one another within an interpersonal space and how this can change through interactions with each other. We experience the world through our relationships with others. In a larger sense it also encompasses the search for meaning and purpose in life (van Manen 1990). The data was explored for the existential of lived human relations. A theme embedded in the participants stories included how in their interactions with friends and family they were discovering who they are, *Sense of connectedness*. A final theme that emerged from the data for this existential is *Merging the person and the illness*. According to Arnett (1990) this is the time of their lives that young people consider future identities who they may or may not become in life. Reflected in this theme is how the emerging adults valued social connections with friends and family and their hope for a future life which aided their journey towards consolidating their identity with illness.

Aspects of the participants' experiences and stories were coded in previous the lifeworld existentials identified in this study. Van Manen observed that the four lifeworld existentials are not isolated entities and while they are explored individually here they are interconnected features of the phenomenon of living with childhood chronic illness (Rich *et al.* 2013; Moene, Bergbom and Skott 2006).

7.5.1 SENSE OF CONNECTEDNESS WITH PEERS

Connections with peers in particular were identified as important to the emerging adults in this study. Participants relayed stories of their friendships providing protection, shielding from ‘sensitised others’ in 7.2.1 *Transitioning to the adult world with illness* and 7.3.2 *Fitting in: the desire for normalcy*. Returning to the participants in the hermeneutic interview (Online Forum) participants described their experiences seeking connections with the social world. Many participants experienced some degree of social isolation as a result of their illness missing out on activities growing up, such as sleepovers and sporting activities. Participants reported that the relationships they had with both family and friends’ members were important in developing their sense of self. Regardless of their background, emerging adults carry influences from family and friendship with them as they move towards adulthood which can influence who and what they become as adults. Most of the participants recalled the quality of their family support as strong and also made mention of their siblings and other friendships. Ellen affirmed the importance of friendships in her story:

My friends are great I don't know what I would do without them one night I remember we were all going out on a mad night out I remember it well we were getting ready and they were having a few drinks in a friends house. I actually don't drink just like one or two maybe because of my meds. One of my friends noticed I was having a drink and she said look I am not going to drink tonight so you don't have to feel like you have to drink we will still have great time. She didn't want me to feel left out of the crack everyone was having. I just remember feeling relieved because I knew I shouldn't really have a drink but instead of lecturing me she just said she didn't need to drink so I wouldn't feel the pressure to. I hugged her because I knew she was doing it for me putting me first or my illness. She was letting me know I was ok and didn't need drink to have fun I learned something from that, that I need to drink to try to be myself and not just fit in she helped me realise that [Ellen: 2012:2]

During emerging adulthood young people are learning to be who they are and who they are going to be (Arnett 2004). The influence of this experience for Ellen was that she became more comfortable with being herself in that instance. While that does not mean that she would have this experience again it may influence how she will act in the future circumstances. While there are limited studies exploring connectedness, there is evidence in the literature of the link between connectedness and health behaviours.

As previously discussed, participants often felt the need to explain their illness or treatment to friends. They sought more long term relationships with friends to avoid having to explain their illness to strangers. As they moved through adolescence they had difficulty forging new friendships and often concealed their illness unsuccessfully. This drove them towards risky type behaviours including non-adherence to treatment. Emerging adults face growing demands of navigating to adulthood with uncertainty of their future that can bring about anxiety and identity confusion (Arnett 2006; Dyson and Renk 2006). Most participants related similar difficulties starting college or the workforce where they had to build a new network of friends. Lisa [2013:1] reported telling her new friends about her diabetes in a casual dismissive way “*I was like I kinda have diabetes so that’s why I stick needles in myself*” Others had issues with absences from college which made it more difficult to forge new friendships.

Starting college was hard I had decided I wasn’t going to tell anyone then after just one week I was out for a couple of weeks so when I returned it was like where have you been and I need the get the notes from class so I remember I just decided to tell one of the girls I had been friendly with the first week I kind of blurted it out though I just said oh I have CF (Cystic Fibrosis) so why I was out I was sick for the last 2 weeks and she was like ‘God that’s awful’ we were in class at the time whispering I remember deciding to tell her there so that I didn’t have to talk about it much because the lecturer would hear. She just asked if I was ok now and I said yeah I remember feeling crap I was hoping I could get through longer than few weeks before everyone knew now I was going to be the one with CF. I wondered what would happen would she tell everyone but I thought she actually she mightn’t. Everyone seemed to have got to know each other more since I had been sick [P4: 2013:2].

Several participants talked about they felt some kind of connection towards other people with the same condition “*I never talked to him but you sort of feel connected to someone with CF*” [P15: 2013:2]. “*There was this girl in my school with epilepsy too but I never spoke to her we just kinda acknowledged each other cos we both knew we had it*” [P5: 2013:2]. However at the same time participants seem to avoid developing relationships with peers that had the same chronic illness. *I don’t want to be identified as the diabetic so there’s no need to be friends with every diabetic [P11:2013:2].* There was a strong feeling amongst participants that while they felt a connection with other people with the same illness because they knew what they were going through they did not seek friendships with them. They expressed concern that this would interfere with their identity. Their individuality may be disrupted by being identified with other people with the same illness.

In addition several participants reported being members of existing Internet-based support groups during the online forum. They discussed among themselves the mixed feelings they had with these online support groups.

I found a website online... they share their stories, I never actually made friends through that but I can ask some questions or just tell them my story and they would be like oh you should try this or that. It can be good. They'll be like, don't do this it can trigger your asthma. [P8: 2013:2].

Yeah I'm the same it can be good to ask questions and be anonymous but sometimes people are kinda negative and I don't want to get into that. This girl I was talking to for ages she was pretty sick a lot of the time in and out of hospital and she was filling my head with so much stuff that you can't do it was all negative. Like she said to me one day "our lives will be shorter do you realise that" that really scared me I don't want to think like that but I did get sucked into it for a while you have to live your life [P10: 2013:2].

While being anonymous in the online environment seemed to allow them up to ask questions without identification it also meant that it exposed them to some negative social connections.

While many participants recalled having to explain their illness or the treatment because of its visibility when they were younger as they moved towards adulthood and new relationships, they avoided explaining or identifying their illness to others. In the forum Participant 13 recalled having to tell his work colleagues that he had epilepsy reluctantly. Telling them was like breaking the connection between him and his friends. A sense of connectedness is important, people need to feel like they belong, that they are a part of a community, that we are connected to the social world. Illness may sabotage this sense of connectedness for young people.

My mates are grand I don't broadcast it, if it comes up, it comes up but I don't go around(shrugs) Like there would be loads of people that I'd be friends with who wouldn't know I have epilepsy. The most important people would know, do you know what I mean like one experience that sticks out is in this part time summer job I had. It was a factory. One day I was there and my mates were all having a go of driving the forklift just within the factory just joking around. We were having a laugh but they were trying to get me to have a go. I thought about it for a bit you see I am not allowed drive with my epilepsy but I didn't want to tell him I thought if I tell him then they are going to say you should have told us and would probably be a bit weird around me but if I don't I'll have to drive it and I wasn't sure. I remember thinking god I just want to not be identified as the epileptic but it follows you around theres so many random things in life that force you to tell people. I ended up telling them and they were ok but it was me I just felt different [P13 :2013:2].

While this was conceived as concealing their illness in the Spatiality lifeworld existential theme *Transitioning to the adult world with illness* it also addresses their sense of identity. It is clear that many of the participants strove to develop relationships and maintain connectedness with fellow friends socially, as much as they could. While they often faced difficulties, they valued their friendships. Most had managed to keep up friendships from school and develop new friends in college or the workforce and were optimistic of their friendship networks. Jill's story demonstrates how we experience the world through the relationships with others. She felt touched by her friends concern she felt secure, homely, 'like a warm blanket' because of her friends caring nature. The relationship between Jill and her friend allowed her to feel secure and she valued it because it represented security when she was feeling unwell.

Yeah once I settled into university I made friends like for life they are great really I can be myself and they know if I'm getting bad my breathing they can tell the signs no. Like recently I haven't been well I got a virus and then my exams were coming up so I was studying this night quite late actually and taking my nebuliser My friend heard me wheezing and she kept checking in on me. She recognised my breathing was getting worse and told me to take a break she brought me in some food and a drink and just stayed up in case I got worse. Even though she didn't have any exams she looked after me made sure I was ok I was really touched by it there's no fuss just looking out for me I really felt like I would be ok. I remember thinking I am not on my own here I'm going to be ok it was like a warm blanket over me like home, its great to have friends like that you don't feel you are a burden to them I would be lost without my close friends like her [P4: 2013:2].

Several participants reported that this connectedness allowed them to feel secure and "be themselves". Chronic illness may interfere with young peoples' connectedness with friends and family. This may impact on their journey in discovering who they are. More than any other period of life, emerging adulthood is the Age of Identity Exploration. At a recent conference Schwartz (Society for the Study of Emerging Adulthood Conference, Oct 2013) acknowledged the answer to the question 'who am I?' is identity. Emerging adulthood is a specific developmental period which is traditionally set aside for identity development (Arnett 2000; Erikson 1968). This is the time of their lives that young people consider future identities who they may or may not become in life. The final theme that emerged from the data for this existential is *Becoming me: merging the person and the illness*.

7.5.2 MERGING THE PERSON AND THE ILLNESS

In addition to the lived human relations, participants had to find a liveable relation with their body. In van Manen's (1998) seminal work on *Modalities of Body Experience in Illness and Health* he contends that health professionals must work to help individuals with illness reunite with their body. Our awareness of our body only becomes vivid when we are ill. The body is broken, injured or disrupted. The participants struggled to find a ways to live with the disruption of the illness so that they could 'be'. In section 7.4.1 their stories of hopefulness for future life was presented. *I'm keeping positive and hopeful, believing that this will work and help improve my health rather on focusing on the bad [2013:2]* and the support of family and friends in particular aids this journey *The support of my family and friends has played a tremendous role in the 'fixing' of my negative mentality [2013:2]*. These emerging adults appear to have remained connected to friends and family, in spite of considerable illness-related disruption. Their stories brought insights about the influence of a childhood chronic illness on identity and experiences growing up particularly as they were older now and more distanced from it.

In this existential theme *Merging the person and the illness* there's a final acceptance from the participants that 'this is the way its' always going to be'. This seems to allow them to move on with their lives. The question 'who am I' began to unfold for them. During the forum Participant 13 and Participant 15 discuss the time when they realized that they had begun to accept their illness as being part of them. Participant 13 describes feeling relieved that she was no longer fighting the illness she recognized that she had passed through as phase of not accepting to final acceptance of the illness.

I'm 22 now and I have 100% accepted my condition. I control it as best I can everyday. I can't really imagine life without Diabetes now as it's just a part of me and a way of life now. There wasn't really a "moment" where I accepted it properly, but one time I do remember was when I was so fed up feeling sick because I was not sticking to my diet and often not bothering to check my blood sugar. I had so many hospitalisations I just decided NO MORE I am in control I am taking back control of my body this is who I am I am a diabetic like it or not. The day I realised I just felt relief like nothing else I was no longer fighting against something I would never win. It was like waking up and realising this is me this is my life just get on with it but I was thinking also what damage have I done but since then I have not been as sick I don't know if that's all down to me coping on and growing up a bit but I think a lot of

people with diabetes might go through a phase of not accepting it, in order to finally accept it [P3: 2013:2].

It's like a weight of you when you just decide yeah I have this but so what just get on with it there's worse things in life I mean it annoys me when I hear friends crib about something small just get on with it I live my life now accepting me for myself. There was a time about a year ago and I missed out on going away with my mates we were supposed to be going away after exams it was all booked I had paid my deposit and then I got sick I knew it was my own fault I hadn't been sticking to the regime I am on. You just get so sick of it. I just remember that day when I knew I wouldn't be going away my doctor spoke to me and said you need to come in (Hospital) I was so angry with myself and everyone else but I knew it was my own fault after that I just made a decision to accept this thing I have its not going away You have to accept it its not giving up its acceptance and its a hell of alot easier when you do believe me [P15: 2013:2].

I thought about my own responsibility to myself this feeling came over me what am I doing I am going to do some damage if I am not careful I felt responsible some of the chances I have taken in the past. I got a wake-up call last year when I ended up in Intensive care I had been in and out of hospital a bit my blood sugars were all over the place I could see my parents were so worried and one day my mum was sitting beside the bed and I looked over and she was crying I kept telling her I was fine now to stop worrying she never said anything to me she just looked so sad sitting there that day I felt so guilty but it made me think god what am I doing I am responsible for my future so I need to cop on I have a responsibility to myself. I realised I was doing everything to [P11:2013:2].

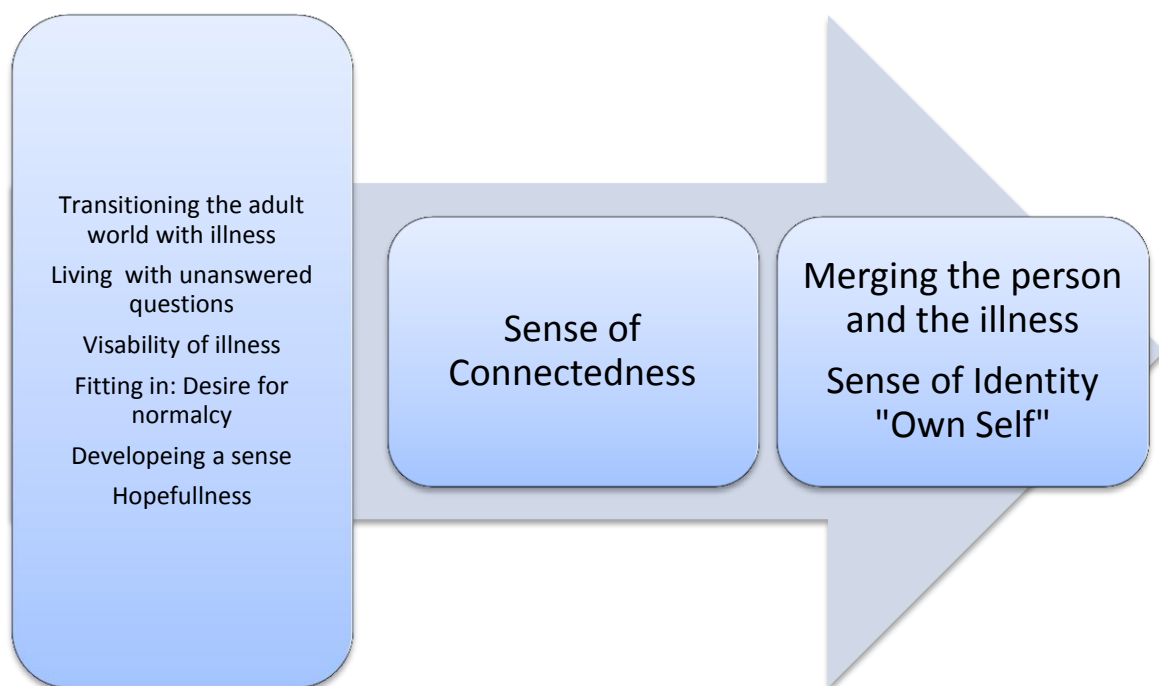
A common thread throughout the participant stories were descriptions of fighting their illness and ignoring their illness which often led to maladaptive behaviours. They reported "fighting my own body". It appeared that by doing so, the illness was not part of who they were as individuals and not part of their identity. In van Manen's seminal work on *Modalities of Body Experience in Illness and Health* he argues that the role of the nurse is to reunite patients to their liveable body. While he is referring mainly to those who are recovering from illness or surgery it may also be applicable to those learning to live with chronic illness. A key underlying theme of 'identity' and how the participants become who they are going to 'be' was a common thread throughout all emergent themes in this study. In the adult literature Kralik *et al.* (2004) found that older people diagnosed with illness re shape their lives around the illness and reconstruct their self-identity by exploring their personal limitations or boundaries. While emerging adults with COCI have possibly had their illness for most of their lives they have not been primarily responsible for it. In emerging adulthood the parental

role is being relinquished and they are gaining control over their lives with illness. How emerging adults reconfigured their lives and explore their limitations and boundaries set by their illness will depend on how they construct their self-identity as adults. Goffman's (1959) describes the renowned 'front stage' and 'back stage' dichotomy where he likens the interactions in everyday life to theatre with actors playing a variety of roles. In the front stage we often present our idealised self to others whereas in the back stage is where the "impression fostered by the performance is knowingly contraindicated as a matter of course" (Goffman 1959, p.112). The back stage is where the work takes place so that we can present our idealised self (Hogan 2010). Identity exploration is an important developmental stage for emerging adults who are focusing on forming an identity, especially with respect to relationships and work (Erikson 1968). The participants in this study described experiences of denying their illness and hiding their illness so that they could present themselves to others without illness. However outside influences often interfered with this like needing to take insulin or an inhaler or being unable to join their peers in drinking alcohol. This often led to exacerbations of their illness. While Goffman agrees that individuals often present an idealised self in the front stage, for emerging adults with a chronic illness this could be hazardous for the management of their illness. One of the main features of Arnett's theory of emerging adulthood includes the age of identity exploration, of trying out various possibilities. Harnessing identity development could help as a resource in coping with and adjusting to illness. Successful transition programs will need to be based on our understanding of these developmental issues.

The issues that hindered the participants developing their sense of identity in this study included 7.2.2 *Living with unanswered questions*, 7.3.1 *Visibility of chronic illness* and in 7.4.2 *Developing a sense of self*, the subtheme 7.4.2.1 *Taking control back*. The literature is clear there are significant declines in adherence in chronic illness populations during this period of transition to adulthood (Annunziato *et al.* 2007; Watson 2005; Watson 2000) and increased maladaptive behaviours such as non-adherence and risky style behaviours. Developmental psychologists contend that identity precedes emotional adjustment Schwartz, Klimstra *et al.* 2011; Luyckx (2008; 2011). Luyckx *et al.* (2008) study of emerging adults with type 1 diabetes examined whether identity development was affected and argued that clinicians need to consider identity development in emerging adults with diabetes. Thus harnessing identity development could help as a resource in coping with and adjusting to

diabetes. Schwartz *et al.* (2013) concurs arguing that the study of identity in its various forms to identify specific constructs can be used to promote well-being and wellness in emerging adults and facilitate a successful transition to adulthood. The findings of this study not only report that a sense of connectedness with peers is important for emerging adults living with illness but also concur with the literature that emerging adults sense of identity can be hindered by illness. This study contributes to the understandings of the lived experience of emerging adults living with chronic illness.

Figure 7.3 The lived experience of emerging adults with childhood chronic illness



7.6 CONCLUDING COMMENTS

The emerging adults in this study were articulate, knowledgeable and capable in relation to their experiences living with illness. Their aim was not to be defined by their illness, seeking instead to establish and maintain their individual identity as they approached adulthood. The

findings illustrated that emerging adults growing up with chronic illness had difficulties transitioning to the adult world with their illness. They reported experiences of *living with unanswered questions, the visibility of their illness, fitting in* and *their desire for normalcy, and hope for future life*. However further emergent themes from the second phase of the study begun to yield the essence of their lived experiences. The Hermeneutic interview which was conducted as an online forum revealed that a *sense of connectedness* with peers aided their journey towards developing a sense of identity and merging the person and the illness.

This chapter provided the findings of this study. The application of van Manen four lifeworld existentials offered a means to identify, describe and interpret the lived experience of emerging adults who have grown up with chronic illness. The themes that emerged in this study were embedded in the participants' stories of growing up and living with a childhood chronic illness. While the meanings of the stories were often difficult to ascertain, van Manen's process of analysis aided the process of understanding the experience of living with chronic illness. This doctoral thesis was guided by the research question what is the lived experience of emerging adults growing up with childhood chronic illness. The following chapter presents a detailed discussion of the findings in relation to the existing literature.

CHAPTER 8 DISCUSSION

8.1 INTRODUCTION

In this final chapter, I consider the implications of this study as a whole. The findings and conclusions of this study are discussed throughout this chapter in relation to the current literature. I consider the original aims of the study and how they were achieved. This chapter summarises what Gadamer (1975) refers to as my historical horizon. This is presented in *Figure 8.1 An overview of the contribution of this study* as ‘What I knew’, ‘What the data say’ and ‘What I might change in what I know’. The hermeneutic cycle of moving back and forth between the ‘part and the whole’ or the reader and the text (Gadamer) became increasingly significant as themes emerged. Gadamer refers to this as ‘merging the historical horizon’. The lived experience of the emerging adults in this study is considered in light of the existing literature. The discussion considers how the study contributes to existing knowledge about emerging adults’ experience of growing up with childhood chronic illness and what implications for further research and for practice there might be. The chapter closes with a critical reflection of the limitations of the work and what conclusions can be reasonably drawn. The emerging adults in this study were articulate, knowledgeable and capable in relation to their experiences living with illness. Their aim was not to be defined by their illness, seeking instead to establish and maintain their individual sense of identity as they approached adulthood.

Figure 8.0 An overview of the contribution of this study

What I knew - My historical horizon	What the data says	Merging my historical horizon
<ul style="list-style-type: none"> •Chronic illness is emerging as major health problem in the developing and developed world (Michaud, Suris & Viner 2000). • ↑ prevalence of COCI such as asthma and (Kepreotes et al. 2010; Perrin et al. 2007). •Successful management of COCI has meant that young people with previous lethal diseases are now living successfully into adulthood. •An average of 50% of patients fail to follow their prescribed treatment by health professionals in the developed world (WHO report Adherence to long-term therapies 2003). • Changes to young adult's lives over the last 50 years in the developed world has led to the development of a Theory of Emerging Adulthood. •Delayed transition to adulthood with its responsibilities and weakening of the safety net present in childhood. (Park et al. 2006) • Vulnerable populations such as those with illness can suffer from changes in support leaving them to navigate to adulthood healthcare with less supports (Osgood et al. 2005). • Future research should explore meanings and understandings for emerging adults with Chronic illness because of its link with adapting to illness (Schwartz et al. 2013). •Management of chronic illness needs to change (Newbould, Taylor and Bury 2006) and current models of health care delivery are unlikely to cope with future demand. •Online forum can aid researchers to access previously difficult to engage participants and provide an environment for greater disclosure of personal information (Bowker and Tuffin 2004) 	<ul style="list-style-type: none"> •The lived experiences of the participants in this study confirm that young people are often 'left in the dark' with unanswered questions regarding their future. •They had issues with the visibility of their illness, fitting in and their desire for normalcy. • A sense of connectedness with peers aided the emerging adults' journey towards developing their sense of identity with COCI. •The overarching theme identified within the data from all participants was how participants' redefined their sense of identity in living with COCI in Merging the person and the illness. This explained the link or relationship between the themes created from the data. •In this study the online forum yielded benefits that included improved access to participants, allowed participants time to recall past experiences and provided a medium familiar to the emerging adults in the study. •Potential limitations were identified including limited access to computers for some participants - developments in mobile phone technology provided the solution 	<ul style="list-style-type: none"> •. •Developing a sense of identity for emerging adults can often be hindered by COCI. •This study identified that a sense of connectedness with peers aided the journey towards developing a sense of identity for the participants. •How emerging adults reconfigured their lives and explore their limitations and boundaries set by their illness will depend on how they construct their self-identity as they move toward adulthoods. •Successful transition programs must be based on understanding of the developmental issues of this group, emerging adults. •New innovative ways to engage with EA with COCI needs to be considered so that they feel supported and socially connected to peers, family and health care providers. •The Internet is increasingly used as a tool in qualitative research, researchers need to be aware of current trends in online resources and be responsive to the way different groups communicate including those with illness.

8.2 THE LIVED EXPERIENCE OF EMERGING ADULTS WITH CHILDHOOD CHRONIC ILLNESS

Developing a sense of identity was a strong underlying theme through all of the existential themes that emerged through the data. The developmental literature acknowledges that this is the period of life emerging adults are discovering who they are and who they will become (Schwartz *et al.* 2013; Luyckx, Seiffge-Krenke and Schwartz 2008; Arnett 2000). Specifically identity development begins in early adolescence and by the time an individual has reached emerging adulthood they are consolidating their personal sense of identity (Schwartz *et al.* 2011; Arnett 2000). The participants of this study found that developing their sense of identity was often hindered by their illness. For instance the theme 8.2.2 *Living with unanswered questions* hindered participants, in particular the girls, as they considered issues like parenting. When emerging adults reflect on whether parenting may be something they would consider in the future they are considering the role and responsibility that is attached to parenting. However participants in this study reported that they often did not receive information or answers to questions about their future life with illness. In addition the participants described their struggle to take over from parental control of their illness management in 8.2.1 *Transitioning to the adult world with illness* and reported difficulties establishing an independent identity because of the visibility of their illness in 8.3.1 *Visibility of chronic illness* all of which may impede the consolidation of their sense of identity during emerging adulthood. The developmental literature recognises that a strong sense of identity is linked to less disease-related problems and more adequate coping strategies (Schwartz *et al.* 2013; Luyckx, Seiffge-Krenke and Schwartz 2008). Thus having a strong sense of personal identity could protect against risky behaviours that result in maladaptive outcomes like non adherence to treatment. This knowledge is crucial for health professionals who come in contact with emerging adults with childhood chronic illness who are at risk of maladaptive behaviours.

Emergent themes of connectedness developed from the data discussed in section 8.5.1 *Sense of connectedness with peers* aided the participants' journey towards merging the person and the illness and thus developing their sense of identity. The story of hopefulness described in 8.4.1 *Hope for future life* conveyed by participants of this study supports Arnett's theory of emerging adulthood. Arnett (2004) describes the Age of Possibilities that emerging adults

experience. More than any other stage of development, emerging adulthood is the age of possibilities, greater opportunities and where anything seems possible. Participants experiences of the challenges they faced growing up with chronic illness typically conveyed a hopeful attitude toward their future life. Their stories were one of hope for their future life. They had recalled past experiences of growing up with chronic illness that included frustration and anxiety at missed opportunities and missed 'growing up type' experiences (sports, sleepovers, driving). However now as emerging adults they offered new meanings to these experiences which included more positive connotations (embracing the illness, accepting it, winning, and gaining control). Moreover the experience of living with chronic illness since childhood may enable emerging adults to face future disappointments or challenges. Arnett (2004) voiced concern that emerging adults may set themselves up for disappointment in this age of possibilities if they set their expectations too high. Tanner *et al.* (2007) argues that emerging adults who experience problems becoming independent in their adult lives have faced past challenges meeting developmental tasks. However the participants of this study who have faced the challenges of growing up with illness may be more equipped to deal with setbacks later in their adult life.

Overall these emerging adults strongly valued their relationships with family and their friendships to help them stay connected and feel valued despite the social isolation associated with their chronic illness. These findings suggest that emerging adults growing up and living with chronic illness have a sense of hopefulness for future life and value their social connections which aid their journey towards consolidating a personal sense of identity. While their sense of identity may be hindered by their illness, hopefulness and connectedness may facilitate a better sense of identity for emerging adults with chronic illness. Despite the consequences it is reported in the literature that the level of risky behaviours is the same in emerging adults with illness and without illness (Palladino *et al.* 2013). Equally having a strong sense of identity is linked to less maladaptive behaviours. This study has shown that having a sense of connectedness with peers was important for emerging adults growing up with chronic illness. It appears to aid them in merging the person and the illness. The data from this study can inform both health professionals working with emerging adults with childhood chronic illness and policy makers designing programmes for those transitioning to adult services. The lack of structured transition programs to assist the transition of young people with chronic illness from paediatric to adult care was identified in earlier in Chapter 2

of this thesis. With only half of young people receiving structured transition programmes (de Beaufort *et al.* 2010) and a lack of adequately trained healthcare professionals capable of providing developmentally appropriate care (Reiss and Gibson 2005) strategies need to be identified to promote adherence and prevent maladaptive behaviours. The new freedoms associated with emerging adulthood, highlighted extensively in the developmental psychology literature, come with new responsibilities to self-manage illness. Reiss (2012) urges that health professionals and parents' guide emerging adults with chronic illness towards self-efficacy and the final step of individuation, and independence. Evidence from this study shows that emerging adults are not receiving the information needed to make informed decisions. While emerging adults may be increasingly involved in more independent decisions making during this period it is an emerging skill and requires opportunities for applying new knowledge, practicing decision making skills and learning from mistakes (Reiss 2012).

The literature on transition to adulthood health service highlights that young people feel ill prepared (Steinbeck *et al.* 2008) and lack in understanding about the consequences of non-adherence to treatment (Hogan *et al.* 2006). The experiences of the participants in this study confirm that young people are often 'left in the dark' when it comes to questions regarding their future. Once they have made the transition to adult health services they begin to get the information they require. While policy-makers have recognised the need to ensure a smoother transition between children and adult services, transition to adult health care is still considered to be ad hoc (Simon 2009; Wedgewood 2007). Despite the introduction of holistic, individualised, and person-centred care, issues with transition and non-adherence remain. If emerging adults are to negotiate the transfer of their health care from child to adult services successfully they need to be informed. Future models of care need to incorporate education and support so that they are not kept in the dark about their illness.

The literature is clear that emerging adults are at greater risk of non-adherence to treatment and increased risky behaviours than any other developmental group. In order for health professionals to understand why this situation exists we need to ask the relevant questions. What kind of knowledge do health professionals need to deal with this problem? What is the experience of growing up and living with childhood chronic illness for emerging adults?

What meanings does it have for them? How should nurses act to improve the situation for emerging adults with childhood chronic illness? The phenomenological understandings gained from this study provide the nursing knowledge needed to act with ‘tact and thoughtfulness’ as van Manen urges. It provides knowledge to inform nursing practice and curriculum. Knowing that emerging adults growing up and living with chronic illness value their sense of connectedness with peers is relevant for nurses. This study contends that their sense of connectedness with their peers seems to aid their journey towards merging the person and the illness.

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8.3 SENSE OF CONNECTEDNESS WITH PEERS

A sense of connectedness with peers emerged as a major theme in this study. Lee and Robbins (2011) describe a sense of connectedness as relationships that emphasize forms of intimacy and physical proximity. They involve the social world of the person and can include family friends and co-workers. This study of the lived experience of emerging adults highlighted a sense of connectedness with peers as important for participants. The study of sense of connectedness is not new and has been studied under controlled scientific conditions in past (Andrews 1996; Resnick and Harris 1993). Indeed a sense of connectedness and the experience of feeling consciously connected with others have been found to promote physical and mental health, or well-being. Psychologists have linked a sense of connectedness to health outcomes (Sawyer, Drew, Yeo and Britto 2007; Mitchinson *et al.* 2007; Cohen 2004) and argue that creating and nurturing social networks can impact health. This study contends that emerging adults with COCI value their sense of connectedness with peers in preventing social isolation and facilitating their journey towards developing a sense of identity. Arnett (2006) highlighted the influence of family relationships and family support on the developmental trajectories of emerging adults. Increasingly social isolation is recognised as having potential negative effects on the health of individuals and is becoming a focus of public health policy. Since the WHO (World Health Organization)- Ottawa Charter for Health Promotion¹⁰ in 1986 research has begun to focus on the social and relational factors of health. Evidence suggests that when individuals perceive that they have established connectedness there is associated health benefits that include lower blood pressure rate, improved immune responses, and reduced levels of stress hormones, which can help to prevent of chronic disease (Uchino *et al.* 1996).

However gaps exist in our knowledge of the influence of relationships and connectedness among emerging adults who have grown up and live with chronic illness. Emerging adults in this study emphasised the importance of their relationships with friends in their narratives. Specifically they indicated that their friendships provided protection, shielding from

¹⁰ Strategies that emerged during the Ottawa Charter were 'building health public policy, to create supportive environments, to strengthen community action, to develop personal skills, and to reorient health services'.

‘sensitised others’ in sections 8.2.1 *Transitioning to the adult world with illness* and 8.3.2 *Fitting in: the desire for normalcy* and helping them to develop their sense of identity in section 8.4.2 *Developing a sense of self*. Yet we know that having a childhood chronic illness can predispose them to periods of isolation particularly from friends. Psychologists have identified that reduced periods of isolation will also lead to better health behaviours (Cacioppo and Hawkley 2003) and that establishing connectedness is directly related to improved management of stress and anxiety (Duru 2008). A sense of connectedness and a feeling of belonging with the social world, has been recognised as an important part of physical and emotional well-being (Mount *et al.* 2007; Young, Russell and Powers 2004; Lin and Bauer-Wu 2003; McNeely 2002). Moreover a recent report published by the *European Foundation for the Improvements of Living Conditions and Working Conditions* identified the need for contact with friends and family as a unique characteristic of this specific developmental group. The report claims that 53% of young people meet their friends every day or almost every day and 89% meet once a week higher than any other group (Goffe 2014.) Not only could a lack of connectedness have a possible negative impact on health, well-being, and psychological functioning of emerging adults but also in their health behaviour (adherence to treatment, risky behaviours). In this study emerging adults reflected how their social connections often helped their ‘negative mentality’ about living with illness and allowed them to ‘be who they are’ without the illness label. Even though their relationships were often plagued by disruptions (hospitalisations and educational milestones like starting university) they felt optimistic about their friendship network. This knowledge is crucial for health professionals who come in contact with emerging adults with childhood chronic illness who are at risk of maladaptive behaviours. It is also important to consider any negative outcomes from connectedness therefore new models or programs of care should reflect both positive and any negative aspects in the design. Nurses are ideally placed to engage with emerging adults with COCI in the developments of such programs.

How young people connect with friends has changed rapidly over the last decade with digital media communication. There has been a shift from phone and face to face contact to textual based interactions (Schwarz 2011) and an increasing need to be constantly connected to peers (Timmis 2012). Over the last decade the literature has highlighted both pro social and some of the more undesirable effects of social media communication including that it supports

social isolation and secondly that it may encourage disinhibited online behaviour. With young people spending increasingly more time communication using technology face to face interaction is lessened. New technologies particularly those van Manen refers to as “technologies of expression” such as social media sites like Facebook, encourage young people to “spend time with their friends,” which translates into pressing thumbs or fingers on a mobile handset or computer keyboard (van Manen 2010). While young people may feel more digitally close to their friends, contact is often less intimate. The growing popularity of online interaction is increasingly thought to be transforming social relationships. Debate has emerged in recent years in efforts to understand why there is an increasing need to be in constantly connected. Robert Putnam explored the modern American disconnectedness in his book “Bowling Alone” arguing that increased travel and working away from home has led to a social isolation that digital media communication can remedy. The online intimacy of social media sites can offer a way to ‘feel less alone’. However Ito *et al.* (2008) argue that this should not be viewed as a simple fix for social isolation.

Concerns such as online disinhibition effect (Tanis 2007; Tanis and Postmes 2007) where there are less social restrictions and inhibitions than with face to face interaction, can lead to negative style online behaviour. Joinson (2007) explains that disinhibition on the Internet is characterised by a reduced concern for self-presentation whether that be due to anonymity remains uncertain. The study of connectedness and technology has tended to take alternative viewpoints either targeting the harmful media effects (Melville 2010; Hinduja and Patchin 2010) or the pro social aspects of modern media (Lenhart 2010). However the therapeutic effect of increased social interactions, self-disclosure, revealing hidden emotions or fears needs consideration. van Manen’s (2010) recent work *The Pedagogy of Momus Technologies: Facebook, Privacy, and Online Intimacy Privacy*, reveals the critical role that social media plays in the development of self-identity, autonomy, intimacy, and the ability of learning to negotiate closeness and distance in social relations for young people. For those living with illness who are pre disposed to periods of social isolation, social media has huge benefit. In their review paper on online support groups Baraka, Boniel-Nissima and Suler (2008) found that writing stories online about personal difficulties and handicaps even in a casual format and “even to laugh about them, seems to induce a sense of personal empowerment by bringing about emotional relief and a better sense of control”.

Young people are increasingly living their social lives in a digital world (Lenhart 2010). This issue highlights three considerations. Firstly, with social media now being the ‘norm’ for emerging adults as a means of communicating with friends, health professionals need to consider the isolation aspect particularly for those growing up and living with illness. While some studies find that high levels of Internet use may result in less time spent with others and increased loneliness (Nie, Hillygus and Erbring 2002) others show that social networks can let people feel more connected to family and friends (Gentile et al. 2012; McDaniel, Coyne and Holmes 2012). Secondly there are opportunities for health professionals to harness social media to capture the attention of emerging adults as a means of communicating health education. While other disciplines have harnessed social media to communicate with young people including the film, music industry and politics with success, nursing and indeed health care has been slow to engage (Korda and Itani 2013). Recently there have been increasing interest in adopting digital technology (Schneider and Panzera 2013) and social media to improve patients’ self-management of chronic disease (Martinasek *et al.* 2011).

Without doubt health professionals who work with emerging adults with chronic illness will need to adapt their communication strategies if they want to engage with emerging adults in a medium that fits with their needs. The use of digital technologies is as ubiquitous in Ireland as it is in the rest of the developed world particularly among young adults. Mobile digital devices are becoming increasingly popular to access the Internet which suggests opportunities for nurses to engage with patients so that they can be informed (Lenhart 2010). The next generation of children with chronic illness will be growing up with new and emerging digital tools, technology will play an increasingly important role in connecting with, communicating and educating this demographic group particularly.

In particular, nurse educators need to incorporate communication technologies such as social media into their curriculum if we are to meet the needs of this demographic group. The Nursing and Midwifery Board of Ireland (NMBI) has recently published guidelines to support to nurses on social media use and social networking practice (2013). While many benefits to social media use have been highlighted (continuous professional development, access to research, professional discussion forums for nurses) harnessing social media to engage with patients is yet to be utilised. Yet social networking practice may bring huge

benefits to emerging adults living with chronic illness to encourage their sense of connectedness not only with health professionals but also with their peers. The benefits of improved connectedness that communication technology can provide are too great to ignore, they include possible improved adherence to treatment for this age group, improved communication strategy and improved sense of identity. Thirdly searching for health information online is the second most common activity among adults (Fox and Duggan 2013). Patients have begun to rely more on the Internet than healthcare professionals for health information (Vance, Howe and Dellavalle 2009). Worried young people tend to search the Internet for general health information, most citing general search engines such as Google (Panzera et al. 2013). Moreover some childhood chronic conditions can be rare and with information limited young people and their families become experts themselves. Social media like Facebook can make life easier by connecting those with similar conditions or rare disorders to share that expertise. Nurses and other healthcare professionals need to be aware of the pervasive use of social media networks as a medium to improve patient care.

A noteworthy concern is that as the advances in communication technology have increased, a disconnect in digital knowledge has likely emerged between young people and practitioners (Goodall *et al.* 2013). The digital navigation skills of young people far exceed that of adult practitioners. Equally while many young people navigate the Internet with ease they may not be expert in Internet safety which could expose them to negative online social behaviour. Thus a collaborative approach is needed between nurses and young people to developing communication technologies that are suited to enhancing their feeling of connectedness with both their peers and with health professionals. The challenge will be that a whole generation of nurses will need to learn new technological approaches and new digital skills in the current atmosphere of cutbacks and increased workloads. However the benefits are too great to ignore.

This study contends that a sense of connectedness with peers is important for emerging adults who are often left in the dark regarding illness management and future lives, and are at risk of social isolation. What is known is that connectedness can influence health outcomes of chronically ill adolescents (Sawyer, Drew, Yeo and Britto 2007) and in the acute setting is associated with improved outcomes in pre and post operation recovery (Mitchinson *et al.*

2007). This study has shown that emerging adults in this study living with chronic illness value a sense of connectedness as they transition to adult life. It offers protection, shielding them from ‘insensitive others’ and aids their journey towards developing their sense of self. Social media may provide ways for emerging adults living with illness to connect with the social world so that they can move towards adulthood with a sense of identity. Developing a sense of identity is linked to coping and adjustment in emerging adults with a chronic illness (Luyckx *et al.* 2008). While it is acknowledged that a sense of connectedness may be different for male and females, this was not investigated in this study. However future research on this topic would be valuable.

8.4 MERGING THE PERSON AND THE ILLNESS

Emerging adulthood has been considered in part as the “age of identity exploration” (Arnett, 2007b, p. 69). In the adult literature, research strongly suggests that adults living with chronic disease can experience strong disruptions in their sense of self (e.g., Charmaz, 1983; Bury 1982). However differences lie in the fact that these emerging adults have grown up with their illness through all the stages of child development. How much identity contributes to the study of adaptation to those growing up with chronic illnesses is unknown. Schwartz *et al.* (2013) argues that while developing a sense of identity has become increasingly important for emerging adults, it has become increasingly difficult to navigate. Living with chronic illness and the disruption that entails will add to that struggle. Several participants relayed stories of fighting the illness and ignoring the illness which led to maladaptive behaviours. In 8.3.1 *Visibility of chronic illness* and 8.3.2 *Fitting in: The desire for normalcy* they reported struggles with fitting in and how the illness often sabotaged their desire for normalcy. They reported “fighting my own body”. It appeared that by doing so the illness was not part of who they were as individuals. In this thesis I returned to Goffman’s (1959) influential work on identity in the *Presentation of Self in Everyday Life* as discussed in section 2.4.1 *Age of Identity exploration*. Goffman describes the renowned ‘front stage’ and ‘back stage’ dichotomy where he likens the interactions in everyday life to theatre with actors playing a variety of roles. In the front stage we often present our idealised self to others whereas in the back stage is where the “impression fostered by the performance is knowingly contraindicated as a matter of course” (Goffman 1959, p.112). The back stage is where the work takes place so that we can present our idealised self (Hogan 2010). Identity exploration

is an important developmental stage for emerging adults who are focusing on forming an identity, especially with respect to relationships and work (Erikson 1968). The emerging adults lived experiences in this study described experiences of struggling to present their idealised self to others. Hiding their illness was sometimes sabotaged by symptom occurrence or the visibility of their treatment. Participants also struggled with finding a liveable relation with their body. van Manen (1998) work on *Modalities of Body Experience in Illness and Health* contends that health professionals must work to help individuals with illness reunite with their body. Our awareness of our body only becomes vivid when we are ill. The body is broken, injured or disrupted.

The literature also acknowledges that there is a strong link between a coherent well-adjusted sense of identity and illness related coping in those living with chronic illness (Schwartz *et al.* 2013; Lee and Newberg 2005). Thus health care professionals in contact with emerging adults with chronic illness need to be attentive to their behaviour patterns and consider ways to educate those at risk. Finding ways to help emerging adults with illness consider alternative ways to explore their identities rather than adopting risky behaviours or not adhere to treatment is a priority for health professionals. Historically medical issues related to illness and complications tend to take precedence over issues related to their health behaviours in healthcare interactions. Schwartz, Zamboanga and Luyckx (2013) argue that there is a need to examine the role of identity in helping to manage disease and adapt to chronic illnesses. Indeed studies show that emerging adults can foster a sense of normalcy by identifying common behaviours, feelings, or needs among their peers with illness (Wilkins, D'Agostino and Penney 2014; Corbeil *et al.* 2009).

A key underlying theme of 'sense of identity' and how the participants merge living with their illness as they move towards adulthood was a common thread throughout all emergent themes in this study. A main feature of Arnett's theory of emerging adulthood, the age of identity exploration includes trying out various possibilities as part of their development. Developmental psychology literature has debated the link between identity and positive emotional and psychological development (Schwartz, Klimstra *et al.*, 2011; Luyckx 2008, 2011). Luyckx, Seiffge-Krenke and Schwartz (2008) examined whether identity development was affected in emerging adults with Type 1 Diabetes and argued that clinicians need to

consider identity development in emerging adults with diabetes. This he argued was because harnessing identity development could help as a resource in coping with and adjusting to diabetes. Given the struggle that emerging adults have growing up with chronic illness as identified in this study there is a need for health professionals to understand, support and navigate them successfully into adulthood. Ensuring successful adjustment is the responsibility of everyone in the emerging adult's support network. Emerging adulthood is a time for reflecting on future plans for work and relationships and figuring out who one is and where one's life is headed (Schwartz, Luyckx and Vignoles 2011). However those living with chronic illness have an added burden in the construction of their own identity and in considering their future. The illness can sabotage efforts to fit in, seek normalcy and figure out their identity. However participants in this study sought ways to overcome the hindrance of the illness. Taking control back from parents even though that was somewhat slow process, developing friendships and future hopefulness aided their journey towards a sense of their own identity their "own self".

8.5 CONTRIBUTION TO KNOWLEDGE

Despite a relatively small sample size, this study builds on the existing body of knowledge that explores the lived experience of childhood chronic illness. Due to the varying dimensions that contribute to the chronic illness phenomenon there are great opportunities for researchers of all disciplines and levels to take advantage of the findings in this study. Key insights are that a sense of connectedness with peers seems to aid emerging adults' journey towards developing their sense of identity. Whether new Web 2.0 technologies such as social media have the opportunity to enhance emerging adults sense of connectedness growing up and living with chronic illness needs further study. While the new eHealth Strategy 2013 in Ireland should go some way to improve information sharing for emerging adults with chronic illness, connectedness requires more than access to the right information. Social media could aid emerging adults to maintain connections particularly with their peers during periods of isolation or hospitalisation.

This study's focus was the lives of 15 emerging adults who I was privileged to know during this study. They offered their stories and experiences willingly. Most of the participants

revealed that they had never spoken about the experiences of growing up and living with their illness to anyone before. As a nurse educator I found this very worrying. One participant articulated what I was hearing from many other participants in this study:

Interviewer: And do you get the chance to discuss that with your nurse or doctor?

Interviewee: Not really, they don't go into that. So you have had to deal with that by yourself. Their main concern is just the epilepsy, the seizures, are they controlled? You can't chat about life issues or how it affects you having epilepsy and you can't ask at home because they'd be like what's wrong, somethings wrong isn't it so you say nothing

Despite the fact that the Chronic Illness Framework (Health Service Executive (HSE) 2008) acknowledges the importance of minimising and managing the impact of chronic illness on individuals it seems from the experiences of these emerging adults that little has changed. It is well recognised both nationally and internationally that the management of chronic illness needs to change (Newbould, Taylor and Bury 2006) and that current models of health care delivery are unlikely to cope with future demand. However little has been introduced to explore manage or minimise the impact of chronic illness on younger populations. Yet younger populations have higher non adherence rates (60% in adolescents) with significant declines in adherence in the transition to adult healthcare (Annunziato *et al.* 2011; Shemesh *et al.* 2011; Watson 2005). Investment is needed to support patients to live with chronic illness and manage the impact of their disease on their lives. Chronic illness consumes between 70-80% of all health care spending, with those living with chronic illness much more likely to attend their General Practitioner (GP) (80% of GP consultations relate to chronic illness) or present at an Emergency Department. Knowledge that a sense of connectedness was identified as a major issue for emerging adults and how it influences their sense of identity is important. Developing a sense of identity has been previously linked to coping and adjustment in emerging adults with a chronic illness (Luyckx *et al.* 2008). A developmentally appropriate model of care for emerging adults with childhood onset chronic illness proposed that acknowledges the importance of connectedness and incorporates social media as a tool to promote their successful transition to adult healthcare.

Links between a sense of connectedness with peers and technology and how technology can be developed to help emerging adults live well with their illness need to be developed. As

previously discussed (*Section 2.11 Emerging adults and the digital age*) disciplines such as education have found positive results in the learning interactions and communication of university students with digital media (Timmis 2012; Timmis *et al.* 2010). This study promotes greater understanding of the lived experiences of emerging adults who have grown up and now live with chronic illness. This can inform processes of chronic illness transition and management and support nurses and other healthcare professionals to engage with young people living with illness.

8.6 RECOMMENDATIONS FOR PRACTICE

Over one third of the Irish population report having a chronic illness. The burden of chronic illness can be improved in this population with lifestyle changes, lifestyle choices such as adherence to treatment, risk factor modification and better transitional care. New approaches are needed to engage with this developmental group. The social networks of this population and how they maintain a connection with others can aid their journey towards developing a sense of self. Emerging adults have an advantage over other developmental groups such as the elderly with chronic illness as they are very much attuned to health technology. They are more adapt at visiting health consumer Web sites than any other developmental group. In 2011 there were 2.2 billion (32.7% of the global population) internet users. New communication technologies will have a more significant impact on the lives of young people than other past technological innovations. The shift in health policy towards promoting wellness in chronic illness is all very well but how we encourage and promote wellness is key. Nurses are well placed to be involved in the development of communication technologies for those living with illness. While there is a digital divide among social economic groups and the developed and developing countries, undoubtedly there is an opportunity to utilise digital technologies to promote and improve connectedness with young people with chronic illness.

A sense of connectedness emerged as a major theme in the lived experience of emerging adults with chronic illness. Further research is warranted in this area as connectedness appears to be a highly understudied area. The increasing dominant role of social media in the lives of young people while not the focus of this study emerged as a critical factor in contemporary society for emerging adults and will no doubt shape future research agendas.

Recommendations for practice, education and future research are:

- Successful transition programs must be based on understanding of the developmental issues of this group, emerging adults. Therefore there is a need to work collaboratively with emerging adults to consider new models of chronic illness management to promote illness management including adherence to treatment. Understanding the issues that influence chronic illness management is critical in order to appropriately assist those within this particular developmental group of emerging adulthood with the challenges related to managing their illness.
- The potential for modern media to play a beneficial role in the lives of young people with chronic illness has not been realised. Need to investigate opportunities for empowering emerging adults with childhood chronic illness teenagers to improve their illness management using information communication technology. A sense of connectedness may not only promote wellbeing but also their healthcare management. It can do this by helping emerging adults to connect with each other, with their local health service and by providing emotional support which can create healthy social norms and increase health literacy within social networks.
- Need to consider emerging adulthood in full spectrum of transition to adulthood with illness
The information from this study is vital for the development of specific strategies to help both paediatric and adult providers care for the transition needs of this vulnerable population with chronic illness particularly in Ireland where transitional care remains ad hoc.
- Need to include this specific developmental group with chronic illness in nursing research studies to build the on the theory of emerging adulthood.
- The Internet is increasingly used as a tool in qualitative research, researchers need to be aware of current trends in online resources and be responsive to the way different groups communicate including those with illness.

8.7 PHENOMENOLOGY AS INSPIRATION AND METHOD

This study utilised a phenomenological methodology underpinned by the philosophy of Martin Heidegger and the more contemporary Max van Manen. This helped to guide and shape the study as I strove to understand what it meant to grow up and live with a childhood chronic illness. Through acknowledging each participants experiences within their lifeworld and the very essence of their sense of Being, it was possible to explore the chronic illness phenomenon. The decision to employ a phenomenological approach was prompted by reading Van Manen's textbook *Van Manen, M. (1990) Researching lived experience: Human science for an action sensitive pedagogy*. The current knowledge of how young people experience childhood chronic illness originates from large longitudinal studies discussed throughout the literature review chapters. However failing to explore the experiences of emerging adults living with childhood chronic illness may mean that we are failing to ask the right questions in large longitudinal studies. I recognised that hermeneutic phenomenology would encourage a deep understanding of the lived experience of emerging adults growing up and living with childhood chronic illness and the meanings offered by them in this study. The aim of applying hermeneutic interpretive phenomenology was that practical acts of living with childhood onset chronic illness, accessed through "narratives" (whether they are sourced via face to face interviews or web based forum) would reveal meaning. The combination of data collecting methods in this study allowed it to move from researcher driven to collaboratively constructed where participants not only had control over the location and time but also had time for reflection. The online forum encouraged a collaborative approach where participants took greater ownership of the processes of narrative construction at times leading the discussion in new directions and taking the their narratives further. Markham (2004) argues that this feature of using online social research methods of data collecting is methodologically important as interaction reflects the shape of the phenomena being studied.

The contribution of phenomenology to this study ensured that the wealth of data and rich thick descriptions gleaned from both interviews and the online forum was explored in such a way as to enable each individual's experiences of the same phenomenon to be considered in a thoughtful, measured iterative manner until a deeper understanding was reached of what it is meant to live with childhood chronic illness since childhood. Hermeneutics provided the method of analysis so that not just present simple phenomenology precepts were presented.

To prevent being blinded by pre understandings and lifetime habits following a long career in nursing I engaged activities that acknowledged prior assumptions (Bracketing interview) in order to clear the way for new thinking. The creative process' facilitated by the writings of Derrida allowed me to find new ways of seeing, new ways of engaging with the process of reflecting on their experiences. Often in nursing we believe we understand patient experiences from their situation. However there is often a need to suspend our belief and be open to understanding the phenomenon we are studying. To find the meaning can be a difficult process and often involved periods of reflection away from writing. These reflective periods involved both listening to the data over long walks in the park and 'thinking'. My 'thinking' involved questioning my historical horizon that included 'What I know', 'What the data says' and 'What I might change in what I know'(Prof Paul Fry, Open Yale Lecture 2012). The hermeneutic cycle of moving back and forth between the 'part and the whole' or the reader and the text (Gadamer) became increasingly significant as themes emerged. Gadamer calls this 'merging the historical horizon'.

Criticisms in the literature of the use of phenomenology as a methodology in the nursing studies concerned me throughout the study. Many of the criticisms concern poor examples of the application of phenomenology in nursing studies that focus on the descriptions of participant experiences rather than offering a way to identify the phenomenon common to individuals, the original intention of phenomenology (Langridge and Ahern 2003; Mayoh and Onwuegbuzie 2013; Giorgi 2000b; Crotty 1996). Throughout the study I was continually conscious of the aim of this study to not only uncover the participants lived experiences of childhood chronic illness but develop meanings and practical knowledge to assist those who come in contact with emerging adults living with childhood chronic illness.

8.8 STUDY LIMITATIONS

The limitations in using hermeneutic phenomenology to explicate the phenomenon were acknowledged and discussed and suggestions for further research were outlined. The number of participants may be considered small. However this study aimed to explore richness and complexity of experience. Moreover a criticism sometimes levelled at phenomenological nursing research concerns poor examples of the application of phenomenology in nursing studies that focus on the descriptions of participant experiences rather than offering a way to

identify the phenomenon common to individuals, the original intention of phenomenology (Mayoh and Onwuegbuzie 2013; Langridge and Ahern 2003; Giorgi 2000b; Crotty 1996). Throughout the study I was continually conscious of the aim of this study to not only uncover the participants lived experiences of childhood chronic illness but develop meanings through interpretation of the data. The research process used in this study allowed knowledge to emerge that will not only assist those who come in contact with emerging adults living with childhood chronic illness but also assist in the development model of future models of care.

Using the online forum I was dependent on the information technology knowledge of the participants. If they were not able to log on to the site they were not be able to contribute. However this developmental group are notably technologically savvy and I experienced minimal technological problems. The attraction of using Google Docs was that there were few steps involved in logging in and postings were in one document making it easy for participants to read through the discussion and join in. Thus I would certainly consider this method of data collecting with older participants in future studies.

8.9 CONCLUSION

This study explored the experiences of 15 emerging adults who have lived with chronic illness since childhood. I explored their experiences and developed phenomenological understanding through interpreting the data using van Manen's phenomenology approach. Several themes emerged from the participants lived experience including the major theme of *Sense of connectedness with peers*. Emerging adults in this study value their social connections particularly with friends. In line with current trends, this specific age group often use the internet to develop and sustain their relationships and to keep in touch with normality and with friends and family. As discussed at the beginning of this thesis any study exploring the lived experience of emerging adults needs to appreciate how much of their lives have changed with the digital age. Young people spend on average more than seven hours per day using some form of modern media (Strasburger, Jordan and Donnerstein 2010). Health promotion interventions need to consider connectedness and the social networks of emerging adults if they are to make strides in influencing this population. New approaches should be considered for conceptualizing emerging adults lived experience with illness and for how they can establish and maintain a sense of connectedness with the people around them. The

link between chronic illness and connectedness is complex and need further study. The study of connectedness and chronic illness has often escaped empirical analyses in studies exploring the social determinants of health (e.g. social economic status). However this study has identified that emerging adults identify a sense of connectedness with peers as important in developing their sense of identity as they move into adulthood.

This doctoral study used Web 2.0 technology to elicit data from the participants in an attempt to capture the attention of this particular demographic group. While the ethics of research using the internet and the particular challenges of doing so with young people remains under-developed it proved a valuable resource for gathering data in this study. There is consensus in the literature that we need to develop and refine our understanding of emerging adults so that we can guide them through the transition to adulthood. Keeping the conversation going with emerging adults with chronic illness will provide much needed information for developing chronic illness management strategies. Moreover if we fail to explore the experiences of emerging adults living with childhood chronic illness we may not ask the right questions in large longitudinal studies. It is hoped that knowledge from this study of emerging adults with COCI will build on the theory of emerging adulthood particularly from a nursing perspective.

As the current emphasis in chronic illness management encourages wellness and living well with illness it becomes important for nurses to engage with young people to promote healthier lives. Greater effort is needed to understand issues such non-compliance with treatment and illness behaviour among emerging adults living with chronic illness. With only 50% of respondents received structured transition programs (de Beaufort *et al.* 2010) and a lack of adequately trained healthcare professionals capable of providing developmentally appropriate care for young emerging adults with chronic illness, priority now is to find ways to develop strategies to promote adherence (Reiss and Gibson 2005). The information from this study is vital for the development of specific strategies to help both paediatric and adult providers care for the transition needs of this vulnerable population with chronic illness particularly in Ireland where transitional care remains ad hoc. The exclusion of emerging adults in samples covering the complete adult spectrum may mask the issues that arise in the transitional period between adolescence and adulthood. A sense of connectedness can not only promote wellbeing but also their healthcare management. It can do this by helping

emerging adults to connect with each other, with their local health service and by providing emotional support which can create healthy social norms and increase health literacy within social networks (Kim *et al.* 2008). Understanding the issues that influence chronic illness management is critical in order to appropriately assist those within this particular developmental group of emerging adulthood with the challenges related to managing their illness. While this doctoral study finds that emerging adults value a sense of connectedness as means to develop and establish their sense of identity a continued study of how they integrate their illness into their lives is warranted. I contend that this study represents a first step in addressing developmental psychologists, Schwartz *et al.* (2013) call to explore “How do young people with diabetes and other chronic diseases find meaning in their illnesses and in their lives? What specific turning points and life themes emerge in these individuals’ narratives?” (p.96).

Sociologists have for some time now highlighted the importance of social networks for people living with illness (Young 2004; Cockerham 2000). Previous work has examined the role of connectedness to social networks and found increased healthy lifestyle choices and use of preventative health care (DiMatteo 2004; Gallant 2003). Direct links between social networks and compliance to treatment (DiMatteo 2004) and coping and adjustment in emerging adults with a chronic illness (Luyckx *et al.* 2008) are found in the literature. This study highlights the importance of social connections in emerging adults with chronic illness acknowledges the importance of having a sense of connectedness with peers. Future chronic illness models of care need to consider new innovative ways to connect with this population and encourage their social connections with friends and family. Incorporating Web 2.0 technology, of which social media is one example, as a tool to promote their successful transition to adult healthcare needs to be explored. This study is a first step in a process that promotes a developmental approach to supporting emerging adults living with COCI. Future post-doctoral work will be continue this process engaging collaboratively with this population to examine ways to build a conceptual framework that will aid their journey towards successful transition to adult healthcare and managing their illness. Connectedness has evolved dramatically in the digital age and may provide practical, emotional and relational support for those living with chronic illness. It’s ability to connect individuals to relevant information all of which may increase the likelihood of developing their sense of identity, wellness and adhering to their treatment.

Web 2.0 technologies that include social media may have the potential to aid nurses and other health professionals to communicate with and support those growing up and living with illness. Studies have shown that new media can provide current information on safe health practices (Lenhart 2010; Collins Elliot, Berry 2003) for young people and indeed foster a connectedness among like-minded people (Valkenberg 2009). The potential for modern media to play a beneficial role in the lives of young people with chronic illness has not been realised. As new views and shifting perspectives of chronic illness emerge and government strategies for dealing with chronic illness widen their focus to include wellness and well-being new ways to communicate with emerging adults must be embraced. Health professionals need to appreciate the fact that young people living with chronic illness since their childhood have grown up in a digital age of communication and facilitate their needs.

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APPENDICES

APPENDIX 1REC ETHICAL APPROVAL

Emerging Adults experience of growing up and living with Chronic Illness.

EACI

A research study conducted by Siobhan MacDermott as part of a Doctoral Study

Researcher

School of Nursing and Human Sciences,

Dublin City University

Are you between 18 and 29 years of age?

Do you have a chronic illness such as asthma, diabetes or epilepsy etc. since your childhood?

Would you like to take part in an online forum about what it is like to grow up and live with a chronic illness since childhood?

If you are unsure about your chronic illness you can check with Siobhan at siobhan.macdermott@dcu.ie

This study is being conducted by Siobhan MacDermott as part of a doctoral study in Dublin City University. Please click on the following link to the study website www.emergingadulthealth.com or contact Siobhan MacDermott by email Siobhan.macdermott@dcu.ie for more information on this study.

Emerging adult health (EAH) Website

Information about a study of young adults with a chronic illness since childhood.

Young adults experience of living with childhood chronic illness.

My Name is Siobhan MacDermott and I am a lecturer in the School of Nursing, Dublin City University. I am currently completing my doctoral studies in DCU. This research study will explore what it is like for young people to live with chronic illness. I would to invite you to take part in the study. The study is about young adults' experience of growing up and living with childhood chronic illness and the impact this has on your life. I am asking you to participate because you have had a chronic illness since childhood.

With your help I would like to find out more about young people with chronic illness and what it is like for people your age to live with chronic illness. It is hoped that the results will provide a better understanding of the issues and provide better services to young people with chronic illness in the future.

The study involves me asking you some questions, for about an hour, about what it is like to have chronic illness. In addition you will be asked to contribute to an online forum on this subject. The Online forum will be private and only the participants of the study and me the researcher will have access to it. I hope that it will be a positive experience for you and a chance to share your own experiences, memories and stories.

If you feel you would like to take part in the study you can click on the email link on this page that will direct you to the researcher who will clarify any questions you may have regarding the study and what is involved. Whilst we would be grateful for your help, you do not have to take part in the study if you don't want to. Your choice will not have an effect on the help you are receiving.

Please also feel free to contact me to discuss any questions that you may have. My contact details can be found on this webpage.

Many thanks for your time.

Siobhan JMacDermott

Researcher

Dublin City University

Phone: 017007156 Email: Siobhan.macdermott@dcu.ie

APPENDIX 4 CONSENT FORM

Project: Emerging Adults' experience of growing up and living with childhood chronic illness.

I, the undersigned, confirm that (please tick box as appropriate):

1.	I have read and understood the information about the study, as provided on the Information sheet dated _____.	<input type="checkbox"/>
2.	I have had an opportunity to ask questions and discuss this study	<input type="checkbox"/>
3.	I have received satisfactory answers to all my questions	<input type="checkbox"/>
4.	I have been given the opportunity to ask questions about the study and my participation.	<input type="checkbox"/>
5.	I voluntarily agree to participate in the study.	<input type="checkbox"/>
6.	I am aware that my interview will be audiotaped	<input type="checkbox"/>
7.	I understand I can withdraw at any time without giving reasons and that I will not be penalised for withdrawing nor will I be questioned on why I have withdrawn.	<input type="checkbox"/>
8.	The procedures regarding confidentiality have been clearly explained (e.g. use of names, pseudonyms, anonymization of data, etc.) to me.	<input type="checkbox"/>
9.	The use of the data in research, publications, sharing and archiving has been explained to me.	<input type="checkbox"/>
10.	I understand that I have said or written as part of this study will be used in reports, publications and other research outputs	<input type="checkbox"/>
11.	I, along with the Researcher, agree to sign and date this informed consent form.	

Participant:

Name of Participant

Signature

Date

Researcher:

Name of Researcher

Signature

Date

While the overall question in this phenomenology study is: What is the lived experience of emerging adults with childhood onset chronic illness (COCI)?

However we rarely ask that question in phenomenology studies instead opting to probe for moments and stories in the participants lives (Adams 2014).

The following are probes used to elicit the information around living with chronic illness:

Remembering back - how it all started.

I asked participants to take me on a journey of their experiences and lives with illness. Using probes like “tell me about a time when ----- happened?”

General probes included asking the participants to describe experiences and stories about school life, social life, family life and how they manage lives having a chronic illness.

APPENDIX 6 IN-DEPTH INTERVIEWS AND ETHICAL CONSIDERATIONS

1. Terminate the interview and offer the participant the opportunity to withdraw.
2. Offer the opportunity to spend time debriefing the participant as close to the incident as possible.
3. The researcher would contact the doctoral supervisor immediately to confer about the incident.
4. Data collection would be put on hold until the issue was resolved.
5. The researcher has had training and experience in one to one interviewing and has worked as a nurse for over 20 years and has therefore developed expertise in identifying and monitoring stress and managing situations that may arise.
6. The researcher was sensitive to the fact that the interview may raise uncomfortable feelings for the participants and therefore will observe participants closely throughout the interview process.
7. A participant's right to withdraw from the project at any stage was respected.
8. Any risks were minimized by the researchers being clear to participants about the boundaries of the research, by treating informed consent as a process and by ensuring adequate training in methods of data collection was completed prior to the study.
9. Participants in this study were informed that should they withdraw from the study they will have a right to require that any data pertaining to themselves, including any recordings, transcriptions and online postings could be removed and deleted at their request.

APPENDIX 7 ONLINE FORUM GROUND RULES

The rules should be valid for both the researcher and the participants. The rules were drawn up by the researcher in close collaboration with participants in order to be more effective. Therefore at the beginning of the study the participants will have the opportunity to examine the ground rules and add or edit them.

Rules

1. Online forum accounts are considered "personal space." As such, they are not open to global search engines, such as Google.
2. You should never share your username and/or password with anyone.
3. Be honest and fair. Participants should be honest and fair in communicating with their peers within the forum.
4. Never disrespect someone else in your posting, whether it's a person, an organisation, or just a general idea.

The aim of this forum is to connect your thoughts and reflections together; making it easier to share your experience and interact with each other and the researcher.

Being a responsible participant in the online conversation, I pledge that I will:

Always treat all people with respect. I will never use information to cause harm or appear to cause harm to any person or group of people

Respect and protect the confidentiality of the participants on this forum

Researcher:

Participant:

Date:

APPENDIX 8 GUIDELINES FOR ETHICAL PRACTICE IN THE ONLINE RESEARCH FORUM IN THIS STUDY

Kinkus (2002) referred to four areas of security in Internet data confidentiality, integrity, authentication and availability:

Confidentiality refers to whether the information can be accessed by unauthorized individuals. The data collected from the online forum were protected in the same manner as all other data (Interview transcripts). All computerised data and information was stored in a computer accessed only via a coded password. The data and participant information was stored for the duration of the study, i.e. until the work is fully reported and disseminated in the form of the doctoral thesis and will be deleted/destroyed accordingly. The online forum in this study did not have public access and was accessed by participants using a username and password. Participants were asked to register on the forum site and use a pseudonym to maintain their anonymity. Participants who agreed to take part in the study were invited to join the online forum by the researcher and pseudonyms of participants were assigned by the researcher. Participants often use the same pseudonyms as their individual identities across many online environments (Hudson and Bruckman 2005) therefore to protect participants these were assigned by the researcher. The researcher discussed the boundaries of confidentiality and anonymity with each of the participants and obtained their agreement that no information will be revealed that can be attributed to a specific individual, institute or allow identification of a participant.

Integrity refers to whether the information on the forum can be protected from interference. Im and Chee (2006) found both potential viral infection and hacking attempts in their study using online forums with cancer patients. Thus the priority in this study was to ensure that software including the firewall was installed and regularly updated.

Authentication refers to whether participants are who they say they are within the forum. While this issue been raised frequently in the literature researchers argue that the in-depth nature of qualitative research requires an understanding of the topic that would be difficult to preserve beyond initial encounters (Im and Chee 2012; Mann and Stewart 2005). In addition keeping the forum private with only those who were invited and had consented to take part in the research may help to eradicate the problem in this study.

Availability raises the issue that resources must be made available to authorized parties. All participants would need access to the Internet and be able to navigate the Internet. It is important for researchers using online mediums to collect data to be aware of current trends in online activities. 77 per cent of Irish internet users now use mobile devices (phones, tablets and netbooks) as the preferred choice for younger demographic groups to access the internet, compared to a global average of 69 per cent (www.socialbakers.com). Ensuring access to the online forum via a smart phone was a priority in this study. In a recent Irish study evaluating an online peer support forum Horgan, McCarthy and Sweeney (2013) urged that smart phone access using applications should improve retention for participants. The following table illustrates the guidelines for ethical practice in the online research forum in this study.

Verifying Identity	- the forum is private with only those invited and consented to take part in the research.
2. Public/Private space	– continuously aware of perceived risks to Internet research acknowledging the changing nature of internet technology.
3. Informed Consent	– participant autonomy was protected by using the process of informed consent. The study website contained full detailed description of the study and contact number/email of the researcher was available should participants have any questions.
4. Level of Control	- a balance between moderating the site on a daily basis to avoid any confusion for participants and facilitating a non-intrusive environment was maintained.
5. Withdrawal	– Participants had the right to withdraw at any point during this study and without incurring any penalty.
6. Debriefing	– Since the study employs a non-invasive approach to data collection it was anticipated that there would be no negative implications for participants. However if any participant display signs of discomfort or distress during the online forum process the researcher offered participants the opportunity to discuss spend time debriefing as close to the incident as possible. The researcher was sensitive to the fact that the interview could have raised uncomfortable issues/feelings for the participants and therefore observed participants closely throughout the data collection process.
7. Deception	- <i>Authentication</i> refers to whether participants are who they say they are within the forum. While this issue been raised frequently in the literature researchers argue that the in-depth nature of qualitative research requires an understanding of the topic that would be difficult to preserve beyond initial encounters (Im and Chee 2013; Mann and Stewart 2005).
8. Monitoring	-Ground rules were established with participants at the beginning of the study. Careful monitoring of online interactions.
9. Protection	- forum was checked daily by the researcher and the moderator was available for advice.
10.Data protection	- Regular updating internet security software including the firewall installation which was regularly updated.

APPENDIX 9 VAN MANEN'S INTERPRETIVE PHENOMENOLOGICAL RESEARCH APPROACH

Van Manen's ((2001, 1990, 1989) methodical approach provide a framework for the interpretive process in this research study. van Manen's (1990) 6 step approach and the corresponding steps in this study are detailed below.

van Manen research approach	Steps in this study
1.Turning to the experience which seriously interests me and confining myself to this experience	Choosing the topic of interest Understanding the relevant literature Literature Review Identifying a gap in the literature Framing the Research Question Ethical approval Sample selection Clarifying prior assumptions and pre understandings
2.Investigating the experience as it is lived rather than as a conceptualisation of it	Recruitment strategy: Advertisment via Facebook, Study Wesite www.emergingadulthealth.com Data Collection phase 1Indepth Interviews Data Collection phase 2 Online forum Data management including transcript notes, personal notes and analytical notes (Ajjawi and Higgs 2007; Minichiello et al. 1995).
3.Reflecting on the essential themes that characterise the experience	Data analysis 1. Holistic approach - researchers view the text as a whole and try to capture its meanings. 2.Selective or highlighting approach - researchers highlight or pull out statements or phrases that seem essential to the experience under study. 3. Detailed or line by line approach - researchers analyze every sentence. In addition to identifying themes from the participants' descriptions.
4.Describing the experience through the art of writing and rewriting	Interpretation Writing, editing and revising the interpretation of the data
5.Maintaining a strong and oriented relation to the lived experience	Returning to the participants Reflection

6. Balancing the research context by considering the parts and the whole

Returning to the participants

Interpretation of the emerging themes

APPENDIX 10 FRAMEWORK TO EXPRESS RIGOR IN THIS INTERPRETIVE PHENOMENOLOGICAL STUDY

Framework to express rigour in Nursing Interpretive Phenomenological studies (deWitt and Ploeg 2006).		Examples within the study	Explanation
Balanced integration	The balance between the voice of the participants and the philosophical explanation	<p><i>Yes you might get the odd adult staring....you would feel a little bit conscious of what you looked like.</i> [Sinead: 2012:1]</p> <p>Sinead experience is what Sartre (1956) in his seminal work has described as the negative consequence of the objectified look. A look or glance from someone can be experienced as affirmative, critical, subjective or objective. Now immersed in the adult world Sinead felt 'conscious' and 'embarrassed' by a look or stare she received. van Manen (1998) describes how the person with visible illness may consider their body as conspicuous</p>	This demonstrates the characteristic of integrating data with philosophical explanation of the philosopher Sartre and the more contemporary van Manen
Openness	Researchers should maintain a sense of openness throughout the study - demonstrated in decision process throughout.	<p>Openness was sought during this 'thinking phase' of data analysis by using creative processes, clarifying any prior assumptions, bracketing the researchers perspective and finally reflecting on my own history and life experience related to illness (Section 5.1 Self Reflection: Exploring my own history).</p> <p>Maintaining a reflective blog during the study. Blog excerpt reflects decision process:</p> <p><i>"During the interview process with participants I began to consider a method more appropriate for this age group who communicate more via social media."</i></p>	The research for an alternative data collection method congruent with emerging adults
Concreteness	van Manen (1997) – the researcher can situate the reader in the context of the phenomenon under study by linking the research to the readers lifeworld experiences and the context of the phenomenon.	The findings from this study were linked to van Manen (1990) four existential life world themes that aid phenomenologists to explore peoples' experience in the world lived: Spatiality (lived space, felt space), Corporeality (lived body), Temporality (lived time) and Rationality (lived other). They describe the way human beings experience the world. While each lifeworld emphasizes different aspects of the lifeworld they also overlap.	

Resonance	Understanding is not just recognised but also involves the 'felt effect' (van Manen 1997).	With regards to accepting my illness, I think the feeling that it led to was overall positive. I had been essentially <u>fighting my own body</u> , which naturally was something I couldn't win. After I accepted it and got into a proper routine... I generally felt a lot more optimistic and more in control of my life.	The depth of expression from this participant evokes a feeling in the reader beyond simple recognition
Actualization	Data continues to be interpreted, it does not end when the study ends.	In Chapter 7 the reader is invited to explore new understandings rather than generalisable statements. Similar to the phenomenon of chronic illness which is often unpredictable and uncertain there is no attempt to give a sense of resolution to this study rather I sought to write the participants unending stories (Defenbaugh 2008).	Unending stories

APPENDIX 11 EXCERPT OF MY REFLECTIONS ON RESEARCHING THE LIVED EXPERIENCE

Pre-understandings

While I embrace the interpretive concept of hermeneutic phenomenology I also aspire to be an action researcher. I am concerned with the essence of the phenomenon growing up and living with childhood chronic illness both introspectively and retrospectively. For instance I don't just want to know the experiences of emerging adults living with chronic illness I want to know what new knowledge can be generated from the phenomenological understandings of their lived experience living with chronic illness. As a healthcare educator I am encouraged to engage in critical subjectivity inspired by action research. As a researcher I wish to engage in research that incorporates both understanding and action. The goal is to understand the experiences presented to me and work collaboratively with the participants to generate knowledge of what it is like to live with a childhood chronic illness. The collaborative nature of action research will allow me to create appropriate recruitment and data collection tools to uncover this knowledge with this particular demographic group who have been left in a 'demographic limbo' (Furstenberg 2006) within research spheres. It is this phenomenological understanding of what it is like to live with childhood chronic illness that guides the action within the research study. While I acknowledge that understanding alone is considered an action in itself (Sandelowski 2004) as a researcher I wish to advance the concept of living with chronic illness and aid active participation of emerging adults living with chronic illness since childhood. Partnering phenomenological understanding with an action research approach is somewhat novel and has produced challenges. However I not only acknowledge these challenges but in bringing them to the forefront to address I have created the 'fabric' of my research.

Posted by Siobhan MacDermott at 02:38 No comments: 

Monday, 31 March 2014

Reflections Nov 2012

As a children's nurse I had always felt empathy for children with chronic illness particularly as they got older and their hospitalisations meant that they had possibly missed out on childhood activities. Listening to the stories of my participants evoked memories of similar experiences in my childhood. Was I looking at myself in their stories?

Posted by Siobhan MacDermott at 08:34 No comments: 

Monday, 24 March 2014

I am finding the transcribing process very arduous work however I realise I am developing familiarity with the data I might not have otherwise had. I start transcribing the interviews the same day that the interview had taken place, and although a slow tedious process, it does help with recalling my participants body language used, tone of voice, pauses and periods of silence to be recorded on the data sheet.

Posted by Siobhan MacDermott at 05:29 No comments: 

Studying the lived experience of emerging adults with chronic illness

I am a doctoral student completing a study in the lived experience of emerging adults who have grown up with childhood chronic illness. This is a reflexive blog that I set and maintained as a research tool to aid the journey towards.

The hope is that this will enable me to describe and interpret my experiences throughout the study (Koch 1996) in order to appreciate how I reached the findings or conclusions of the study.

Posted by Siobhan MacDermott at 05:27 No comments: 

APPENDIX 12 EXCERPT FROM INTERVIEW TRANSCRIPT

Interviewer: What did that actually feel like?

Interviewee: I felt like I was infectious, I really did because it used to be me here and you there and you'd be just sitting there and looking at me and I'd be trying to write. It was very awkward and then she'd be like, 'are you ok, are you all right, do you need to check your blood sugar, are you ok?' And I was like, I am fine, there is nothing going to happen to me, I have worked so hard to do this leaving cert and I got put in a room on my own and not told, anything. Like I thought I should have been informed, I thought I should have got a letter from the hospital because I know my friends who have diabetes, they have to request it themselves, they don't get it, they have to say, 'well I might go low.' And then they have to get a letter from the hospital. But they put me in this room with a teacher and made me sit there, it was just so awkward and horrible. I forgot most of my stuff because when you are doing an exam and people are looking at me, you know that thing, oh stop looking at me. And I'd forget this and I'd forget that. So I used to say if I don't sleep the night before I won't forget anything, I'll remember everything. I remember the one night I slept and I forgot everything. I did higher everything and I forgot my Irish paper 2 and I was just looking at it and, I can't do it. She was like, 'check your blood sugars.' And I was like, 'no I just can't, I forget it.' So all these things you learn. I am trying to think what else did I do. The camps were good. I went to an older camp then, over 18s and that was brilliant. We all had diabetes, we had doctors from xxxxx, we had nurses from xxxxx and one of them had diabetes, so it was great that she had diabetes she could relate to my concerns about college and how I would manage

Interviewer: How are you managing?

Interviewee: There is one other lady but she is a mature student so I am the only young person. I thought there was going to be someone that I'd be like, oh no way you are doing same course? Because when you say you doing this course say, 'look I am a diabetic.' 'And you are allowed to do medicine?' Why wouldn't I? Like I have this sign every time I come in, I mean I don't need any special treatment, I get my lunch like everyone else gets their lunch. When I get a tea break, everyone else gets a tea break, I don't need anything extra. Or if people say to you, 'you are looking very pale, are you low?' 'No I just didn't wear any make up today.' Everything is so shaped, everything you are doing with the diabetes, you know what I mean, like everything you do like...

Interviewer: What does that feel like when they do that?

Interviewee: You feel like you are sick, you feel like you should go in and put something on to look better. We are not allowed wear much make up in work so what am I supposed to do? We can't wear a tan or anything like that but I don't mind, it doesn't bother me because I don't have to keep doing it. But people always say to you, 'are you low?' It bugs me. Even my mam, today like, every single day she is like, 'did you take this, did you take that, did you check your blood before you got into that car, did you check your blood before you got out of that car?' I have diabetes, I am not a diabetic as they say, you are not labelled, like they say that diabetes is the illness, is the name of the illness, it is the way you control it is the way it ends up. And I did it to myself, I gave myself retinopathy, you know what I mean, and I gave it to myself, I can't blame anyone else. I told myself I wasn't a diabetic and pretended to take

insulin but wasn't I did all the wrong things for years I told myself I wasn't didn't have diabetes. I still can't believe I did that cos I am left with the consequences no, for life. But it was the way in which people perceived me. I am still like that, I have to show people, no I can do that. If someone said to me, 'you can't do that.' 'No I can do that.' I will find a way to do it

APPENDIX 13 EXCERPTS FROM THE ONLINE FORUM

Hello all, P4 here. I'd like to say that I can definitely relate with both P1 (the stopping of inhalers) and P7 (with the not being very consistent in the taking of my meds) which would have probably helped me manage my chronic illness sooner. I was pretty young though, so I guess I never took it seriously until it spread and now I have atopic dermatitis literally covering my body. I suffer from severe eczema, but I haven't always had it. When I was younger, respiratory asthma was my main health problem (my family has a history of it). I moved to Ireland when I was around aged 9. When I was 11, I developed eczema and the worse my skin got, the better my asthma did. Now I rarely get asthma attacks but my eczema is one of the worst the doctors here have seen apparently. It's even gone as far as having photos of me taken to be used in medical books :/ To be honest it took me a long time to accept my illness (it's impossible to ignore it), I wanted so badly to be seen as a "normal" person who could do "normal" things that everyone else could do on a daily basis. But that wasn't really the case, I spent most of my teenage years as a recluse, afraid to go out into the sun (which made my condition worse) or get judged by people. It's funny because most people don't really care about my appearance and I was thankfully lucky enough to have good friends who never judged me about my skin condition. But it definitely crippled my confidence, it made me unmotivated because moving was a chore as my skin hurt too much sometimes to even move. It was very bad for my mental health because I became so negative and wrapped up in the 'why me' mentality. This lasted for... 8 years? It's only this year that I've finally accepted my illness as a part of me. And I no longer see it as a punishment or a curse, I actually embrace it and like to see it as something that's been given to me because maybe, had it been given to someone else, they might not be able to handle it at all. The support of my family has played a tremendous role in the 'fixing' of my negative mentality. I actually spent a year before entering university this year back in my country of origin for this main reason, because I was sick and tired of being sad and depressed all the time, feeling like I was the only one feeling this way. But wow okay I've rambled on way too much! I think I went way off course haha, I'm so sorry. - P4

P3: I was diagnosed with type one diabetes when I was nearly 11. Growing up with it I always tried to ignore it as I didn't want to feel like I was different, ie. I would never refuse chocolate or sweets even though they aren't the best for me to be eating just to prove that it wouldn't hold me back! But growing up I have learned it is something which is very manageable and I am lucky it isn't worse. I've grown to accept it as part of my daily routine and eating properly and regular exercise keep me in shape and my sugar levels down.. all in all a win win!

P1: Hi, to the person that asked why I stopped taking my inhaler-- one of my main reasons for doing it was the idea I had that I was "becoming dependent" on the inhaler. Some of it was outside influences, a lot of people who'd talk about "using medication as a crutch" which

made me feel as though I shouldn't have been relying on it. I understand now that people use crutches when they can't walk without them, and likewise I need my preventative inhaler to ensure I continue breathing, so really it wasn't the best frame of mind (as well as this, though, I did definitely feel guilty about the expense, as my family is quite large and most of my siblings don't have asthma). (P4, I definitely relate to the feelings of wanting to be "normal"- - I can't even remember the number of times I've felt weird because I had to be nebulised with friends around, it felt so uncomfortable!) With regards to accepting my illness, I think the feeling that it led to was overall positive. I had been essentially fighting my own body, which naturally was something I couldn't win. After I accepted it and got into a proper routine-- taking my preventative inhaler, not being afraid to take my reliever inhaler in front of people-- I generally felt a lot more optimistic and more in control of my life. Has that been the same for anyone else?

P12: I was diagnosed with type 1 Diabetes was I was 7 years old, a few weeks before my first communion. I accepted it straight away and my illness was well controlled by my mother. I almost never ate anything I shouldn't have and had a very good medical record. That was until I was about 11 or 12 years old. I remember one time specifically which made me think "this isn't fair, I'm not going to do this anymore". I was in 5th class in school and it was the final week before summer. The teacher decided to get everyone in the class a Sparkler ice pop as a treat! I remember she came back into class after lunch with the bag of ice pops and told each row of us to come up one by one and take an ice pop. I didn't go up to get one as my mother's rule of not to eat anything sweet or anything which I'm unsure about was going through my mind. After everyone had gotten their ice pop the teacher was asking who didn't get one as there was one left in the bag. When she spotted me not eating one she made a big ordeal of apologising about forgetting I can't have one. This was one of the main events as a child which made me hate myself for having Diabetes. Just the fact that all the attention was on me and my condition, all the other kids eating their ice pops and staring at me, and the fact that I felt guilty for causing the scene. I cried when I went home and I think it was then that I suddenly came to the realisation that this condition was for life and I was never going to get better. I then started to rebel and my blood sugar levels went way way out of control. I still took my insulin as normal, but I ate as if I wasn't diabetic - all kinds of sugary foods, chocolate etc. I had bad visits to my doctor where I lied about not knowing why my levels were so high and I felt chuffed when I thought I got away with it and had fooled them. This continued up until I was about 16. One day I was looking up something to do with Diabetes online and I came across a forum where people were talking about Diabetes. I decided to have a look and found a thread where people were giving advice. I read numerous stories about older people with Diabetes who were begging for any young people with Diabetes to take notice and control their Diabetes. People were saying they regret ignoring the condition and that they are paying for it in their older years. I read comments from people saying they had lost a foot, had lost feeling in their toes, had lost the sight in an eye, women who had had a baby with a defect from having high blood sugars etc. Obviously I had heard of these kind

of complications before, but to hear them coming from real people who were saying they had ruined their life and had so many regrets from not controlling it properly gave me such an awful shock that it changed my whole perspective there and then. I imagined myself as one of these older people who didn't take care of myself and realised it didn't have to be like that for me if I woke up and started taking care of myself. Throughout the next few years I gained control over my life and Diabetes and was congratulated numerous times by my doctor on how much I had improved my control. When I began university, I even went to a seminar in Croke Park for young people with Diabetes, where I met hundreds of other Diabetics and heard talks from people about breakthroughs in research, new ways to control it, and people in the world who were famous and Diabetic and how it didn't stop you from doing much at all! I'm 22 now and I have 100% accepted my condition. I control it as best I can everyday. I can't really imagine life without Diabetes now as it's just a part of me and a way of life now. There wasn't really a "moment" where I accepted it properly, but over time I did and now it makes me feel good. I think a lot of people with chronic illnesses might go through a phase of not accepting it, in order to finally accept it.

P4: Wow, your stories are all so heart-warming because they're all so relatable in one way or another even if they're all very different illnesses. Fair play to you P12 and P1. And P1, I did that with my inhalers too! And I never really "grew out" of my asthma either. Part of me thinks it's because of me neglecting/refusing to take my inhalers the way I should have. My parents weren't very strict so I kind of got to do what I want and now I'm paying that price. The main reason my eczema is so bad was because it was badly maintained. It's only this year that I started to take meds and put creams on consistently. I wish I had started and realized earlier how important it would impact my health. I've now had to resort to starting immunosuppressants and that's gonna bring about a whole slew of other problems! But I'm keeping positive and hopeful, believing that this will work and help improve my health rather on focusing on the bad. So basically the same as P1 and P12 in terms of accepting my illness after being properly educated about it I suppose. "I think a lot of people with chronic illnesses might go through a phase of not accepting it, in order to finally accept it." For sure. - P4