



EXPERIENCES OF SUPPORT SERVICES FOR EATING DISORDERS IN
IRELAND: AN EXPLORATORY STUDY

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LIST OF ABBREVIATIONS

ACMTQ	The Autonomous and Controlled Motivations for Treatment Questionnaire
AMHS	Adult Mental Health Service
AN	Anorexia Nervosa
AN-R	Anorexia Nervosa – Restrictive subtype
AN-BP	Anorexia Nervosa – Binge-Purge subtype
BD	Body Dissatisfaction
BED	Binge Eating Disorder
BMI	Body Mass Index
BN	Bulimia Nervosa
BN-P	Bulimia Nervosa purging type
BSED	Bulimia Spectrum Eating Disorders
CAMHS	Child and Adolescent Mental Health Services
CEBT	Cognitive Emotional Behavioural Therapy (CEBT)
CMHT	Community Mental Health Team
CBT	Cognitive Behaviour Therapy
CBT-E	Enhanced Cognitive Behaviour Therapy
CRT	Cognitive Remediation Therapy
DBT	Dialectical Behaviour Therapy
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders 4 th Edition
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders 4 th Edition, Text Revision
EDNOS	Eating Disorder Not Otherwise Specified
GP	General Practitioner

GSH	Guided Self-Help
HBT	Health Behaviour Theory
HSE	Health Service Executive
IBW	Ideal Body Weight
IPA	Interpretative Phenomenological Analysis
IPT	Interpersonal Therapy
MDT	Multi-disciplinary Team
MET	Motivational Enhancement Therapy
MFT	Motivation-focused Treatment
MI	Motivational Interviewing
NICE	National Institute for Clinical Excellence [now National Institute for Health and Clinical Excellence].
NIMH	National Institute of Mental Health
NES	Night Eating Syndrome
OPC	Involuntary Outpatient Commitment
PD	Purging Disorder
RCT	Randomised Controlled Trial
RDoC	Research Domain Criteria
RMI	The Readiness and Motivation Interview
ROI	Republic of Ireland
SAN	Sub-threshold Anorexia Nervosa
SBN	Sub-threshold Bulimia Nervosa
SDT	Self-determination Theory
SSRI	Selective Serotonin Reuptake Inhibitor
TAU	Treatment as Usual
TOuCAN	Treatment Outcome of Child and Adolescent Anorexia Nervosa

TTM

The Transtheoretical Model of Change

ABSTRACT

The purpose of this MSc project was to investigate qualitatively eating disorder (ED) patients' perspectives on their treatment experiences and expectations, within the Irish context. Semi-structured interviews were conducted with a purposive female sample of current (N=11) and discharged (N=3) ED service users, ranging in age from 18 to 31 years (M= 23.21, SD= 4.19). An interpretive thematic analytic approach, comprising both inductive and deductive methods of analysis, was employed to identify key themes in the data. Participants described the importance of both structural aspects of the treatment environment and interpersonal aspects of care for therapeutic engagement. Of particular importance was a therapeutic approach which guided participants to a personal understanding of their ED. Participants underscored the value of supportive relationships which emphasised reciprocal exchange, and the need for collaboration and control in treatment decisions. Findings provide several practical recommendations for ways in which current ED services in Ireland might more effectively meet the need of service users. An in-depth understanding of treatment factors that both strengthen and weaken engagement for ED patients can inform health policy and future service development, enhancing the quality of care provided.

Chapter One

INTRODUCTION

INTRODUCTION

The current classification system of psychiatric disorders, the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text revision [DSM-IV-TR], American Psychiatric Association, 2000) delineates three eating disorder (ED) diagnostic categories; anorexia nervosa (AN), bulimia nervosa (BN) and eating disorder not otherwise specified (EDNOS). ED most commonly manifest in adolescent females (Hudson, Hiripi, Pope & Kessler, 2007) and often characterise a protracted and debilitating course of illness. Although precise causal mechanisms have not yet been elucidated, research postulates a profusion of risk factors in the development of ED, including; biological, psychological, and social and cultural influences (Keel, Brown, Holland & Bodell, 2012). ED are associated with a multitude of psychological and physical sequelae. In particular, comorbid psychiatric disorders pervade eating disorders (Hudson et al., 2007) and are associated with poorer outcome from illness (Keel & Brown, 2010).

Within the Irish context, the Department of Health and Children estimates over 200,000 eating-disordered individuals in Ireland (DOHC, 2006). Moreover, it is posited that approximately 400 new cases emerge yearly, resulting in 80 deaths per annum (DOHC, 2006). Health care utilisation among this clinical population is high (Simon, Schmidt & Pilling, 2005), eventuating in a considerable burden on health care resources (Mitchell et al., 2009). Current knowledge on how to appropriately treat the eating disorders is limited (Keel & Haedt, 2008) and is further hampered by a dearth of empirical evidence to support the majority of current treatment approaches (Wilson, 2005).

Clinical and research accounts concur that engaging individuals with eating disorders in therapeutic interventions can be difficult (Knowles, Anokhina & Serpell, 2012; McFerron, Baker, Patton & Sawyer, 2006) and a pattern of low responsiveness to treatment is commonly evidenced (Waller, 2012). As such, premature dropout from treatment is a highly prevalent phenomenon amongst this clinical population (Campbell, 2009; Mahon, 2000; Malson, Finn, Treasure, Clarke, & Anderson, 2004; Vandereycken & Vansteenkiste, 2009).

Many factors appear to moderate treatment response, including; patient factors, clinician factors and treatment approach (Mahon 2000; Gellar Brown, Zaitsoff, Goodrich & Hastings, 2003). One factor that has received considerable recent attention is motivation for treatment (Mansour et al., 2012). Motivational issues are consistently identified as barriers in effectively engaging ED patients in the therapeutic process (Vansteenkiste, Soenens & Vandereycken, 2005). Mansour and colleagues (2012) emphasise the importance of attending to the interplay between the individual and their environment when studying the motivational processes underpinning ED treatment trajectories. It is further recognized that the motivational processes associated with treatment engagement are dynamic in nature and can change considerably over the course of treatment. Research also indicates that patients' experiences and expectations of treatment can change throughout the recovery process (Noordenbos & Seubring, 2000; Offord, Turner & Cooper, 2006). Specifically, it is surmised that, the illness perception of ED patients at various stages of the illness trajectory can strongly influence their evaluation of treatment. De la Rie, Noordenbos, Donker & van Furth (2006) suggest that views of illness controllability and curability may affect expectations of treatment. Most importantly,

as these perceptions fluctuate throughout various stages of the treatment trajectory, patients' expectations of, and motivation to engage in treatment, may also change. As such, previous investigations concerned with patient experiences of treatment have included heterogeneous samples of ED patients at various stages of the treatment trajectory (Vanderlinden, Buis, Pieters & Probst, 2007). Further, it is argued that simultaneously exploring the views and experiences of both current and former patients permits a more in-depth view on the dynamic nature of treatment and processes of therapeutic engagement (de la Rie, Noordenbos et al., 2006). Zaitsoff and Taylor (2009) deduce that, an understanding of the variables associated with greater motivation for change could serve to identify important areas to address in treatment for ED individuals who experience ambivalence toward treatment and recovery.

Aims and Objectives

To date, there remains a dearth of published research investigating ED within the Irish context. Moreover, to our knowledge, there are no published research studies which have investigated the treatment experiences of ED patients in the Republic of Ireland. Accordingly, the purpose of this research was to explore qualitatively the treatment experiences and expectations of eating disorder patients in the Republic of Ireland. Specific objectives of the this study include;

- Explore the views, experiences and suggestions for change of adult females (18yrs and older) who are either currently availing of professional treatment or who have previously availed of professional treatment for ED in the Republic of Ireland.

- Interpret the initial thematic findings of patients' treatment experiences in light of self-determination theory (SDT; Deci & Ryan, 1985; Ryan & Deci, 2000).

Study Design

A qualitative research design was employed in the current study. Qualitative approaches are commonly employed in research investigations concerned with patients' experiences of health care (Peters, 2010; Pope, van Royen & Baker, 2002), and have been attributed an important role in exploring ED patients' experiences of treatment (Vanderlinden et al., 2007). Qualitative methods are expedient in addressing policy questions that do not readily lend themselves to experimental or multifactorial designs (Davidson, Ridgway, Kidd, Topor & Borg, 2008). Most notably, qualitative research designs permit in-depth access to a range of phenomena not readily captured by quantitative methods. Moreover, important policy implications have been yielded by qualitative investigations (Davidson et al., 2008). Semi-structured interviews are one of the most commonly utilised methods of data collection in qualitative research and represent an ideal method of gathering data pertaining to complex topics of enquiry (Willig, 2008).

Summary of Introduction Chapter

Recent research documents a high prevalence of eating disorders in Western society (Hudson et al., 2007; Keel et al., 2012). Although significant health care costs are associated with the eating disorders, treatment effectiveness is limited. Given the limited success of extant treatment interventions (Wilson, Grilo & Vitsouek, 2007) and the high rates of dropout that pervade clinical and research

accounts of ED (Campbell, 2009), it is imperative to explore components of treatment interventions which impact on patients' engagement in the therapeutic process. Therefore, this study employs a qualitative research design to investigate the treatment experiences of ED patients.

This thesis is presented in five chapters. Chapter two comprises a review of the literature in the area of eating disorders, including; aetiological and risk factors for ED, and the prevalence, course and outcome for each DSM-IV-TR eating disorder diagnostic category. Further areas of enquiry include; the current evidence base and best-practice guidance governing clinical care for ED, current treatment pathways for ED in the Republic of Ireland, challenges in service delivery, the process of change over the course of illness and, investigation of the 'patient perspective'. Chapter three outlines the research methodology and design of the study. This section describes the participant sample and delineates several important processes of the current investigation, including stages of recruitment, data collection and data analysis. Justification for the chosen methodological framework is also outlined. Consideration is given to the ethical issues associated with sensitive research and, the trustworthiness of findings are also reviewed.

Chapter four presents the main themes and sub-themes arising from the interpretive thematic analysis undertaken. Findings are anchored within the theoretical constructs of Self Determination Theory (SDT; Deci & Ryan, 2008). Chapter five considers the qualitative findings of the current study in line with previous investigations in this research domain. Limitations of the research are also considered and fruitful avenues for future research are proposed. This thesis

concludes with a delineation of several key findings and their applicability to clinical practice in the treatment of eating disorders.

Chapter Two:

LITERATURE REVIEW

LITERATURE REVIEW

This chapter reviews the fundamental evidence on eating disorders. It commences with an investigation of the aetiological and risk factors associated with ED, and outlines the prevalence, course and outcome of AN, BN and EDNOS. It follows with a delineation of the current evidence base and best-practice guidance governing the clinical care of each ED diagnostic cohort. Limitations of the existing evidence base and recommendations for the DSM-5 are also outlined. Subsequent sections of this literature review delineate the current treatment pathways for adolescent and adult patients in the Republic of Ireland and highlight the persistent challenges associated with service delivery for ED. The process of change over the course of illness is also presented, with a particular focus on stages of denial, treatment resistance, treatment dropout, motivation for change and, recovery. Particular emphasis is given to current motivational approaches in the treatment of ED. This chapter concludes with an examination of extant qualitative health research concerned with ED patients' subjective experiences of health care.

The key sources utilised in the current investigation of the literature included; online databases and journal articles, books, government reports and conference proceedings. The search strategy was also guided by the published works of prominent research figures and seminal research investigations in the domain of ED and qualitative health research. Online databases (MEDLINE via EBSCO, PsycINFO) were searched using several key terms relating to the domain under investigation. Following this, reputable journals with a high impact factor (e.g. Health Psychology, Qualitative Health Research) were targeted. Several questions

helped to narrow the search, including; key issues and debates on this topic, key theories, concepts and ideas on this topic, main questions and problems that have been addressed thus far and, the strengths and weaknesses of the various arguments on this topic. Journal articles providing concise and recent information took precedence. The reference lists of the articles found were also checked for additional studies. Literature was most commonly included on the basis of methodological strengths, robust research findings, novel results yielded and innovative concepts proposed. Literature was most commonly excluded on the basis of methodological weaknesses and poor validity or reliability of results.

2. 1. Eating Disorders

2. 1. 1. Aetiology and Risk Factors

Extant research concurs that the aetiology of eating disorders are multidimensional in nature and relate closely to vulnerability and risk factors (Striegel-Moore & Bulik, 2007). These are commonly subsumed under the three broad categories of; biological influences, psychological influences and, social and cultural influences. Although precise causal mechanisms have not yet been established, Polivy and Herman (2002) posit that it may be possible to distinguish between stronger and weaker contributory factors in the development of ED. Accordingly, the authors conceptualise causal factors along a continuum ranging from weaker, broad level factors at one end to stronger, individual considerations at the other. Stice, South and Shaw (2012) deduce that the interaction of genetic, biological and temperamental vulnerabilities with sociocultural factors increases risk of ED development.

2. 1. 1. 1. Social and Cultural Influences

Media influences

Beginning at the broadest level factors, sociocultural elements have frequently been implicated in the manifestation of ED, with particular emphasis placed on media exposure and the idealisation of thinness (Becker, Burwell, Gilman, Herzog & Hamburg, 2002; Keel & Forney, 2013; Mooney, Farley & Strugnell, 2009; O'Connor, Friel & Kelleher, 1997.). Investigating the impact of media influences on eating attitudes in a sample of young, male and female Irish adolescents, McNicholas, Lydon, Lennon and Dooley (2009) found that the majority of their adolescent participants (71.4%) felt adversely affected by media portrayal of weight and shape. Moreover, their results illustrated a significant correlation between perceived adverse effects of media impact and higher eating psychopathology. Although the authors identify media influences as an important interaction factor in the manifestation of ED, they remain cautious in inferring a causal link between media influence and pathological eating.

Family Environment

Familial influences are also surmised to stimulate ED development. In particular, family dysfunction and critical family environment featuring coercive parental control are postulated to aggregate the disorder (Polivy & Herman, 2002). In the case of AN, higher parental control is associated with risk contribution (Keel et al., 2012). In the case of BN and BED, low parental contact and high parental expectations are associated with risk contribution (Keel et al., 2012). However,

although families may transmit eating concerns, such transmission may be insufficient for the development of an ED (Polivy & Herman, 2002).

Peer Influence

Peer influence has also been implicated as a contributor to ED (Keel & Forney, 2013), although the relative importance of peer influence in the process of ED manifestation remains unclear (Polivy & Herman, 2002). In their sample of Irish adolescent females, Mooney et al. (2009) found that peers influenced body dissatisfaction and dieting practices. Congruently, findings from longitudinal research suggest that the development of bulimic symptoms and weight control behaviours may be more vulnerable to peer influence (Keel et al., 2012; Zalta & Keel, 2006). However, the literature on the relative impact of peers is confined to the evaluation of peer influence on risk of bulimic symptoms only, thus limiting generalizability of these findings to other ED diagnoses.

2. 1. 1. 2. Psychological Influences

Temperament and Personality

Toward the other end of the continuum are risk factors related to the individual. Several authors concur that such risk factors comprise both pre-dispositional features (i.e. personality traits) and adverse life events (Fairburn & Harrison, 2003; Polivy & Herman, 2002). Affective influences (i.e., stress and negative mood) are commonly reported antecedents for EDs (Corstorphine, 2006). Research commonly deduces that AN and BN are characterized by negative emotionality and perfectionism (Striegel-Moore & Bulik, 2007). Whereas anorexia nervosa – restrictive type (AN-R) is also characterised by constraint, anorexia

nervosa binge-purge type (AN-BP) is characterised by impulsivity (Keel et al., 2012). Low self-esteem is further identified as a poor prognostic factor (i.e. predictive of adverse outcomes) (Polivy & Herman, 2002).

Almost all approaches to ED make reference to body dissatisfaction (BD) - subjective feelings of unhappiness involving negative thoughts and feelings associated with one's physical appearance (Mooney et al., 2009). Hilda Bruch first identified body image disturbances as an important clinical feature of ED (Bruch, 1962) and most current models of ED continue to attribute a prominent causal role to body dissatisfaction (BD) (Keel et al., 2012). Research posits that BD peaks during adolescence, is predominantly observed in females, and can increase the possible incidence of ED behaviours (Mooney et al., 2009).

Cognitive Impairments

Neuropsychological impairments have also been implicated in the manifestation and maintenance of ED, most notably in the case of anorexia nervosa (Danner et al. 2012). In particular, reduced cognitive flexibility appears to be one of the most pervasive neuropsychological consequences of AN (Tchanturia, Davies & Campbell, 2007). Roberts, Tchanturia and Treasure (2010) found that patients with the most marked deficits in cognitive flexibility had higher levels of anxiety and depression, longer illness duration and lower self-esteem. Investigations of neurocognitive functioning in AN have found a persistence of cognitive inflexibility post weight restoration, thus suggesting a trait, rather than a state basis for these abnormalities (Tchanturia et al. 2004).

2. 1. 1. 3. Biological Influences

Genetic Factors

Biological factors are further postulated as precursors in the manifestation of ED and research demonstrates that eating disorders commonly aggregate in families (Keel et al., 2012). Twin studies of eating disorders suggest substantial genetic contribution in the development of AN (48% - 76%) and BN (50% - 83%) (Striegel-Moore & Bulik, 2007). However, Polivy & Herman (2002) argue that, although family studies indicate aggregation of ED in families, they often fail to delineate strict boundaries between genetic and environmental transmission.

Gender

Research and clinician accounts of ED consistently document a skewed gender distribution in ED, with females illustrating greater susceptibility to the manifestation of pathological eating in comparison to males (Hudson et al. 2007; Keel & Forney, 2013; Smink, van Hoecken & Hoek, 2012; Striegel-Moore & Bulik, 2007). Although commonly conceptualised as a female illness, there is a growing evidence base to support the increasing prevalence of ED in males (Harvey & Robinson, 2003). Although research widely concurs more convergence than divergence across male and female ED, two primary gender differences have been reported in this domain. First, the typical age of onset in male ED is later than in their female counterparts and an illness history of higher pre-morbid weight is more frequently observed in male populations (Gueguen et al. 2012). Notwithstanding, the diagnostic distribution across ED presentations in males is similar to reports of female ED (Bramon-Bosch, Troop & Treasure, 2000). Recent findings suggest that outcomes from ED are more favourable for males than females (Støvning, Andries, Brixen, Bilenberg, & Hørder, 2011).

2. 1. 2. Eating Disorders in the Irish Context

Investigating child and adolescent psychiatric admissions in Ireland in 2008, Daly and Walsh (2009) reported that eating disorders signified the second highest level of diagnosis of all admissions. Moreover, a recent Irish report estimated an average of 165 annual admissions for service users with eating disorders to psychiatric facilities in recent years, and almost double the quantity of admissions to general hospitals (HSE, 2011). A national study investigating dieting behaviour in school children in Ireland (HSBC, 2006) conducted on 10,334 school children aged 10-17 years revealed that 11.5% of Irish children and adolescents report dieting, a figure which the authors infer has remained stable since 2002.

A recent qualitative investigation into the opinions of adolescent females regarding their body image concerns and dieting practices in the Republic of Ireland (ROI) documented high levels of body dissatisfaction (BD) and dieting in Irish adolescent females (Mooney et al., 2009). Similarly, in a study of over 3,000 Irish adolescents, McNicholas and colleagues (2009) documented high levels of weight and body image concerns and a higher than expected incidence of bulimia nervosa. More specifically, the authors found that 33.7% of females exhibited significant body dissatisfaction, 27.2% exhibited clinical levels of bulimia and 16.9% reported a significant drive for thinness. Taken collectively, these findings highlight the ongoing and future challenge facing the Irish health care system.

2. 1. 3. Eating disorders: Prevalence, Course and Outcome

The following section provides an overview of each DSM-IV-TR eating disorder diagnostic category and reviews the literature on current prevalence estimates, clinical features and outcome for each ED cohort. Due to the

heterogeneous nature of the EDNOS category, various subgroups will also be identified and explored with regards to this ED population.

2. 1. 3. 1. Anorexia Nervosa

DSM-IV-TR Diagnostic Criteria for Anorexia Nervosa

According to DSM-IV-TR, the diagnostic criteria for AN include (1) maintaining a body weight at a level less than 85% of normal weight for age and height, (2) an intense fear of fatness, disturbed experience of one's body weight or shape, and (3) the incidence of amenorrhea (menstruation cessation) for at least three consecutive menstrual cycles (see Appendix A). Two subcategories reside within the diagnostic category of AN. The first, AN restrictive-subtype (ANR), encompasses individuals illustrating severe dietary restriction. The second subcategory, AN binge-purge subtype (AN-BP) comprises a division of patients who alternate between periods of starvation and uncontrollable eating binges, followed by engagement in purgative behaviours.

Anorexia Nervosa: Prevalence Estimates

AN typically manifests in early to mid-adolescence and onset after adolescence is relatively uncommon (Hudson et al., 2007; Smink et al., 2012; Striegel-Moore & Bulik, 2007). Although infrequent, cases of late onset anorexia nervosa have been documented previously (Eisler et al. 1997). International lifetime prevalence estimates of DSM-IV anorexia nervosa are .9% among women and .3% among men (Hudson et al. 2007). While the overall incidence rate of AN has remained stable over the past decades (Shinkwin & Standen, 2001), recent findings

suggest an increase in the high-risk group of 15-19 year old girls (Smink et al., 2012; van Son, van Hoeken, Bartelds, van Furth & Hoek, 2006).

Anorexia Nervosa: Clinical Features

Core clinical features associated with AN include; cognitive inflexibility (Danner et al., 2012), rigid behaviours around eating (Tchanturia, Campbell, Morris and Treasure, 2005) clinical perfectionism (Shafran, Cooper & Fairburn, 2002) and low core self-esteem (Keel & Forney, 2013). Starvation is associated with a progressively poor response to treatment and illustrates profound adverse effects on mood and cognition (HSE, 2011).

Although there is evidently much overlap between the various ED categories, AN is quite distinctive from BN or EDNOS in several respects. Most notably, the phenomenon of *egosyntonicity* pervades clinical and research accounts of AN (Guarda, 2008; Vandereycken, 2006a). Egosyntonicity describes the perception of AN patients toward their disorder –namely attributing virtue to their disorder and perceiving their resultant emaciation as ‘an accomplishment rather than an affliction’ (Vitsouek, Watson & Wilson, 1998). The egosyntonic nature of many AN symptoms represents a particularly robust reinforcing factor for the disorder (Vandereycken & Van Humbeeck, 2008). As such, individuals with AN illustrate a significant lack of cognitive insight and emotional reactions concerning their debilitated physical and psychological health (Hasler, Delsignore, Milos, Buddeberg & Schnyder, 2004). This in turn further strengthens their ambivalence toward change (Blake, Turnball & Treasure, 1997). The egosyntonicity of AN, particularly its role in reinforcing and maintaining disordered eating, will be discussed further in the accompanying sections of this review.

Outcome from Anorexia Nervosa

AN is associated with a worse prognosis for short-term and long-term outcome compared to BN, BED and other atypical ED (Keel et al., 2012). In particular, AN encompasses a multitude of serious physical complications including; severe cardiovascular problems, gastrointestinal problems and chronic renal failure (Zipfel, Löwe, Reas, Deter & Herzog, 2000). Findings from outcome studies suggest that consequences are significantly worse for individuals within the binge-purge subtype (AN-BP) than those classified as the restricting-type (AN-R) (Sharp & Freeman, 1993; Zipfel et al. 2000). Moreover, research documents a powerful correlation between purging behaviour and increased mortality (Støving et al., 2011). Investigating a sample of AN-purging and EDNOS patients, Støving et al. (2011) proposed the concept of ‘dual purging behaviour’ – the simultaneous engagement in vomiting and laxative abuse. Specifically, Støving and colleagues suggest that dual purging behaviour is associated with most severe medical complications. The authors documented poorest remission rates amongst AN purging patients, with less than 20% of AN purging patients remitting after 10 years of illness.

Poor prognosis in AN is frequently associated with low body weight (BW) (Støving et al. 2011), severity and duration of illness (Keel & Brown, 2010) and severe psychiatric comorbidity including; depression, mood and anxiety disorders, and substance abuse. Hudson et al. (2007) reported that 56.2% of anorexia nervosa participants met criteria for at least one of the core DSM-IV mood, anxiety, impulse-control and substance-use disorders. Depression, anxiety and obsessive-compulsiveness are particularly pervasive in AN individuals (O’Brien & Vincent, 2003).

With the highest mortality rate of all psychiatric illnesses, researchers and clinicians conclude that anorexia nervosa represents ‘the most lethal of all psychological disorders (Sharp & Freeman, 1993). Sullivan (1995) estimates that the collective annual mortality associated with AN is more than 12 times higher than the yearly death rate due to all causes for females aged 15-24 and over 200 times higher than the suicide rate of females in the general population. In their prospective long-term follow-up of 84 AN patients 21 years after initial hospitalization, Zipfel et al. (2000) reported that 50.6% of participants had achieved full recovery, 10.4% continued to meet full diagnostic criteria for AN and 15.6% died from causes related to AN. Congruently, a review of outcome studies from 1953 to 1999 reported that a full recovery from AN was observed in 46% of patients, a partial improvement documented for 34%, and 20% of patients had developed a chronic course (Steinhausen, 2002). Causes of death in AN are generally subsumed within four areas; suicide, starvation and emaciation, infection, and gastro-intestinal complications (Flahavan, 2006; Zipfel et al. 2000).

2. 1. 3. 2. Bulimia Nervosa

DSM-IV-TR Diagnostic Criteria for Bulimia Nervosa

Bulimia Nervosa was introduced as a diagnostic entity in 1979 by Gerard Russell. The DSM-IV-TR criteria (American Psychiatric Association [DSM-IV-TR], 2000) for bulimia nervosa include recurrent episodes of bingeing followed by engagement in compensatory behaviours (such as purging, exercising, or fasting) to prevent weight gain from overeating. These behaviours must occur at least twice weekly for a minimum of 3 months. Additionally, self-evaluation is overly dependent on body weight and shape in bulimic individuals (see Appendix A).

Ambivalence often surrounds the boundaries between the bulimic subtype within AN (AN-BP) and full-syndrome bulimia nervosa, particularly with regards a lack of clear guidance on precise definitions of a binge (Polivy & Herman, 2002). Since the pattern of binge eating and subsequent purging is correlated with both AN-bulimic subtype and full syndrome BN, the only differentiating factors between the two appear to be (1) the weight level around which patients fluctuate and (2) amenorrhea (American Psychiatric Association [DSM-IV-TR], 2000; Polivy & Herman, 2002) BN has a slightly later age of onset than AN (Harvey & Robinson, 2003) and a significant proportion of patients with BN have a history of AN (Keel et al., 2012; Mitchell et al., 2009).

Bulimia Nervosa: Prevalence Estimates

Research suggests that the incidence of bulimia nervosa has increased significantly in the second half of the twentieth century (Hudson et al. 2007; Shwinken & Standen, 2002). Lifetime prevalence estimates of DSM-IV bulimia nervosa are 1.5% among women and .5% among men (Hudson et al., 2007). Turnball, Ward, Treasure, Jick and Derby (1996) reported that between 1988 and 1993, a threefold increase was observed in the recording of BN cases in primary care. Recent Australian population-based data found that specific bulimic behaviours (binge-eating and purging) increased two fold over a 10-year period from 1995 to 2005 (Hay, Mond, Buttner & Darby, 2008). Contrastingly, other studies suggest a decrease in the incidence of BN in recent decades (Keel, Heatherton, Dorer, Joiner & Zalta, 2006). As such, evidence for an increase in the incidence of BN remains inconclusive.

Bulimia Nervosa: Clinical Characteristics

Compensatory behaviours are perhaps the most distinguishing clinical characteristic associated with bulimia nervosa. Compensatory behaviours are primarily concerned with inducing weight loss or preventing weight gain, and commonly include; self-induced vomiting, laxative abuse, diuretics, fasting and excessive exercise (Shapiro et al. 2007). Unlike AN, the majority of bulimic behaviours such as bingeing and purging are identified as being largely *ego-dystonic* (Kaplan & Garfinkel, 1999) - behaviours that are felt to be repugnant and distressing. In particular, loss of control over eating is a great source of distress for BN individuals (Blake et al., 1997) and they often experience significant shame and guilt around bulimic symptoms (Kaplan and Garfinkel, 1999).

Outcome from Bulimia Nervosa

Severe cardiac complications are also associated with BN. Self-induced vomiting can result in a multitude of physical complications including; fluid and electrolyte disturbance, gastro-intestinal bleeding, teeth erosion and muscle weakness (Khan & Chowdhury, 2011). Axis I and Axis II psychiatric comorbidity are also prevalent in this diagnostic cohort. Hudson et al. (2007) found that 94.5% of participants with bulimia nervosa met criteria for at least one of the core DSM-IV mood, anxiety, impulse-control and substance-use disorders. In line with this, extant research attests to the pervasiveness of depression and anxiety in BN (Fairburn & Harrison, 2003; O'Brien & Vincent, 2003). Research concurs that negative prognostic indicators for outcome from BN are related to severity of psychiatric comorbidity in BN individuals (Berkman, Lohr & Bulik, 2007; Keel & Brown, 2010).

In their 12-year prospective longitudinal study with five cross-sectional assessments, Fichter and Quadflieg (2004) investigated the long-term course and outcome of bulimia nervosa in a large sample of female BN-P patients. Employing logistic regression analyses, their results revealed that lifetime psychiatric co-morbidity emerged as the strongest and most stable predictor of poorer outcomes. An illness history of AN and older age of disease onset are further postulated to predict a worse outcome in BN patients (Berkman et al. 2007). Unlike AN patients, a low mortality rate is commonly evidenced in BN patients (Berkman et al. 2007; Fichter & Quadflieg, 2004).

2. 1. 3. 3. Eating Disorder Not Otherwise Specified (EDNOS)

DSM-IV-TR Diagnostic Criteria for EDNOS

Current diagnostic classifications for this ED category simply state that this diagnosis includes disorders of eating that do not meet criteria for AN or BN (American Psychiatric Association [DSM-IV-TR], 2000). In addition, DSM-IV-TR provides six examples of clinical presentations that warrant a diagnosis of EDNOS (see Appendix A). Unlike diagnoses of AN or BN, there are no positive diagnostic criteria for EDNOS, which commonly involves diagnosis through exclusion (Fairburn & Bohn, 2005). As such, several authors have questioned the utility of the current diagnostic system, primarily criticising the DSM-IV stringent criteria for AN and BN. As a result of current rigid diagnostic criteria, a significant proportion of patients within the EDNOS category commonly fail to receive a diagnosis of AN or BN on the basis of strict weight and behavioural criteria. Investigating a sample of adult ED patients presenting at a UK community ED service, Turner and Bryant-Waugh (2004) reported that 35% of their EDNOS sample were not assigned a

diagnosis of AN on the basis of weight and/or menstrual status. Similarly, a further 37% missed a diagnosis of BN on the basis of frequency of bingeing and/or weight control behaviours. A similar degree of psychological distress is also evidenced in individuals who do not meet the stringent diagnostic criteria for AN or BN (Eddy, Doyle, Hoste, Herzog & le Grange, 2008; Fischer, Schneider, Burns, Symons & Mandel, 2001; Keel, Haedt & Edler, 2005; Turner & Bryant-Waugh, 2004).

EDNOS: Prevalence Estimates

The 'residual' diagnosis of EDNOS represents the most common eating disordered presentation observed in most clinical samples, and encompasses the majority of patients who present for treatment to both outpatient and community settings (Button, Benson, Nollett & Palmers, 2005; Crow, 2007; Rockert, Kaplan & Olmsted, 2007; Fairburn & Bohn, 2005; Fairburn et al., 2007). In addition, a high percentage of EDNOS cases is consistently documented in inpatient treatment settings (Dalle Grave & Calugi, 2007). Specifically, the prevalence of EDNOS is approximated to range from 40% (Rockert et al. 2007) to 67% (Turner & Bryant-Waugh, 2004) in adult samples and, although scarce, available findings from adolescent studies suggest a similar prevalence of EDNOS in this age cohort (Eddy et al., 2008)

Sub-classification of EDNOS individuals

Presently, very little is known about how to sub-classify EDNOS patients. As previously stated, there are no positive diagnostic criteria for EDNOS and as such, significant contention exists as to whether EDNOS represents a homogeneous or heterogeneous group of ED individuals. Rockert et al. (2007) suggest that some

proportion of the broad EDNOS cohort resembles full syndromal AN or full syndromal BN, and that the remainder of the group appears heterogeneous. Congruently, Fairburn and Bohn (2005) distinguish between two subgroups within EDNOS; sub-threshold AN and BN and, ‘mixed cases’ - where clinical features of AN and BN are combined in diverse ways to that seen in the two recognized syndromes.

Findings from extant research concur with this supposition as several investigations have found that there still remain a proportion of patients who present with symptoms and psychopathology which do not fit with the criteria for either full syndrome or partial syndrome AN or BN (Dalle Grave & Calugi, 2007; Eddy et al., 2008; Fairburn et al., 2007). However, a number of trends can be discerned from recent research. Researchers who argue that EDNOS represents a heterogeneous group of individuals have outlined four main subgroups within this diagnostic category (Turner & Bryant-Waugh, 2004; Eddy et al. 2008), including; sub-threshold AN (SAN), sub-threshold BN (SBN), Binge Eating Disorder (BED) and Purging Disorder (PD).

Binge Eating Disorder

In particular, binge eating disorder (BED) has garnered specific attention (Crow, 2007). The DSM-IV-TR diagnostic criteria for BED include; binge eating in the absence of the extreme methods of weight control as seen in bulimia nervosa and anorexia nervosa (American Psychiatric Association [DSM-IV-TR], 2000) (See Appendix A). Although often regarded as a transient condition, research suggests that BED is often as chronic and stable as AN or BN (Striegel-Moore & Franko, 2008). Moreover, the prevalence of BED surpasses that of AN and BN, with recent

statistics estimating lifetime incidence rates of 3.5% among women and 2.0% among men (Hudson et al. 2007). BED is strongly correlated with severe obesity and exhibits significant comorbidity with other psychiatric conditions. Hudson and colleagues (2007) reported that 78.9% of participants presenting with binge-eating disorder met criteria for at least one of the core DSM-IV mood, anxiety, impulse-control and substance-use disorders.

Purging Disorder

Purging disorder (PD) is characterised by ‘recurrent purging in the absence of objective binge episodes among normal-weight individuals’ (Keel et al., 2005, p.191). PD manifests in individuals with no prior history of BN (Keel et al., 2005; Tasca et al., 2012). PD comprises a substantial proportion of atypical ED cases and prevalence estimates comparable to those reported for AN and BN are documented for this ED cohort (Keel & Striegel-Moore, 2009). Most recently, Tasca et al. (2012) reported that PD comprised 17.3% of EDNOS cases in their adult treatment-seeking sample. Moderate prevalence rates have also been evidenced in ED community samples (Rockert et al., 2007).

PD is surmised to share many clinical characteristics with BN, and several authors have suggested that no significant differences exist between BN and PD individuals on measures of general psychopathology or dietary restraint (Keel et al., 2005; Rockert et al., 2007). Previous research has found similar levels of depression and anxiety in BN and PD individuals (Rockert et al., 2007). However, recent studies have failed to confirm these findings (Tasca et al., 2012). With respect to eating disorder psychopathology in PD individuals, Tasca and colleagues (2012) evidenced higher levels in PD compared to AN-R patients. Moreover, previous investigations

provide evidence to suggest that PD individuals are more likely to use laxatives for weight control compared to BN individuals (Rockert et al., 2007; Tasca et al., 2012). Research has also evidenced significant emotional distress in PD individuals (Tasca et al., 2012). Important differences have been discerned between BN and PD individuals. Specifically, when compared to PD, BN is associated with significantly greater eating concerns and disinhibition (Keel et al., 2005). In light of these findings, several authors conclude that little evidence exists to validate the supposition that PD represents a more severe eating disorder compared to BN (Keel et al., 2005).

The psychological and medical morbidity associated with purging behaviour has previously been documented (Keel et al., 2005). Most significantly, purging behaviour is associated with an increased risk of mortality (Støvning et al., 2011) and time to remission is significantly longer for purging compared to non-purging AN and EDNOS patients (Støvning et al., 2012). Keel and colleagues (2005) yielded similar remission rates for BN and PD at 6-month follow-up. Congruently, Tasca et al. (2012) found that PD individuals exhibited remission rates and treatment completion rates comparable to AN and BN patients. Evidently, the knowledge base concerning the clinical characteristics and severity of PD is inconclusive and there remains a notable absence of data on the course, outcome and treatment of individuals who meet criteria for PD (Keel & Striegel-Moore, 2009). Nonetheless, a growing body of literature attests to the clinical distinctiveness, and utility of PD as a unique ED nosology (Keel et al., 2005; Keel & Striegel-Moore, 2009; Rockert et al., 2007; Tasca et al., 2012).

EDNOS: Clinical Characteristics

There is a widely held assumption in clinical practice that partial syndromes are less severe and less clinically significant than full syndromes (Turner & Bryant-Waugh, 2004). However, many authors assert that the residual classification of EDNOS includes several discrete categories of patients with eating behavior, psychopathology and psychosocial impairment comparable to full syndrome AN and BN (Rockert et al. 2007; Fairburn and Bohn, 2005; Fairburn et al., 2007). Button and colleagues (2005) found that EDNOS patients exhibited similar levels of eating pathology as AN and BN individuals, with 69% of their sample engaging in restrictive eating most days. The authors also found that, similar to BN individuals, 36% of EDNOS patients engaged in strenuous exercise weekly. Furthermore, engagement in compensatory behaviours remained at a level in-between AN and BN. Their findings also yielded evidence to suggest similar levels of attitudinal concern (intense fear of weight gain, body image disturbance etc.) in AN, BN and EDNOS patients (Button et al., 2005).

In their community sample of women with PD, BN or no eating disorder, Keel et al. (2005) found that women with purging disorder did not differ significantly from women with BN on measures of eating disorder severity, body image disturbance, or dietary restraint. Moreover, Rockert and colleagues (2007) found that duration of illness is often longer in sub-threshold EDNOS categories when compared to their full-threshold counterparts. The frequency and replication of these findings across studies have led several authors to call for a re-examination of the boundaries of AN and BN diagnoses. The issue of re-evaluating the diagnostic criteria for AN and BN will be discussed in detail in latter stages of this literature review.

Outcome from EDNOS

The literature base on outcome from EDNOS is particularly weak, with extant studies merely reporting descriptive information on outcome factors in this residual category (Berkman et al., 2007). In their systematic review of course and outcome in ED, Keel & Brown (2010) reported a remission rate of 75% in EDNOS cases and approximated a probable chronic course for the remaining 25% of cases not achieving remission. Keel & Brown (2010) reported higher remission rates in EDNOS (82%) than in AN (57%) or BN (47%).

Several researchers suggest a protracted illness in the course of BED (Striegel-Moore & Franko, 2008). Specifically, Pope et al. (2006) reported a retrospectively assessed, mean lifetime duration of 14.4 years for BED, a finding which was significantly longer than that of AN (5.9 years) or BN (5.8 years) patients in their study. Poor psychosocial functioning and impaired quality of life are commonly associated with BED and several authors also suggest the presence of increased psychiatric comorbidity within this ED cohort (Wilfley et al. 2002). BED is further associated with considerable health-related morbidity, a probable consequence of obesity (Striegel-Moore & Franko, 2008; Wilfley, Bishop, Wilson & Agras, 2007).

2. 1. 4. Conclusion

The current classification system for ED (DSM-IV-TR) outlines three ED diagnostic categories; anorexia nervosa, bulimia nervosa and the atypical eating disorders, also commonly referred to as EDNOS. International lifetime prevalence estimates for the eating disorders universally demonstrate that EDNOS is the most frequently occurring ED, followed by BN, with AN remaining relatively uncommon.

A range of aetiological and risk factors have been postulated in the development and maintenance of disordered eating, the majority of which are subsumed under the rubric of biological, psychological and, social and cultural influences. Precise causal factors have not yet been delineated, but extant research differentiates between strong and weak contributory factors.

Eating disorders are associated with distinctive core psychopathology (Fairburn & Harrison, 2003) and psychiatric comorbidity is highly prevalent within this clinical population (Hudson et al., 2007). In particular, occurrences of depression, anxiety and OCD are evidenced most frequently (O'Brien & Vincent, 2003). ED individuals frequently transition from one diagnosis to another throughout the duration of their eating disorder, with a migration from AN to BN most commonly reported (Keel et al., 2012). AN is associated with a much poorer prognosis than BN or EDNOS (Keel et al., 2010). Outcomes are less favourable for ED individuals who engage in purging behaviour (Støving et al., 2011). Given the often protracted course of illness, eating disorders are associated with significant health care costs (Mitchell et al., 2009; Simon et al., 2005). Research pertaining to ED within the Irish context is limited. However, extant research reports significant levels of body dissatisfaction and dieting practices within both male and female Irish adolescents (McNicholas et al., 2009; Mooney et al., 2009).

2. 2. The Current Evidence Base and Best-Practice Guidelines for ED

The following section reviews the current best-practice guidelines for ED and evaluates the empirical evidence on treatment effectiveness for AN, BN and

EDNOS. As such, it outlines prioritised clinical guidelines for each ED category and delineates the evidence base on the psychological, pharmacological and physical treatment of each diagnostic cohort. Given the paucity of research investigating treatment effectiveness in EDNOS samples, and thus an evident lack of best-practice guidance identified for this diagnostic cohort, current clinical guidelines are restricted to the identification, management and treatment of BED individuals. This section concludes with an investigation of limitations associated with the current diagnostic classification system for ED (DSM-IV-TR) and reviews the proposed changes outlined in the DSM-5.

2. 2. 1. Best-practice Clinical Guidance for Eating Disorders: The NICE Guidelines

Established in 2004, the National Institute of Health and Clinical Excellence [now National Institute for Health and Clinical Excellence] (NICE) guidelines were developed to advise on the identification, treatment and management of AN, BN and ‘related conditions’ in individuals aged 8 years and over. The NICE guidelines have generated over 100 recommendations concerning the physical, pharmacological and psychological treatment of eating disorders. Recommendations are accredited based on the presence or absence of strong empirical evidence supporting them. The NICE guidelines are established upon various standards of evidence and thus recommendations are graded along a scale, ranging from an A grade (denoting strong empirical support from well-conducted randomised controlled trials) to a B grade (denoting evidence from well conducted clinical studies in the absence of randomised controlled trials on the topic) to a C grade (denoting expert clinical opinion in the absence of empirical data). The majority of NICE recommendations

produced are at a level C standard and thus are not established upon robust research evidence.

2. 2. 1. 1. Anorexia Nervosa: The Evidence Base

The evidence base on the most efficacious intervention in the treatment of anorexia nervosa remains weak, with a notable absence of any category A recommendations for this diagnostic cohort. The NICE (2004) clinical guidelines prioritise three recommendations for implementation in the treatment of anorexia nervosa (Wilson & Shafran, 2005). Of these recommendations, the only B level recommendation advocates that *“family interventions that directly address the eating disorder should be offered to children and adolescents with anorexia nervosa”* (NICE 2004, p.90). Secondly, it is recommended that inpatient services should combine re-feeding and psychosocial interventions (grade C). The guidelines further recommend that *“most people with anorexia nervosa should be managed on an outpatient basis, with psychological treatment (with physical monitoring) provided by a healthcare professional competent to administer it and to assess the physical risk of people with eating disorders”* (NICE, 2004, p.89).

Psychological Treatment of AN

Research supporting the provision of treatment for AN on an outpatient basis has demonstrated that lengthy inpatient treatment programmes are costly and do not foster favourable clinical outcomes in the case of adolescent AN. For example, the largest population-based, randomised controlled trial (RCT) on AN conducted to date – the TOuCAN trial (Gowers et al. 2010) – compared the effectiveness of inpatient treatment, general outpatient treatment (CAMHS) and specialist outpatient

treatment for young people (12-18 years) with AN at 1, 2 and 5 year follow-up. Using intent-to-treat analysis, the authors reported no difference in clinical effectiveness for inpatient compared with outpatient treatment, or specialist over generalist treatment. However, specialist treatment illustrated clinical advantages over time. The specialist outpatient programme was also strongest in terms of incremental cost-effectiveness. Further, patients randomised to the specialist outpatient treatment condition demonstrated greater adherence to treatment (77%) than patients randomised to general outpatient treatment (71%) and inpatient treatment (49%) conditions.

In the absence of any empirically validated treatment modalities demonstrating superior results for the treatment of AN, the NICE guidelines suggest an array of diverse psychological interventions which may be appropriate in the treatment of AN. These include; cognitive analytic therapies (CAT), cognitive behavioural therapies (CBT), focal psychodynamic therapies, interpersonal therapies (IPT) and family interventions focused on eating disorders. Variants of family therapy have demonstrated efficacy in adolescents but overall remain ineffective in the treatment of adults (Bulik, Berkman, Brownley, Sedway & Lohr, 2007; Keel et al., 2012). Evidence is strongest for the Maudsley Model of Family Therapy for treatment of AN in younger adolescents (Wilson, 2005). Pike, Walsh, Vitsouek, Wilson and Bauer (2003) provide tentative evidence for the efficacy of CBT in reducing risk of relapse in AN adults after weight restoration. NICE (2004, p.90) also recommends that the provision of psychological treatment for AN in inpatient settings should integrate “a focus both on eating behaviour and attitudes to weight and shape, and on wider psychosocial issues with the expectation of weight gain”.

Pharmacological Treatment of AN

NICE (2004) guidelines oppose employment of medication as the primary treatment for AN. The guidelines caution the use of medication due to the complications inherent in using medication to treat comorbid symptoms in individuals with a very low body weight. Since low mood is often consequential of starvation, there is limited evidence to support the use of anti-depressants in the treatment of AN (Bhadoria, Webb & Morgan, 2010). In their systematic review of randomised controlled trials (RCT) for AN, Bulik, Berkman and colleagues (2007) reported that no psychopharmacological intervention demonstrated a significant effect on weight gain or on the psychological disturbances of AN. However, Bissada, Tasca, Barber and Bradwejn (2008) provide preliminary results to suggest that Olanzapine, an atypical antipsychotic, may increase appetite and promote weight gain in AN patients.

Physical Treatment of AN

As previously discussed, anorexia nervosa is associated with severe cardiovascular, gastrointestinal and renal complications (Sharp & Freeman, 1993), and the psychological ramifications of starvation are manifold (Polivy, 1996). As such, the NICE (2004) guidelines provide an array of recommendations for the physical management of AN, with particular emphasis placed on the management of weight gain and physical risk. NICE (2004) opposes parenteral nutrition and similarly cautions 'feeding against the will of the patient'. The guidelines recommend that, during instances of severe physical risk, a physician or paediatrician with expertise in treating medically compromised patients with AN should be involved. Dependant on the severity of the acute physical risk and the

availability of services, high risk patients should be offered inpatient admissions in a specialist eating disorder unit or an acute medical ward (NICE, 2004). All recommendations concerning the physical management of anorexia nervosa carry a grade C level of recommendation.

2. 2. 1. 2. Bulimia Nervosa: The Evidence Base

In contrast to anorexia nervosa, the evidence base on bulimia nervosa is much more extensive and, several of the NICE recommendations for this diagnostic group embrace a methodological grade of A and B. In line with this, the strongest recommendation for bulimia nervosa (grade A) is to employ cognitive behavioural therapy (CBT) for 16-20 sessions, over a period of 4-5 months (NICE, 2004). Manual-based CBT is currently the most effective treatment for BN. Comprising three distinct stages, CBT focuses on motivation and reduction of dietary restraint, cognitive-restructuring techniques and relapse prevention issues. A notable advantage of CBT is that early response to therapy best predicts outcome in BN (Agras et al. 2000).

Psychological Treatment of BN

In their systematic review, Shapiro et al. (2007) conclude that CBT has demonstrated efficacy in reducing core behavioural and psychological features of BN in both the short and long-term. In particular, CBT is associated with maintenance of therapeutic and treatment gains, improved ED outcomes and better social adjustment in the long-term (Keel & Haedt, 2008). Interestingly, group CBT has been associated with greater decreases in anxiety, whilst individual CBT demonstrates higher rates of abstinence from compensatory behaviours (Shapiro et

al., 2007). Most importantly, CBT has demonstrated superiority when compared to other psychological interventions (Keel et al., 2012) including, nutritional counselling (Keel & Haedt, 2008) and stress management (Shapiro et al. 2007). In the largest controlled study of BN, Agras and colleagues (2000) compared the efficacy of CBT and IPT in the treatment of BN. Employing intent-to-treat analysis, CBT proved significantly superior than IPT in reducing binge-eating and purging (29% versus 6%) and dietary restraint. Moreover, treatment completion was higher in the CBT condition (45%) than in the IPT condition (8%).

Albeit it's ostensible success, the limited effectiveness of CBT must be noted. Wilson (2005) surmises that CBT removes binge eating and purging in approximately 30-50% of all cases. Although many of the remaining cases demonstrate improvement, several BN patients remain unresponsive to CBT. Interpersonal Therapy (IPT) and Dialectical Behaviour therapy (DBT) are suggested as viable alternative interventions for BN when CBT is unsuccessful (NICE, 2004). IPT is associated with similar treatment outcomes to CBT, although behavioural changes are protracted (Agras et al. 2000). DBT incorporates cognitive-behavioural techniques in conjunction with aspects of mindfulness, meditation and psychodynamic psychotherapy. Bhadoria and colleagues (2010) propose that DBT may be appropriate for BN patients who demonstrate difficulty with affect regulation and unresponsiveness to CBT.

NICE (2004, P.128) also recommends that, "as a possible first step, patients with bulimia nervosa should be encouraged to follow an evidence-based self-help programme" (Grade B). Self-help modalities comprise either guided self-help (i.e., therapist-led) or unguided self-help. Research indicates that guided self-help (GSH)

is an effective initial intervention for a subset of BN patients, but only when therapists administering the treatment are experienced in treating ED (Palmer, Birchall, McGrain & Sullivan, 2002).

Pharmacological Treatment of BN

NICE (2004) suggests using an anti-depressant drug in conjunction with, or as an alternative to using an evidence-based self-help programme for adults with BN (Grade B). Selective serotonin reuptake inhibitors (SSRIs) are the first choice of pharmacological treatment for BN. In particular, Fluoxetine has demonstrated short-term effectiveness in decreasing the core symptoms of binge-eating and purging and associated BN psychopathology (Shapiro et al. 2007; Keel et al., 2012). Moreover, Fluoxetine has demonstrated efficacy even in the absence of comorbid depression, thus suggesting that its effectiveness is not simply consequential of the anti-depressant effect (Bhadoria et al., 2010). However, Wilson (2005) asserts that the absence of evidence for long-term efficacy coupled with high dropout rates represents enduring problems with the use of any medication in the treatment of BN. Nice (2004, p.133) recommends that ‘no drugs other than anti-depressants are recommend for the treatment of Bulimia Nervosa’.

Physical Treatment of BN

With an array of severe physical complications resulting from the range of behaviours associated with BN, physical monitoring is essential in the treatment of this diagnostic group (Mitchell & Crow, 2006). Compensatory behaviours such as self-induced vomiting can result in a multitude of physical complications including fluid and electrolyte disturbance, gastro-intestinal bleeding, teeth erosion and muscle

weakness (Khan & Chowdhury, 2011). NICE (2004) recommends the assessment of fluid and electrolyte balance in patients frequently engaging in compensatory behaviours such as vomiting and laxative misuse.

2. 2. 1. 3. Eating Disorder Not Otherwise Specified: The Evidence Base

Similar to AN, there is a considerable dearth of empirical evidence on the psychological treatment of the atypical eating disorders. EDNOS are widely acknowledged as the most common diagnostic category of eating disorders (Turner & Bryant-Waugh, 2004) and represent the most frequently encountered ED in clinical practice (Fairburn & Bohn, 2005). Reflecting the absence of a well-established evidence base for EDNOS, clinical guidelines merely advise that “the clinician considers following the guidance on the treatment that most closely resembles the individual patient’s eating disorder” (NICE 2004, p.161; Grade C). The majority of established clinical recommendations for the atypical eating disorders pertain to the diagnostic category of BED.

Psychological Treatment of Binge-Eating Disorder

Within the EDNOS category, binge eating disorder (BED) has received the most research attention. NICE (2004) clinical guidelines recommend a specifically adapted form of CBT (CBT-BED) in the treatment of adult BED (Grade A). In their systematic review of BED, Brownley, Berkman, Sedway, Lohr, and Bulik (2007) report that individual or group CBT reduces binge-eating and improves abstinence rates for up to 4 months post-treatment, but does not lead to weight loss. Although preliminary results suggest its efficacy in treating BED, CBT has not emerged as significantly superior to alternative psychological treatments (Keel et al., 2012).

Results from adult BED studies suggest that CBT and IPT demonstrate similar efficacy in the treatment of BED. In their comparative study of group CBT and group IPT, Wilfley et al. (2002) reported equivalent binge-eating recovery rates for CBT (79%) and IPT (73%) post-treatment and at 1-year follow-up (59% and 62% respectively). Wilson (2005) suggests that DBT also represents a viable alternative treatment for BED. In line with these research findings, NICE (2004) assigns a B grade recommendation to IPT and DBT in the treatment of BED.

Pharmaceutical Treatment of Binge-Eating Disorder

With respect to pharmaceutical interventions, it is suggested that SSRI's may play a role in the reduction of binge-eating, although the long-term effects remain unclear. Brownley and colleagues (2007) found that fluoxetine emerged as superior to other second-generation antidepressants, tricyclic antidepressants and anticonvulsants. Specifically, fluoxetine was associated with a lowered weight gain and a significant decrease in weekly binge frequency, illness severity and clinician-rated depression. Keel et al. (2012) reported that an appetite suppressant termed sibutramine, has exhibited efficacy in the reduction of both binge eating and weight in BED individuals.

Physical Treatment of Binge-Eating Disorder

Although successful in initiating and often maintaining remission from binge-eating, specialized psychological interventions and guided self-help (GSH) interventions demonstrate limited efficacy on weight-loss in obese BED patients (Brownley et al., 2007; Wilson, 2005). NICE (2004) recommends that patients should be informed of the limited efficacy of psychological interventions on body

weight and assigns an A grade to this guideline. In line with this, the guidelines endorse the provision of interventions focused on the management of comorbid obesity in conjunction with psychological treatment for BED. Behavioural Weight Loss treatments (BWL) and self-help interventions have been implicated in the physical management of BED (Iacovino, Gredysa, Altman & Wilfley, 2012; Wilson, 2005). Advantages associated with BWL comprise short-term, clinically significant weight-loss and simple dissemination of treatment (Wilson, 2005). Contrastingly, in their recent review of psychological treatments for BED, Iacovino and colleagues (2012) surmise that, for the majority of individuals, BWL is not an effective treatment for binge-eating in the short- or long-term.

2. 2. 2. Limitations of the Existing Evidence Base and Current Clinical Guidelines for ED

Considering the paucity of A and B level recommendations in the NICE guidelines, there remain several shortcomings in current disseminated best practice clinical guidance for ED (Dalle Grave, 2011). Although advocated for the clinical management and treatment of individuals aged 8 and over, the available clinical guidelines fail to cover other eating disturbances prevalent in children and young adolescents such as; Food Avoidance Emotional Disorder, Selective Eating, Functional Dysphagia & Pervasive Refusal Syndrome (Keel & Haedt, 2008). However, the relevance of inclusion of such eating disturbances within the ED spectrum has been questioned previously by the assertion that, feeding disorders are quite distinct from eating disorders, particularly in terms of underlying core cognitions (Gowers & Bryant-Waugh, 2004). The dearth of treatment research in the child and adolescent ED literature presents additional problems in the effective

management and treatment of ED (Couturier & Lock, 2007; Gowers & Bryant-Waugh, 2004).

Secondly, the evidence base for EDNOS and AN is particularly weak across the age ranges (Dalle Grave, 2011; Keel et al., 2012). A further limitation of the current evidence base is the notable absence of male participants from treatment studies. Treatment studies across the spectrum of ED have involved female samples and thus, it remains unclear whether these treatments are applicable to the treatment of male ED. With recent studies estimating that between 19-30% of children with AN are boys (Khan & Chowdhury, 2011), the need to establish gender differences in treatment efficacy is evidently a research priority.

2. 2. 3. Toward DSM-5

2. 2. 3. 1. Problems associated with the DSM-IV-TR Diagnostic Criteria for ED

Recent research highlights enduring problems with the current DSM classification system for ED (DSM-IV-TR). Specifically, the diagnostic criteria and cut-off points for AN and BN are not evidence-based (Keel et al., 2012; Thaw, Williamson & Martin, 2001; Wilfley et al., 2007), and the amenorrhea and weight threshold criteria required for a diagnosis of AN are not empirically supported (Thaw et al., 2001). Research findings also question the empirical validity of the frequency criterion for binge eating episodes in BN (Thaw et al., 2001). Other criticisms pertain to the EDNOS category. Specifically, the “residual” status assigned to this diagnostic category has met with much contention for two fundamental reasons. Firstly, EDNOS is the most commonly encountered ED diagnosis in both research and

clinical accounts (Mitchell et al., 2007; Turner & Bryant-Waugh, 2004). Secondly, individuals assigned to the EDNOS category do not have residual symptoms. In light of the consistency of these findings, several authors have called for a re-evaluation and modification of the individual diagnostic criteria for AN and BN (Keel et al., 2012).

As such, five primary suggestions have been proposed to alter the current diagnostic criteria for AN and BN. In the case of anorexia nervosa, research consistently advocates; the removal of the amenorrhea criterion (Fairburn & Bohn, 2005), an upward adjustment of the weight threshold criterion, and a redefinition of the ‘core psychopathology’ of AN (Fairburn & Bohn, 2005). In the case of BN, it is principally argued that the minimum twice-weekly threshold for frequency of binge eating and purging be lowered to once weekly (Fairburn & Bohn, 2005) and that the definition of a binge be expanded to include episodes of uncontrolled eating not involving the consumption of a large amount of food. The introduction of dimensional criteria to ED diagnoses has also been advocated, as it is surmised that dimensional components may permit the emergence of informative cut-points not permissible through categorical criteria (Wilfley et al., 2007), which in turn would enhance both clinical care and research endeavours. Wyckes & Callard (2010) infer that dimensional components could also have important implications for describing clinical features that lack clear boundaries, and would permit clinicians a rating of severity in diagnosing eating disorders.

2. 2. 3. 2. Altering the DSM-IV-TR Diagnostic Criteria for AN and BN

Systematic evaluations of the impact of altering the AN and BN diagnostic criteria on the prevalence of EDNOS provide modest support for the aforementioned

recommendations. Investigating a heterogeneous sample of ED patients recruited from both clinical and community settings, Thaw and colleagues (2001) reported that elimination of the amenorrhea criterion and adjustment of the weight loss threshold from 15% to 10% modestly reduced the prevalence of EDNOS from 55.9 to 44%. Moreover, when the frequency for binge eating was reduced from at least twice per week to once per week, the prevalence of EDNOS decreased from 55.9% to 51.3%. In a similar investigation employing a sample of 170 ED patients participating in an outpatient psychotherapy research trial, Fairburn et al. (2007) found that criterion modifications impacted minimally on the relative prevalence of EDNOS. Moreover, a notable drop in the relative prevalence of EDNOS was only yielded when the expanded definition of a binge was applied. Based on these findings, Fairburn & colleagues deduced that a small proportion of ED cases could be re-classified as cases of AN, BN or BED, but that the vast majority of EDNOS cases differ in their precise clinical presentation. Most recently, in a sample of both adolescent and adult ED patients in an inpatient treatment setting, Dalle Grave and Calugi (2007) found that a combination of DSM-IV criterion modifications significantly reduced the number of patients receiving an EDNOS diagnosis. Moreover, the authors found that criterion modifications significantly increased the number of patients receiving an AN diagnosis but did not influence the number of patients diagnosed with BN. This is in contrast to the findings of Fairburn & colleagues (2007) who yielded a relative increase in the incidence of BN, but not AN, due to criterion modifications.

2. 2. 3. 3. *Proposed Changes to Eating Disorder Diagnostic Criteria in the DSM-5*

It is expected that DSM-5 will be launched in June 2013 with the introduction of four fundamental changes to the diagnostic criteria for AN and BN. In the case of anorexia nervosa, the amenorrhea criterion in post-menarchal females has been removed and the BMI threshold has been raised. In the case of bulimia nervosa, the minimum average frequency of binge eating and purging has been reduced from two episodes per week to one episode per week and, the definition of a binge has been expanded. Most significantly, BED is now a formally recognised diagnosis, differentiated from AN, BN and EDNOS categories. With regards to the EDNOS category, the DSM-5 proposal comprises several named syndromes, each accompanied with a brief description, but lacking formal research criteria. The named syndromes include; Subthreshold AN (SAN), Subthreshold BN (SBN), Subthreshold BED (SBED), Purging Disorder (PD) and Night Eating Syndrome (NES).

2. 2. 3. 4. Enduring Limitations Associated with the DSM Classification System

Although identified as an improvement to the current diagnostic criteria, Keel and colleagues (2012) assert that proposed DSM-5 diagnoses continue to lack robust evidence of etiological validity. Moreover, several diagnostic criteria still remain problematic and potentially impede clinical practice. This has augmented the argument for a conceptualisation of ED within a dimensional framework (Keel et al., 2012). These sentiments are reflected in the recently proposed *Research Domain Criteria* (RDoC) by the National Institute of Mental Health (NIMH). The RDoC is a dimensional approach to the research classification of psychiatric disorders which

focuses on etiological validity, and thus stands in contrast to DSM's categorical approach emphasising predictive validity (Keel et al., 2012).

2. 2. 4. Conclusion

In conclusion, evidence of efficacy for treatment interventions across the eating disorder spectrum is limited by several methodological factors including; an inadequate number of extant investigations, small sample sizes, lack of appropriate control conditions or randomization procedures (Keel & Haedt, 2008), and the absence of long-term follow-up (Wilson, 2005). As widely acknowledged, evidence for the management of child and adolescent eating disorders is universally weak across the spectrum of eating disorders (Courturier, Kimber & Szatmari, 2013; Gowers & Bryant-Waugh, 2004). As such, studies that target effective interventions in children and adolescents warrant a high research priority (Gowers & Bryant-Waugh, 2004; Keel & Haedt, 2008; Wilson, 2005).

The absence of data on the clinical management of AN and EDNOS has led to limited A and B standard recommendations for effective treatment interventions in these diagnostic cohorts (Wilson et al. 2007). Presently, the only robust guideline concerning treatment for anorexia nervosa recommends the use of family interventions in the treatment of adolescent AN (Keel & Haedt, 2008; Rutherford & Couturier, 2007). No specific treatment intervention has been identified as significantly efficacious in treating adult AN.

Bulimia Nervosa is rarely seen in children and is uncommon in younger adolescents (Gowers & Bryant-Waugh, 2004). CBT is the treatment of choice for older adolescents (17+ years) but it remains unclear whether family-based

interventions or CBT-guided care are most appropriate for younger adolescents (12-16 years) (Rutherford & Couturier, 2007). Ambiguity concerning the most appropriate intervention for BN in young adolescents is reflected in current best-practice guidelines, which advise that, “adolescents with bulimia nervosa may be treated with CBT-BN, adapted as needed to suit their age, circumstances and level of development, and including the family as appropriate” (Grade C) (NICE, 2004, p.128). CBT-BN remains the first-line treatment of choice for older adolescents and young adults with BN. However, since CBT remains ineffective in 50-70% of patients (Wilson, 2005), current clinical guidelines suggest that IPT and DBT may represent alternative efficacious interventions (NICE, 2004).

Clinical recommendations pertaining to the atypical eating disorders are confined to the diagnostic cohort of BED. At present, there remains no established first-line psychological intervention for EDNOS individuals, with research illustrating similar efficacy for CBT, IPT and DBT interventions in BED populations (Brownley et al., 2007). Specifically, NICE (2004) recommends an adapted form of CBT (CBT-BED) for the treatment of adult BED. Pharmaceutical treatment, specifically SSRI's, are postulated to effectively reduce the occurrence of binge-eating, and behavioural weight loss treatments are associated with short-term physical improvement in BED (Brownley et al., 2007). With limited research available to guide clinical practice, the majority of recommendations for disorders falling within this ‘residual’ ED category have received mostly cautious or consensus statements.

It is hoped that the forthcoming DSM-5 will address many of the limitations of the current classification system, most notably with respect to current strict

diagnostic criteria and threshold boundaries. Research investigating the impact of altering current diagnostic criteria for AN and BN has yielded mixed findings (Fairburn et al., 2007; Thaw et al., 2001). However, these studies provide tentative evidence to suggest that, when specific diagnostic criteria are collectively eliminated or decreased, the prevalence of EDNOS cases can be modestly reduced (Dalle Grave & Calugi, 2007; Thaw et al., 2001). In light of such evidence, the DSM-5 introduces four fundamental changes to the diagnostic criteria for AN and BN. Additionally, BED is included as a formal diagnosis and the EDNOS category includes several named syndromes. However, some researchers continue to question the validity of the DSM's categorical classification of ED and argue for a dimensional approach to the taxonomy of eating disorders (Keel et al., 2012).

2. 3. Current Treatment Pathways for Eating Disorders in the Republic of Ireland

2. 3. 1. Present Service Model for Eating Disorders in the Republic of Ireland

Presently, there remain no standard policies or protocols developed in Ireland for the management of eating disorders (Rowell, Nolan & O'Donnell, 2008). For the vast majority of clients with an eating disorder, the initial point of contact with health services is the primary care team. Primary care services provide first-level contact that is entirely accessible by self-referral. At the primary care level, clients either seek help directly for their eating disorder or for common comorbid symptoms including; depression, anxiety, obsessive compulsive behaviours and gastrointestinal and menstrual symptoms. Subsequent to the detection of clients with eating disorders at the general practice level, the standard procedure is to treat the patient on an

outpatient basis, except in cases of severe physical and psychiatric disturbances, which thus require hospital admission. Eating disordered patients are presently managed within primary care, acute services, child and adolescent mental health services (CAMHS) and adult mental health services (AMHS).

Service commissioning and delivery for eating disorders takes place at four levels; primary care, secondary care, intensive community care and tertiary care. At the least intensive level of care, individuals can access medical treatment at the primary care level. Currently, there remains an absence of specialist provision for eating disorders within primary care. Generic mental health services (i.e. CAMHS, AMHS) delivered by community mental health teams (CMHT) are provided within secondary care. At a more intensive level of care, specialist mental health treatment is available in the form of community outreach services. When primary care interventions fail or there is a poor response to treatment at secondary care or intensive community care, individuals are referred to tertiary care treatment centres which provide specialist inpatient interventions (See Figure 2.3).

2. 3. 2. Specialist Services for Eating Disorders in the Republic of Ireland

Although limited, treatment for eating disorders in the Republic of Ireland can be accessed through both private and public channels. At present, there are four specialist eating disorder services accredited by the Mental Health Act commission in Ireland; St. Vincent's Hospital, Fairview (SVF), St. John of Gods Hospital Ltd, Stillorgan (SJOG), St. Patrick's University Hospital (SPUH) and Lois Bridges (LB) Treatment Centre. All four specialist treatment centres are based in Co. Dublin. St. Vincent's Hospital, Fairview, St. Patrick's University Hospital and St. John of Gods

Hospital, Stillorgan provide specialised treatment for adolescents with ED. All four centres provide treatment for adult ED (See Figure 2.3).

St. Vincent's Hospital, Fairview is the only public mental health service accredited by the Mental Health Act in Ireland. St. Vincent's Hospital, Fairview works in partnership with the Health Service Executive (HSE) and the Mater Misericordiae University Hospital. St. John of Gods Hospital Ltd, Stillorgan, St. Patrick's University Hospital and Lois Bridges Treatment Centre, Dublin are independently governed mental health (MH) providers. St. John of Gods, Stillorgan provide specialist inpatient and outpatient treatment for both adolescents and adults suffering from AN. St. Patrick's University Hospital provide specialist inpatient, outpatient and day treatment services for both adolescents and adults seeking help for all types of eating disorders. St. Patrick's has also established a number of community mental health clinics - termed the 'Dean Clinics'. There are currently seven Dean Clinics in operation nationwide, with five of these operative in Co. Dublin. The two remaining clinics are based in Co. Cork and Co. Galway. Specialist services for adult ED are available at the Dean Clinic Cork and the Dean Clinic Sandyford (Dublin). Lois Bridges treatment centre is Ireland's only dedicated residential treatment centre for eating disorders and provides specialist inpatient and outpatient treatment for adult ED (See Figure 2.3). The following sections will delineate structural aspects of treatment programmes for both adolescents and adults in the aforementioned service providers, proceeding with a summary of the former. Since the treatment programme at St. John of Gods is structured similarly for both adolescents and adults, a summary of the overarching treatment programme will be presented under the rubric of adolescent treatment services.

2. 3. 2. 1. Specialist Treatment Services for Adolescent ED

St. Vincent's Hospital, Fairview (SVF)

St. Vincent's Hospital, Fairview administers treatment for adolescent ED on both an inpatient and outpatient basis. St. Joseph's adolescent inpatient unit is a tertiary care service currently operating within St. Vincent's Hospital, Fairview. The six-bed inpatient programme is not dedicated exclusively to the treatment of ED but rather provides treatment for 16 to 18 year old adolescents presenting with severe mental health difficulties, including eating disorders. St. Joseph's Adolescent and Family Service offers outpatient care for adolescents aged 13 to 18 years presenting with a variety of complex mental health problems. The referral process to St. Joseph's is initiated with referrals from consultants within child and adolescent mental health services (CAMHS) and adult mental health services (AMHS) from within the specified catchment area (i.e. Dublin North-East administrative area). The multi-disciplinary team (MDT) at St. Vincent's Hospital include staff from a variety of disciplines including; psychiatry, psychology, nursing, speech and language and, education. Treatment programmes include a combination of medical examinations, drug therapy and psychosocial interventions. St. Vincent's Hospital also provides an educational programme to enable adolescents to continue with their education whilst receiving treatment.

St. Patrick's University Hospital

Willow Grove adolescent unit is a 14-bed inpatient unit currently operating within St. Patrick's University hospital, providing treatment for a diverse range of mental health problems in adolescents aged 13-17 years. Similar to St. Joseph's

adolescent inpatient unit, it is not dedicated solely to the treatment of eating disorders, but instead treats a range of mental health disorders. Referrals to the service are accepted from primary and secondary care services. The Willow Grove MDT comprises; doctors, nurses, cognitive-behavioural therapists, a clinical psychologist, social worker/family therapist, occupational therapist, psychotherapist and dietician. Fundamental components of the inpatient treatment programme include; individual and group psychotherapy, occupational therapy, family therapy, cognitive behaviour therapy, the eating disorder programme and sensory integration. Therapeutic components of both the inpatient and day-patient programme focus on; mindfulness, social skills, assertiveness, communication skills, self-esteem, teen advisory groups, relaxation and stress management, group psychotherapy, group CBT, and other recreational activities (e.g. cookery, sports, creative arts). Willow Grove also provides an educational programme to enable adolescents to continue with their education whilst receiving treatment. Community-based treatment for adolescents presenting with a variety of mental health problems, including ED, is accessible through the adolescent mental health service located at the Dean Clinic, Lucan (Dublin).

St. John of Gods Hospital, Stillorgan

The ED treatment programme at St. John of Gods is administered to both adolescents and adults, and can be received on an inpatient or day-patient basis. The treatment programme is predominantly group-based and approximately 12 weeks in duration. Inpatient adolescents and adults reside in separate psychiatric units within the hospital. The Ginesa Suite is a 12-bed inpatient unit which provides treatment to adolescents presenting with a variety of severe mental health problems including

eating disorders. Similarly, inpatient adults receive treatment within an acute psychiatric ward. The structure of the inpatient programme for both adolescents and adults incorporates outpatient assessment, inpatient admission and post-treatment care. Referrals to St. John of God are accepted from a range of professional disciplines. Emergency admissions of patients are accepted from the patients GP, external medical staff, external consultants and consultants associated with St. John of God hospital. The MDT at St. John of Gods include; consultant psychiatrists, psychologists, social workers, nurses, an occupational therapist and an art therapist. The treatment programme is comprised of group therapy, family therapy, individual therapy and a weight restoration programme. Therapeutic components of group therapies include; education, body image, eating behaviours, goal attainment, physical exercise, socialisation and family meetings. St. John of Gods also provides an educational programme to enable adolescents to continue with their education whilst receiving treatment.

2. 3. 2. 2. Specialist Treatment Services for Adult ED

St. Vincent's Hospital, Fairview

St. Louise's Ward is an acute admission unit currently operating within St. Vincent's Hospital, Fairview. The 30 bed inpatient programme is not dedicated exclusively to the treatment of ED, but instead provides treatment for adults presenting with a range severe mental health difficulties. Admission to the unit is dependent upon psychiatric assessment, and most commonly accessible to individuals with severe and enduring mental illness who are unable to receive adequate treatment in a community setting. The core treatment programme emphasises; knowledge development, health promotion activities, development of

social skills and encouragement of self-expression. Treatment is delivered in both structured and unstructured group formats, and groups are primarily nurse-led. The multi-disciplinary team governing the treatment programme at St. Louise's Ward comprises the consultant psychiatrist, non-consultant hospital doctors and nursing staff.

St. Patrick's University Hospital

Adult eating disorder services at St. Patricks University hospital comprise inpatient treatment, outpatient treatment, day service treatment and aftercare. Inpatient treatment, day service and aftercare treatment programmes are located within the grounds of St. Patricks University Hospital, whilst out-patient services are located at the Sandyford Dean Clinic, Dublin. Referrals to all services are made by GPs. All patients are assessed at the outpatient service at the Dean clinic in Sandyford. The structure of the inpatient programme incorporates low intensity group work, individual support, education, and individual psychotherapy where required. The outpatient service is a less intensive form of treatment available in a community mental health setting. Similar to inpatient treatment, it comprises a comprehensive assessment, treatment and follow-up care. The day care service is approximately eight weeks in duration and takes place from Monday to Thursday from 9:30 – 4:30. The day care service represents a less intensive treatment option for individuals not requiring hospitalisation but in need of greater support than that offered by outpatient services. The day service is administered predominantly in a group format, although individual therapy is also available. The aftercare treatment programme is based on the Wellness Recovery Action Plan (W.R.A.P.) and is

accessible to patients who have recently been discharged from inpatient or outpatient treatment and day services.

Dietetic assessment, medical observation and psychological assessment are structured into all adult ED services offered by St. Patrick's University hospital. Therapeutic components common to all three ED services include; family support and skills education programme, Cognitive Behavioural Therapy for eating disorders (CBT-E), Motivational Enhancement Therapy (MET) and Occupational Therapy. The inpatient treatment programme and day service treatment also integrate meal support therapy, art therapy, mindfulness-based stress reduction, personal development and recreational activities. Individuals receiving in-patient treatment or attending day services may also avail of other programmes which are administered in the hospital, including; the anxiety programme, depression programme and, addictions and dual diagnosis programme.

Lois Bridges Treatment Centre

Most recently accredited by the Mental Health Act Commission in Ireland in 2010, Lois Bridges is the only dedicated residential treatment centre for eating disorders in Ireland. Unlike SJOG and St. Patricks University hospital, Lois Bridges provides specialist treatment exclusive to adult ED. Treatment is available on both an inpatient and outpatient basis. GP referral is required for admission into both inpatient and outpatient programmes and entrance into the programme is also contingent upon assessment. The six-bed, inpatient programme incorporates inpatient admission, outpatient treatment and post-treatment care. Therapies within this programme are administered in both group and individual formats.

Lois Bridges also provide a separate intensive outpatient programme for individuals not requiring inpatient care. This programme is administered on a six-day-a-week basis, over a period of 10 weeks. The intensive outpatient programme offers a range of therapies including; Group Gestalt Therapy, Dietetic Groups, Cookery Groups, Self-Esteem Groups, Confidence Building Groups and Family System Groups. The MDT at Lois Bridges includes specialised practitioners from a multitude of disciplines including; medical, nursing, social work, dietetics, family therapy, psychiatry and psychology. Specific psychotherapeutic domains available to clients include; Cognitive Behaviour Therapy (CBT), Cognitive Analytic Therapy (CAT), Dialectical Behaviour Therapy (DBT), Interpersonal Therapy (IPT), Motivational Enhancement Therapy (MET), Nutritional Therapy, Gestalt Psychotherapy, Systemic Family Psychotherapy, Creative Arts Psychotherapy and Guided Imagery Therapy. A number of body-focused alternative therapies such as Reiki and Tai-Chi are also incorporated into the programme.

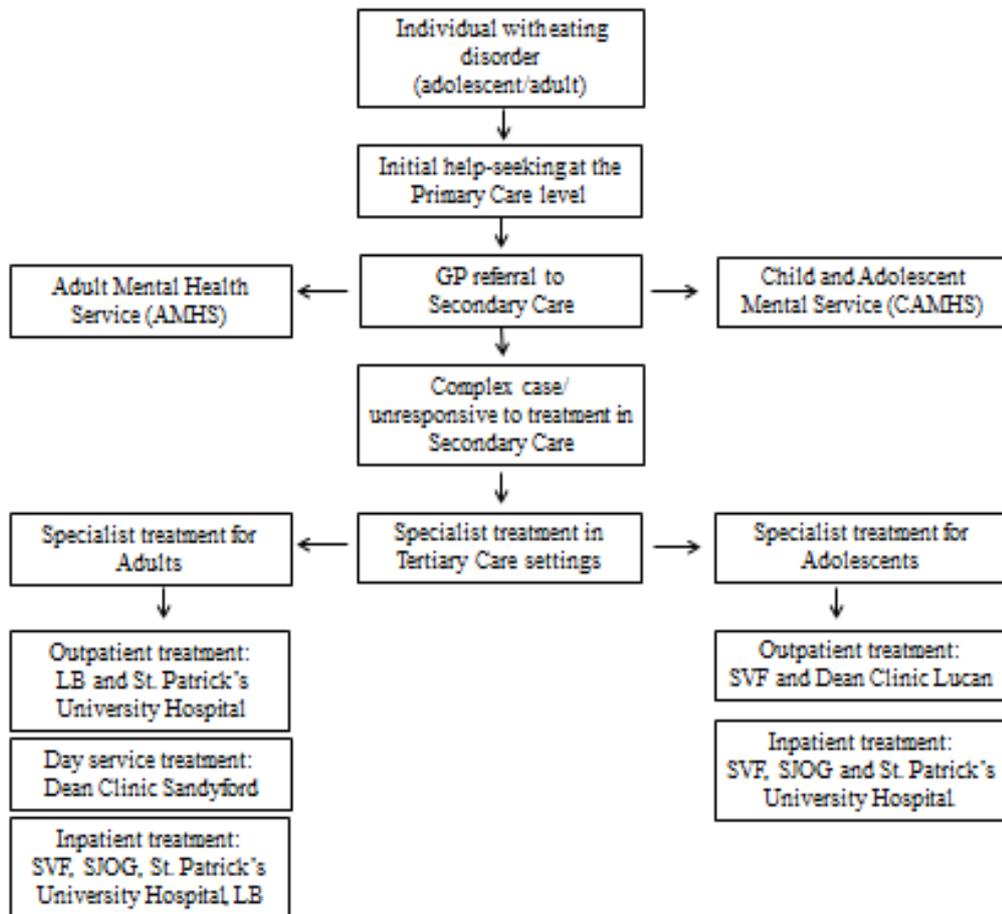


Figure 2. 3: Current ED treatment pathway for eating disorders in the Republic of Ireland. Abbreviations: LB, Lois Bridges; SJOG, St. John of Gods; SVF, St. Vincent's Hospital, Fairview.

2. 4. Challenges in Service Delivery for Eating Disorders in the Republic of Ireland

2. 4. 1. Challenges at the Primary Care Level

For most individuals suffering from eating disorders, primary care is typically the first point of contact for professional help (Green, Johnston, Cabrini, Fornai, & Kendrick, 2008; Linville, Benton, O’Neil & Sturm, 2010). Specifically, GPs play a critical role in the initial assessment and diagnosis of an eating disorder, and the preliminary co-ordination of treatment (Currin, Schmidt, & Waller, 2007; Linville et al., 2010; NICE, 2004). Paradoxically however, research consistently demonstrates a significant under-detection of eating disorders at the primary care level (Flahavan, 2006; Walsh, Wheat & Freund, 2000). Despite the establishment of a multitude of recommendations for primary care practitioners, studies in this domain report wide variation in the diagnosis and referral rates of GPs (Currin, Schmidt et al., 2007). GP referral decisions are pertinent in terms of the consequential impact on the care patients receive and the associated demands on psychological services (Green et al., 2008). Within the Irish primary care setting, it has been deduced that the absence of an efficacious and standard methodical screening process available to GPs further complicates the effective screening, assessment and diagnosis of ED (Flahavan, 2006).

Research implicates both patient variables and clinician variables as influential factors in the referral decisions of health care providers at the primary care level (Currin, Schmidt et al., 2007; Feeney, Noble, & Waller, 2007; Hugo, Kendrick, Reid & Lacey, 2000), although other studies have failed to confirm these findings (Green et al., 2008). Employing a case vignette methodology, Currin,

Schmidt et al. (2007) investigated clinical and non-clinical patient characteristics surmised to influence the diagnosis and treatment of ED within the primary care setting. Using two separate case vignettes - low weight presentation and bingeing presentation – the authors found that only 68.5% of the hypothesised cases were given a primary diagnosis of ED by primary care practitioners. Further, in low-weight presentation vignettes, only 57.3% received a primary diagnosis of disordered eating. Most importantly, BMI level and weight status did not influence the likelihood of successfully diagnosing an ED within this group, nor did it influence the decision to refer to secondary mental health services. These findings are further replicated by Green and colleagues (2008).

2. 4. 2. Poor Adherence to Evidence-based Practice Guidelines

Health services research consistently demonstrates a significant disparity between best practice guidelines and applied clinical care (Grol & Grimshaw, 2003). Grol and Wensing (2004) suggest that factors at different levels of healthcare systems account for the lack of adherence to evidence based guidelines. Primary care practitioners represent one such professional cohort demonstrating a particularly poor awareness of, and adherence to, best-practice clinical guidelines (Carlson, Glenton & Pope, 2007). In the context of ED, Currin, Waller et al. (2007) found that only 9 of the 236 (4%) GP participants in their study reported using a published guideline or protocol when managing an ED case. Moreover, none of the GP participants reported using national guidelines to guide their clinical practice for ED care. Congruently, in a study of Irish GP respondents, Flahavan (2006) reported that none of the GP participants in her study were aware of any formal guidelines available to guide ED management and care at the primary care level.

2. 4. 3. Difficulties in Accessing Specialist ED Services

There is widespread acknowledgement concerning the dearth of specialist services specific to the treatment of eating disorders in Ireland (Maher & Nwachkwu, 2012). In addition, the national availability of in-patient beds signifies a gross inadequacy in current ED care provision. Maher & Nwachkwu (2012) reported an availability of three designated specialist beds for ED in the public mental health service. This has resulted in the treatment of ED patients on general medical wards or in general psychiatric hospitals (Maher & Nwachkwu, 2012). Services within the private division comprise 2 eight-bed units and 1 six-bed unit. Investigating the distribution of mental health resources in Ireland, O'Keane, Jeffers, Moloney, & Barrett (2004) found that only 12% of the population had immediate access to specialist eating disorder services. HSE (2011) concludes that, the inadequacy of Irish ED services has resulted in the use of specialist resident facilities outside of Ireland, namely in the United Kingdom - the majority of which is paid for by the HSE. The on-going, and increasing costs associated with transfers outside the Republic of Ireland for specialist services will continue to augment issues concerning continuity of care for ED patients (HSE, 2011).

In their independent review of mental health services in Ireland in 2006, The Department of Health and Children (DOHC) highlighted the deficiency of specialist services for children in Ireland. Irish GP's similarly document a lack of eating disorder services appropriate to the adolescent population (Flahavan, 2006). Congruently, O'Keane et al. (2004) found that dedicated adolescent psychiatric services were only available to 12% of the population in Ireland (O'Keane et al. 2004). The poor distribution of services nationwide also represents a significant

barrier to accessing appropriate treatment. O’Keane and colleagues (2004) found that geographical proximity to location of services emerged as the primary determinant of access to specialist psychiatric services, with the vast majority of services restricted to the Dublin area. Moreover, DOHC (2006) infers that the Dublin-based location of the majority of specialist ED services presents significant problems for outpatient follow-up care.

2. 4. 4. Transitioning Between Tiers of Service

Transitions between tiers of services can be challenging for both professionals and patients (Treasure, Schmidt & Hugo, 2005) and often results in fragmented care in the treatment of ED (Arcelus, Bouman & Morgan, 2008). Current clinical guidelines urge caution in managing the transition between services, particularly in the case of AN, and recommend that “healthcare professionals managing patients with anorexia nervosa, especially those with the binge-purging sub-type, should be aware of the increased risk of self-harm and suicide, particularly at times of transition between services or service settings” (NICE 2004, p. 114). In particular, the interface between CAMHS and AMHS is commonly identified as being particularly problematic (Arcelus et al., 2008; DOHC, 2006; Flahavan, 2006). The greatest issue concerns a lack of clarity on the CAMHS – AMHS divide, namely where CAMHS ends and AMHS begins (Singh, Paul, Ford, Kramer and Weaver, 2008). CAMHS and AMHS use stringent age cut-offs to demarcate service boundaries (Arcelus, et al., 2008; Singh, 2009) and CAMHS services in the Republic of Ireland are responsible for the care of young people under the age of 16. Since AMHS provide treatment to adults aged 18 years and over, patients aged 16-18 years are often placed at a significant disadvantage in terms of accessing further treatment.

2. 4. 5. *Development of Eating Disorder Services in Ireland*

A number of documents, frameworks and guidelines pertaining to eating disorders have been published in recent years. Most recently, HSE (2011) has outlined a succession of proposals in the *National Mental Health Programme Plan* concerning the enhancement of eating disorder care in Ireland. Specifically, this proposal emphasises the importance of early intervention in ED. In line with this, the proposal acknowledges the significance of appropriate screening, referral and treatment interventions as fundamental components of early intervention, and outlines a number of recommendations accordingly. To increase ED detection rates, the proposal recommends the provision of education programmes to primary care teams coupled with the establishment of a simple and efficient screening measure. Recommendations associated with appropriate referral to services include; increasing professional awareness of available services, rapid access to regional services and, efficient organisation of the referral process.

The proposal also recommends the implementation of three new programme interventions to existing services – guided self-help programmes, family interventions and cognitive behaviour therapy. To ensure appropriate evaluation of the proposed clinical programme, the strategy outlines a role for service user and carer evaluations. Other key objectives proposed concern improved access to services regionally (i.e. in each of the four health care regions nationwide) - namely the provision of four in-patient beds per health care region and the reduction of wait time for services to a maximum of two weeks. The proposal also formulates a recommended structure for the ED Clinical Programme – ‘The Governance Structure’ - comprising four regional ED teams, local CMHTs, a clinical lead for ED

and executive clinical directors. HSE (2011) surmises that this anticipated national clinical care network will strive to ensure continuity of care through enhanced communication between services and effective transitions between services.

HSE (2011) also designates a significant role to the voluntary sector in providing support and guided self-help to ED individuals. Bodywhys are the only national voluntary organisation in the Republic of Ireland offering free and exclusive support to individuals affected by eating disorders. They are a non-profit organisation offering the following services to both adolescent and adults in the Republic of Ireland; a Lo-Call helpline, weekly internet support groups and an email support service. Fortnightly and monthly support groups are also provided for ED individuals as well as friends and family members. Further to this, Bodywhys have devised a schools education programme for eating disorders which is delivered nationwide in secondary-level schools upon request.

There are some auspicious prospects for eating disorder care in Ireland in the near future. Specifically, eating disorders have received significant attention within CAWT's 2007-2013 'Putting Patients, Clients and Families First' project, securing the second highest quantity of funding after Acute Hospital Services. Cooperation and Working Together (CAWT) represents the affiliation between the Health and Social Care Services in Northern Ireland and the Republic of Ireland. Since its inception in 2010, CAWT have established a cross-border eating disorder network, a cross-border eating disorders voluntary group and clinical pathways group.

2. 4. 6. Conclusion

Research studies and government policy frameworks assign an important role to primary care services in the efficient assessment and management of eating disorders during preliminary stages of care (DOHC, 2006; HSE, 2011; Walsh et al. 2000). However, pervasive incongruity in the diagnosis and referral rates of general practitioners has contributed to a significant under-detection of ED in primary care settings (Currin, Schmidt et al., 2007). Practitioners' poor awareness of, and adherence to best-practice guidelines further aggravates problems concerning appropriate referral and management of care within this clinical population (Currin, Waller et al., 2007). Access to specialist services represents an additional obstacle in the pursuit of high-quality treatment and services, with research reporting that 88% of the Irish population do not have immediate access to specialist ED services (O'Keane et al., 2004). Moreover, recent government policy frameworks highlight significant disparities between public and private services for (DOHC, 2006). Problematic transitions between tiers of service - namely the interface between CAMHS and AMHS - contributes to patient disengagement from services and discontinuity of care provision (Arcelus et al., 2008). The recently disseminated *National Mental Health Programme Plan* (HSE, 2011) highlights the prominence of early intervention in ED care. Accordingly, the proposal provides a succession of recommendations concerned with increasing ED detection rates, enhancing appropriate referral to services and improving access to specialist services.

2. 5. The Process of Change in Eating Disorders

The following section delineates the process of change in eating disorders - an evidently recursive process comprising stages of denial, resistance, motivation for

change, and recovery. The proceeding overview commences with an investigation of the process of denial, with particular reflection on factors influencing denial of illness in ED. The overview follows with an investigation of treatment resistance and dropout from services. Concluding parts of this section outline the process of recovery in ED patients, emphasizing the role of motivational processes in initiating and maintaining positive change. Since the majority of research on the process of change in ED is largely confined to AN samples, delineation of the aforementioned processes will be evaluated primarily with respect to this diagnostic cohort.

2. 5. 1. Denial

Denial of illness is often considered characteristic of AN, since individuals with AN often minimize their ED or completely deny their illness symptoms (Pryor, Johnson, Wiederman & Boswell, 1995). The clinical significance of symptom denial is reflected in the current classification system for ED (DSM-IV-TR). Clinical perceptions of symptom denial and treatment resistance in AN often surmise that they represent conscious and active attempts by patients to conceal and protect their illness (Vitsouek et al. 1998). However, a number of researchers differentiate between deliberate denial and unintentional denial (Vandereycken, 2006b; Vandereycken & Van Humbeeck, 2008). These inferences are further supported in the qualitative literature. Investigating ED patients' internal help-seeking processes, Schoen et al. (2012) reported that patients themselves differentiated between 'true denial', 'subconscious awareness' and, 'concealment'.

Factors influencing denial

A wealth of research attests to the highly valued nature of several eating disorder symptoms, (Kaplan and Garfinkel, 1999; Serpell & Treasure, 2002; Serpell, Treasure, Teasdale and Sullivan, 1999; Vandereycken & Van Humbeeck, 2008; Vitsouek et al. 1998) - a phenomenon termed 'egosyntonicity'. Anorexic symptoms are commonly associated with arrogance and perceptions of superiority (Pryor et al., 1995). Moreover, the ego-syntonic nature of many AN symptoms induce the patients' sense of the anorexia nervosa being a part of themselves or their identity and represent powerful positive reinforcers which often strengthen denial of illness (Vandereycken, 2006a). Not only does denial impede early identification of ED but the resultant lack of motivation presents considerable difficulties for treatment interventions.

2. 5. 2. Treatment Resistance and Dropout

With respect to AN, denial commonly manifests as the initial form of resistance (Vitsouek, et al., 1998). Treatment resistance is pervasive and insidious in eating disorders (MacDonald, 2002) and a significant proportion of ED patients remain treatment refractory (Kaplan and Garfinkel, 1999). As such, high rates of disengagement and premature dropout from treatment are prevalent within this clinical population (Campbell, 2009; Knowles, et al., 2013; Mahon, 2000; Malson et al., 2004; Vandereycken & Vansteenkiste, 2009).

Factors influencing Treatment Resistance and Dropout

Dropout from treatment is generally perceived as an indication of non-compliance, resistance or treatment failure (Vandereycken & Vansteenkiste, 2009). However, the reasons behind the failure of ED patients to engage with services are

poorly understood (Leavey, Vallianatou, Johnson-Sabine, Rae & Gunpath, 2011). Mahon (2000) surmises that factors influencing patient drop out from treatment for ED can be subsumed under three main areas; patient factors (e.g. comorbidity), treatment factors (e.g. treatment approach), and the interaction between patient and therapist.

Treatment Resistance and Coerced Engagement with Services

Coerced or involuntary treatment is commonly observed in the treatment of psychiatric patients who demonstrate poor engagement with services or resistance to treatment (Guarda et al., 2007). Coerced treatment is a highly controversial and debated issue within the field of mental health, and conflicting results on the impact of forced treatment on patient outcomes have been yielded (Swartz & Swanson, 2004). Within the domain of eating disorders, there remains limited literature concerning the effect of coercion on patient outcomes and extant studies provide mixed findings. On the one hand, involuntary treatment has been shown to result in equivalent weight gain compared with voluntary hospitalization (Guarda et al., 2007). On the other hand, it is also argued that coerced treatment in the case of ED patients elicits defiance or superficial compliance from patients (Guarda et al., 2007) - both of which are associated with poor engagement in treatment. Moreover, coerced treatment is surmised to entail considerable adverse implications for the therapeutic alliance (MacDonald, 2002). However, taken collectively, extant research supports the use of coercive pressure and involuntary treatment in seriously ill and medically compromised ED patients (Guarda et al., 2007; Tan, Stewart, Fitzpatrick & Hope, 2010; Watson, Bowers & Anderson, 2000). The following section reviews the literature on motivation for change in the treatment of eating disorders. Specifically,

it investigates the importance of motivation to instigate a positive change process. The effectiveness of extant motivation-focused treatments (MFT) will also be explored.

2. 5. 3. Motivation for Change

Motivation is posited a central feature in the process of change in ED individuals (Ryan, Lynch, Vansteenkiste & Deci, 2011). Within the ED literature, several studies have highlighted the significance of motivation for change in influencing patients' engagement with services (Allen et al., 2012) and outcome from treatment (Jones, Bamford, Ford & Schreiber-Kounine, 2007; Wade, Frayne, Edwards, Robertson & Gilchrist, 2009; Zaitsoff & Taylor, 2009). Specifically, greater motivation for change has been associated with symptomatic improvement, decreased eating pathology, and treatment completion (Jones et al., 2007; Wade et al., 2009). As such, there has been widespread endorsement of the necessity of fostering motivation to change in poorly motivated eating disorder patients (Dray & Wade, 2012; Waller, 2012; Vansteenkiste, Soenens & Vandereycken, 2005).

2. 5. 3. 1. Motivational Approaches to the Study of ED

The significant ambivalence and poor motivation for change that ED individuals commonly experience (Dray & Wade, 2012; Knowles et al., 2012) has led to the recent exploration of motivational approaches in this clinical population (Waller, 2012). Often, these brief motivational enhancement interventions are employed as a prologue to treatment interventions or integrated into treatment (Ryan et al., 2011). Such interventions include; the Transtheoretical Model of Change (Prochaska & DiClemente, 1983), Motivational Interviewing (Miller & Rollnick,

1999; 2002) and Motivational Enhancement Therapy (Treasure & Ward, 1997). Most commonly, these clinical models are based on a decisional balance model or on the concept of 'stages' of change. However, Waller (2012) argues that the sense of helplessness and hopelessness which many ED sufferers experience is a crucial aspect which has been largely overlooked by extant motivational models. A brief evaluation of the aforementioned motivational models will be presented below.

The Transtheoretical Model of Change

The transtheoretical model of change (TTM; Prochaska & DiClemente, 1983) has been previously employed as a guiding framework for conceptualising change efforts related to both cessation of high-risk behaviours and the adoption and maintenance of positive change (Ryan et al., 2011; Wade et al., 2009). The model comprises three dimensions of change; stages of change, processes of change and, level of change (Treasure, Katzman, Schmidt, Troop, Todd, & de Silva, 1999). The TTM views behaviour change as a gradual process, divided into phases (Hasler et al., 2004). As such, the model differentiates between five stages of change; pre-contemplation (unwilling to change or unaware of a problem), contemplation (considering change), preparation for action (intent to change), action (actively working to facilitate change) and maintenance (working to prevent relapse). Other components of the model include the decisional balance (i.e. pros and cons of change), self-efficacy and temptations - all of which are postulated to influence movement through the stages of change (Treasure & Schmidt, 2001).

Although TTM has previously being identified as an efficacious model for conceptualising ambivalence and change in ED patients (Blake et al., 1997; Treasure et al., 1999), several authors surmise that the commonly accepted formulation of

sequential or cyclical ‘stages of change’ encompasses little clinical utility (Allen et al., 2012; Waller, 2012; Wilson & Schlam, 2004). In particular, the stage-matching hypothesis of TTM has received considerable criticism as research studies rarely yield findings to support the supposition that therapeutic interventions should be tailored according to the patients’ stage of change (Wilson & Schlam, 2004). The one-dimensional nature of TTM has also received significant criticism since the problem behaviours associated with ED intensify issues of motivational change (Treasure et al., 1999). Specifically, TTM does not sufficiently reflect the fluidity of change and the inconsistency with which ED patients engage and disengage with change over the course of their disorder (Allen et al., 2012; Waller, 2012).

Motivational Interviewing

Developed by Miller and Rollnick (1991), motivational interviewing (MI) was originally employed in the domain of addictions. MI is ‘a client-centred, directive method for enhancing intrinsic motivation to change by exploring and resolving ambivalence’ (Miller & Rollnick, 2002, p.25). MI is based on the premise that a confrontational therapeutic style induces patient resistance, whereas a client-centred therapeutic style increases patient motivation. Specifically, MI explores maintaining mechanisms of the problem behaviour and seeks to aid the client in adjusting the decisional balance of pros and cons into the direction of change. Simultaneously, it covers interpersonal aspects of the therapeutic relationship which are most conducive to facilitating such change (Treasure & Schmidt, 2001). In short, the primary objective of MI is to aid patients to reach a decision to change by increasing their intrinsic motivation (Feld, Woodside, Kaplan, Olmstead & Carter, 2001).

The therapeutic techniques and strategies of MI are underpinned by four core principles; the expression of empathy, the development of discrepancy, rolling with resistance, and support for self-efficacy (Miller & Rollnick, 2002). Therapist empathy is perceived as a crucial aspect in creating a climate conducive for the successful exploration of change to occur (Markland, Ryan, Tobin & Rollnick, 2005). The ‘development of discrepancy’ describes the process of exploring the pros and cons of both current behaviours and alternative behaviours (Markland et al., 2005). ‘Rolling with resistance’ defines the process of avoiding engagement in conflict with patients or attempting to challenge a patients’ argument against change (Miller & Rollnick, 1991; 2002). These principles have demonstrated effectiveness in a number of domains, including; addiction treatment, diet, exercise, hypertension, diabetes and bulimia (Vansteenkiste & Sheldon, 2006). Investigating motivational change in an inpatient AN sample, Wade et al. (2009) found that MI did not significantly increase motivation or decrease eating pathology but their findings yielded some evidence of successfully retaining patients in therapy compared to treatment-as-usual (TAU) (Wade et al., 2009). Recent investigations concerning the efficacy of MI in the treatment of ED deduces minimal therapeutic benefit of MI interventions for patients who experience poor motivation for change (Dray & Wade, 2012; Knowles et al., 2012).

Motivational Enhancement Therapy

Motivation Enhancement Therapy combines the principles of TMC with the strategies of MI. The central therapeutic focus of MET concerns the therapist’s approach in supporting patients to reach their own change-focused conclusions (Dean, Touyz, Rieger & Thornton, 2008). The therapeutic strategies employed in

MET are primarily concerned with engaging resistant patients in the treatment process (Dean et al., 2008). Research investigating the effectiveness of MET interventions has produced conflicting findings. Treasure et al. (1999) compared four weeks of MET with four weeks of individual cognitive behaviour therapy for BN patients and reported no differences between outpatient-MET and outpatient-CBT in terms of symptom reduction (binge eating, vomiting and laxative abuse), enhanced readiness to change or therapeutic rapport.

In their pilot study, Feld and colleagues (2001) evaluated the efficacy of a pre-treatment group MET intervention on measures of motivation to change, ED psychopathology (EG) and general psychopathology (EG). Results indicated a significant increase in patients' recognition of the ED as problematic behaviour and an increase in patients' motivation to change at post-treatment follow-up. However, comparing the effectiveness of a group MET intervention with TAU in a sample of acute AN patients, Dean et al. (2008) found no statistically significant differences between treatment groups on formal physical, behavioural and psychological measures. These findings are further echoed in a recent RCT comparing CBT versus MET and, group versus individual CBT (Katzman et al., 2010).

In their randomised controlled trial comparing participants who received five weeks of motivation-focused treatment (MFT) compared to participants randomly assigned to a wait-list control condition, Geller, Brown & Srikameswaran (2011) reported comparable improvements in terms of readiness to change and eating disorder symptomology. Finally, evaluating the effectiveness of a motivation-focused intervention prior to individual cognitive-behavioural eating disorder treatment (CBT-E), Allen et al. (2012) documented comparable outcomes between

treatment (MFT + CBT-E) and control groups (CBT-E) in terms of symptom reduction and treatment completion. Interestingly however, the authors reported a trend for greater efficacy of MFT effects in bulimia-spectrum patients compared to AN-spectrum patients. As such, the authors surmise that, diagnostic differences in the effects of motivational sessions must be taken into account when assessing the efficacy of MFT.

2. 5. 3. 2. Alternative Motivational Frameworks

Evidently, there is some significant conceptual overlap in current motivational approaches to ED. Firstly, all approaches concur that ED patients possess a powerful potential for change (Vansteenkiste et al., 2005). Secondly, all frameworks focus primarily on *how* treatment is delivered rather than the content of treatment (Vansteenkiste et al., 2005). Furthermore, motivational approaches proactively encourage patients to take greater responsibility for change (Vansteenkiste et al., 2005). However, taken collectively, the diverse research findings outlined above make it difficult to accurately conclude that extant motivation-focused interventions are associated with advantages in the treatment of ED (Allen et al., 2012).

Recently reviewing the ED outcome literature, Waller (2012) infers that the efficacy of these interventions in instigating clinical change in ED populations has been poorly validated. Specifically, evidence for the enhancement of patient motivation or treatment outcome by motivational interventions is varied and there is a clear lack of evidence to confirm their efficacy in improving treatment engagement (Dray & Wade, 2012; Knowles et al., 2012). Evidence that motivation interventions improve ED psychopathology is also inconclusive as research studies have shown

that general psychopathology is only improved in BED populations (Knowles et al., 2012; Waller, 2012). Moreover, Vansteenkiste et al. (2005) deduce that extant motivational approaches lack a comprehensive conceptualisation of the important motivational processes which may account for any effectiveness resulting from these therapeutic techniques. In light of this, the authors suggest that self-determination theory (Deci & Ryan, 1985; Ryan & Deci, 2000) could provide a robust, overarching conceptualisation of important motivational processes in the treatment of ED. Recent empirical investigations have also provided preliminary support for the application of SDT to the study of motivational dynamics in ED (Mansour et al., 2012; Vandereycken & Vansteenkiste, 2009). The fundamental tenets of self-determination theory are outlined below and discussed in light of the empirical support the model has received.

2. 5. 3. 3. Self-determination Theory

Self-determination theory (Deci & Ryan, 1985; Ryan & Deci, 2000) is an empirically based theory of human motivation, development and well-being. The theory focuses principally on volitional, or self-determined behaviour, and the socio-contextual conditions that facilitate or forestall it (Ryan & Deci, 2008). SDT also postulates a set of basic psychological needs, namely those for autonomy, competence and relatedness. The fulfillment of these psychological needs is considered necessary for optimal functioning and development (Ryan & Deci, 2000).

The Self-Determination Theory Continuum of Motivation

One of the distinguishing features of SDT is that it focuses on *types* (quality), in addition to, amount (quantity) of motivation. Figure 2. 5. shows the self-

determination continuum, which ranges from non-self-determined behaviours to highly self-determined behaviours. Positioned on the left side of Figure 2. 5. is *amotivation*. People are said to be amotivated when they exhibit a low level of motivation. People can experience amotivation for a variety of reasons, including; when they feel incompetent to achieve an outcome, experience a lack of contingency, or do not value the behaviour or outcome (Ryan & Deci, 2000; Ryan et al., 2011) As such, amotivation is postulated to be highly non-self-determined.

SDT further distinguishes between four types of extrinsic motivation, proposing that extrinsic motivation can vary greatly in its degree of autonomy (Ryan & Deci, 2000). As such, SDT postulates that extrinsic motivation is not always controlling but can also be self-endorsed (Deci & Ryan, 2000). *External regulation* represents the least autonomous form of extrinsic motivation, and refers to actions that are undertaken in order to gain an external reward, avoid punishment or meet external expectations. In the context of external regulation, actions are fuelled by the feeling that one “must” partake. In the context of ED, this is commonly evidenced when patients enter treatment due to externally regulated pressure (Vandereycken & Vansteenkiste, 2009). External regulation is also used within treatment, when health care providers use reinforcement contingencies in attempts to control and sustain positive behaviours (Ryan et al., 2011). *Introjected regulation* describes another form of engagement which is externally controlled. However, in these instances, the source of the control is internal (e.g. shame, guilt, ego-enhancements) and actions are motivated by the feeling that one “should” engage in an activity (Ryan et al., 2011).

A more autonomous, or self-determined, form of extrinsic motivation is *identified regulation*. Identification describes a motivational state in which

individuals are willingly engaged in the process of positive change because they have fully accepted the value of change (Ryan et al., 2011). Identification is a stable and persistent form of motivation (Ryan & Deci, 2000). *Integrated regulation* represents the most volitional form of extrinsic motivation (Markland et al., 2005; Ryan et al., 2011). People exhibit integrated regulation when they not only accept the value of change, but also come to identify themselves with change. In other words, the value of change has been ‘taken in’ within their self-structures (Ryan et al., 2011). The motivational states of identified regulation and integrated regulation are influenced by processes of internalisation and integration. Broadly speaking, internalisation describes the degree to which non-enjoyable behaviours (i.e. extrinsically motivated behaviours) are integrated into people’s self-structures, so that they come to identify themselves with change (Ryan & Deci, 2000). When people personally endorse the regulation of the behaviour, they experience their behaviour as an expression of their personal values and commitments, and thus will engage in it with a sense of volition or autonomy (Vansteenkiste et al., 2005). On the right-hand side of Figure X is *intrinsic motivation*. When people are intrinsically motivated, they engage in an activity because they experience it as interesting and enjoyable (Ryan & Deci, 2000). As such, intrinsic motivation is viewed as automatically self-determined (Vansteenkiste et al., 2005).

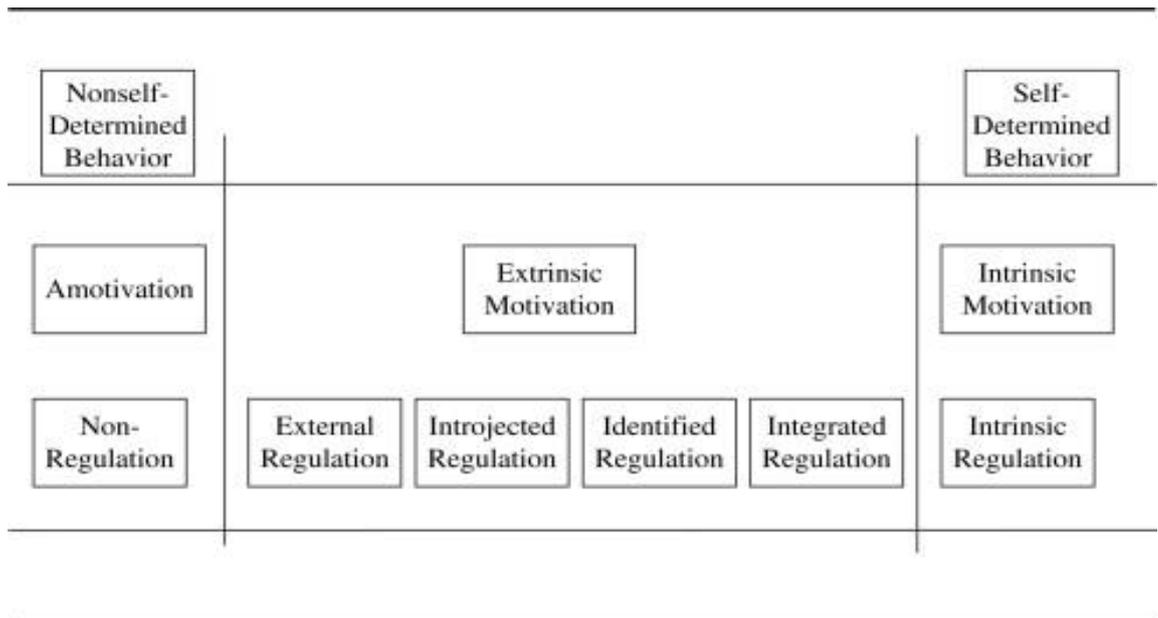


Figure 2. 5.: The self-determination theory continuum of motivation

Psychological Needs

SDT is also fundamentally concerned with investigating of the social-contextual conditions that both facilitate and forestall the natural processes of self-motivation and healthy psychological development (Ryan & Deci, 2000). SDT identifies three innate psychological needs that are universal and developmentally persistent; the needs for *autonomy*, *competence* and *relatedness* (Ryan & Deci, 2000). SDT posits that satisfaction of these needs results in enhanced self-motivation and mental health and when diminished, leads to reduced motivation and well-being (Ryan & Deci, 2000). The need for autonomy requires a sense of volition or self-endorsement to accompany one's actions (Ryan & Deci., 2000; Ryan, Patrick, Deci & Williams, 2008). The need for competence concerns supports for efficacy with respect to autonomously selected objectives or areas of development. People perceive themselves to be competent when they feel able to control important outcomes and perceive themselves to be incompetent when they feel unable to control those outcomes (Williams, McGregor, Zeldman, Freedman & Deci, 2004). Relatedness refers to the sense of being cared for, respected and understood, and the sense of feeling connected with another (Ryan & Deci, 2000). Findings from previous SDT-focused investigations demonstrate a positive association between need satisfaction and self-determined motivation (Edmunds, Ntoumanis & Duda, 2007).

Facilitating the Integration of Extrinsic Motivation

SDT argues that an autonomy-supportive environment, in which patients' psychological needs are supported, is critical to patients' active engagement and adherence toward positive change (i.e. processes of internalisation and integration of

behaviour change) (Markland et al., 2005). The experience of autonomy is postulated to facilitate internalisation, and is a crucial component for the integration of a regulation (Ryan & Deci, 2000). In the context of psychotherapy, the more autonomously engaged a patient is in the therapeutic process, the greater the likelihood they will integrate learning and behaviour change (Ryan & Deci, 2008). Experiences of autonomy are enhanced through the provision of autonomy support (Ryan & Deci, 2000; Ryan & Deci, 2008). Autonomy support is evidenced when health care providers foster or encourage patients' opinion, elicit and acknowledge patients' perspectives, initiative and choice (Ryan et al., 2011), and provide a meaningful rationale for change (Ryan & Deci, 2008) whilst minimising the use of controls, contingencies, or authority as motivators (Ryan et al., 2011; Williams et al. 2004; Williams et al., 2006).

SDT suggests that relatedness is also crucial for the internalisation of extrinsically motivated behaviour (Ryan et al., 2008), because people are more likely to adopt change promoted by those whom they trust and feel connected to (Ryan et al., 2008). Relational support is promoted by unconditional positive regard and involvement (Markland et al., 2005; Ryan et al., 2011). In addition, perceptions of authenticity and genuineness must accompany relational support in order for patients to experience a sense of relatedness (Ryan & Deci, 2008; Ryan et al., 2011). Perceived competence is also implicated as an important component for internalisation because people are more likely to adopt positive change when they feel efficacious with respect to specific activities (Ryan & Deci, 2000). Competence support is afforded through the provision of effectance-relevant inputs, clear feedback and supports for structure (Ryan & Deci, 2008). As such, the patient is

provided with supports to develop the skills and tools for change, and is supported in the presence of competence-related barriers (Ryan et al., 2011). According to SDT, all three nutrients are required to facilitate optimal internalisation of behavioural regulation and integration (Markland et al., 2005).

The Application of SDT to Health Behaviour and Psychotherapeutic Change

The application of SDT in studies of health-related behaviour change has focused on how factors in treatment environments associated with patients' autonomy, competence, and relatedness impact on the initiation and maintenance of positive change (Ryan et al., 2008). Autonomous motivation for engaging in treatment has been found to be an important predictor of positive symptom improvement and overall well-being amongst individuals in the domain of alcohol cessation (Ryan, Plant & O'Malley, 1995), smoking cessation (Williams et al., 2006) addiction (Zeldman, Ryan & Fiscella, 2004), glycemic control for diabetes (Williams et al., 2004) and depression (Zuroff et al., 2007; McBride et al., 2010).

Recently, motivation research has been extended to the domain of psychotherapy, where the applicability of SDT has received theoretical and empirical validation (Ryan & Deci, 2008; Ryan et al., 2011, Zuroff et al., 2007; McBride et al., 2010). SDT proposes that individuals who are more autonomously engaged in the therapeutic process will benefit more greatly from the intended purpose of therapy because they experience themselves as making decisions and choices toward behaviour change as opposed to doing so because of outside pressure or sources (Mansour et al. 2012). The experience of a sense of autonomy or volition with respect to one's behaviour also represents a critical condition to foster the personal endorsement of therapeutic change (Vansteenkiste et al., 2005) and in turn, the

attainment and maintenance of treatment outcomes (Ryan & Deci, 2008). In contrast, externally produced motivation is surmised to undermine lasting change. Accordingly, SDT argues that experiences of pressure and coercion inadvertently stimulates an external regulation within patients, which commonly manifests in either resistance or passive compliance toward the intended action (Vansteenkiste et al., 2005).

Empirical research has illustrated that, the less autonomous the motive for change, the more SDT predicts poor engagement in therapy and lowered long-term success (Pelletier et al., 1997; Zeldman et al., 2004). Pelletier, Tuson & Haddad (1997) found that greater autonomous reasons for entering treatment have been associated with greater valuing of the therapeutic process, greater satisfaction with therapy, greater intention to persist, higher self-esteem and greater life satisfaction (Pelletier et al., 1997). Investigating the relative autonomy of treatment goals in a sample of psychiatric outpatients, Michalak, Klapheck & Kosfelder (2004) found that autonomously motivated patients experienced more positive therapeutic outcomes.

Recent research also attests to the positive impact of autonomous motivation on outcome from treatment. Investigating associations between autonomy support, autonomous motivation, and treatment outcome in a sample of 95 depressed outpatients randomly assigned to IPT, CBT or pharmacotherapy with clinical management conditions, Zuroff et al. (2007) found that autonomous motivation was a stronger predictor of improved outcome (i.e. remission of depression) compared to the therapeutic alliance. However, McBride et al. (2010) deduce that autonomous motivation may only play a significant role in less chronic psychiatric conditions.

Investigating the association between motivation and IPT treatment outcome in patients with chronic depression compared to those with less recurrent depression, McBride and colleagues reported that, although both autonomous motivation and the therapeutic alliance predicted remission in less recurrent depression, only the therapeutic alliance predicted remission in chronically depressed patients. Within the context of eating disorders, Mansour and colleagues (2012) found that higher levels of autonomous motivation at pre-treatment were associated with lower general psychopathology, lower ED psychopathology and improvements in relationships with self and others.

Autonomous motivation is fostered by the socio-contextual condition of autonomy support (Ryan et al., 2011). As such, the therapeutic environment can be more or less conducive of patients' basic need for autonomy (Ryan et al., 2011; Vandereycken & Vansteenkiste, 2009). In their quasi-experimental study, Vandereycken & Vansteenkiste (2009) compared the effects of autonomy-supportive versus autonomy-thwarting interventions on dropout from treatment and change in weight status in an inpatient sample of AN, BN and EDNOS patients. Specifically, the authors found that the autonomy-supportive intervention (i.e. provision of choice) significantly reduced patient dropout rates during the initial four weeks of inpatient treatment. However, weight change in AN patients was not moderated by treatment approach and results illustrated no significant differences between both interventions with respect to weight gain or treatment dropout after four weeks.

In the context of therapeutic change, most people are not intrinsically motivated for therapy (Markland et al., 2005; Ryan et al., 2011; Vansteenkiste et al., 2005; Vansteenkiste & Sheldon, 2006) and behavioural change efforts - particularly

cessation behaviours - are generally assumed to be extrinsically motivated (Markland et al., 2005; Vansteenkiste & Sheldon, 2006). Thus, the development and maintenance of change is contingent on clients' internalisation and integration of values and skills for change (Markland et al., 2005; Ryan et al., 2011; Vansteenkiste et al., 2005). As such, maximising patients' experience of autonomy, competence and relatedness in treatment environments is associated with fostering endorsement of, and enhanced adherence towards, therapeutic change (Ryan & Deci, 2008; Ryan et al., 2011). In sum, motivational dynamics are posited a central role in patients' active engagement in the therapeutic process, completion of treatment and maintenance of positive change. Accordingly, several authors have called for the focus of treatment interventions to shift away from manualised methods designed to target behavioural outcomes to instead emphasise strategies that focus on the process of change (i.e. *how* change occurs) and the optimal application of tools and skills enhanced by treatment interventions (Ryan & Deci, 2008).

2. 5. 4. Recovery in Eating Disorders

It is estimated that less than half of eating disorder patients recover and remain at serious risk of developing a chronic illness (Steinhausen, 2002). However, in the absence of a standard or benchmark for recovery, it is difficult to accurately compare patient outcomes across studies (Couturier & Lock, 2006), which has resulted in considerable variety concerning recovery rates (Noordenbos & Seubring, 2006). This is further amplified by the varied range of time spans used in definitions of recovery, with time durations in extant research ranging from 8 weeks to 79 months (Strober, Freeman & Morrell, 1997). Notwithstanding, research concurs that fundamental aspects of recovery from an ED includes physical rehabilitation,

psychological restoration and psychosocial adjustment (Couturier & Lock, 2006). The forthcoming sections will delineate both physical and psychological elements associated with recovery in eating disorders. In doing so, this section investigates both objective and subjective accounts of recovery (i.e. quantitative and qualitative research). Since there remains an insufficient literature base concerning the recovery process in the atypical eating disorders to draw firm conclusions from this diagnostic cohort, the proceeding section will primarily delineate stages of recovery with respect to AN and BN exclusively.

2. 5. 4. 1. Recovery: Symptomatic Improvement or Psychological Rehabilitation?

Research widely concurs that symptomatic improvement and weight restoration do not signify holistic improvement from an eating disorder (Noordenbos & Seubring, 2008). Moreover, all symptoms do not disappear concurrently (Clausen, 2004). In their study of 95 AN patients, Strober et al. (1997) found that weight, eating behaviours and menses recovery took 4.7 years to normalise, whilst restoration of psychosocial criteria was only indicative after 6.6 years. Similarly, in their longitudinal investigation of recovery in adolescent AN, Couturier and Lock (2006) yielded a mean time of 11.3 months to symptom remission in weight and a mean time of 22.6 months to symptom remission in psychological functioning.

These findings also extend to BN individuals. In a sample of AN and BN patients, Noordenbos & Seubring (2006) found that it took a further two years after weight and eating behaviour restoration for patients to report psychosocial recovery. Clausen (2004) provides further evidence for the remission of physical symptoms prior to psychological symptoms in AN and BN. Specifically, the author found that

the behavioural and physical symptoms of purging (8 months), amenorrhea (8 months), bingeing (9 months) and weight (11 months) were the first symptoms to remit. Psychological symptoms took almost twice the length of time to remit, with symptoms correlating to body perception, fear of weight gain and obsession with weight and shape demonstrating a median time to remission of 20, 23 and 24 months respectively.

Neuropsychological investigations offer further insight into mechanisms of recovery in ED. Collectively, extant neuropsychological findings illustrate that weight restoration does not lead to comprehensive psychological rehabilitation (Danner et al., 2012; Lopez, Tchanturia, Stahl & Treasure, 2009; Roberts et al., 2010; Tchanturia et al. 2007). Qualitative investigations lend further support to the enduring prevalence of emotional and cognitive problems after physical symptoms have subsided in ED patients (Noordenbos & Seubring, 2006). Specifically, studies concerned with the patients' experience of illness report that 'residual disordered thinking' remains a constant and challenging aspect of daily life for recovering ED individuals (Woods, 2004).

2. 5. 4. 2. Conclusion

Recovery from an ED is consistently identified as an arduous and protracted process (Cockell, Geller & Zaitsoff, 2004; Offord et al. 2006). Both therapists and patients emphasise the significance of psychological, emotional and social functioning for recovery from an ED, in addition to weight restoration and behaviour reduction (Noordenbos & Seubring, 2006). Weight restoration occurs significantly premature to psychological recovery and remains a poor marker of psychological and psychosocial recovery (Couturier & Lock, 2006). The evidence from both

neuropsychological studies and qualitative investigations with AN and BN patients suggest that several neuropsychological weaknesses and associated cognitive and emotional impairments remain largely invariant and persistent even after weight restoration (Danner et al., 2012). Nonetheless, research does suggest that, albeit the prevalence of ED symptoms, patients can experience recovery and control over their own health (Cockell et al., 2004; Pettersen & Rosenvinge, 2002; Woods, 2004).

2. 6. Qualitative Research and the ‘Patient Perspective’

2. 6. 1. The Value of Researching the ‘Patient Perspective’

The value of drawing upon service user feedback to inform service development has been highlighted previously (Jenkinson, Coulter, Bruster, Richards & Chandola, 2002; Kravitz, 2001; Swain-Campbell, Surgenon, & Snell, 2001). From a policy perspective, understanding patients’ concerns, expectations and needs is imperative for evaluating the quality of health care, the delivery of health services, and the associated costs of care (Kravitz, 2001). Taking into account the difficulties associated with engaging ED patients in treatment (Leavey et al., 2011) in addition to the increasing rates of dropout from treatment in this clinical population (Campbell, 2009), it is disquieting that relatively little is known about patients’ subjective perceptions about the treatments they receive. The patients’ perspective of treatment could inform the therapeutic process and provide a greater understanding of recovery. Escobar-Koch et al. (2010) assert that the views of ED patients on treatments and interventions are likely to significantly influence the therapeutic relationship and treatment engagement and completion. Specifically, it has been

postulated that identification of the perceived strengths of services can provide knowledge on enhancing motivation for change (Swain-Campbell et al. 2001) and patient perspectives concerning service weaknesses can inform relapse prevention programmes (Escobar-Koch et al. 2010).

2. 6. 2. Extant Findings from Qualitative Investigations of Patient Experiences

Within the context of ED, a patient perspective has most frequently been adopted to investigate experiences of ED causes, symptoms (Serpell et al., 1999), relapse and recovery (Federici & Kaplan, 2008; Keski-Rahkonen & Tozzi, 2005). Although limited, research specific to the treatment experience has explored several dimensions of ED care including; perceived barriers to seeking treatment (Schoen et al., 2012), perceived barriers to accessing care, (Leavey et al., 2011) and both helpful and unhelpful components of care (de la Rie, Noordenbos, Donker & van Furth, 2008). Such studies have provided valuable information and insight into how ED care and service delivery may be refined and improved. Several common themes have emerged and a summary of these findings are presented below.

Barriers to Treatment Seeking

Schoen et al. (2012) posit a significant influence for problems associated with processes of awareness of denial in the help-seeking process. Fear of weight gain and perceptions of loss of control are also commonly highlighted as factors impeding the treatment-seeking process (Reid, Burr, Williams & Hammersley, 2008; Williams & Reid, 2010). Fear of change, pre-conceived notions of treatment, and prior experiences in treatment have also been identified as negatively impacting help-

seeking attempts (Schoen et al., 2012). As such, ambivalent feelings toward treatment often results in variable motivation to seek treatment (Schoen et al., 2012).

Barriers to Accessing Care

In the most recent international comparison of service users' views of ED services, Escobar-Koch et al. (2010) found strong evidence to support the assumption that barriers to care differ internationally and across diverse models of health care. In particular, this study highlighted the poor availability of, and accessibility to care - which accounted for almost one third of US and nearly one half of UK service user concerns. Whereas financial constraints (e.g. financial accessibility to services, inadequate insurance coverage) comprised the majority of US service user concerns, the lack of availability of specialist services emerged as the most commonly cited concern (10.9%) among UK respondents. Extensive waiting lists and problems within primary care also emerged as significant problems, as reported by 7.7% and 6.1% of UK respondents respectively. Since help-seeking commonly occurs during stages of desperation (Schoen et al., 2012), long referral times have also been identified as a source of patient concern (Reid et al., 2008).

Valued Components of Care: Psychological Interventions

Investigations which have employed both current and former patients suggest that patients attribute significant importance to specific treatment interventions in the recovery process (Reid et al. 2008; Federici and Kaplan, 2008). Pettersen & Rosenvinge (2002) found that factors related to professional treatment were the most frequently cited motivating factors in the recovery process, as reported by 58% of ED patients in their qualitative investigation. Psychological treatments represent an

essential component of treatment for ED patients internationally (Escobar-Koch et al. 2010) and are consistently favoured over pharmacological and medical interventions (Escobar-Koch, Mandich & Urzúa, 2012). In particular, psychotherapy is important to patients for enhancing their motivation for recovery (Espindola & Blay, 2009) and in developing an internal understanding and insight into their ED (Escobar-Koch et al. 2012). Specifically, patients identify several cognitive-behavioural techniques as helpful factors in the recovery process (Escobar-Koch et al., 2012; le Grange & Gelman, 1998; Reid et al., 2008). Although effective in treating adolescent AN, patients tend to evaluate family-based interventions negatively (Bell, 2003; Offord et al., 2006).

Characteristics of Care Providers: Professional Versus Humanistic

Qualitative investigations of the therapeutic alliance have revealed that ED patients value both personal and professional characteristics of care providers (Escobar-Koch et al. 2012), although some studies report that patients place the greatest value on personal characteristics of professionals, such as empathy and understanding (Escobar-Koch et al. 2010). In a UK sample of ED patients, Escobar-Koch and colleagues (2010) found that personal qualities of staff were valued almost twice as much as professional characteristics. Not surprisingly, the therapeutic relationship is widely acknowledged as an essential feature of ED treatment (de la Rie et al., 2008; Federici & Kaplan, 2008; Colton & Pistrang, 2004; Escobar-Koch et al. 2010; Escobar-Koch et al. 2012), with its value consistently noted by both eating disorder therapists (de la Rie et al. 2008) and current and former ED patients (Federici & Kaplan, 2008). Specifically, its importance has been implicated in patient engagement and treatment completion (de la Rie et al. 2008; Pettersen &

Rosenvinge, 2002) and a poorly developed therapeutic alliance is commonly associated with dropout from treatment (Federici & Kaplan, 2008). With regards professional characteristics, patients voice concerns over a lack of coordination and communication amongst the various health care professionals involved in their treatment, which often entails serious implications for the therapeutic alliance (Escobar-Koch et al. 2012). Moreover, the dearth of available professionals with appropriate experience and expertise in treating ED is a further patient concern (Escobar-Koch et al. 2010).

Focus of Treatment Interventions

The perceived focus and aim of treatment interventions are central to patients' experiences of treatment (Linville et al., 2011). Particularly important is a treatment which focuses on problems underlying the eating disorder as well as the behaviours and symptoms of the disorder (de la Rie et al., 2006). Interventions focused on emotion regulation are favoured highly by patients and prove instrumental in maintaining recovery (Federici & Kaplan, 2008). Not surprisingly, research persistently documents that the largest sources of ED patients' discontent concern a primary focus on weight gain in treatment (Bell, 2003; Linville et al., 2011). Patients negatively evaluate interventions primarily focused on behavioural goals since they often fail to address the psychological or emotional aspects of their ED (Federici & Kaplan, 2008; Colton & Pistrang, 2004; Eivors, Button, Warner and Turner, 2003; Reid et al., 2008) and view psychological aspects of the ED as secondary to eating behaviours (le Grange & Gelman, 1998). Moreover, a narrow focus on weight gain and symptom reduction often induces a sense of lost control (Bell, 2003).

Experiences of Collaboration and Coercion

There is growing evidence to support the assertion that the manner in which treatment is delivered is also of significance to ED patients (Eivors et al., 2003; Reid et al. 2008). The importance of an integrated approach to treatment from the onset is further documented (Escobar-Koch et al. 2012) and patients often express a desire to be active collaborators in their treatment decisions (Colton & Pistrang, 2004; Offord, et al., 2006). Contrastingly, treatment approaches emphasising a lack of negotiation are commonly associated with treatment resistance and drop-out (Cockell et al., 2004) and coercive measures in treatment can have serious implications for the therapeutic alliance and patients' adherence to treatment (Eivors et al. 2003). Although patients often positively evaluate structure in treatment (Eivors et al. 2003), restrictive and coercive measures are viewed negatively (Escobar-Koch et al. 2012; Colton & Pistrang, 2004; Reid et al. 2008).

Supportive Treatment Environments

Supportive treatment environments remain one of the most widely cited treatment factors conducive to recovery (Colton & Pistrang, 2004; Federici & Kaplan, 2008; Reid et al., 2008). Patients frequently assign importance to continuity of care and sustained support for maintaining recovery (de la Rie et al. 2006). Consequences of an inadequate support system include an induced sense of loneliness and isolation (Escobar-Koch et al., 2012) which commonly escalates into relapse (Federici & Kaplan, 2008). Support from other ED patients is often perceived as valuable (Pettersen & Rosenvinge, 2002), particularly in reducing the loneliness and isolation associated with eating disorders (Colton & Pistrang, 2004). However, treatment environments are not always supportive, and rivalry and competition

amongst patients is commonly documented (de la Rie et al., 2006; Offord et al., 2006; Eivors et al., 2003). Although self-help groups were once perceived as supportive and valued by service users (de la Rie et al., 2006), recent international research found that self-help groups were identified as an essential treatment component by only 2.2% and 2.8% of US and UK ED patient samples (Escobar-Koch et al. 2010).

2. 6. 3. Limitations of the Existing Literature Base

Knowledge concerning the patients' perspective of their treatment journey remains limited. Specifically, Escobar-Koch and colleagues (2012) assert that important areas of service provision, such as ED service users' experiences of accessibility to, and availability of, services have thus far been neglected in extant research. To date, research specific to eating disorders in the Irish context remains limited. Moreover, qualitative studies investigating patients' experiences of their treatment journeys in Ireland are non-existent.

The need for qualitative research to investigate service users' views of negative aspects of ED service provision also remains an area in need of further investigation. Not only is it important to ascertain what patients value in ED care, but research suggests that it may be of equal importance to explore and analyse service user concerns (Escobar-Koch et al. 2010). Greenwood, Key, Burns, Bristow & Sedgwick (1999, p.162) surmise that "by listening to those who are able to voice discontent, we can deepen the dialogue with patients and develop services to reflect their experiences".

A further limitation of previous investigations is the tendency to investigate the treatment experiences of a single diagnostic category. In particular, the experience of anorexia nervosa has received considerable attention in the literature on ED treatment experiences (Bell, 2003; Vanderlinden et al., 2007). This has resulted in a further dearth of research concerning the treatment experience of BN and EDNOS patients. Therefore an additional aim of this research was to explore the treatment experiences of a sample of patients receiving, or having received treatment for AN, BN and EDNOS.

Studies explicitly concerned with the treatment experiences of ED patients commonly investigate single treatment trajectories and have focused for the most part on general psychiatric inpatient services (Offord, et al. 2006) and specialist inpatient services (Colton & Pistrang, 2004). Few studies have taken the entire patient journey into account. Consequently, there exists considerable knowledge of treatment outcomes but a limited knowledge base on the earlier stages in the treatment journey (Waller et al. 2009). Recent research suggests significant problems in the current ED treatment pathway and highlights substantial attrition throughout stages of referral, assessment, treatment and discharge (Waller et al. 2009). Taking into account the high attrition and poor recovery rates associated with eating disorders, it is imperative to study perceived barriers to recovery (Escobar-Koch et al., 2012) and elements in the treatment process which may help patients to recover (Vanderlinden et al. 2007). As such, ascertaining the views of both current and former service users can generate valuable information concerning problem areas of patients' treatment trajectories where ED individuals are frequently lost to services. This body of work employed a sample of current and discharged ED patients to

obtain data on the treatment experiences of patients from initial help-seeking phases to stages of treatment completion.

A final aim of the current investigation was to interpret the thematic findings in light of self-determination theory (Deci & Ryan, 1985; Ryan & Deci, 2000). Alternative theories were initially considered as viable interpretive frameworks, including; *Contingencies of Self-Worth* (Crocker & Knight, 2005) and *Social Cognitive Theory* (Bandura, 1977; 1986). However, SDT was the chosen interpretive framework in the current investigation due its focus on humanistically informed motivational recommendations. Given that motivational factors are attributed a prominent role in the efficacy of treatment interventions for ED (Dray & Wade, 2012; Knowles et al., 2012), it is commonly surmised that SDT may be particularly theoretically compatible with investigations concerned with investigations in this research domain (Vansteenkiste et al., 2005).

Moreover, SDT has been subjected to rigorous scientific investigation (Sheldon, Joiner & Williams, 2003) and has been successfully employed in previous motivation-focused research as a guiding framework to interpret inductive thematic findings (e.g. Tassell & Flett, 2011). In the domain of mental health research, SDT has been utilised as a framework to understand processes of engagement and treatment completion within psychiatric populations (Ryan & Deci, 2008). SDT provides a framework for understanding *how* motivation-focused interventions may increase treatment engagement and effectiveness (Markland et al., 2005). In doing so, SDT takes into account individual and socio-environmental influences on patient behaviour and acknowledges the central role that clinicians play in creating a

supportive therapeutic environment for clients (Britton, Patrick, Wenzel & Williams, 2011).

2. 7. Overall Conclusion

The current nosological system for eating disorders, (4th ed., text revision [*DSM-IV-TR*], American Psychiatric Association, 2000) comprises three distinct eating disorder categories; anorexia nervosa, bulimia nervosa and eating disorder not otherwise specified. Etiologic research posits that eating disorders are multidimensional in nature (Stice et al., 2012) and are closely linked to vulnerability and risk factors (Striegel-Moore & Bulik, 2007). It is commonly accepted that the profusion of genetic, biological and temperamental vulnerabilities in conjunction with sociocultural factors increases the risk of ED development (Stice et al., 2012).

AN typically manifests in early adolescence and is largely associated with extreme and rigid dietary restriction (Dalle Grave, 2011). In comparison to BN and the atypical eating disorders, AN is associated with a worse long-term prognosis and a high mortality rate (Keel et al., 2012). BN has a slightly later age of onset than AN and a significant proportion of patients with BN have a history of AN (Keel et al., 2012). BN is associated with a range of compensatory behaviours including; self-induced vomiting, laxative abuse, diuretics, fasting and excessive exercise, which frequently manifest in severe physical complications (Shapiro et al. 2007). The diagnostic cohort of EDNOS is the most commonly observed ED in both clinical practice and community samples (Smink et al., 2012), yet there remains a paucity of information on the long-term course and outcome of this diagnostic category (Keel et al., 2012).

Whilst knowledge of empirically supported treatments for ED has been advanced in recent years (Stice et al., 2012), information on how to appropriately and effectively treat the eating disorders remains limited (Keel et al., 2012). In particular, the evidence base for EDNOS and AN is particularly weak across the age ranges (Dalle Grave 2011; Keel et al., 2012). In the case of adolescent AN, the evidence base is most robust for the Maudsley model of family therapy (Keel & Haedt, 2008). Manual-based CBT is acknowledged as the most effective treatment for BN in older adolescents and young adults (Wilson, 2005). Virtually nothing is known about how to appropriately treat EDNOS individuals (Dalle Grave, 2011).

Although limited, treatment for eating disorders in the Republic of Ireland can be accessed through both public and private channels. Presently, there are four specialist eating disorder services in the Republic of Ireland which have received accreditation by the Mental Health Act commission. ED services and treatment interventions are delivered at four levels; primary care, secondary care, intensive community care and tertiary care. For the vast majority of eating-disordered individuals, primary care is the first point of contact for professional help. Although primary care services are well placed to provide initial assessment and management of eating disorders during preliminary stages of care (Linville et al 2010), there remains a significant under-detection of eating disorders at the primary care level (Flahavan, 2006).

Furthermore, appropriate referral to services and management of care for ED individuals is significantly hampered by practitioners' poor awareness of, and adherence to, best-practice guidance (Currin, Waller et al., 2009). The sub-standard quality of care for ED evidenced in the Republic of Ireland is further aggravated by

poor access to specialist services (Maher & Nwachkwu; 2012; O’Keane et al., 2004), particularly with respect to services in the public sector (DOHC, 2006). Moreover, problematic transitions between tiers of services augment issues concerning continuity of care. The recently proposed *National Mental Health Programme Plan* (HSE, 2011) outlines a succession of recommendations focused on processes of early intervention in the treatment of ED, the enhancement of extant services, and the implementation of several new programme interventions.

Recovery from eating disorders involves indices of physical rehabilitation, psychological restoration and psychosocial adjustment (Couturier & Lock, 2006; Noordenbos & Seubring, 2006). Extant research findings evidence the remission of physical symptoms prior to psychological symptoms in AN & BN individuals (Clausen, 2004). Furthermore, weight restoration is a weak indication of psychological and psychosocial recovery (Couturier & Lock, 2006; Danner et al., 2012).

High rates of disengagement and premature dropout from treatment pervade clinical and research accounts of ED (Campbell, 2009; Knowles et al., 2012; Waller et al., 2009). The reasons behind ED patients’ failure to engage with services remain poorly understood (Leavey et al., 2011). Patient factors, treatment factors and the therapeutic alliance have all been implicated as powerful factors contributing to ED patients’ poor response to treatment interventions. Recently, motivational issues are also consistently identified as barriers to effectively engaging ED patients in the therapeutic process (Allen et al., 2012) and the need to study motivational dynamics in the treatment of ED is commonly highlighted (Vansteenkiste et al., 2005). Furthermore, recent motivation-focused research posits that self-determination theory (Deci & Ryan, 1985; Ryan & Deci, 2000) may be particularly applicable to

the study of motivational processes in ED (Vansteenkiste et al., 2005), as it is fundamentally concerned with the socio-contextual conditions which foster the growth of patients' psychological needs for autonomy, competence and relatedness (Ryan & Deci, 2008).

Qualitative investigations are posited an important role in accessing the 'patient perspective'. Extant qualitative research in the domain of ED offer valuable information on several dimensions of ED care, including; perceived barriers to seeking treatment (Schoen et al., 2012), perceived barriers to accessing care, and helpful and unhelpful components of care (de la Rie et al., 2008). To date, research specific to eating disorders in the Irish context remains limited. Moreover, qualitative studies examining patients' experiences of their treatment journeys in Ireland are non-existent. The current study represents an important first step in addressing several shortcomings of the qualitative literature base on eating disorders, including; limited information on patients' entire treatment trajectories, insufficient knowledge of the treatment experiences of BN and EDNOS individuals and, poor qualitative knowledge of ED service user concerns. In response to the aforementioned gaps in the current literature base on eating disorders, the primary aim of the current study was to explore the treatment experiences of a sample of current and discharged ED patients. A further aim of this investigation was to interpret the initial thematic findings in light of self-determination theory (Deci & Ryan, 1985; Ryan & Deci, 2000).

Chapter Three

RESEARCH METHODOLOGY AND DESIGN

RESEARCH METHODOLOGY AND DESIGN

This chapter discusses the methodology employed in the current study. Introductory sections of this chapter describe the participant sample and delineate stages of the recruitment process. Ethical issues are also outlined, with a particular focus on issues associated with the conduct of sensitive research on vulnerable populations. Subsequent sections explicate the process of data collection. Justification for the methodological framework employed is provided along with an exploration of the suitability of alternative frameworks to the objectives of the current investigation. The integrated approach to data analysis is also discussed and a rationale for the utilization of SDT as the interpretive lens is provided. Concluding sections of this chapter outline issues concerning the trustworthiness of findings in qualitative research investigations, in conjunction with the steps taken in the current study to minimise researcher bias and bolster the robustness of findings.

3.1 Study Design

The current investigation examines the views, experiences and suggestions for change of adult females who are either currently availing of, or have previously availed of, professional treatment for eating disorders in the Republic of Ireland. In addition, the initial thematic findings were interpreted in light of self-determination theory (SDT; Deci & Ryan, 1985; Ryan & Deci, 2000). The choice of research design was primarily guided by the aims and objectives of the study. As such, it was deemed appropriate to employ a qualitative approach, which seeks to elicit the perceptions, feelings, attitudes and experiences of participants. Qualitative research

designs are particularly suited to mental health research investigations (Davidson et al., 2008; Peters, 2010). Since the majority of mental health research investigates sensitive and private issues, qualitative methodologies often encourage patient engagement with mental health research (Peters, 2010). Moreover, qualitative designs facilitate an understanding of both valued aspects of services and barriers to engagement with treatment interventions, which can in turn inform clinical practice (Peters, 2010).

3. 2. Participants

With institutional ethical approval, 14 females aged 18 to 31 years ($M=23.21$; $SD=4.19$) were recruited to participate in the current study. The final participant sample included 14 adult participants who were either currently enrolled in ($n=11$), or discharged from ($n=3$), one of two professional ED services in the Republic of Ireland. Purposive sampling was used to ensure that participants reflected a variety of ED diagnoses and treatment status. Permission to access participants was also sought and granted by the clinical directors of both recruitment sites. Seventeen participants were originally recruited and interviewed. However, three interviews were subsequently removed from the analysis. It was originally intended that an equal representation of adults and adolescents would be recruited for this study. However recruitment of adolescent participants proved more difficult than anticipated and only two adolescents patients were recruited in total. Considering the inadequate representation of adolescent accounts in the participant sample, the two adolescent interviews were omitted from the final analysis. A further adult interview was also extracted from the analysis, as it later emerged that the ED was not a primary diagnosis for this participant. As such, it was felt that the

interview data obtained was incongruous to the aims and objectives of the current investigation.

To be eligible for participant inclusion in the current service user sample, the patient had to be 18 years of age or older and currently involved in a professional in-patient or out-patient treatment programme for their eating disorder. In total, 14 adult patients currently enrolled in services were recruited. All current service user participants were receiving out-patient treatment at the time of the study. Each participant met clinical criteria for anorexia nervosa (n=6), bulimia nervosa (n=2) or EDNOS (n=3). Three participants reported currently receiving treatment for diagnostic criteria of both AN and BN (see Table 3.1).

Table 3.1. Participant information: Demographic data

Participant number	Age at research	Age of ED awareness	Diagnosis	Treatment Received	Treatment Status
1	20	14	AN	Inpatient & Outpatient	Discharged
2	18	14	AN	Inpatient & Outpatient	Discharged
3	25	18	AN	Inpatient & Outpatient	Current
4	24	16	AN	Inpatient & Outpatient	Current
5	31	17	AN/BN	Inpatient & Outpatient	Current
6	19	18	AN	Outpatient	Current
7	27	16	AN	Inpatient & Outpatient	Current
8	23	16	AN/BN	Inpatient & Outpatient	Current
9	27	21	BN	Inpatient & Outpatient	Current
10	23	14	EDNOS	Outpatient	Current
11	22	18	AN/BN	Inpatient & Outpatient	Discharged
12	29	19	BN	Outpatient	Current
13	19	19	EDNOS	Outpatient	Current
14	18	18	EDNOS	Outpatient	Current

Abbreviations: AN, anorexia nervosa; BN, bulimia nervosa; BED, binge eating disorder; EDNOS, eating disorder not otherwise specified

3. 3. Recruitment Process

To recruit current service users, the on-site collaborating clinician at each recruitment site initially selected individuals from patients whom they felt were physically and cognitively capable to participate and provide informed consent. These participants were then informed of the study during scheduled treatment sessions and given an information sheet (see Appendix C) detailing the study requirements. Interested individuals were subsequently given a consent form (see Appendix E) to complete. Once the on-site clinician had received participants' consent forms, the researcher (GS) contacted patients to schedule a suitable time and date for the interviews.

For inclusion in the discharged service user sample, participants had to be 18 years of age and older and to have completed a course of professional treatment in one of the two recruitment sites. In total, three adults who had been discharged from professional ED services were recruited. Discharged patients had received treatment for AN (n=3) on both an in-patient and out-patient basis (see Table 3.1). Once potential participants had been identified by the collaborating clinicians, a letter of invitation, information sheet and consent form (See Appendices B, D and F) were sent to them from the study team. Those individuals who expressed an interest in participating in the study were asked to return a signed consent form in a pre-stamped envelope to the relevant on-site clinician. Once the collaborating on-site clinician received the participants' consent forms, the researcher contacted patients to schedule a suitable time and date for interviews.

This study sought to recruit a sample of adolescent and adult, male and female, ED patients. However, at the time of the study, no male patients were participating in a treatment programme at either recruitment site. In addition, the majority of patients at both recruitment sites were adults. Twenty-three females were initially invited to participate in the current study. Of this, six individuals failed to return consent forms and a final number of 17 individuals consented to, and took part in the study. Fourteen participant accounts were included in the final analysis. There were no dropouts from the study. The majority of reasons for non-participation are unknown. One individual was residing outside of Ireland at the time of the study and was thus unable to participate. Another individual who had originally consented to participation but later declined involvement in the study, contacted the collaborating clinician post data collection and expressed a further desire to participate. Clinical differences between individuals who consented to participation and those who declined participation are also unknown, as this information was unavailable to the research team. Figure 3. 2. below outlines the recruitment process of the participant sample.

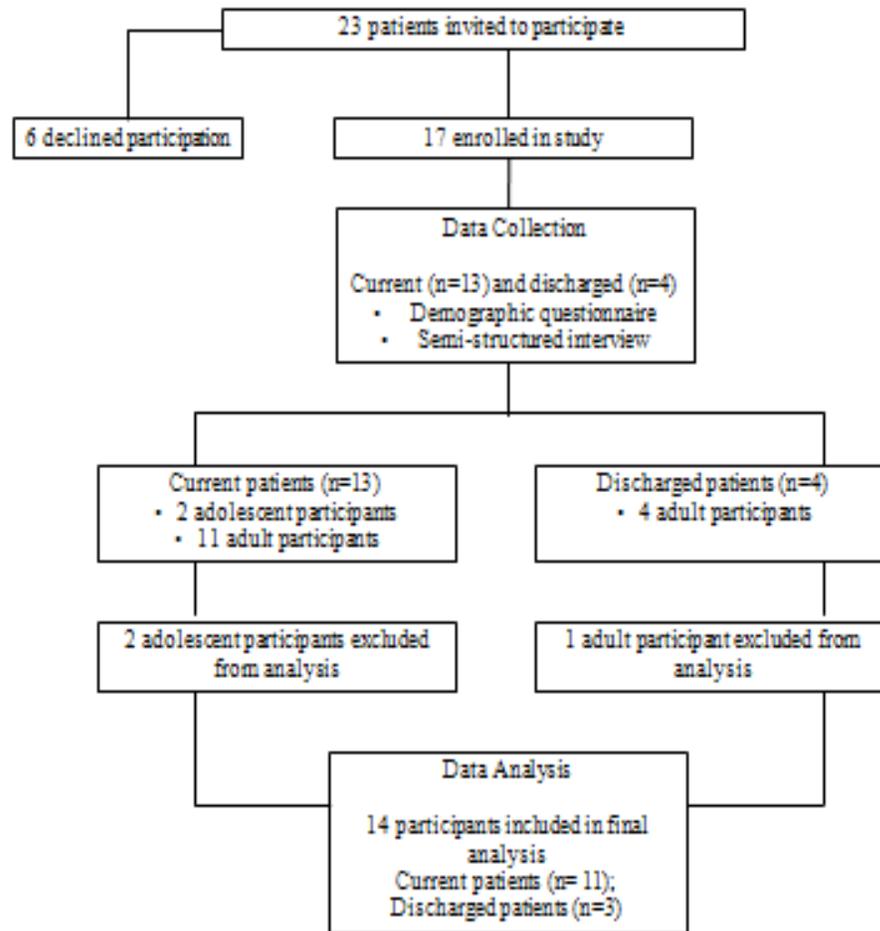


Figure 3. 2. The recruitment process of the participant sample

3. 4. Ethical Issues

In addition to standard issues of confidentiality and risk management, ethical issues specific to in-depth interviewing have also been noted (Allmark et al., 2009). In particular, the conduct of sensitive research is surmised to have greater implications for participants (Jorm, Kelly & Morgan, 2007) which can include; issues of privacy, participant distress and, power and exploitation (Allmark et al., 2009; Ensign, 2003; Jorm et al., 2007; Richards & Schwartz, 2002).

Confidentiality and Privacy

To protect participants' identity, specific locations of the recruitment sites are not presented here. Participants were informed that codes would be used to protect their identity in any published data. Participants were also given assurance that there would be privacy in the handling and storage of data collected. Digital recordings of the interviews were stored on the researcher's computer and were password protected to ensure confidentiality of all electronic records. Interview transcripts, hard-copies of the demographic questionnaires and signed consent forms were stored in a locked filing cabinet, to which only the primary and secondary investigator had access to. Issues of privacy also pervade semi-structured interview research since the largely unstructured nature of interviews can take the topic of inquiry into unanticipated areas (Allmark et al., 2009). Participants were reminded at the onset and throughout various stages of their interview that they should only discuss issues which they felt comfortable disclosing. It should be noted that the vast majority of participants reported a desire and willingness to share both helpful and difficult parts of their treatment trajectories with the researcher.

Issues of Power

Issues of power are also associated with interview research, particularly for individuals with mental health difficulties (Allmark et al., 2009). Specifically, it is postulated that patients may feel obliged to partake in the research (Richards & Schwartz, 2002) or feel pressured to discuss private or sensitive topics (Allmark et al., 2009). However, in the current study, the researcher was not known to participants prior to commencement of interviews. Participants were informed that refusal to participate in the research study would not affect their treatment. Furthermore, participants were also informed that they should only discuss aspects of their experiences with which they felt comfortable disclosing.

Participant Distress

Health services research commonly investigate sensitive topics of enquiry (Richards & Schwartz, 2002). Consequently, interviews can often become emotionally intense (Allmark et al., 2009; Jorm et al., 2007). As such, some participants may experience distress (anxiety, embarrassment, discomfort) during data collection practices (Jorm et al., 2007). In particular, individuals with mental health difficulties may be particularly susceptible to experiencing distress during research endeavours (Allmark et al., 2009; Jorm et al., 2007). However, there is no robust evidence to indicate long-term harm to distressed participants (Jorm et al., 2007) and participants who may experience distress often positively evaluate the research (Jorm et al., 2007). Congruent with previous findings (e.g. Allmark et al., 2009), participants in the current

investigation were not averse to discussing painful issues and experiences since they felt the research was purposeful.

In line with current recommendations (e.g. Allmark et al., 2009; Jorm et al., 2007; Richards & Schwartz, 2002), several strategies were undertaken in the current investigation to minimize the risk of harm to participants. Allmark and colleagues (2009) highlight the importance of available formal and informal networks of support for the researcher and, on-going education and training for novice researchers. In the current study, frequent supervision and debriefing took place between the researcher and primary supervisor. Moreover, the researcher embraced considerable knowledge and practical experience as a result of working with eating-disordered individuals in a voluntary capacity – a further recommendation of extant research (Ensign, 2003).

The availability of appropriate information and support for all participants has also been identified as an important component of ethically sound research (Richards & Schwartz, 2002). In the current study, participants were informed of the purpose of the research and the types of questions they were likely to be asked prior to the commencement of interviews. All participants were provided with information detailing the name and contact details of both the researcher and primary supervisor should they have any concerns or require additional information about the study. Moreover, every participant was informed that one follow-up session with the on-site clinician was available to them after their interview, in the event that the interview would raise any issues for them. All interviews took place either at the site where participants were either currently availing of treatment or where they had previously availed of treatment. For each individual interview, the relevant collaborating clinician was present on-site.

Moreover, a research assistant was present alongside the researcher throughout the majority of interviews.

3. 5. Data Collection

Qualitative methodology employing semi-structured, individual interviews were used in the current study. Interviews were audio recorded and lasted from approximately 41 minutes to 107 minutes with the average interview lasting 70.34 minutes in length. A semi-structured interview topic guide was collaboratively developed by the research team. The interview guide was then reviewed by an expert team of clinicians in the area of eating disorders and by a current adult service user for feedback and approval. The topic guide was piloted through a preliminary one-on-one interview with a discharged adolescent service user. Minor amendments, namely question phrasings, were made to ensure clarity of questions. (See appendices I-J for the final interview topic guide).

At the beginning of each interview, participants were asked to fill out a short demographic information sheet (see Appendices G-H). Participants were reassured of confidentiality and their right to terminate participation at any stage during the interview or research process. All participants were reminded that support would be made available to them in the event that the interview would raise any issues for them. Participants were encouraged to speak openly about their perceptions and beliefs and were probed occasionally by the interviewer to develop and expand on their disclosures. At the end of each interview, the research assistant provided a verbal summary of the main topics of discussion for the participant's approval. Upon completion of each interview, the researcher made a journal entry commenting on the interview process and

initial thoughts about what the participant had discussed. By the concluding stages of the data collection process, it was felt that no new concepts were emerging and thus, that data saturation had been sufficiently achieved. All interviews (including the pilot) were conducted by the researcher (GS) under the supervision of Dr. Siobhain McArdle (primary supervisor) and Dr. Paul Gaffney (co-supervisor). Dr. McArdle and Dr. Gaffney were not present in any of the interviews but supervised the interview process.

Prior to stages of data collection, the primary researcher embraced previous experience as an ED support group facilitator. Thus, she had being sufficiently exposed to the difficulties that ED patients often experience and was competent in managing patients' vulnerabilities or emotional moments. For the most part, it was felt that the researcher had developed sufficient rapport with participants which, in turn, facilitated their candid exposure of experiences. However, within a minority of interviews, it was difficult to establish a personal rapport with participants. For example, one current patient had recently been coerced into treatment by her family and as such, a sense of hostility was evident throughout various parts of the interview. Nonetheless, a friendly and non-judgemental stance was maintained throughout all interviews. In some interviews, a detached and objective position was difficult to maintain, particularly when patients recounted distressing experiences with health care services. Numerous debriefing sessions were conducted between the researcher and primary supervisor throughout the data collection process which helped to bolster the neutral position of the researcher throughout the remaining interviews.

3. 6. *Methodological Framework*

This study takes the theoretical position of the constructivist paradigm as it sought to obtain interpretive, open-ended and contextualized perspectives. Within a constructivist philosophical stance, knowledge is constructed through an individual's subjective engagement with objects in their world (Caelli, Ray & Mill, 2003). With respect to methodological frameworks, the methodologically similar analytic frameworks of thematic analysis, IPA and grounded theory were considered during processes of data collection and again during stages of analysis. Thematic analysis and IPA are epistemologically similar, since both analytical approaches seek to provide rich descriptions and interpretations of individual subjective experiences.

Although initially posited as a viable and interesting methodological framework, IPA was not selected for several important reasons. Firstly, the content area of the corpus of IPA studies suggests that IPA is particularly suited to analysing a particular *aspect* of the individual experience. Indeed, one of the defining features of this methodological approach is that it provides a detailed and nuanced examination of lived experience (Smith, Flowers & Larkin, 2009). As such, this can pose a problem for broad research questions (Smith et al., 2009). Investigating instances of both strong and weak IPA research, Smith 2011 (p.24) infers that, "papers providing detail of a particular aspect rather than a broad reconnaissance are more likely to be of high quality".

Secondly, IPA investigations typically involve small sample sizes. The authors of IPA themselves advocate a maximum sample size of three participants for a Masters-level IPA study (Smith et al., 2009). Smith (2011) highlights the danger of producing a

large number of descriptive or superficial themes from a large number of participants. Previous IPA research in the domain of ED have typically involved small sample sizes (e.g. Fox, Larkin & Leung, 20011; Offord et al., 2006). Finally, within IPA research, generalisations are not feasible (Pringle, Drummond, McLafferty & Hendry, 2011). Although it is acknowledged that qualitative research is not primarily concerned with making generalisations, the current investigation did seek to provide some recommendations for clinical practice to health care professionals working with eating disordered patients.

A grounded theory framework was also not employed since it is primarily concerned with developing theory exclusively through the inductive analysis of data. A directed content analytic approach, as outlined by Hsieh & Shannon (2005), was further proposed as a potential analytic framework. However, this approach is concerned with the application of deductive categories, where raw data is coded using predetermined codes. Instead, the current research investigation sought to embrace both inductive and deductive analytic processes. Thematic analysis was the chosen methodological approach in the current investigation, as it can be a constructionist method (Braun & Clarke, 2006) and encompasses a choice of methods and analytical techniques appropriate to the aims and objectives of the current exploratory research.

3. 7. Data Analysis

The interviews were transcribed verbatim by the research assistant (see Appendices M-N). Transcripts were closely reviewed and checked against original audio recordings by the primary researcher to ensure translation accuracy. The methodological

approach integrated both inductive and deductive methods of data analysis. Specifically, the developing analysis was influenced by both primary material (i.e. interview transcripts) and secondary sources (i.e. a review of the literature) (see Appendix K). Transcripts were firstly analysed using a descriptive thematic analytic approach, as outlined by Braun and Clarke (2006). As such, they were analysed thematically with initial codes and themes identified inductively from the raw data. Once the initial descriptive thematic analysis was complete, it was evident that there was a strong resonance between the categories derived from the raw data and the constructs of self-determination theory (Deci & Ryan, 1985; Ryan & Deci, 2000). Subsequently, the analytical process was extended and evolving themes were interpreted within the theoretical framework of self-determination theory (Deci & Ryan, 1985; 2000). By employing an integrated approach to analysis – particularly the use of an initial inductive thematic analysis – it was ensured that the raw data were not forced into predetermined categories.

A particularly recurrent challenge encountered during stages of analysis concerned the definition of boundaries between themes, due to the significant interconnection between them. During such points in the analysis, illustrations and diagrams provided clarity and fresh ideas. Undoubtedly, progressing the data from a descriptive to an interpretive level often characterised an insurmountable challenge but through the interpretation of initial thematic findings within a theoretical perspective, elucidation of detail, complexity, and meaning beyond the initial thematic analysis was permissible. This approach also facilitated the establishment of conceptually driven,

authoritative conclusions about the data that were deemed relevant to policy and practice.

Several authors attest to the value of employing an integrated approach to qualitative data analysis, particularly within health services research (Bradley, Curry & Devers, 2007; Brouwer, Drummond & Willis; 2012; MacFarlane & O'Reilly-de Brún, 2012). Previous investigations attest to the utility of employing pre-existing theories in effectively shaping qualitative analyses (Reeves, Albert, Kuper & Hodges, 2008). Specifically, it is argued that, orienting concepts can sensitize researchers to relevant issues, processes and interpretations which may be overlooked using a predominantly inductive approach (MacFarlane & O'Reilly-de Brún, 2012). Within the context of health policy and patient care, Reeves and colleagues (2008) argue that using theories as a lense to analyse research problems is crucial as they facilitate insights which provide health care practitioners with a comprehensive understanding of the situations they encounter in clinical practice.

3. 8. Trustworthiness of findings

The current investigation employed a range of verification strategies for establishing reliability and validity of the research findings in conjunction with the framework of rigour as outlined by Morse, Barrett, Mayan, Olson & Spiers (2002). Morse and colleagues (2002) negate the utility of post-hoc evaluation procedures (e.g. member-checking) as advocated by previous quality frameworks (e.g. Guba & Lincoln, 1981) and instead focus on processes of verification throughout the research process. Congruent with this framework, specific verification strategies employed in the current

investigation included; methodological coherence, appropriate sampling and negative case analysis. Given that the researcher was a novice qualitative researcher, additional verification strategies were deemed appropriate to ensure attainment of the highest standards of rigour within the study. These included the use of a reflexive journal and frequent debriefing sessions with the research team.

Methodological coherence is widely held as an important aspect of rigour in qualitative inquiry (Caelli, et al., 2003; Morse et al., 2002). In the preliminary stages of the current investigation, consideration was given to various methodological approaches and consensus was reached between the primary researcher and primary supervisor concerning the methodological and analytical framework employed. As advocated by Morse and colleagues (2002), this decision was based on the congruence between the methodological framework and the research question. The recruitment of participants who best characterise the topic under investigation is a further indication of reliability and validity of findings. In the current study, the recruitment of both current and discharged service users who had experienced various forms of treatment, ensured that a holistic perspective of the entire treatment trajectory across the spectrum of eating disorders was obtained.

Negative case analysis refers to the process of exploring instances and cases that do not fit with the common pattern of results (Shenton, 2004). As such, it is a useful means of confirming that the analysis addresses all cases within the data (Mays & Pope, 2000). In the current investigation, one such instance of conflicting perspectives within participant accounts was evident within the lower-order theme of *Therapeutic*

Relationship. Specifically, disparity in participant accounts with respect to the perceived importance of humanistic and professional qualities of therapists become evident in the early stages of data analysis. Through an iterative process of moving back and forth between participant accounts, it was construed that interpersonal features of the therapeutic relationship (e.g. sense of friendship) were of greater significance during adolescent ED stages whereas professional qualities (e.g. providing appropriate challenges and structure) were valued more during adult stages of illness. The examination of multiple perspectives on this theme facilitated a holistic and conceptual understanding of this particular aspect of the treatment experience.

Clarification of researcher bias and the use of reflexive writing is one of the most widely cited verification strategies in qualitative research (Shenton, 2004). This process involves researcher self-disclosure of personal beliefs, values, biases and assumptions that may shape their inquiry. Since the imposition of researcher bias is unavoidable (Shenton, 2004), it is important that researchers acknowledge and make transparent the social, cultural and historical influences that shape their interpretation, to enable readers to understand their positions (Creswell & Miller, 2000). Throughout stages of participant recruitment, data collection and analysis of findings in the current study, the researcher consistently engaged in reflexive writing as a method of documenting and identifying any subjectivities, biases or previous experiences which may have imposed on the analysis. Frequent debriefing sessions between the researcher and members of the research team were also scheduled. Specifically, such collaborative sessions were used to discuss data collection procedures, approaches to data analysis and to develop emergent ideas and interpretations.

3. 9. Conclusion

A qualitative methodology employing semi-structured individual interviews was used in the current investigation to elicit the views, experiences and suggestions for change of adult female ED service users. Ethical issues specific to the conduct of sensitive research and to the process of in-depth interviewing were attended to. Specifically, issues of privacy and instances of participant distress were minimised through on-going support, supervision and training for the researcher, and through the provision of appropriate information, reassurance throughout the interview process, and follow-up support for participants.

An interpretive thematic analytic framework which integrated both inductive and deductive processes of analysis was employed to interpret participants' subjective experiences of treatment. As such, initial descriptive thematic findings were interpreted within the theoretical framework of self-determination theory (Deci & Ryan, 1985; 2000). An integrated approach to the analysis of qualitative data within health services research has been employed successfully in previous investigations (e.g. Bradley et al., 2007; Brouwer et al., 2012; McFarlane & O'Reilly-deBrún, 2012), and the significance of using theoretical frameworks as a lens to analyse research findings has also been formerly documented (Reeves et al., 2008).

Several verification strategies were applied throughout the research process to bolster the reliability and validity of evolving results. In line with the framework of rigour outlined by Morse and colleagues (2012), specific verification strategies employed in the current study included; methodological coherence, appropriate

sampling and negative case analysis. Frequent debriefing sessions between the research team and the use of reflexive writing were also employed to ensure verification of findings. The final analysis, as presented in the proceeding chapter, is based on the qualitative accounts of 14 adult female, eating disorder patients.

Chapter Four:

RESULTS

RESULTS

One comprehensive, overarching theme of *The Therapeutic Milieu* evolved from analysis of participants' accounts. The therapeutic milieu was composed of both structured (e.g. organisation of care delivery) and unstructured (e.g. interpersonal relationships) aspects of the treatment environment and contained four interrelated, sub-ordinate themes: *treatment setting and programme structure*, *being in control versus being controlled*, *understanding and support* and *exploring and maintaining positive change*. Each of these sub-ordinate themes were further sub-divided into a number of lower-order themes (see Appendix L). Each sub-ordinate theme, along with their lower-order themes will be discussed in turn below, and the main findings pertinent to each sub-ordinate theme will then be discussed in relation to their applicability to the theoretical concepts of SDT.

4. 1. Treatment Setting and Programme Structure

The sub-ordinate theme of *treatment setting and programme structure* was further sub-divided into the lower order themes of *pathogenic versus salutogenic models of health care* and *structural aspects of care*. Analysis of the transcripts revealed that the structure of the physical environment significantly impacted on patients' experiences of treatment, specifically in terms of patients' willingness to engage with services. Particularly important in fostering participants' initial therapeutic engagement was a treatment programme accentuating salutogenesis (i.e. promoting factors that support

health development, holistic treatment of ED) and de-emphasising pathogenesis (i.e. focusing on disease development, medically-oriented treatment). When reflecting on treatment programmes in which they had participated, structural aspects of care deemed important for engagement included group size and the programme design.

4. 1. 1. Pathogenic versus Salutogenic Models of Health Care

In many instances, participants had previous experiences of treatment in several diverse settings. Those who had experienced both residential and hospital-based services favoured treatment in a residential setting because the context was more realistic and home-like. As such, residential treatment settings were associated with perceptions of normality. For participants in the current study, perceptions of normality were fostered when treatment settings created a relaxed environment which encouraged the continuation of everyday life activities. Conversely, perceptions of normality were weakened when the treatment environment exaggerated perceptions of illness.

“They [staff] have the right attitude and they come in here not thinking that, you know, there are very sick people. They come in here and they, like they really, really, try and they get you back to a regular lifestyle” (Susie, discharged patient, adult).

“...make it as normal as you can, that’s what I loved about [named treatment centre] is that you had school, you had a garden, you had, like, your own room, your own bathroom, like a kitchen, whatever. It was just normal things, whereas in a hospital, the environment’s not great at all. It’s just completely wrong” (Rachel, discharged patient).

A treatment environment in which participants felt normal proved crucial for harnessing patients' initial willingness to engage with services.

“So to eventually come here and have a kind of a home environment, like it’s a house, is very important cause I know for a fact that I wouldn’t have, I wouldn’t have managed another hospital environment, I couldn’t take it anymore”
(Emma, current patient).

“And I think that helps like, whereas you don’t feel like you’re cooped up like or you don’t feel you know like you’re crazy or anything like (laughs)...you know, it’s made more normal...it’s more comfortable here” (Katie, current patient).

Conversely, participants felt uncomfortable and unable to relax in a clinical environment often perceived as bizarre and abnormal.

In XXXX [named treatment centre] you had a minder who used to come in in the night and shine a light in your face to make sure that you were still there and you weren’t allowed to get up, you know, early in the morning and have a shower because she was afraid you were going to hang yourself in the shower. And it was just, just really crazy stuff and you were told to go to bed at a certain time”
(Susie, discharged patient).

Moreover, intense emotional implications were associated with the clinical environment as it often compounded participants' sense of abnormality. Some participants described feeling a profound sense of fear during inpatient treatment experiences in a psychiatric hospital setting. Others who had received treatment in a general medical ward described

feeling lonely and isolated. Such feelings of fear, loneliness and isolation were described by participants as having negative implications for engagement in the recovery process. For example, one participant reflected that the seclusion she experienced in a general medical hospital setting reinforced her denial of her ED.

“You’re in more denial when you’re on your own. And in a hospital environment cause you think you’re on your own and no one cares and everyone else is wrong” (Rachel, discharged patient).

In addition, previous experience with in-patient psychiatric services was identified by participants as a barrier to engaging with future treatment programmes based in a psychiatric environment.

“I think I would be terrified now if somebody told me I needed to go back in for treatment but, that I had to go back into treatment in a psychiatric hospital. I would be completely deterred from going in” (Susie, discharged patient, adult).

The environmental context in which care was received (i.e., medical or holistic) also impacted on relational aspects of care, most notably the therapeutic alliance. Several participants noted that the home-like atmosphere created in residential environments was more conducive to the development of supportive relationships. Specifically, because the residential environment did not accentuate perceptions of illness, participants were more relaxed and therefore more open to developing connections with both therapists and fellow patients.

“I was kinda shocked cause I was expecting like a hospital type thing [environment] but it’s kind of open. It’s totally different than the rest of them, it’s more, it’s a relaxed atmosphere...it’s really kinda peaceful here and you can relax more. And I was more willing to, to talk to her [therapist] when I started rather than just with the other places, I didn’t want to have anything to do with them” (Laura, current patient).

“it’s a house but it kinda becomes your home after a while. You just...share a house with other people and you kinda develop relationships and make friends...it’s very much like regular life” (Emma, current patient).

4. 1. 2. Structural Characteristics of Care

Participants’ accounts revealed that two aspects of treatment programme structure were consistently referred to as being central to programme engagement, namely a multimodal treatment approach and group size. The majority of participants reported the value and benefits of a treatment programme which comprised of multiple modes of therapy and addressed the complexity of the ED. Participants’ accounts revealed a difference in dynamics and outcomes between individual, group and alternative therapies, with each different mode of therapy carrying a distinct value for patients’ recovery.

“I think they [modes of therapy] kind of, they kinda look at different, they cover different angles” (Lisa, current patient).

Group therapies represented an opportunity for shared exploration and understanding with similar others. However, most valued by participants was one-on-one therapy, where patients gained personal strength, acquired an in-depth understanding and developed the necessary skills and tools to allow them to confront enduring difficulties with their ED.

“I think the one-on-ones [therapy sessions] are a really key part of [treatment], doing group sessions are great, obviously because everyone gets to share and it’s always helpful, but I think the one-on-one is when you actually do your real work” (Susie, discharged patient).

On the other hand, participants identified a number of disadvantages in large numbers when conducting group therapy for ED. For example one participant reflected,

“a lot of work is done in groups, it’s all group therapies and that, so I didn’t find that helpful at all cause I would be a shy person and I just didn’t...didn’t interact within the groups at all...I just kinda sat there and nothing was really going in so...that wasn’t very helpful” (Hannah, current patient).

Alternative therapies provided a ‘break from the ED’ and encouraged a re-integration and interest in normal life activities. Moreover, participants’ accounts illustrated that alternative therapies were often particularly effective in cultivating patients’ interest in the treatment programme, and thus augmented their engagement in the therapeutic process.

“And then we had OT as well which I thought was actually class (i.e. brilliant) over there [named treatment centre], like art therapy as well which I thought was really good especially for people who were so creative” (Rachel, discharged patient).

Although directed at different aspects of the ED and related problems, for some patients, the different modes of therapy also worked in unison, addressing the multi-faceted nature of ED issues. As such, several participants expressed the view that a successful treatment intervention should provide a ‘happy medium’ of traditional and alternative modes of therapy in order to maximise patient engagement in the therapeutic process.

Treatment programmes which comprised multiple of modes of therapy also addressed the complexity of the ED as a transdiagnostic illness. One adult participant who had struggled with her ED for more than 15 years reflected on the importance of a multimodal approach in addressing the ED as a changing illness. In particular, a treatment approach which was individually formulated to treat the person rather than a particular ED diagnosis was positively evaluated by participants.

“And because I was suffering from a bout of anorexia then like...the bulimia is and always will be the remaining underlying factor with me and that wasn’t tackled so...you can’t take one and not take the other” (Vicky, current patient).

Some participants also positively evaluated the availability of a multi-disciplinary health-care team in their treatment interventions as it separated the treatment of physical aspects of their eating disorder from the highly valued individual and group therapies.

“...well we see a dietician then every week as well individually for around an hour as well and em, it’s kinda good that that’s kept separate from your therapy. Like she’s the one who deals with the weight and the food and the physical side of things like and it’s left there...the rest of the therapists then don’t even really talk about food and weight you know” (Katie, current patient).

Group size referred to the number of patients participating in an inpatient treatment programme or outpatient therapy group, and most participants defined an optimal group size as comprising a maximum of three to four patients. Group size was viewed by participants as having implications for the development of supportive interpersonal relationships and for engagement in group work.

“...it’s difficult to kinda...settle in [inpatient] and that but it was easier in [named treatment centre] cause it was a smaller group. I think that’s important actually, smaller, more kinda, not intimate but just like...you get to know people easier, like it’s smaller” (Hannah, current patient).

“Yeah you can’t really hide behind the other person. But em, no it’s good because eh, like that you’ll get to know therapists a lot better like and become a lot closer” (Katie, current patient).

Participants who had experience of both small and large group programmes during inpatient treatment stays surmised that when programmes were comprised of small treatment groups, treatment was experienced as more personalised. Moreover, in small programmes, patients felt that their specific needs were being met.

“In XXXX [named treatment centre (A)] there could be anything from 10 to 12 you know in a group and [named treatment centre (B)] there might only be two of us in a group or three so it’s a lot smaller. And I think everyone’s seen a lot more individually like” (Katie, current patient).

Another participant felt that the probability of recovery reduced as group size increased because the quality of support depreciated with attempts to treat an expanding number of patients.

“...the problem is, if you start taking in more and more, your chances of, your perceptions of people that get a full recovery goes down cause you’re spreading yourself too thin...people are going to slip through the cracks, they’re gonna end up relapsing...” (Susie, discharged patient).

In addition to perceived negative implications for engagement and support, numerous participants recounted experiences where large group numbers had created a ‘competitive’ therapeutic environment which often interfered with the therapeutic process.

“I suppose just the large numbers that were there...[because] eating disorders like [by] their own nature...there’s the whole competitiveness in it like and I found that in XXXX [named treatment centre] you know” (Katie, current patient, adult).

4. 1. 3. Conclusion

Physical components of the treatment environment impacted significantly on patients' experiences of treatment. Specifically, pathogenic versus salutogenic models of treatment had distinct implications for motivation and the therapeutic process. From a Self-Determination theory perspective, perceptions of the motivational climate are crucial in determining whether needs are enhanced versus thwarted and consequently whether optimal motivation will be impeded or enriched (La Guardia & Patrick, 2008). It would seem that salutogenic models of health care –which focus on promoting well-being and the normal continuation of everyday life activities - fostered patients' perceptions of autonomy, competence and relatedness. When treatment was experienced as such, participants' engagement in the therapeutic process was enhanced. Conversely experiences of pathogenic models of health care, such as those embraced by psychiatric and medical hospital environments were described as promoting feelings of loneliness, incompetence, and loss of control. Such environments were viewed as having negatively impacted on patients' emotional wellbeing and quality of motivation for treatment.

Results also indicated that structural aspects of care, such as multimodal treatment interventions, were experienced as enjoyable and, in the majority of cases, effectively enhanced patients' quality of motivation in the therapeutic process. SDT maintains that when psychotherapeutic activities are experienced as fun or interesting, patients can become intrinsically motivated in the therapeutic process (Ryan et al., 2011). Other structural factors such as the group size of inpatient treatment programmes and outpatient treatment groups further affected psychological need fulfillment.

Specifically, smaller group sizes were more conducive to the development of supportive relationships with therapists and other patients and thereby fostering perceptions of relatedness. Moreover, perceptions of competency were weakened in larger groups because patients felt that the therapeutic support required to facilitate this progress was inadequate.

4. 2. Being in Control versus Being Controlled

The subordinate theme of *being in control versus being controlled* was a particularly recurrent theme resonating throughout both adolescent and adult participant accounts. Perceptions of autonomy had significant implications for the quality of treatment engagement. The subordinate theme of *being in control versus being controlled* is composed of two lower-order themes; *coercion* and *collaboration*.

4. 2. 1. Coercion

The vast majority of participants reported experiences of coercion and pressure in treatment. For participants in the current study, coercion was associated with perceived pressure (both internal and external) to engage in the therapeutic process and the type of treatment approach. Most frequent were experiences of coercion to enter treatment, and for the majority of participants this was evidenced during adolescence stages of illness. Participants reflected that coercion to enter treatment impacted negatively on their willingness to engage with services.

“I never wanted, I was never actively looking for anything [treatment] ...I was being told what to do, something I had to do and that was it” (Emma, current patient).

“And if the parents fecking the kids for treatment against their will, you’ll be guaranteed, I used to see that and not really understanding the younger ones...and being forced to get well, just wasn’t going to work” (Vicky, current patient).

In several cases, coercion to enter services was accompanied by a perceived loss of control, which in turn resulted in a sense of helplessness.

“I suppose the lack of control, I thought if someone was going to take my, you know like take my control away from me...like I was really depressed in general and it was like the only thing I could kinda get right” (Eleanor, discharged patient).

On other occasions, participants reported entering treatment to satisfy others or to avoid conflict with family members and partners rather than for themselves. In these instances participants reported feeling that they “should” participate in treatment but perceived very little therapeutic gain from their efforts.

“I only kind of went to get people off my back, I wasn’t particularly ready to, for treatment...any sort of that myself. Like I went to counselling to keep everyone else happy you know...I didn’t really participate in it like, so it wasn’t really beneficial to me at all at the time” (Natalie, current patient).

“Like I never found I was benefiting from it, you know. I didn’t come away thinking I got something from it...I just used to go cause I felt I had to” (Hannah, current patient).

“I never really wanted to come here in the first place so...I don’t know if I was really engaging with it that much” (Emma, current patient).

As such, the majority of participants highlighted that, in order to effectively engage within the therapeutic process, they needed to own the decision to enter treatment.

“...I’m so glad I didn’t get ‘found out’ if that’s the word you want to use, years ago by my family because they would have tried to get me treatment when I wasn’t ready. And it wouldn’t have worked” (Samantha, current patient).

Congruently, several participants reflected on the change in their quality of motivation when they entered treatment with a sense of volition.

“I will say this in any treatments I went into after I started going looking for [help], I never once...made myself sick” (Vicky, current patient).

Experiences of coercion were also expressed by participants who *did* seek help for their eating disorder. In these cases, participants reported that during the initial help-seeking process, information concerning the physical risks of ED was commonly delivered in a coercive manner. In many cases this strategy was also employed by therapists during treatment through the delivery of psycho-education. However, participants reported that such coercive strategies did not stimulate their engagement in the therapeutic process.

“...it doesn’t matter how many times someone says to us...it doesn’t scare you into getting better so I just, em, I did nursing in college so...even though I had the education, it didn’t make any difference to me so” (Julie, current patient).

With respect to treatment approach, methods which de-emphasised patient choice and promoted forced weight gain led to perceptions of disempowerment and negative emotions.

“...the food here is very different to like in XXXX [named treatment centre]. You were kinda sat down at the table and you were, food was put down in front of you and you had to eat it. You had no choice in the matter like. And you were kinda given things that you, your biggest fear like. Ice-cream was put in front of you and you’d be freaking out like” (Katie, current patient).

A system based on contingent rewards and punishments was often employed in the treatment of younger ED patients as an incentive for weight gain. This approach not only undermined treatment engagement, but also negatively impacted on patients’ sense of selves.

“At one stage I wasn’t allowed to see my parents for two weeks...two weeks! There was no way that was happening. I tried to hop out windows, like tried to run out of the unit. Like, no way, this is not happening, that’s why it made me even more angry. It fed my anorexia once again, made me more motivated...I just sat there thinking I’d rather die than be in here. I wasn’t allowed to do anything” (Rachel, discharged patient).

“I felt they took everything away from me and you know I suppose it was an incentive to eat more but at the same time I felt really low and I didn’t think there was a need to be so harsh...I felt like I really had no one at the time like...it’s very, very hard for a patient going in there [general medical hospital], particularly when I was only fourteen like and had nothing” (Eleanor, discharged patient).

The physical limitations imposed on patients (e.g. bed rest) in an inpatient treatment environment further added to perceptions of loss of control and diminished patients’ motivation for treatment. Whilst describing experiences of controlling treatment climates, three participants utilised a metaphor of ‘imprisonment’. One participant referred to the sense of being confined within the physical boundaries of the hospital as ‘imprisoned in these four walls’ (Rachel, discharged patient). Other participants described a sense of emotional confinement where they felt dominated and manipulated by rules and threats.

“...they were always threatening like with something, like going to England...I think it’s hard when you’re told that, it’s kinda like you’re a prisoner or something and kinda like ‘if you don’t do such and such you’re going to such and such a place” (Eleanor, discharged patient).

In some cases, patients revealed that greater physical limitations and environmental control during treatment motivated patients to *protect* their eating disorder.

“It makes you worse though cause when you’re in a room full, like, of four walls, 24 hours a day, all you’re doing is being thrown food, getting sick or like hiding stuff, what’s your next plan, what’s your next like exercise you’re gonna do”
(Rachel, discharged patient).

“Well everyone is so afraid because the approach is so abrasive or invasive that everyone’s petrified and looking after their own corner...it drives you into protecting, or would drive everyone, by the looks of it, into protecting it rather than actually wanting to get well cause the techniques are that scary...I mean all that does in your head is put super, like super focused on the food, super afraid and you’re so freaked out you can’t hear the type of help that’s being talked to you” (Vicky, current patient).

In response to the demands of controlling treatment environments - particularly forced weight gain - several participants reported learning and adopting new, detrimental behaviours in desperate attempts to protect their ED. In some cases, the coercive approach used in treatment was perceived to exacerbate their ED.

“It was too much too soon and it has the backlash effect...I took up laxatives, I took up smoking, eh, I took up some great weight losing techniques...because I was so afraid I was trying doubly hard to lose the weight put on plus more”
(Vicky, current patient).

“You’d fall back because you’d get so panicked, the eating disorder completely takes over and you just, you feel like you’ve got not control (Susie, discharged patient).

The degree of autonomy afforded by the treatment approach also had long-term implications. Many participants reported the difficulty in adapting to life post-treatment because the rigidity of the rule-governed approach stood in stark contrast to the flexibility of everyday life. The following participant highlights the long-term implications of controlling treatment climates for adopting positive behaviour change, namely low perceived competency.

“...there was a lot of rules involved with there, it wasn’t, you almost became obsessed with their rules...when I got home on the weekends everything had to be exactly as it was in the hospital and I became obsessed with having, I wouldn’t have anything extra, I would have exactly what was put down on the menu in the hospital” (Susie, discharged patient).

Controlling treatment climates also negatively impacted upon the development of important relationships, namely the therapeutic alliance. When patients felt controlled or coerced, their perceptions of safety and support were weakened, which in turn threatened the development of a trusting alliance between patient and therapist. The combination of a poorly developed therapeutic rapport coupled with elevated anxiety levels further diminished patients’ motivation to engage with treatment.

4. 2. 2. Collaboration

Participants' narratives demonstrated that a sense of 'being in control' was manifested when treatment was experienced as a collaborative endeavour between therapist and patient. Not surprisingly, experiences of collaboration were positively evaluated by patients. For participants, a collaborative approach consistently reinforced patients' choices and promoted the control of the patient in the decision-making process. Moreover, participant accounts illustrate a positive relationship between experiences of collaboration and enhanced motivation for treatment. The extent to which the treatment approach was initially perceived as coercive or supportive significantly impacted on patients' willingness to engage during the admission process. Furthermore, perceptions of collaboration in the initial stages of treatment proved crucial in encouraging patients to engage with behaviour change.

“I left feeling like there was a tiny bit of hope whereas anywhere else you'd be, you'd just feel like they're trying to haul it [eating disorder] off you” (Vicky, current patient).

Perceptions of collaboration in treatment also impacted positively on relational aspects of care and were deemed crucial in the initial engagement of patients in the therapeutic process.

“When I'd seen how fair XXXX [therapist name] could be, I began to trust someone when I came in and that's when I wanted to try [to recover] (Vicky, current patient).

“But I think when I came here, the fact that I was able to kinda maybe, I had more choice in what I was going to eat like I had more choice, is what I found easier and was a big help” (Katie, current patient).

Particularly important was a treatment approach which gently guided, rather than coerced, patients towards positive behaviour change. Many participants felt that the process of actively negotiating the goals of their care plans in a supportive environment was an effective means of fostering engagement.

They still give you guidance, they still, you know, to a certain extent, not took control from you but they always guided you, they never let you go a kind of random route, you could go a really wrong way” (Susie, discharged patient).

“She [dietician] recommends the amount and...all the rest but like it’s food that I like to eat, and she won’t tell me like I have to have, to do this, and I want you to eat this...yea just very encouraging” (Anne, current patient).

By providing patients with more control and choice with issues concerning food and mealtimes, and trusting patients with more responsibility with regards their care plans, patients were more willing to engage in behavioural change because their actions and decisions were perceived as more self-determined and personally controlled.

“She went in, she showed me the kitchen and she said ‘you cook your own meals, you get involved in the recipes, you start that’, and it kind of, it takes the power out of food, you know?” (Susie, discharged patient).

“I think giving people...more kinda freedom around food...you have to be able to do it for yourself you know...you can’t just send somebody somewhere and put food in front of them and make them eat it, put on weight, get bigger. You have to make that decision yourself. So em, I think somewhere like this where yeah, the responsibility of your recovery is your own” (Katie, current patient).

4. 2. 3. Conclusion

The sub-themes of coercion and collaboration are closely aligned with the concepts of autonomous versus controlled motivation within SDT. Reflecting on their experiences of entering treatment, participants consistently acknowledged that in order for them to engage with the aims of treatment and initiate behaviour change, they needed to ‘be ready for treatment’ and own the decision to enter treatment,. This aligns closely with the concept of autonomous motivation in SDT. SDT posits that autonomous motivation for therapy is experienced when patients view their participation as freely chosen (Mansour et al., 2012). However, for the most part, the reasons cited for entering treatment in participants’ narratives (e.g., perceived pressure from others, coercion) appear to explicitly reflect extrinsic motivational processes. On the other hand, participants who experienced a sense of volition in decision-making towards behaviour change illustrated greater autonomous engagement in the therapeutic process.

SDT argues that controlling treatment approaches which compel the patient to accept expert advice and force the patient to change their behaviour are not helpful because they elicit significant resistance from the patient (Vansteenkiste et al. 2005). When patients feel pressured to change, they commonly demonstrate ardent resistance

or passive compliance with these externally controlling forces (Vansteenkiste et al. 2005). SDT surmises that, externally regulated behaviour stemming from a desire to avoid punishment or to appease others is reflective of low self-determination (Deci & Ryan, 1985).

These results yield support for previous SDT research which demonstrates the ineffectiveness of contingent rewards and punishments in eliciting sustained behaviour change (Ryan & Deci, 2000). SDT theorists posit that extrinsic rewards consistently undermine intrinsic motivation (Ryan & Deci, 2000). Specifically, threats, directives and imposed goals diminish intrinsic motivation by fostering an external perceived locus of causality (Ryan & Deci, 2000). In contrast, provision of choice and acknowledgment of feelings have been found to augment intrinsic motivation by enhancing perceptions of autonomy (Ryan & Deci, 2000). These findings also support studies which argue that developing a sense of autonomy and competence are critical to processes of internalization and integration (Ryan et al., 2008). Autonomy support allows individuals to actively transform values into their own (Ryan & Deci, 2000). Participants' narratives illustrate that experiencing a sense of volition in decision-making towards behaviour change resulted in greater autonomous engagement in the therapeutic process. According to SDT, when patients are more autonomously engaged in the therapeutic process, they are more willing to develop and maintain positive behavioural outcomes (Mansour et al., 2012). Furthermore, patient accounts of collaborative therapeutic approaches aimed at promoting personal control also facilitated the development of their perceived ability to sustain change, which in turn revealed persistence towards positive change.

4. 3. Understanding and Support

The subordinate theme of understanding and support captured the crucial role of interpersonal relationships in shaping the core of participants' experiences. This subordinate theme was further sub-divided into two lower-order themes; *therapeutic relationship* and *experiences with other patients*. The therapeutic relationship proved instrumental in fostering psychological growth, change and healing for patients, and participants' accounts illustrated that the motivational implications of the therapeutic alliance were manifold. Interactions and communication with similar others were important for normalisation of experiences, emotional support and a sense of connectedness. In particular, relationships that were perceived as understanding and supportive were instrumental in positively impacting on participants' motivation to engage in treatment.

4. 3. 1. Therapeutic Relationship

The therapeutic alliance represented a fundamental source of patient motivation for treatment in the current study. Specifically, patients assigned an important role to the therapist as an agent of motivation and vehicle for change. The positive motivational implications of the interpersonal process often helped patients overcome their ambivalence towards change. Participants placed importance on both the humanistic and professional qualities of therapists. A particularly interesting finding was the importance of perceptions of reciprocity within the therapeutic alliance, where participants highly valued a reciprocal relationship between patient and therapist in which they were accepted as an equal relational partner.

“Like the fact that I actually got to know her as a person as well, it was a two-way system...” (Rachel, discharged patient).

Participants’ accounts suggest that during adolescent stages of their ED, greater emphasis was placed on interpersonal features of the therapeutic relationship. Although the humanistic qualities of therapists emerged as important constructs throughout the treatment trajectory, interpersonal aspects featured more prominently during adolescent stages of illness, whilst participants tended to place more emphasis on the professional qualities of therapists during later stages of their ED. Specifically, participants reported that a ‘sense of friendship’ within the therapeutic relationship was important during adolescent stages, and perceptions of equality and mutuality were crucial in facilitating this. During these early illness stages, when patients perceived the therapeutic relationship as similar to that of a friendship, their willingness to engage in treatment was enhanced.

However, throughout later illness stages, participants were less concerned with ‘having a friend’ in a therapist and more concerned with learning and developing the necessary skills required for successful and sustained behaviour change. Specifically, patients favoured a more structured approach to treatment which focused on appropriately challenging them.

“It was sort of just, I’d come in and we’d have a chat. I didn’t really feel like there was any proper work done...I sort of liked it at the time, but now I’m looking back and thinking ‘you know, I wish I had done something that would have grounded me a little bit more’ (Eleanor, discharged patient).

Indeed, many participants reported that they ‘needed a bit of a push sometimes’ and thus, a therapeutic approach which they felt adequately ‘challenged them’ was perceived as particularly important.

“some therapists can be very kind of, em, too nice and you actually get nowhere because they, they never challenge you and you never have to talk about anything that you don’t want to talk about” (Julie, current patient).

Participants valued therapist self-disclosure as it represented an opportunity for experiential learning. Therapists’ honest recall of difficult issues they experienced and the way in which they overcame them enabled patients to obtain alternative problem-solving techniques to apply to their own problems.

“...it helps sometimes if they share parts, their own parts of their own experiences with you. You know, difficulties that they’ve had and the tools they used to overcome them” (Laura, current patient).

Participants were also acutely sensitive to perceived hierarchies within the patient-therapist relationship. Several participants recounted occasions where they felt care providers adopted an attitude of authority, which ultimately led to a divide within the therapeutic relationship and weakened opportunities for establishing rapport.

“She wasn’t very friendly, she was like a professional, sitting there in her formal voice” (Eleanor, discharged patient).

“...I suppose with XXXX [therapist], it was slightly like you were being lectured at rather than going into a counsellor” (Laura, current patient).

Whilst reflecting on their relational encounters with health professionals, participants described various levels of understanding. On a basic level, participants expected therapists and health care professionals to encompass a fundamental understanding of eating disorders. This comprised an understanding of the ED as a mental illness, the physical and emotional aspects of an ED alongside the ability to competently treat the ED through appropriate expertise and experience. On a more advanced level, participants also expressed a keen desire to be understood as a person separate to their ED. For patients, the highest level of understanding entailed a comprehension of the ED interlinked with the individual. Particularly valued was an appreciation and understanding of the idiosyncratic nature of each individual's ED.

“...not just understanding that you have a problem as an eating disorder, but understanding exactly where you're at, at the time when you're with them. Cause that changes and that they're able to adapt to how that changes” (Barbara, discharged patient).

Perceptions of therapist understanding were associated with therapist competency to effectively, and compassionately, treat the patient's ED. Several participants described instances where health care professionals illustrated an inadequate understanding of the disorder and the associated difficulties for patients.

“I used to go in and he'd [GP] say, em, 'how was the vomiting this week?' and I'd say 'not good' whatever, he'd say, 'well next week, no vomiting', like and I'd just be like if I could just stop I would, do you know, I don't want to be doing this, it's not like...a choice” (Natalie, current patient).

Perceptions of lack of therapist understanding and competency within the therapeutic alliance directly impacted on patients' motivation for treatment and most frequently resulted in patient disengagement and drop-out from treatment.

“She had no knowledge of eating disorders or anything about food at all, and although I do agree that it's not, it's not to do with the food really, like, she wasn't helping me and I decided myself I wasn't going to go back there and that was it” (Laura, current patient).

“This lady [therapist] was older like, she was in her late fifties I'd say and she basically told me you know em like, play music, cause I play piano and violin, play a bit of music and read a few books and stuff like, you know, ridiculous stuff like, and it just makes you say 'right well I'm not gonna see her again” (Natalie, current patient).

Participants' accounts suggest that a lack of therapeutic understanding and expertise often lead therapists to adopt an authoritarian stance within the therapeutic alliance. Perceptions of power and authority within the therapeutic relationship were negatively evaluated by patients and established a controlling treatment climate. This in turn weakened the bond between patients and therapists and impacted negatively on patients' motivation for treatment.

“Yea there's things that motivate ya...in XXXX [named treatment centre] there was some therapists over there and they'd actually get angry at the patients because they wouldn't listen to them, or they'd look away from them...and they'd

[therapists] actually shout at them, which means they're [patients] gonna get more angry and anxious... if they're not actually trained in eating disorders, there's things that people do, they don't realise, but they motivate ya even more to get worse" (Rachel, discharged patient).

Of particular importance to the development of therapeutic rapport was perceived empathy, where participants valued emotional responsiveness and a sensitive awareness from therapists. Perceptions of therapist empathy were promoted through validation of patient emotions and experiences.

"I think you need to feel that they're feeling what you're going through for it to work. And for them to show...if it's upsetting and that's fine because, you know, it might help you realise that they actually are listening to you" (Samantha, current patient).

A sense of connectedness between patient and therapist was also deemed important for patients to actively engage in helpful relational processes, such as self-disclosure.

"there was no gel there. I'd talk to her but, em, I wouldn't divulge anything or there was no, there was nothing there" (Vicky, current patient)

The highly valued sense of connectedness between patient and therapist was strengthened and maintained by consistency within the therapeutic relationship.

“I like having the same people like cause you can get to know them better”
(Eleanor, discharged patient).

Not surprisingly, inconsistency in the therapeutic alliance weakened perceptions of connectedness and participants reported that when the ‘paths to recovery’ were broken due to therapist inconsistency, issues of trust were augmented and patient engagement in treatment diminished.

“...I kinda felt the jump from one to another was, you know, it was hard to kind of like trust someone...I did feel it like, you know, prevented me from connecting properly with a therapist...” (Eleanor, discharged patient).

“...they know my story, background, and if you’re chopping and changing all the time, and repeating yourself and that, it didn’t work out anyways” (Hannah, current patient).

For one participant, the experience of countless interactions with numerous health care professionals elicited a resistance to treatment.

“...mam made me go to at least eight different people in total...and you just, you get to the stage where you’re like ‘no, no more’...you just want to be left to your own routine...” (Laura, current patient).

When patients felt that their feelings and experiences were invalidated or negated, they reported significant difficulty in establishing a positive and robust therapeutic alliance. The majority of participants also reported the need to feel safe and supported within their therapeutic environment in order to initiate and sustain motivation for change.

Participants' accounts illustrate that perceptions of safety and security were enhanced when therapists conveyed a genuine interest in patients' recovery. Perceptions of authentic concern on the part of the therapist fostered perceptions of connectedness and trust within the therapeutic relationship, which in turn positively impacted on patients' motivation for treatment. Not surprisingly, perceived insincerity undermined the development of a trusting relationship. Participants were acutely sensitive to insincerity within the therapeutic relationship and some participants recounted how experiences of insincerity diminished patients' engagement with treatment and negatively impacted on future help-seeking attempts.

"...it was kinda like false hope. He was like 'you should be in here within the next two to three weeks and we'll get you better' and all this...then absolutely nothing out of it so it's kinda...when you kinda set your hopes up, 'oh in a few weeks I'll be back on track' ...I didn't want to go see anyone after that for ages"
(Laura, current patient).

4. 3. 2. Experiences with Other Patients

Interpersonal relationships with other ED patients played a significant role in shaping patients' experiences and represented an important motivational force within the therapeutic milieu. When patients were exposed to the struggles of similar others, they experienced a sense of normalisation with regards to their own experiences and behaviours. This was often deemed crucial for acceptance of their ED as a problem and for subsequent motivational processes associated with initial engagement. Participants experienced comfort and security in the knowledge that others 'in the same boat'

struggled with similar experiences. As such, being able to relate to the experience of others and having others relate to their struggles aided in fostering patients' engagement within the therapeutic milieu.

“I actually liked hearing other people’s stories because it felt like ‘Jesus I’m not the only one here’, you know. It was supportive in a sense when you heard other people’s pain... and their experiences...” (Samantha, current patient).

The majority of participants reported that being exposed to the struggles of others reduced the pervasive sense of loneliness and isolation entrenched within their ED. In turn, this fostered opportunities for reciprocity and perceived support between ED patients.

“...you get to know other people and you know that you’re not kind of on your own going through it” (Lisa, current patient).

“it just made you feel not as alone...that there were other people out there experiencing the same, the same feelings as yourself” (Samantha, current patient).

One participant recounts how the reduced sense of loneliness and increased sense of optimism achieved through interactions with other patients helped to instill perceptions of confidence with regards recovery.

“...I had been feeling totally lost with the eating disorder, I didn’t know anyone that had ever had one and I didn’t, eh, confide in my friends about it either...so initially it was really helpful because em I didn’t feel so alone in the problem and

em, it was kinda like 'okay well there is something I can do about this...' (Lisa, current patient).

Experiences with other patients often helped to establish a positive learning environment within the therapeutic milieu, where relational exchanges between patients helped to stimulate new concepts on how people could handle their own difficulties.

And then if they, if they spoke about their realisations about, you know, em, themselves...now and again a lightbulb would go off in your head...so they helped you as well in, em, realise why maybe you did certain things or behaved in a certain way...' (Samantha, current patient).

Some patients noted the irrelevance of diagnostic labels in establishing a shared understanding amongst diverse group members. Participants' accounts suggest that all individuals who have experienced pathological eating, in its various forms, share a common understanding.

"The person with the anorexia can even relate to the person with the overeating, you know, there's all crossways there" (Vicky, current patient).

"...everyone is different and everybody has their own kinda circumstances and their own story but at the end of the day everybody does have an idea of where you're coming from and there's always something that's going to be in common" (Emma, current patient).

Of particular significance to participants was contact with recovered ED patients who often represented important motivating agents. A sense of hope was instilled in

participants when they witnessed similar others overcome their ED difficulties and thus, recovery became an attainable possibility. Participants' accounts suggest that contact with recovered individuals and the subsequent promotion of optimism for recovery often formed the basis of patients' initial motivation for change.

“If you show people [patients] at weaker stages that there actually is hope and they want to get better then it motivates you on the other side” (Rachel, discharged patient).

“maybe at the start to talk to someone whose recovered...to let them tell ya how much better it is to be better, so that gives you encouragement to get better” (Lucy, discharged patient).

Evident within the accounts of inpatients receiving treatment in a residential setting was a strong sense of unity within the therapeutic climate. This sense of connectedness within the inpatient therapeutic milieu was particularly effective in encouraging patients to actively engage in treatment.

“...well the group of girls that I was inpatient with here, we definitely clicked, we got on like a house on fire and I found the group work with them very easy...and the fact that we trusted one another and we did feel comfortable in opening up and I trusted them...” (Samantha, current patient).

Although interactions with other patients were often perceived as a powerful motivational force within the therapeutic milieu, participants recognised that these interactions could also negatively impact the therapeutic process, particularly during

vulnerable stages in their ED. ‘Competition’ and ‘comparison’ were the most frequently reported detriments, predominantly amongst AN patients, where evaluations of others’ physical appearance often triggered panic and anxiety and reinforced detrimental ED behaviours. Correspondingly, several participants described experiences of learning and engaging in new, detrimental behaviours in a therapeutic environment where ‘negative talk’ was common. A minority of respondents felt that being exposed to the continued struggles of other patients during the aftercare stage of treatment reinforced a sense of helplessness and despair for patients, and negatively impacted on patients’ self-belief in their own ability to sustain recovery.

“I suppose if you’re struggling it’s [aftercare] ...not very helpful like you know and...everyone kind of seemed to be struggling in the groups, so it’s hard to listen to everyone else’s problems you know” (Katie, current patient).

“I thought it was the most depressing thing in the world, everyone was just talking about how crap their life was since they’d been discharged” (Susie, current patient).

4. 3. 3. Conclusion

The above findings illustrate that interpersonal relationships play a pivotal role in initially engaging patients in treatment and in enhancing their sustained motivation for change. Dyadic interactions between patient and therapist were crucial in fostering perceptions of autonomy, competence and, particularly relatedness. Relationships with other ED patients proved important for the initial acceptance of ED issues and for

motivation to engage with services. Accordingly, SDT argues that close personal relationships serve an important function because they provide an individual with a sense of safety and security and are more likely to fulfil the needs of autonomy, competence and relatedness (Downie, Mageau & Koestner, 2008; McBride et al., 2010). In the current study, the extent to which patients experienced a reciprocal, trusting relationship with therapists impacted on their quality of motivation for treatment. Validation of patient experiences and perceptions of sincerity were important for patient engagement. Congruently, SDT infers that, relational support must be perceived as genuine to have the functional significance of relational support (Ryan et al., 2011).

SDT theorists posit that a sense of relatedness is crucial for the internalisation of health behaviour change since people are more likely to adopt values and behaviours promoted by those whom they feel connected to and whom they trust (Ryan et al., 2008). Ryan and colleagues (2011) propose that a sense of being respected, understood and cared for is essential to create a sense of trust, therefore facilitating the internalisation of positive health behaviour change.

4. 4. Exploring and Maintaining Positive Change

The subordinate theme of *Exploring and Maintaining Positive Change* was further subdivided into the lower-order themes of *Finding the ‘root of the problem’* and *“Learning how to cope with life”*. Almost all participants reported the need to acquire a personal understanding of their ED and to embrace the necessary tools to maintain positive change. This was most commonly facilitated through a treatment approach

which addressed the emotional issues inherent in their ED. Moreover, an approach which encouraged self-exploration and self-examination in therapy was deemed instrumental in fostering participants' confidence in their ability to recover.

4. 4. 1. Finding the 'root of the problem'

The vast majority of participants expressed a keen desire to understand their eating disorder. Such an understanding comprised; the underlying mechanisms and causal explanations of the illness, the function of their ED and the way in which the ED has influenced relationships in their life. Of importance, analysis of accounts suggest that this was not dependent on the content of therapy (i.e., CBT, CAT) but rather the manner in which therapy was delivered. As such, having the opportunity to express and identify the feelings associated with their ED was deemed particularly helpful by patients.

"I lost my sister back in 2001 and coming here made me realise that I hadn't grieved for her and I never realised that before I came here. And they made me realise here that that was, the bulimia was my coping mechanism for my sister's death basically, how I dealt with that. So that was a big revelation for me I suppose" (Samantha, current patient).

"I think definitely like trying to get some insight into why you're having the same problems over and over again or, em, where the problems are coming from, that's helpful" (Lisa, current patient).

Some participants reported the difficulty in accessing and dealing with painful emotions, but recognised that this was vital in order to successfully progress past underlying problems and ensure sustained change over time. Accordingly, one participant recognised her avoidance in attending to the emotional underpinnings of her ED as a primary contributor to her numerous relapses.

“...and I think that was probably my downfall was that I never really dealt with the issues that had caused me to have an eating disorder...so that was probably why I kept relapsing” (Katie, current patient).

Another participant identified her enhanced awareness of emotions and their functions, and being in touch with her core needs as one of the most successful outcomes of her treatment experience.

“It’s probably the fact that I’m more in tune with who I am, my wants and needs and my feelings, definitely my emotions, that they’re there for a reason” (Samantha, current patient).

Participants were very sensitive to any approach that placed greater emphasis on the physical aspects of their eating disorder, such as weight and ED behaviours, at the expense of disregarding the vital emotional aspects. One participant below illustrates how treatment approaches which emphasised the physical aspects of the ED negatively reinforced her illness, thus weakening her engagement in treatment.

“...like here [treatment centre]...obviously there’s a lot of emphasis on weight and stuff but it’s not the root of the problem. I think in some places it’s seen as the root of the problem and I think that can drive the eating disorder even more”

(Natalie, current patient).

Another participant felt that the substantial emphasis placed on physical aspects of her ED in comparison to the fractional attention ascribed to emotional aspects, contributed to her enduring ED problems. Here, it seems that the over-emphasis on weight gain compromised the patients’ ability to develop adequate the cognitive and emotional skills to cope with the underpinnings of her ED in the long-term, inevitably resulting in failure to sustain maintained change over time.

“I just felt like when I was there it was more so based on you know the physical, the physicality’s of gaining weight. It wasn’t as much on the emotional side cause I even find now...I’m still an emotional eater, I still have issues...”

(Eleanor, discharged patient).

For some participants, the path to recovery involved a re-definition of identity and their narratives suggest that the development of positive self-definitions may be an important factor in recovery. Several participants described the loss of social and personal identities and the resultant difficulty in defining themselves devoid of their ED. Participants’ accounts described a sense of self that had become so consumed by the ED and a self-value which had become contingent upon perceived ED capabilities.

“what you need to do is rediscover who you are...you need to discover new things about yourself...cause when you take away an eating disorder from somebody who’s had it...I felt like my identity was completely taken away. I didn’t have any...I didn’t know who I was, I had to define myself by an eating disorder, I didn’t know, I didn’t have any personality, I was just...I was just that” (Susie, discharged patient).

Therapeutic approaches which addressed identity impairment and placed significant emphasis on the development of new positive selves was highly favoured by participants. Particularly important here was a therapeutic approach which refocused and transformed participants’ negative self-perception into a more understanding and compassionate attitude towards the self.

“...she [therapist] just, I suppose helped me feel again which was just was a, was alien to me. So brought you back to who you actually are, who I actually was as a person, you know, em, not who I thought everybody wanted me to be” (Samantha, current patient).

4. 4. 2. Learning how to Cope with Life

In order for patients to experience sustained motivation for recovery, they needed to first develop the skills and tools required to activate and maintain positive change. Particularly instrumental in achieving this was a treatment approach which afforded patients opportunities for self-exploration and self-reflection. Also important to patients was a sense of structure within therapeutic sessions and a therapeutic context in

which patients felt adequately challenged, thus enhancing perceptions of progress and competency. Participants' accounts suggest that therapists' active listening skills and the provision of feedback and guidance were important therapeutic constructs in propelling patients' motivation to explore alternative behaviours. Patients favoured a non-directive approach where they were supported and encouraged to explore the deeper meaning of concepts and events related to their disorder.

"...like they [therapists] understand you so much...they just listen and give like, they make you think about what you're actually saying" (Lucy, current patient).

"she listens to ya, she doesn't tell ya how ya feel...she's helping you sort it out in your own head whereas you don't realise that until you actually don't really need therapy anymore" (Rachel, discharged patient).

Participants' narratives suggest that self-exploration was one of the most effective therapeutic strategies for successfully engaging patients in treatment. In several instances, providing support for open curiosity nurtured patients' interests and encouraged their active engagement in the therapeutic process.

"I felt it was really interesting that XXXX [therapist] used to explain different psychotherapy things...and it kinda helped me as well to understand myself you know" (Eleanor, discharged patient).

Moreover, treatment approaches and therapeutic relationships which emphasised self-examination and exploration encouraged patients to recognise and enhance their own internal resources.

“...like this is much more, em, a way of learning how to cope with life. Of kinda what you learn rather than trying to just, you know, put a patch on the problem”
(Julie, current patient).

In addition to aiding patients in understanding their own personal experiences, providing support for self-exploration encouraged patients to confront barriers to change and take responsibility for behaviour change. Providing clear feedback and guidance helped patients to initiate and organise action. Furthermore, the instigation of a change process was associated with an increased sense of accomplishment in being able to progress past enduring problems. This sense of mastery fostered perceptions of competence in coping with future problems and sustaining recovery.

“they don’t go like giving ya advice or anything...and you, you end up understanding more about yourself...it helps you kinda to get to know, like to understand your own problem and how to help yourself” (Anne, current patient).

Participants’ narratives also suggest that a lack of structure and/or repetition in therapy leads to disengagement with the aims of therapy. Participants reported that it was easy to become lost in unstructured conversation, whereby the goals and aims of therapy had become misdirected.

“she kinda gets you to see things that you might not always notice, noticed before, and I found that really helpful because with, with XXXX [treatment centre] ...if I’m talking about a problem I can just talk and talk and talk and talk and talk around it in circles and eh, it won’t ever get resolved, and I can’t see

where it's coming from or why it's there whereas in XXXX [treatment centre] they kinda help you see that which is quite, em, kinda helps you move past the problem and kind of work a way out of it" (Lisa, current patient).

General counselling approaches were deemed inadequate to address the complexity of the ED because patients felt that such generic therapeutic approaches lacked considerable structure. Contrastingly, structured therapeutic sessions provided participants with concepts to reflect on, explore and develop independently outside of therapy. Perceived progression within therapeutic sessions was a powerful motivational force for participants, as they felt they were continually, albeit gradually, accomplishing their goals towards recovery.

"I suppose it gives you something to take away like 'I did something today in therapy' which is really good yea" (Susie, discharged patient).

Some participants stated the importance of setting goals and targets in therapy as a means to maintain structure in sessions. For these patients, knowing what to expect with regards programme duration fostered their hope in the recovery process.

"I think, em, a structured treatment is good cause, em, I think you need to have some idea of that it will come to an end at some stage and that em...that like you are going to be able to put it behind you at some stage as well" (Lisa, current patient).

A treatment approach focused on developing personal skills and tools served to empower patients and thus proved effective in encouraging patients to apply new coping

strategies and to persistently work at recovery after discharge from services. As such, these treatment approaches helped promote to maintained motivation for recovery post discharge.

“I thought since I’ve been here, I tell them what has been troubling me for the last whatever amount of years and...they’re gonna be fit to give me the answers. But I realise now that it’s actually, that they don’t tell you what to do, they give you tools on how to cope with what you went through and what you’re going to face after you leave here” (Samantha, current patient).

4. 4. 3. Conclusion

In sum, a treatment approach which encouraged autonomous exploration in therapeutic sessions was positively evaluated by patients in the current study and proved crucial in nurturing patients’ interest to actively engage in therapy. In support of this, SDT research argues that autonomy support positively enhances the quality of people’s motivation (Ryan & Deci, 2000) Moreover, in the current investigation, autonomous support, in the form of facilitating self-examination and exploration, fostered patients’ psychological needs for autonomy, relatedness and in particular, competency. In particular, development of personal skills and tools enhanced patients’ perceptions of competency – components deemed vital for sustained change. When participants felt that they were developing and refining the adequate cognitive and emotional skills required to sustain positive change, their motivation for recovery was enhanced. SDT theorists infer that perceptions of competency or efficacy are necessary for all intended action (Ryan et al. 2011) because individuals will only adopt behaviour change when

they feel efficacious with respect to those activities (Ryan & Deci, 2000). SDT argues that, support for competency is evidenced when the patient is afforded the skills and tools for change, and furthered supported when competence or control-related obstacles emerge (Ryan et al., 2008).

4. 5. Summary of Results

The super-ordinate theme of ‘the therapeutic milieu’ captured the essence of patients’ treatment experiences. Analyses of participants’ narratives suggest that the therapeutic milieu comprised several diverse, yet often interrelated components of care. Both structured and unstructured aspects of treatment programmes impacted on patients’ engagement in treatment and their quality of motivation in the recovery process. With regards structural aspects of care, patients’ engagement in treatment was most ostensible in therapeutic environments which focused on holistically treating the ED. Participant accounts suggest that concepts of positive health were more commonly embraced in residential treatment settings. Contrastingly, psychiatric and medical hospital settings were often identified as isolating, lonely and sometimes frightening experiences. As such, these treatment settings exacerbated perceptions of illness and powerlessness, and weakened patients’ engagement with treatment services. A multimodal treatment approach was deemed important to adequately address the medical, social and psychological elements associated with patients’ ED. Individual and group therapeutic sessions were important in supporting patients’ psychological needs for autonomy, relatedness and competency. Non-traditional treatment programmes, which were often

experienced as fun and interesting, further enhanced patients' quality of motivation in the therapeutic process.

When patients were autonomously motivated, their engagement in the therapeutic process and willingness towards positive change was enhanced. However, participant accounts of treatment experiences illustrated frequent experiences of coercive pressure and controlled types of motivation. Coercion was most commonly experienced during entry into services and in addressing the physical aspects of ED (i.e., weight gain). Treatment approaches based on contingent rewards and punishments negatively impacted on patients' emotional wellbeing and engagement in therapy. These results are in line with the tenets of SDT which infer that, patients' quality of motivation for treatment is undermined and sustainment of long-term behaviour change is compromised when the perceived environment is controlling (Ryan & Deci, 2008). Conversely, perceptions of collaboration in treatment decisions and a sense of responsibility for food choices and mealtimes increased patients' willingness to embrace the aims of treatment. As such, experiencing a sense of volition in decision-making towards behaviour change was important in fostering patients' autonomous engagement in treatment.

The therapeutic relationship was often experienced as a positive motivating agent for patients' engagement in the therapeutic process. Specifically, for some patients, a strong therapeutic alliance was effective in altering patients' ambivalence toward positive change. Participants' accounts illustrated that a successful interpersonal process was contingent upon both the humanistic and professional qualities exhibited by

health care providers. Participants identified several therapeutic components as crucial in fostering their engagement in the therapeutic process. Of particular importance were perceptions of reciprocity, trust, and a sense of connectedness. During adolescent stages of their ED, when patients perceived the interpersonal process as encompassing many therapeutic components similar to that of a friendship, their willingness to engage in the therapeutic process was enhanced.

Participants differentiated between the practical and relational knowledge of health care providers and appreciated a combination of both forms of knowledge in appropriately understanding and treating the idiosyncrasies of each individual's ED. Perceptions of lack of therapist understanding and competence often led to disengagement and drop-out from treatment. Other commonly cited negative interpersonal experiences included; perceptions of inequality, invalidation of patient experiences, and inconsistency with therapists. Such experiences significantly impaired the sense of relatedness between patient and therapist, and in turn weakened patients' engagement in the therapeutic process. Communicating and interacting with other ED individuals was evaluated both positively and negatively. However, participants unanimously acknowledged that interacting with other ED patients was a crucial component in the recovery process.

Treatment approaches that focused on weight and pathology were negatively evaluated as they failed to attend to the emotional and cognitive mechanisms which participants often felt were the crux of their disorder. In contrast, when patients were autonomously supported to identify the source of their ED problems and to explore the

emotional and psychological mechanisms associated with their ED, their engagement in the therapeutic process increased. In these instances, perceptions of competency toward maintaining positive change were fostered. As such providing autonomy support for self-exploration was effective in harnessing patients' interest in the therapeutic process.

Chapter Five:

DISCUSSION

DISCUSSION

The purpose of this research was to explore qualitatively the treatment experiences and expectations of eating disorder patients in the Republic of Ireland. In addition, this research sought to interpret the thematic findings of patients' experiences in light of self-determination theory (Deci & Ryan, 1985; Ryan & Deci, 2000). The findings of the analysis revealed that both structured and unstructured characteristics associated with the treatment environment impacted significantly on patients' experiences of care. Specifically, the initial inductive thematic analysis established the super-ordinate theme of 'the therapeutic milieu'. This was composed of a number of sub-ordinate themes, namely; treatment setting and programme structure, being in control versus being controlled, understanding and support and, exploring and maintaining positive change. The main findings pertinent to each sub-ordinate theme will be discussed below with respect to existing literature. Limitations of the study will be outlined and indications for further research that ensue from the findings will also be explored. Recommendations which may be applicable to clinical practice and policy will be identified.

5. 1. Qualitative Findings

5. 1. 1. Treatment Setting and Programme Structure

Previous qualitative investigations have surmised that the context in which care is received impacts significantly on patient experiences of treatment (Eivors et al., 2003). As such, both structured and unstructured components of health care have been

identified in the composition of the therapeutic milieu (Thomas, Shattell & Martin, 2002). Although unstructured aspects of care (e.g. interpersonal relationships) are commonly identified as impacting most significantly on treatment experiences (Bell, 2003), both researchers and patients attest to the importance of structural attributes of the care environment and the organisation of care delivery in shaping patient experiences of treatment (Donabedian, 1988; Eivors et al., 2003; Meyer & Massagli, 2001; Offord et al., 2006; Thomas et al., 2002). Moreover, an important linkage between structure of services, processes of care and treatment outcome has previously been deduced (Donabedian, 1988; Meyer & Massagli, 2001).

Treatment Context

In the current study, psychiatric or medical hospital environments often augmented participants' sense of illness, a finding which echoes through previous ED qualitative investigations (Eivors et al., 2003; Offord et al., 2006). As such, participants negatively evaluated a treatment environment in which they felt like a powerless or helpless patient but instead valued receiving treatment in an environment which recognised the patient as an individual devoid of their illness. Positive and helpful treatment experiences were most frequently associated with residential treatment environments, as they fostered perceptions of normality and encouraged the development of supportive relationships. In addition, participants reported greater willingness to engage in a treatment which focused on empowering patients toward positive change. This aligns closely with the theoretical perspective of *salutogenesis* (Antonovsky, 1979), which emphasises factors promoting health and emphasises the coping abilities and existing resources of the patient, as opposed to focusing on the

development of illness. Congruently, recent empirical research provides support for the effectiveness of interventions based on salutogenic treatment principles in the treatment of mental health disorders. In their randomised controlled trial, Langeland et al. (2006) found that implementing salutogenic treatment principles in therapeutic interventions significantly increased coping capacity for people with mental health problems.

Participants' narratives also suggest that psychiatric and medical hospital environments impacted negatively on participants' emotional well-being. Similar to the findings of Lilja & Hellzén (2008) who explored former patients' experiences of psychiatric care, participants described receiving treatment in a medical setting as lonely and isolating. In the context of ED, Offord and colleagues (2006) found that the psychiatric environment induced perceptions of abnormality, which negatively impacted on patients' sense of selves. Inpatient treatment environments are also frequently associated with patient perceptions of loss of control, which in turn has been associated with poor emotional wellbeing and psychological distress (Williams, Dawson & Krisjanson, 2008; Williams & Irurita, 2005). In their randomized study comparing the treatment environment in residential and hospital-based acute psychiatric care in a sample of veteran patients, Hawthorne, Green, Folsom & Lohr (2009) found that the residential treatment environment was associated with lower costs, equivalent or better patient outcomes, and more positive patient satisfaction ratings. In conjunction with the findings of the current investigation, it is reasonable to assume that psychiatric settings may perpetuate illness perceptions and a sense of loss of control, which in turn thwart adaptive motivational processes. Contrastingly, residential treatment environments can

effectively engage patients in the therapeutic process and facilitate the establishment of supportive therapeutic relationships, thus promoting patients' basic psychological needs.

Components of Care

Results from this qualitative investigation also provide support for the utility of multimodal treatment interventions as a means of engaging patients in treatment and addressing the complexity of the ED as a transdiagnostic illness. In the current study, participants who had experienced alternative therapeutic modes of therapy considered them an important component of treatment because they fostered an interest and curiosity in the therapeutic process. Previous patient-centred research has found that patients themselves evaluate a multi-modal treatment approach as a particularly helpful component of ED treatment interventions (Linville et al., 2012). Extant research also posits an important role for non-traditional or alternative treatment modalities, particularly in the treatment of adolescent ED. McFerran and colleagues (2006) infer that creative therapeutic modalities are particularly appropriate for engaging adolescent patients in therapy, and can be successful in encouraging disclosure and facilitating insight for patients.

The Organisation of Service Delivery

For several participants, it was important to have a multi-disciplinary health-care team coordinating their treatment. Specifically, patients appreciated when issues concerning food and weight status were restricted to treatment sessions with one designated health care professional (e.g. dietician), thus allowing their group and individual therapeutic sessions to focus on the emotional and cognitive aspects of their

ED. This finding bolsters the conceptualisation of Eivors and colleagues (2003) concerning the ‘dual role’ of the therapist - where the therapist is associated with dual roles of managing physical issues and governing psychotherapy. Eivors and colleagues suggest that, although commonly observed in clinical practice, assigning these dual roles to the same therapist can compromise the aims and outcome of therapy for patients. Accordingly, the authors suggest that separate therapists are needed to focus on the long-term psychotherapeutic goals of treatment and management of weight gain.

5. 1. 2. Being in Control Versus Being Controlled

Fostering Patient’s Initial Engagement

These results also suggest that a collaborative approach in the delivery of both medical and non-medical ED care can foster and maintain patients’ engagement in the therapeutic process. Participants’ accounts illustrated that voluntary engagement in treatment was associated with more intrinsic forms of motivation, and consequently, greater engagement in treatment interventions. A treatment approach which encouraged patients to actively collaborate in their care decision proved successful in encouraging patients to engage with positive behaviour change. These findings are reflected in previous qualitative investigations which assert that, the degree to which ED patients perceive themselves as being actively involved in treatment decisions, often forms a significant element in their evaluation of treatment (Colton & Pistrang, 2004; Geller et al., 2003; Offord et al., 2006).

Not surprisingly, a wealth of research attests to the importance of ‘client-focused’ treatment interventions (Corstophine, 2006; de la Rie et al., 2008; Geller et al., 2003; Offord et al., 2006). The findings of the current investigation concur with previous research which infers that, collaborative approaches to treatment are associated with; decreasing patient’s ambivalence towards change (Keski-Rahkonen & Tozzi, 2005), encouraging and maintaining patients’ engagement in the therapeutic process (Reid et al., 2008) and fostering patient empowerment (Aujoulat, Luminet & Deccache, 2007; Offord et al., 2006).

Autonomous Versus Controlled Motivation: Implications for Therapeutic Engagement

The findings of the current investigation also lend considerable support to one of the primary tenets of SDT - that autonomous motivation and controlled motivation lead to diverse therapeutic outcomes. Within SDT, the experience of a sense of autonomy or volition with respect to one’s behaviour represents a critical condition for the personal endorsement (i.e. internalisation) of therapeutic change (Vandereycken & Vansteenkiste, 2009). Participants’ accounts demonstrated that patients who experienced a sense of volition in decision-making towards behaviour change illustrated greater autonomous engagement in the therapeutic process. This is in line with previous psychotherapeutic research which infers that, when patients are more autonomously motivated for treatment they are less likely to dropout, more likely to experience greater therapeutic progress and exhibit enhanced well-being, compared to when their motivation is externally controlled (Mansour et al., 2012; Zuroff et al., 2007). In their quasi-experimental study comparing autonomy-supportive and directive treatment strategies

during the admission process in the treatment of ED patients, Vandereycken & Vansteenkiste (2009) found that the provision of choice and responsibility to ED patients at the beginning of treatment significantly reduced dropout during the first weeks of inpatient treatment.

Investigating autonomous motivation for therapy in a sample of depressed patients, Zuroff et al. (2007) found that patients experienced better outcomes (symptom remission and reduction) when they were more autonomously motivated for treatment. Congruently, McBride et al. (2010) found that controlled motivation emerged as a significant negative predictor of remission of depressive symptoms. In the context of ED, Mansour et al. (2012) found that autonomous motivation was a strong predictor of treatment outcome in bulimia-spectrum eating disorders (BSED). Specifically the authors found that greater autonomous motivation was associated with a decrease in binge eating post-treatment. Ryan & Deci (2008) infer that greater autonomous motivation in the therapeutic process is associated with a greater likelihood of integrating learning and behaviour change, thus resulting in more positive outcomes.

5. 1. 3. Understanding and Support

Motivational Implications of the Therapeutic Alliance

A plethora of patient-centred research consistently underscores the significance of the therapeutic alliance to psychotherapeutic success in the treatment of mental health illnesses, including ED (Cockell et al., 2004; Leavey et al., 2011; Linville et al., 2012). In the current study, the therapeutic alliance was identified as a fundamental source of

patient's motivation for treatment. This is in accordance with previous patient-centred research which widely acknowledges the significant impact of the therapeutic interpersonal process on ED patients' experiences of treatment (Linville et al., 2012; Pettersen & Rosenvinge, 2002). Moreover, the therapeutic alliance has previously been identified as an important vehicle for motivating positive change within ED patients (Ryan et al., 2011). In the current study, participants identified several therapeutic qualities deemed crucial for fostering and maintaining their engagement in the therapeutic process, including; compassion, trust, perceived sincerity and emotional responsiveness toward patient experiences. These findings are consistently documented in the eating disorder literature (de la Rie et al., 2008; Espindola & Blay, 2009; Linville et al., 2012; Tantillo, 2004; Williams & Reid, 2010). In the current study, failure to establish a strong sense of connectedness with therapists also resulted in poor quality of motivation in the therapeutic process. According to SDT, the sense of being cared for and connected with another is crucial to the internalisation and valuing of the therapeutic process (Ryan & Deci, 2008). Ryan et al. (2008) posit that supports for relatedness impact positively on patients' likelihood of complying with therapeutic guidance and feedback.

Reciprocal Exchange within the Therapeutic Alliance

Perceptions of reciprocity within the therapeutic alliance were important to both adult and adolescent patients in the current investigation. Perceived reciprocity fostered a sense of equivalence and encouraged patient self-disclosure. Therapist' use of self-disclosure often enhanced patients' candid disclosure of illness experiences. Therapist self-disclosure was associated with a positive experience of the therapeutic relationship;

a finding previously alluded to by Barrett & Berman (2001). This finding lends some support to previous research investigating various components of psychotherapy. Tantillo (2004) asserts that adolescents respond particularly well to therapist self-disclosure because they often seek authenticity and self-disclosure from therapists. This supposition is somewhat evidenced in our findings, since participants reported the importance of a sense of friendship within the therapeutic alliance during adolescent stages of their ED. Specifically, our findings suggest that in the context of adolescent ED, therapist self-disclosure fosters perceptions of mutuality and reciprocity, and this in turn successfully encourages patients' engagement in the therapeutic process. During adult stages of their ED, participants reported that therapist self-disclosure was deemed more important for enhancing perceptions of competency (i.e. modelling effective coping techniques) than to foster therapeutic rapport.

The concept of therapist self-disclosure is subject to ongoing debate (Barrett & Berman, 2001; Tantillo, 2004). On the one hand, advocates of this therapeutic strategy deduce that it can strengthen the therapeutic relationship and promote positive change (Knox & Hill, 2003; Tantillo, 2004). In their comparative study employing conditions of heightened and reduced therapist disclosure, Barrett & Berman (2001) found that therapist self-disclosure not only proved successful in therapy but also had a positive impact on treatment (e.g. decreasing levels of symptom distress). On the other hand, it is also argued that this therapeutic strategy may inadvertently increase the probability of shifting the focus of therapy away from the client (Knox & Hill, 2003). Accordingly, the use of therapist self-disclosure in psychotherapy is often cautioned.

Practitioner Expertise: Knowledge and Understanding

In the current study, participants distinguished between various types of health care provider knowledge and understanding. For patients, the most basic level of understanding entailed a rudimentary knowledge of ED processes and efficient treatment procedures and an advanced level of understanding comprised a knowledge and awareness of the idiosyncrasies of each individual's ED. Donabedian (1988) previously identified two primary knowledge components in the performance of practitioners – technical knowledge and interpersonal knowledge. Congruently, in their qualitative investigation of inpatient ED treatment experiences, Malson et al. (2004) differentiated between 'medical knowledge' and a further type of knowledge which views the patient holistically.

In the current investigation, not having one's individuality recognised was deemed detrimental to the therapeutic process, because health care providers were failing to see the individual beyond the symptoms of their illness. These findings are well evidenced in previous qualitative investigations (Colton & Pistrang, 2004; Malson et al., 2004; Offord et al., 2006; Pettersen & Rosenvinge, 2002). Specifically, Malson and colleagues conclude that embracing a purely medical knowledge of ED merely views the patient in terms of their pathology and prevents the establishment of an individuated and personalised knowledge unique to each patient. Moreover, the authors suggest that failure to obtain a holistic understanding of the patient may form the basis of treatment resistance in ED patients. Findings of the current study offer some support for this latter supposition since participants' accounts revealed that failure to understand the individual devoid of their ED impacted negatively on patients' engagement in the

therapeutic process. SDT theorists posit that psychological need support is evident, and optimal functioning promoted when need-supportive partners endeavour to understand the interests, preferences and perspectives of the individual (La Guardia & Patrick, 2008).

Connecting with Similar Others

Participants' accounts also suggest that having the opportunity to meet and connect with similar others can impact both positively and negatively on patients' motivation during treatment. Positive consequences associated with interactions with fellow patients included; decreased loneliness and isolation, and normalisation of the illness experience. Communicating with similar others often stimulated and enhanced positive personal resources within patients. The understanding and optimism attained through communicating with recovered ED individuals was helpful in motivating the desire to change. On the other hand, several negative consequences also ensued through interactions with other ED patients, particularly in the context of inpatient treatment experiences. The most commonly cited consequences included; competition with other patients and adoption of negative coping strategies, both of which resulted in increased distress. These findings resonate with findings from extant literature focused on ED treatment experiences (Colton & Pistrang, 2004; Eivors et al., 2003; Espindola & Blay, 2009; Linville et al., 2012; Keski-Rahkonen & Tozzi, 2005; Offord et al., 2006; Pettersen & Rosenvinge, 2002).

Although participants acknowledged the negative implications (physical comparison, competition) of interactions with other ED patients, all participants concurred that interpersonal support from other ED individuals was an important

component in their recovery process. Offord et al. (2006) suggest that patients may only be vulnerable to negative consequences at certain stages of their illness and recovery. However, Colton & Pistrang (2004) found that comparison and competition with other ED patients caused significant distress to patients even when they were nearing discharge. Similarly, Keski-Rahkonen & Tozzi (2005) found that participants positively evaluated group support in the early stages of change, but reported it as a hindering factor in the latter stages of recovery.

5. 1. 4. Exploring and Maintaining Positive Change

The Focus of Treatment

Not surprisingly, participants negatively evaluated treatment approaches which primarily emphasised the physical aspects of their disorder and negligibly focused on the emotional and psychological components. This is a particularly recurrent finding in the qualitative literature on eating disorders (Malson et al., 2004; Offord et al., 2006). Participants' accounts revealed that medically-oriented interventions weakened patients' engagement in the therapeutic process and undermined patient's perceptions of competency toward maintaining positive change. Previous patient-centred research highlights the consequences of a treatment approach narrowly focused on food, eating, and body weight (Eivors et al., 2003; Federici & Kaplan, 2008) and concurs that when weight gain and behavioural reduction form the core of ED treatment interventions, it is not only perceived as unhelpful by patients, but often also impedes recovery (Linville et al., 2012). Findings of the current study echo those of previous investigations, which deduce that, a medically-oriented approach to the treatment of ED induces a sense of

loss of control (Reid et al., 2008), reinforces ED cognitions and behaviours (Eivors et al., 2003) adversely affects patient engagement within the therapeutic process (Espindola & Blay, 2009) and compromises long-term recovery (Colton & Pistrang, 2004; Malson et al., 2004). Research concurs that medically-based interventions are insufficient to address the psychological underpinnings of eating disorders (Cockell et al., 2004) and thus, treatment interventions need to embrace wider psychological issues specific to the individual (Reid et al., 2008). This is congruent with current best practice recommendations (NICE, 2004).

Attending to Emotions and Cognitions

The majority of participants stated that in order to progress towards recovery, they needed to acquire a degree of insight and understanding specific to their own personal experiences. As such, being provided with opportunities to explore and identify the emotional and psychological underpinnings of their ED were deemed crucial for recovery. These findings are in line with previous research (Colton & Pistrang, 2004; de la Rie et al., 2008; Eivors et al., 2003; Vanderlinden et al., 2007). For example, participants in the current investigation also reported that emotional awareness and an increased sense of mastery of emotional expression were important aspects of their recovery process. Congruently, the value of focusing on enhancing emotion regulation skills in the treatment of eating disorders has been highlighted previously as an effective approach for reducing patients' need to engage in maladaptive coping behaviours (Corstorphine, 2006) and increasing patients' self-esteem and perceptions of control (Federici & Kaplan, 2008). SDT theorists propose the importance of *mindful awareness*

(awareness of emotions, introjects and painful experiences) in encouraging patients to integrate feelings, experiences and introjects (Ryan & Deci, 2008). Greater mindfulness is associated with more autonomous regulation, and autonomy-supportive therapists encourage patients to take an interest in, and become more aware of their emotions (Ryan & Deci, 2008).

Sustaining Change: Exploring Core Problem Areas and Developing Competencies

In the current study, participants also recognised the need to develop skills and tools which would enable them to confront enduring ED problems. When participants felt they were successfully developing and refining the adequate cognitive and emotional skills and tools required to sustain positive change, their self-determined motivation for recovery was enhanced. Previous research has also demonstrated that assuming responsibility, gaining autonomy and developing coping skills are identified as important aspects of treatment for ED patients (de la Rie et al., 2008; Reid et al., 2008; Vanderlinden et al., 2007).

Participants' accounts illustrated that an autonomy-supportive context which provided opportunities for self-reflection and self-exploration were crucial in sustaining patients' engagement in the therapeutic process. Exploratory exercises have also previously been identified as effective therapeutic strategies to enhance motivation to change (Ryan et al., 2011). According to SDT, health care practitioners facilitate integration by supporting patients as they explore resistances and barriers to change, and aid them in identifying pathways to positive change (Ryan et al., 2008).

In the context of therapeutic change, Ryan et al. (2011) deduce that experiential and exploratory exercises in therapy can often be experienced as challenging and interesting, which in turn can effectively enhance patients' quality of motivation in the change process. This is an important assertion for clinical practice since research concurs that most health-related behaviours are not intrinsically motivated or inherently enjoyable activities (Markland et al., 2005; Ryan et al., 2008; Ryan et al., 2011; Vansteenkiste & Sheldon, 2006). Congruently, Vansteenkiste et al. (2005) deduce that behaviour change in ED treatment is rarely experienced as an enjoyable activity. Thus, in order for patients to identify themselves with change, the regulation of the 'non-enjoyable activity' must be internalised gradually (Vansteenkiste et al., 2005). Given the egosyntonic nature of many ED symptoms, in addition to the significant ambivalence ED patients often embrace towards recovery, it is reasonable to surmise that, facilitating processes of internalisation and regulation of positive behaviour change may be important objectives to target in psychotherapy when working with this clinical population.

Optimal Therapeutic Challenges: Advancement in Treatment

The need to be 'challenged' was consistently evidenced throughout participants' accounts. Specifically, patients associated optimal therapeutic challenges with progression towards recovery. This was most commonly achieved through frequent therapeutic sessions structured to the patients' individual needs and appropriate to their level of progression in treatment. SDT theorists posit that the provision of clear, consistent, and reasonable expectations and structure nurtures patients' psychological

needs and promotes optimal functioning (La Guardia & Patrick, 2008). In particular, the provision of structure supports competence, because therapists generate opportunities for the patient to expand their skills in an ideally challenging way and provide clear feedback and guidance in order to help the patient initiate and activate action (Ryan et al., 2011). The provision of clear feedback and guidance was also pivotal to fostering perceptions of competency in the recovery process and in enhancing patients' intrinsic motivation toward positive change. These findings are in accordance with SDT which surmises that, when patients are afforded the skills and tools for change in an autonomy-supportive environment, their psychological need for competency is supported. (Ryan et al., 2008). Reid et al. (2008) reported that patients sought clear guidance and goal setting in treatment because they felt that emotional support alone was insufficient to motivate positive change.

Psychological Needs Change during the Recovery Process

Analysis of participants' accounts also suggest that the extent to which patients' psychological needs are met may be differ in importance at various stages throughout the therapeutic process. Specifically, results tentatively suggest that interpersonal processes and relatedness support may play a greater role in harnessing patients' *initial* engagement in the therapeutic process. Contrastingly, perceptions of competence appear to encompass a greater role in *maintaining* engagement towards positive change. Participants' accounts suggest that 'a sense of friendship' in the therapeutic relationship was of greatest significance during adolescent stages of their illness, whereas the professional capabilities of therapists were of greater importance to patients during adult

stages of their ED. Previous research also provides some preliminary evidence to support the supposition of variations in need satisfaction over the course of behaviour change. In the domain of health and exercise, Edmunds et al. (2007) reported that the need for relatedness was of greatest significance during the *initial* stages of exercise adoption (i.e. adherence to behaviour change). Investigating the evaluation of the quality of ED treatment, De la Rie et al. (2008) found that whereas current patients valued “being accepted as you are”, former patients valued “learning to take your own responsibility” more highly.

5. 2. *Limitations*

The findings of this study must be considered in light of a number of methodological issues. This is an exploratory qualitative study with a small sample size which limits the conclusions which can be drawn and the generalizability of results beyond the participants of this study. Further research is needed to assess the commonality of these findings for a broader spectrum of patients, including both males and females treated with an eating disorder within the Republic of Ireland. Moreover, the findings of the current investigation are limited to a female sample of adult ED patients. Findings from previous investigations in this domain suggest that important differences exist between adolescents and adult patients, which are pivotal to consider in the evaluation and treatment of ED (Fisher et al., 2001). For example, Fisher and colleagues (2001) documented significant differences between their adolescent and adult samples in terms of diagnosis, illness severity, denial of illness and desire for help. With regards denial of illness, 21% of adolescents exhibited total denial about their ED

compared to 11% of adults. Not surprisingly, desire for help was significantly stronger amongst adult patients (32%) compared to their adolescent sample (18%). Research explicitly focused on comparing the treatment experiences of both adolescent and adult ED patients is infrequent in the literature base on ED. In line with this, future studies should seek to employ a sample of adolescent and adult ED patients and examine similarities and difference across age cohorts.

A second issue concerns the quality and validity of participants' accounts. One might question the accuracy of participants' descriptions of their treatment experiences. Accuracy of participants' accounts may have been further influenced by retrospective recall, particularly in the case of discharged patients. As such, prospective research is necessary for a more reliable assessment of patients' health care experiences throughout their entire treatment journeys. With respect to current patients, recollection of therapeutic factors that contributed to their treatment experience may have been influenced by their current state of illness. However, exploratory qualitative approaches aim to gain an understanding of respondents' perceptions and experiences as opposed to an objective description of events. The unequal representation of current (n=11) and discharged (n=3) patients must also be noted. The inclusion of more discharged patients would have provided greater insight into the entire treatment spectrum.

A third issue concerns researcher bias. As in any qualitative investigation, subjectivity and previous background of the researcher could have influenced the design, data collection and analytic processes. Strict adherence to rigorous quality guidelines, frequent discussions concerning the progression of the analysis by the

primary and secondary researcher, use of a reflexive journal and verification of identified concepts in the literature may have helped to reduce subjectivity in the current investigation.

5. 3. Implications for Clinical Practice and Health Care Policy

The findings of this study have important clinical implications, both for increasing knowledge of the therapeutic process for treating ED patients and for the possibility of enhancing clinical practice through more advanced understanding. Most significantly, this study makes an important contribution to the dearth of information concerning the treatment experiences of ED patients in the Republic of Ireland. The current investigation provides important clinical recommendations concerning both structured and unstructured components of care in the treatment of disordered eating, and provides direction for the creation of therapeutic environments conducive to supporting patients' psychological needs for autonomy, relatedness and competency. Donabedian (1988) suggests that in order to accurately capture the concept of treatment quality, *structural* aspects of care need to be evaluated. Findings from the current investigation identify opportunities for future service-reorganisation to improve the quality and efficacy of care provided.

The current investigation represents an important progression in bridging the gap between research evidence and service provision, which has been previously identified as an important priority to advance the suboptimal care commonly received by ED patients (Fairburn & Harrison, 2003). Training primary care practitioners and mental health clinicians to treat ED with straightforward, accessible techniques has been

identified as a national health priority as outlined in the recent *National Mental Health Programme Plan* (HSE, 2011). The findings of the current study provide some direction to facilitate and accelerate progress on this issue.

Specifically, the findings of this study provide an explanation of the underlying processes, tasks and individual strategies associated with harnessing ED patients' volitional engagement in the therapeutic process. Therapeutic strategies which enhance the engagement of ED patients in the therapeutic process include; holistic conceptualisation of illness and treatment, reciprocal exchange between patient and therapist, continuity within the therapeutic alliance, provision of control and choice in the change process, and validation of patient experiences. Other therapeutic strategies were deemed crucial in enabling patients to develop and hone the necessary emotional and cognitive skills required for long-term, positive change, including; a focus on emotion regulation, encouraging development of positive self-definitions, provision of clear feedback and guidance, and engaging patients in processes of self-exploration and reflection. Therapeutic strategies which weaken the engagement of ED patients in the therapeutic process include; use of coercion to incite change (e.g. forced weight gain), imposing physical limitations on patients (e.g. bed rest), discontinuity in the therapeutic alliance, a predominant focus on behaviour and weight and, a treatment focused on conditional rewards and punishments. Most importantly, results suggest that particular therapeutic strategies can be more, or less, effective at particular points during the treatment trajectory. Since motivational deficits are recognised as barriers to treatment engagement in other psychiatric disorders (e.g. Britton et al., 2011), it is conceivable

that several findings from the current investigation may extend to other psychiatric populations.

5. 4. Future Research

Considering the importance patients ascribed to treatment environments that promoted a sense of normality in addition to treatment programmes which focused on enhancing patients' internal resources and coping capacity, further examination of treatment interventions based on salutogenic treatment principles could represent a compelling area of enquiry for future research. Indeed, mental health research agendas now call for a focus to shift from diagnosis and medication to the future potential associated with an individual's internal resources and coping proficiencies (Langeland et al., 2006). Future work investigating the motivational dynamics of therapeutic environments should seek to utilise a mixed methods design which incorporates both quantitative indices of motivation and qualitative data concerning patients' subjective experiences of treatment. For example, The Autonomous and Controlled Motivations for Treatment Questionnaire (ACMTQ; Zuroff et al., 2007) possibly represents a viable instrument. Moreover, a longitudinal research design would be useful in exploring patients' motivation throughout their entire treatment trajectory and in examining the relationship between socio-contextual variables and treatment outcome. A longitudinal research design would also permit the exploration of changes in psychological needs over the course of treatment, a supposition which has been tentatively postulated in former investigations (e.g. Edmunds et al., 2007). Since previous studies have identified the importance of facilitating processes of internalisation in the context of ED, future research may benefit from exploring how treatments and therapists can initiate processes

of internalisation and facilitate identified motivation in this often difficult-to-engage clinical population.

5. 5. Overall Conclusion

Findings from this qualitative investigation evidently demonstrate that both structured and unstructured components of care within the therapeutic milieu impact significantly on ED patients' quality of engagement and motivation for treatment. Perceptions of collaboration and a holistic approach to treatment were important for encouraging patients' initial engagement in treatment. Experiences of understanding and support within the therapeutic milieu were important in fostering perceptions of connectedness which were conducive towards valuing and adopting positive change. Practitioner support towards exploration of emotional and psychological aspects of the ED were associated with enhancing patients' autonomous motivation in the recovery process. In sum, these results demonstrate that autonomy-supportive treatment contexts which provide support for patients' psychological needs for autonomy, competence, and relatedness successfully engage ED patients in the therapeutic process and enhance their quality of motivation towards positive change. These findings support the utility of applying the self-determination theory to the study of motivational dynamics in the treatment of ED. In light of the proposed significance of motivational dynamics on treatment engagement and adherence in ED populations (Vansteenkiste et al., 2005), mixed-methods, longitudinal research investigations would provide more insight into the influence of socio-contextual influences on ED patients' quality and quantity of motivation for treatment.

REFERENCES

REFERENCES

- Agras, W. S., Crow, S. J., Halmi, K. A., Mitchell, J. E., Wilson, G. T. & Kraemer, H. C. (2000). Outcome predictors for the cognitive behaviour treatment of bulimia nervosa: Data from a multisite study. *American Journal of Psychiatry*, *157*(8), 1302-1308.
- Allen, K. L., Fursland, A., Raykos, B., Steele, A., Watson, H. & Byrne, S. M. (2012). Motivation-focused treatment for eating disorders: A sequential trial of enhanced cognitive behaviour therapy with and without preceding motivation-focused therapy. *European Eating Disorders Review*, *20*, 232-239.
- Allmark, P.J., Boote, J., Chambers, E., Clarke, A., McDonnell, A., Thompson, A. & Tod, A. (2009). Ethical issues in the use of in-depth interviews: literature review and discussion. *Research Ethics Review*, *5*(2), 48-54.
- American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text revision). Washington, D.C.: Author
- Antonovsky, A. (1979). *Health, Stress, and Coping*. San Francisco: Jossey-Bass.

Arcelus, J., Bouman, W. P. & Morgan, J. F. (2008). Treating young people with eating disorders: transition from child mental health to specialist adult eating disorder services. *European Eating Disorders Review*, 16, 30-36.

Aujoulat, I., Luminet, O. & Deccache, A. (2007). The perspective of patients on their experience of powerlessness. *Qualitative Health Research*, 17(6), 772-785.

Bandura, A. (1977). Self-efficacy: toward a unifying theory of behavioral change. *Psychological Review*, 84(2), 191.

Bandura, A. (1986). Social foundations of Thought and Action. *Englewood Cliffs, NJ*.

Barrett, M. S. & Berman, J. S. (2001). Is psychotherapy more effective when therapists disclose information about themselves? *Journal of Consulting and Clinical Psychology*, 69(4), 597-603.

Becker, A. B., Burwell, R. A., Gilman, S. E., Herzog, D. B. & Hamburg, P. (2002). Eating behaviours and attitudes following prolonged exposure to television among Fijian adolescent girls. *British Journal of Psychiatry*, 180, 509-514.

Berkman, N. D., Lohr, K. N. & Bulik, C. M. (2007). Outcomes of eating disorders: A

systematic review of the literature. *International Journal of Eating Disorders*, 40, 293-309.

Bell, L. (2003). What can we learn from consumer studies and qualitative research in the treatment of eating disorders. *Eating and Weight Disorders*, 8(3), 181-187.

Bhadoria, R., Webb, K. & Morgan, J. F. (2010). Treating eating disorders: A review of the evidence. *Evidence Based Mental Health*, 13(1), 1-4.

Bissada, H., Tasca, G. A., Barber, A. M. & Bradwejn, J. (2008). Olanzapine in the treatment of low body weight and obsessive thinking in women with anorexia nervosa: A randomised, double-blind, placebo-controlled trial. *American Journal of Psychiatry*, 165, 1281-1288.

Blake, W., Turnball, S. & Treasure, J. (1997). Stages and processes of change in eating disorders: Implications for therapy. *Clinical Psychology and Psychotherapy*, 4(3), 186-191.

Bradley, E. H., Curry, L. A. & Devers, K. J. (2007). Qualitative data analysis for health services research: Developing taxonomy, themes and theory. *Health Services Research*, 42(4), 1758-1772.

Bramon-Bosch, E., Troop, N. A., & Treasure, J. L. (2000). Eating disorders in males: A

comparison with female patients. *European Eating Disorders Review*, 8, 321-328.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.

Britton, P. C., Patrick, H., Wenzel, A., & Williams, G. C. (2011). Integrating motivational interviewing and self-determination theory with cognitive behavioral therapy to prevent suicide. *Cognitive and Behavioral Practice*, 18(1), 16-27.

Brownley, K. A., Berkman, N. D., Sedway, J. A., Lohr, K. N. & Bulik, C. M. (2007). Binge eating disorder treatment: A systematic review of randomized controlled trials. *International Journal of Eating Disorders*, 40(4), 337-348.

Brouwer, M. A., Drummond, C. & Willis, E. (2012). Using Goffman's theories of social interaction to reflect first-time mothers' experiences with the social norms of infant feeding. *Qualitative Health Research*, 22(10), 1345-1354.

Bruch, H. (1962). Perceptual and conceptual disturbances in anorexia nervosa. *Obstetrical & Gynecological Survey*, 17(5), 730-732.

Bulik, C. M., Berkman, N. D., Brownley, K. A., Sedway, J. A. & Lohr, K. N. (2007).

Anorexia nervosa treatment: A systematic review of randomized controlled trials. *International Journal of Eating Disorders*, 40, 310-320.

Button, E. J., Benson, E., Nolleth, C. & Palmers, R. L. (2005). Don't forget EDNOS (eating disorder not otherwise specified): Patterns of service use in an eating disorders service. *Psychiatric Bulletin*, 29, 134-136.

Caelli, K., Ray, L. & Mill, J. (2003). 'Clear as mud': Toward greater clarity in generic qualitative research. *International Journal of Qualitative Methods*, 2(2), 1-13.

Campbell, M. (2009). Drop-out from treatment for the eating disorders: A problem for clinicians and researchers. *European Eating Disorders Review*, 17, 239-242.

Carlsen, B., Glenton, C., & Pope, C. (2007). Thou shalt versus thou shalt not: a meta-synthesis of GPs' attitudes to clinical practice guidelines. *The British Journal of General Practice*, 57(545), 971.

Clausen, L. (2004). Time course of symptom remission in eating disorders. *International Journal of Eating Disorders*, 36(3), 296-306.

Cockell, S. J., Geller, J. & Zatisoff, S. L. (2004). Maintaining change following eating disorder treatment. *Professional Psychology: Research and Practice*, 35(5), 527-534.

- Colton, A. & Pistrang, N. (2004). Adolescents' experiences of inpatient treatment for anorexia nervosa. *European Eating Disorders Review, 12*, 307-316.
- Corstophine, E. (2006). Cognitive-emotional-behavioural therapy for the eating disorders: Working with beliefs about emotions. *European Eating Disorders Review, 14*, 448-461.
- Couturier, J., Kimber, M., & Szatmari, P. (2013). Efficacy of family-based treatment for adolescents with eating disorders: A systematic review and meta-analysis. *International Journal of Eating Disorders, 46*(1), 3-11.
- Couturier, J. & Lock, J. (2006). What is recovery in adolescent anorexia nervosa? *International Journal of Eating Disorders, 39*(7), 550-555.
- Couturier, J., & Lock, J. (2007). A review of medication use for children and adolescents with eating disorders. *Journal of the Canadian Academy of Child and Adolescent Psychiatry, 16*(4), 173.
- Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory into Practice, 39*(3), 124-130.
- Crocker, J., & Knight, K. M. (2005). Contingencies of self-worth. *Current Directions in*

Psychological Science, 14(4), 200-203.

Crow, S. (2007). Eating disorder not otherwise specified: Next steps. *International Journal of Eating Disorders, 40, S104-S106.*

Currin, L., Schmidt, U. & Waller, G. (2007). Variables that influence diagnosis and treatment of the eating disorders within primary care settings: A vignette study. *International Journal of Eating Disorders, 40, 257-262.*

Currin, L., Waller, G., Treasure, J., Nodder, J., Stone, C., Yeomans, M. & Schmidt, U. (2007). The use of guidelines for dissemination of “best practice” in primary care of patients with eating disorders. *International Journal of Eating Disorders, 40(5), 476-479.*

Dalle Grave, R. (2011). Eating disorders: Progress and challenges. *European Journal of Internal Medicine, 22(2), 153-160.*

Dalle Grave, R. & Calugi, S. (2007). Eating disorder not otherwise specified in an inpatient unit: The impact of altering the DSM-IV criteria for anorexia nervosa and bulimia nervosa. *European Eating Disorders Review, 15, 340-349.*

Daly, A. & Walsh, D. (2009). *Activities of Irish Psychiatric Units and Hospitals 2008.* Health Research Board: Dublin.

Danner, U. N., Sanders, N., Smeets, P. A. M., van Meer, P., Adan, R. A. H., Hoek, H. W. & Van Elburg, A. A. (2012). Neuropsychological weaknesses in anorexia nervosa: Set-shifting, central coherence, and decision making in currently ill and recovered women. *International Journal of Eating Disorders*, 45(5), 685-694.

Davidson, L., Ridgway, P., Kidd, S., Topor, A. & Borg, M. (2008). Using qualitative research to inform mental health policy. *The Canadian Journal of Psychiatry*, 53(3), 137-144.

Dean, H. Y., Touyz, S. W., Rieger, E. & Thornton, C. E. (2008). Group motivational enhancement therapy as an adjunct to inpatient treatment for eating disorders: A preliminary study.

Deci, E. L. and Ryan, R. M. (1985). *Intrinsic Motivation and Self-determination in Human Behaviour*. New York: Plenum

Deci, E. L. and Ryan, R. M. (2008). Self-determination theory: A macrotheory of human motivation, development and health. *Canadian Psychology*, 49(3), 182-185.

De la Rie, S., Noordenbos, G., Donker, M. & van Furth, E. (2006). Evaluating the treatment of eating disorders from the patient's perspective. *International*

Journal of Eating Disorders, 39(8), 667-676.

De la Rie, S., Noordenbos, G., Donker, M. & van Furth, E. (2008). The quality of treatment of eating disorders: A comparison of the therapists' and the patients' perspective. *International Journal of Eating Disorders*, 41, 307-317.

Department of Health and Children. (2006). "A Vision for Change": Report of the expert group on mental health policy.

Donabedian, A. (1988). The quality of care. How can it be assessed? *JAMA*, 260(12), 1743-1748.

Downie, M., Mageau, G. A., & Koestner, R. (2008). What makes for a pleasant social interaction? Motivational dynamics of interpersonal relations. *The Journal of Social Psychology*, 148(5), 523-534.

Dray, J., & Wade, T. D. (2012). Is the transtheoretical model and motivational interviewing approach applicable to the treatment of eating disorders? A review. *Clinical Psychology Review*, 32, 558-565.

Eddy, K. T., Doyle, A. C., Hoste, R. R., Herzog, D. B. & le Grange, D. (2008). Eating disorder not otherwise specified in adolescents. *Journal of the American*

Academy of Child and Adolescent Psychiatry, 47(2), 156-164.

Edmunds, J., Ntoumanis, N., & Duda, J. L. (2007). Adherence and well-being in overweight and obese patients referred to an exercise on prescription scheme: A self-determination theory perspective. *Psychology of Sport and Exercise*, 8(5), 722-740.

Eisler, I., Dare, C., Russell, G. F., Szukler, G., le Grange, D., & Dodge, E. (1997). Family and individual therapy in anorexia nervosa: a 5-year follow-up. *Archives of General Psychiatry*, 54(11), 1025.

Eivors, A., Button, E., Warner, S. & Turner, K. (2003). Understanding the experience of drop-out from treatment for anorexia nervosa. *European Eating Disorders Review*, 11(2), 90-107.

Ensign, J. (2003). Ethical issues in qualitative health research with homeless youths. *Journal of Advanced Nursing*, 43(1), 43-50.

Escobar-Koch, T., Banker, J. D., Crow, S., Cullis, J., Ringwood, S., Smith, G., van Furth, E., Westin, K. & Schmidt, U. (2010). Service users' views of eating disorder services: An international comparison. *International Journal of Eating Disorders*, 43(6), 549-559.

- Escobar-Koch, T., Mandich, C. C. & Urzúa, R. F. (2012). Treatments for eating disorders: The patients' views, in Lobera, I.J. (Ed.), *Relevant topics in Eating Disorders*. InTech.
- Espíndola, C. R. & Blay, S. L. (2009). Anorexia nervosa treatment from the patient perspective: A metasynthesis of qualitative studies. *Annals of Clinical Psychiatry, 21*(1), 38-48.
- Fairburn, C. G. & Bohn, K. (2005). Eating disorder NOS (EDNOS): An example of the troublesome "not otherwise specified" (NOS) category in DSM-IV. *Behaviour Research and Therapy, 43*, 691-701.
- Fairburn, C. G., Cooper, Z., Bohn, K., O'Connor, M. E., Doll, H. & Palmer, R.L. (2007). The severity and status of eating disorder NOS: Implications for DSM-V. *Behaviour Research and Therapy, 45*, 1705-1715.
- Fairburn, C. G. & Harrison, P. J. (2003). Eating disorders. *The Lancet, 361*(9355), 407-416.
- Federici, A. & Kaplan, A. S. (2008). The patient's account of relapse and recovery in anorexia nervosa: A Qualitative Study. *European Eating Disorders Review, 16*, 1-10.

- Feeney, E., Noble, H., & Waller, G. (2007). Referral patterns to a specialist eating Disorder service: the impact of the referrer's gender. *European Eating Disorders Review, 15*(1), 45-49.
- Feld, R., Woodside, B., Kaplan, A. S., Olmsted, M. P. & Carter, J. C. (2001). Pretreatment motivational enhancement therapy for eating disorders: A pilot study. *International Journal of Eating Disorders, 29*, 393-400.
- Fichter, M. M. & Quadflieg, N. (2004). Twelve-year course and outcome of bulimia nervosa. *Psychological Medicine, 34*, 1395-1406.
- Fisher, M., Schneider, M., Burns, J., Symons, H. & Mandel, F. (2001). Differences between adolescents and young adults at presentation to an eating disorders program. *Journal of Adolescent Health, 28*, 222-227.
- Flahavan, C. (2006). Detection, assessment and management of eating disorders; How involved are GPs? *Irish Journal of Psychological Medicine, 23*(3), 96-99.
- Fox, A. P., Larkin, M., & Leung, N. (2011). The personal meaning of eating disorder symptoms: An interpretative phenomenological analysis. *Journal of Health Psychology, 16*(1), 116-125.

- Geller, J., Brown, K. E. & Srikameswaran, S. (2011). The efficacy of a brief motivational intervention for individuals with eating disorders: A randomised control trial. *International Journal of Eating Disorders*, 44(6), 497-505.
- Geller, J., Brown, K. E., Zaitsoff, S. L., Goodrich, S. & Hastings, F. (2003). Collaborative versus directive interventions in the treatment of eating disorders: Implications for care providers. *Professional Psychology: Research and Practice*, 34(4), 406-413.
- Gowers, S. & Bryant-Waugh, R. (2004). Management of child and adolescent eating disorders: The current evidence base and future directions. *Journal of Child Psychology and Psychiatry*, 45(1), 63-83.
- Gowers, S. G., Clark, A. F., Roberts, C., Byford, S., Barrett, B., Griffiths, A., Edwards, V., Bryan, C., Smethurst, N., Rowlands, L. & Roots, P. (2010). A randomised controlled multicentre trial of treatments for adolescent anorexia nervosa including assessment of cost-effectiveness and patient acceptability – the TOuCAN trial. *Health Technology Assessment*, 14(15), 1-98.
- Green, H., Johnston, O., Cabrini, S., Fornai, G. & Kendrick, T. (2008). General practitioner attitudes towards referral of eating-disordered patients: A vignette study based on the theory of planned behaviour. *Mental Health in Family Medicine*, 5, 213-218.

Greenwood, N., Key, A., Burns, T., Bristow, M. & Sedgwick, P. (1999). Satisfaction with in-patient services. Relationship to patient and treatment factors.

The British Journal of Psychiatry, 174, 159-163.

Grol, R., & Grimshaw, J. (2003). From best evidence to best practice: effective implementation of change in patients' care. *Lancet*, 362(9391), 1225-1230.

Grol, R. & Wensing, M. (2004). What drives change? Barriers to and incentives for achieving evidence-based practice. *Adopting Best Evidence in Practice*, 180, 57-60

Guarda, A. S. (2008). Treatment of anorexia nervosa: insights and obstacles. *Physiology & Behaviour*, 94(1), 113.

Guarda, A. S., Pinto, A. M., Coughlin, J. W., Hussain, S., Haug, N.A. & Heinberg, L.J. (2007). Perceived coercion and change in perceived need for admission in patients hospitalised for eating disorders. *American Journal of Psychiatry*, 164(1), 108-114.

Guba, E. G., & Lincoln, Y. S. (1981). *Effective Evaluation: Improving the Usefulness of Evaluation Results through Responsive and Naturalistic Approaches*. Jossey-Bass.

- Gueguen, J., Godart, N., Chambry, J., Brun-Eberentz, A. B., Foulon, C., Divac, S. M., Guelfi, J. D., Rouillon, F., Falissard, B. & Huas, C. (2012). Severe anorexia nervosa in men: Comparison with severe AN in women and analysis of mortality. *International Journal of Eating Disorders*, *45*, 537-545.
- Harvey, J. A. & Robinson, J. D. (2003). Eating disorders in men: Current considerations. *Journal of Clinical Psychology in Medical Settings*, *10*(4), 297-306.
- Hasler, G., Delsignore, A., Milos, G., Buddeberg, C. & Schnyder, U. (2004). Application of Prochaska's transtheoretical model of change to patients with eating disorders. *Journal of Psychosomatic Research*, *57*, 67-72.
- Hawthorne, W., Green, E., Folsom, D., & Lohr, J. (2009). A randomized study comparing the treatment environment in alternative and hospital-based acute psychiatric care. *Psychiatric Services*, *60*(9), 1239-1244.
- Hay, P. J., Mond, J., Buttner, P., & Darby, A. (2008). Eating disorder behaviors are increasing: findings from two sequential community surveys in South Australia. *PLoS One*, *3*(2), e1541.
- HSBC IRELAND (2006). Dieting behaviour among schoolchildren in Ireland. Research Factsheet No. 6. National University of Ireland Galway: Health Promotion

Research Centre.

HSE (2011). *National mental health programme plan: Consultation document*. Health Service Executive.

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277-1288.

Hudson, J. I., Hiripi, E., Pope, H. G. & Kessler, R. C. (2007). The prevalence and correlates of eating disorders in the national comorbidity survey replication. *Biological Psychiatry, 61*, 348-358.

Hugo, P., Kendrick, T., Reid, F. & Lacey, H. (2000). GP referral to an eating disorder service: Why the wide variation. *British Journal of General Practice, 50* 380-383.

Iacovino, J. M., Gredysa, D. M., Altman, M., & Wilfley, D. E. (2012). Psychological treatments for binge eating disorder. *Current Psychiatry Reports, 14*(4), 432-446.

Jenkinson, C., Coulter, A., Bruster, S., Richards, N. & Chandola, T. (2002). Patients' experiences and satisfaction with health care: Results of a questionnaire study of specific aspects of care. *Quality and Safety in Health Care, 11*, 335-339.

- Jones, A., Bamford, B., Ford, H. & Schreiber-Kounine, C. (2007). How important are motivation and initial body mass index for outcome in day therapy services for eating disorders? *European Eating Disorders Review*, 15, 283-289.
- Jorm, A.F., Kelly, C.M. & Morgan, A.J. (2007). Participant distress in psychiatric research: A systematic review. *Psychological Medicine*, 37, 917-926.
- Kaplan, A. S. & Garfinkel, P. E. (1999). Difficulties in treating patients with eating disorders: A review of patient and clinician variables. *Canadian Journal of Psychiatry*, 44(7), 665-670.
- Katzman, M. A., Bara-Carril, N., Rabe-Hesketh, S., Schmidt, U., Troop, N. & Treasure, J. (2010). A randomised controlled two-stage trial in the treatment of bulimia nervosa, comparing CBT versus motivational enhancement in phase 1 followed by group versus individual CBT in phase 2. *Psychosomatic Medicine*, 72, 656-663.
- Keel, P. K. & Brown, T. A. (2010). Update on course and outcome in eating disorders. *International Journal of Eating Disorders*, 43(3), 195-204.
- Keel, P. K., Brown, T. A., Holland, L. A. & Bodell, L. P. (2012). Empirical classification of eating disorders. *Annual Review of Clinical Psychology*, 8, 381-404.

- Keel, P. K., & Forney, K. J. (2013). Psychosocial risk factors for eating disorders. *International Journal of Eating Disorders, 46*(5), 433-439.
- Keel, P. K., & Haedt, A. (2008). Evidence-based psychosocial treatments for eating problems and eating disorders. *Journal of Clinical Child & Adolescent Psychology, 37*(1), 39-61
- Keel, P. K. Haedt, A. & Edler, O. (2005). Purging disorder: An ominous variant of bulimia nervosa? *International Journal of Eating Disorders, 38*(3), 191-199.
- Keel, P. K., Heatherton, T. F., Dorer, D. J., Joiner, T. E., & Zalta, A. K. (2006). Point prevalence of bulimia nervosa in 1982, 1992, and 2002. *Psychological medicine, 36*(01), 119-127.
- Keel, P. K., & Striegel-Moore, R. H. (2009). The validity and clinical utility of purging disorder. *International Journal of Eating Disorders, 42*(8), 706-719.
- Keski-Rahkonen, A. & Tozzi, F. (2005). The process of recovery in eating disorder sufferers' own words: An internet-based study. *International Journal of Eating Disorders, 37*, S80-S86.
- Khan, F. & Chowdhury, U. (2011). Eating disorders in children and adolescents. *British Journal of Medical Practitioners, 4*(1):a405.

- Knowles, L., Anokhina, A., & Serpell, L. (2012). Motivational interventions in the eating disorders: What is the evidence? *International Journal of Eating Disorders*, 46(2), 97-107.
- Knox, S. & Hill, C. E. (2003). Therapist self-disclosure: Research-based suggestions for practitioners. *International Journal of Clinical Psychology*, 59(5), 529-539.
- Kravitz, R.L. (2001). Measuring patients' expectations and requests. *Annals of Internal Medicine*, 134(9), 881-888.
- La Guardia, J. G. & Patrick, H. (2008). Self-determination theory as a fundamental theory of close relationships. *Canadian Psychology*, 49(3), 201-209.
- Langeland, E., Riise, T., Hanestad, B. R., Nortvedt, M. W., Kristoffersen, K., & Wahl, A. K. (2006). The effect of salutogenic treatment principles on coping with mental health problems: A randomised controlled trial. *Patient Education and Counseling*, 62(2), 212-219.
- Leavey, G., Vallianatou, C., Johnson-Sabine, E., Rae, S. & Gunpath, V. (2011). Psychosocial barriers to engagement with an eating disorder service: A qualitative analysis of failure to attend. *Eating Disorders*, 19, 425-440.

- le Grange, D. & Gelman, T. (1998). Patients' perspective of treatment in eating disorders: A preliminary study. *South African Journal of Psychology*, 28(3), 182- 187.
- Lilja, L., & Hellzén, O. (2008). Former patients' experience of psychiatric care: A qualitative investigation. *International Journal of Mental Health Nursing*, 17(4), 279-286.
- Linville, D., Benton, A., O'Neil, M., & Sturm, K. (2010). Medical providers' screening, training and intervention practices for eating disorders. *Eating Disorders*, 18(2), 110-131.
- Linville, D., Brown, T., Sturm, K. & McDougal, T. (2012). Eating disorders and social support perspectives of recovered individuals. *Eating Disorders: The Journal of Treatment & Prevention*, 20(3), 216-231.
- Lopez, C., Tchanturia, K., Stahl, D. & Treasure, J. (2012). Weak central coherence in eating disorders: A step towards looking for an endophenotype of eating disorders. *Journal of Clinical and Experimental Neuropsychology*, 31(1), 117-125.
- MacDonald, C. (2002). Treatment resistance in anorexia nervosa and the pervasiveness of ethics in clinical decision making. *Canadian Journal of*

Psychiatry, 47(3), 267- 270.

MacFarlane, A. & O'Reilly-de Brún, M. (2012). Using a theory-driven conceptual framework in qualitative health research. *Qualitative Health Research*, 22(5), 607-618.

Maher, C., & Nwachukwu, I. (2012). The challenge of managing severely ill patients with anorexia nervosa in Ireland. *Irish Journal of Psychological Medicine*, 29(2), 69-71.

Mahon, J. (2000). Dropping out from psychological treatment for eating disorders: What are the issues?. *European Eating Disorders Review*, 8(3), 198-216.

Malson, H., Finn, D. M., Treasure, J., Clarke, S. & Anderson, G. (2004). Constructing 'the eating disordered patient': A discourse analysis of accounts of treatment experiences. *Journal of Community and Applied Social Psychology*, 14, 473-489.

Mansour, S., Bruce, K. R., Steiger, H., Zuroff, D. C., Horowitz, S., Anestain, A. S. & Sycz, L. (2012). Autonomous motivation: A predictor of treatment outcome in bulimia-spectrum eating disorders. *European Eating Disorders Review*, 20, 116-122.

Markland, D., Ryan, R. M., Tobin, V. J. & Rollnick, S. (2005). Motivational

interviewing and self-determination theory. *Journal of Social and Clinical Psychology, 24*(6), 811-831.

Mays, N. & Pope, C. (2000). Qualitative research in health care: Assessing quality in qualitative research. *British Medical Journal, 320*, 50-52.

McBride, C., Zuroff, D. C., Ravitz, P., Koestner, R., Moskowitz, D. S., Quilty, L. & Bagby, R. M. (2010). Autonomous and controlled motivation and interpersonal therapy for depression: Moderating role of recurrent depression. *British Journal of Clinical Psychology, 49*, 529-545.

McFerron, K., Baker, F., Patton, G. C. & Sawyer, S. M. (2006). A retrospective lyrical analysis of songs written by adolescents with anorexia nervosa. *European Eating Disorders Review, 14*, 397-403.

McNicholas, F., Lydon, A., Lennon, R. & Dooley, B. (2009). Eating concerns and media influences in an Irish adolescent context. *European Eating Disorders Review, 17*, 208-213.

Meyer, G. S., & Massagli, M. P. (2001). The forgotten component of the quality triad: can we still learn something from "structure"? *Joint Commission Journal on Quality and Patient Safety, 27*(9), 484-493.

- Michalak, J., Klappheck, M. A., & Kosfelder, J. (2004). Personal goals of psychotherapy patients: The intensity and the “why” of goal-motivated behavior and their implications for the therapeutic process. *Psychotherapy Research, 14*(2), 193-209.
- Miller, W. R. & Rollnick, S. (1991). *Motivational Interviewing: Preparing People To Change Addictive Behaviour*. New York: Guilford Press.
- Miller, W. R. & Rollnick, S. (2002). *Motivational Interviewing: Preparing People For Change* (2nd ed.). New York: Guilford Press.
- Mitchell, J. E., & Crow, S. (2006). Medical complications of anorexia nervosa and bulimia nervosa. *Current Opinion in Psychiatry, 19*(4), 438-443.
- Mitchell, J. E., Crosby, R. D., Wonderlich, S.A., Hill, L., le Grange, D., Powers, P. & Eddy, K. (2007). Latent profile analysis of a cohort of patients with eating disorders not otherwise specified. *International Journal of Eating Disorders, 40*, S95- S98.
- Mitchell, J. E., Myers, T., Crosby, R., O’Neill, G., Carlise, J. & Gerlach, S. (2009). Health care utilisation in patients with eating disorders. *International Journal of Eating Disorders, 42*(6), 571-574.

- Mooney, E., Farley, H. & Strugnell, C. (2009). A qualitative investigation into the opinions of adolescent females regarding their body image concerns and dieting practices in the Republic of Ireland (ROI). *Appetite*, 52(2), 485-491.
- Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1(2), 13-22.
- National Institute for Clinical Excellence. (2004). Eating disorders: Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders. London: National Institute of Clinical Excellence.
- Noordenbos, G. & Seubring, A. (2006). Criteria for recovery from eating disorders according to patients and therapists. *Eating Disorders*, 14, 41-54.
- O'Brien, K. M. and Vincent, N. K. (2003). Psychiatric comorbidity in anorexia nervosa and bulimia nervosa: Nature, prevalence, and causal relationships. *Clinical Psychology Review*, 23, 57-74.
- O'Connor, E. A., Friel, S. & Kelleher, C. C. (1997). Fashion consciousness as a social influence on lifestyle behaviour in young Irish adults. *Health Promotion International*, 12(2), 135-139.

- Offord, A., Turner, H. & Cooper, M. (2006). Adolescent inpatient treatment for anorexia nervosa: A qualitative study exploring young adults' retrospective views of treatment and discharge. *European Eating Disorders Review, 14*, 377-387.
- O'Keane, V., Jeffers, A., Moloney, E. & Barry, S. (2004). Irish Psychiatric Association survey of psychiatric services in Ireland. *The Psychiatrist, 28*, 364-367.
- Palmer, R.L., Birchall, H., McGrain, L. & Sullivan, V. (2002). Self-help for bulimic disorders: a randomised controlled trial comparing minimal guidance with face-to-face or telephone guidance. *British Journal of Psychiatry, 181*, 230-235.
- Pelletier, L. G., Tuson, K. M. & Haddad, N. K. (1997). Client motivation for therapy scale: A measure of intrinsic motivation, extrinsic motivation, and amotivation for therapy. *Journal of Personality Assessment, 68*, 414-435.
- Peters, S. (2010). Qualitative research methods in mental health. *Evidence Based Mental Health, 13*(2), 35-40.
- Petterson, G. & Rosenvinge, J. H. (2002). Improvement and recovery from eating disorders: A patients perspective. *Eating Disorders, 10*, 61-71.
- Pike, K. M., Walsh, B. T., Vitousek, K., Wilson, G. T., & Bauer, J. (2003). Cognitive

behavior therapy in the posthospitalization treatment of anorexia nervosa. *American Journal of Psychiatry*, 160(11), 2046-2049.

Polivy, J. (1996). Psychological consequences of food restriction. *Perspective in Practice*, 96(6), 589-592.

Polivy, J. & Herman, C. P. (2002). Causes of eating disorders. *Annual Review of Psychology*, 53, 187-213.

Pope, H., Lalonde, J., Pindyck, L., Walsh, T., Bulik, C., Crow, S., ... & Hudson, J. (2006). Binge eating disorder: a stable syndrome. *American Journal of Psychiatry*, 163(12), 2181-2183.

Pope, C., van Royen, P. & Baker, R. (2002). Qualitative methods in research on healthcare quality. *Quality and Safety in Health Care*, 11(2), 148-152.

Pringle, J., Drummond, J., McLafferty, E., & Hendry, C. (2011). Interpretative phenomenological analysis: a discussion and critique. *Nurse researcher*, 18(3), 20-24.

Proschaka, J. O. & DiClemente, C. C. (1983). Stages and processes of self-change of smoking: Toward an integrative model of change. *Journal of Consulting and Clinical Psychology*, 51, 390-395.

- Pryor, T. L., Johnson, T., Wiederman, M. W. & Boswell, D. L. (1995). The clinical significance of symptom denial among women with anorexia nervosa: Another disposable myth? *Eating Disorders*, 3(4), 293-303.
- Reeves, S., Albert, M., Kuper, A., & Hodges, B. D. (2008). Qualitative research: Why use theories in qualitative research?. *British Medical Journal*, 337(7670), 631-634.
- Reid, M., Burr, J., Williams, S. & Hammersley, R. (2008). Eating disorders patients' views on their disorders and on an outpatient service: A qualitative study. *Journal of Health Psychology*, 13(7), 956-960.
- Richards, H.M. & Schwartz, L.J. (2002). Ethics of qualitative research: are there special issues for health services research? *Family Practice*, 19(2), 135-139.
- Roberts, M. E., Tchanturia, K. & Treasure, J. (2010). Exploring the neurocognitive signature of poor set-shifting in anorexia and bulimia nervosa. *Journal of Psychiatric Research*, 44, 964-970.
- Rockert, W., Kaplan, A. S. & Olmsted, M. P. (2007). Eating disorder not otherwise specified: The view from a tertiary care treatment centre. *International Journal of Eating Disorders*, 40, S99-S013.

- Rowel, D., Nolans, G. & O'Donnell, M. (2008). Eating disorders: best practice guidelines for dieticians. Health Service Executive.
- Ryan, R. M. & Deci, E. L. (2000). Self-determination theory and the facilitation of Intrinsic motivation, social development, and well-being. *American Psychologist*, 55, 68-78.
- Ryan, R. M. & Deci, E. L. (2008). A self-determination theory approach to psychotherapy: The motivational basis for effective change. *Canadian Psychology*, 49(3), 186-193.
- Ryan, R. M., Lynch, M. F., Vansteenkiste, M. & Deci, E. L. (2011). Motivation and autonomy in counselling, psychotherapy, and behaviour change: A look at theory and practice. *The Counselling Psychologist*, 39(2), 193-260.
- Ryan, R. M., Patrick, H., Deci, E. L. & Williams, G. (2008). Facilitating health behaviour change and its maintenance: Interventions based on self-determination theory. *The European Health Psychologist*, 10(1), 2-5.
- Ryan, R. M., Plant, R. W. & O'Malley, S. (1995). Initial motivation for alcohol treatment: Relations with patient characteristics, treatment involvement, and dropout. *Addictive Behaviours*, 20, 279-297.

- Rutherford, L. & Couturier, J. (2007). A review of psychotherapeutic interventions for children and adolescents with eating disorders. *Journal of the Canadian Academy of Child and Adolescent Psychiatry, 16*(4), 153.
- Schoen, E. G., Lee, S., Skow, C., Greenberg, S. T., Bell, A. S., Wiese, J. A. & Martens, J. K. (2012). A retrospective look at the internal help-seeking process in young women with eating disorders. *Eating Disorders, 20*(14), 14-30.
- Serpell, L., Treasure, J., Teasdale, J. & Sullivan, V. (1999). Anorexia nervosa: Friend or foe? *International Journal of Eating Disorders, 25*, 177-186.
- Serpell, L. & Treasure, J. (2002). Bulimia nervosa: Friend or foe? The pros and cons of bulimia nervosa. *International Journal of Eating Disorders, 32*, 164-170.
- Shafran, R., Cooper, Z. & Fairburn, C. G. (2002). Clinical perfectionism: A cognitive-behavioural analysis. *Behaviour Research and Therapy, 40*, 773-791.
- Shapiro, J. R., Berkman, N. D., Brownley, K. A., Sedway, J. A., Lohr, K. N. & Bulik, C. M. (2007). Bulimia nervosa treatment: A systematic review of randomized controlled trials. *International Journal of Eating Disorders, 40*(4), 321-336.
- Sharp, C. W. & Freeman, P. L. (1993). The medical complications of anorexia nervosa.

British Journal of Psychiatry, 162, 452-462.

Sheldon, K. M., Joiner, T. E., Pettit, J. W., & Williams, G. (2003). Reconciling humanistic ideals and scientific clinical practice. *Clinical Psychology: Science and Practice*, 10(3), 302- 315.

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22(2), 63-76.

Shinkwin, R. & Standen, P. J. (2001). Trends in anorexia nervosa in Ireland: A register study. *European Eating Disorders Review*, 9, 263-276.

Simon, J., Schmidt, U., & Pilling, S. (2005). The health service use and cost of eating disorders. *Psychological Medicine*, 35(11), 1543-1551.

Simon, J., Schmidt, U., & Pilling, S. (2005). The health service use and cost of eating disorders. *Psychological Medicine*, 35(11), 1543-1551.

Singh, S. P., Paul, M., Ford, T., Kramer, T. & Weaver, T. (2008). Transitions of care from child and adolescent mental health services to adult mental health services (TRACK Study): A study of protocols in Greater London.

BMC Health Services Research, 8, 135-141.

Singh, S. P. (2009). Transition of care from child to adult mental health services: The great divide. *Current Opinions in Psychiatry*, 22(4), 386-390.

Smink, F. R., van Hoeken, D., & Hoek, H. W. (2012). Epidemiology of eating disorders: Incidence, prevalence and mortality rates. *Current Psychiatry Reports*, 14(4), 406-414.

Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review*, 5(1), 9-27.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. SAGE Publications Limited.

Steinhausen, H. C. (2002). The outcome of anorexia nervosa in the twentieth century. *American Journal of Psychiatry*, 159, 1284-1293.

Stice, E., South, K. & Shaw, H. (2012). Future directions in etiologic, prevention, and treatment research for eating disorders. *Journal of Clinical Child and Adolescent Psychology*, 41(6), 845-855.

Støving, R. K., Andries, A., Brixen, K., Bilenberg, N., & Hørder, K. (2011). Gender

differences in outcome of eating disorders: A retrospective cohort study.
Psychiatry Research, 186, 362-366.

Striegel-Moore, R. H. & Bulik, C. M. (2007). Risk factors for eating disorders.
American Psychologist, 62(3), 181-198.

Striegel-Moore, R. H. & Franko, D. L. (2008). Should binge eating disorder be included
in the DSM-V? A critical review of the state of the evidence. *Annual Review of
Clinical Psychology*, 4, 305-324.

Strober, M., Freeman, R. & Morrell, W. (1997). The long-term course of severe
anorexia nervosa in adolescents: Survival analysis of recovery, relapse and
outcome predictors over 10-15 years in a prospective study. *International
Journal of Eating Disorders*, 22, 339-360.

Sullivan, P. F. (1995). Mortality in anorexia nervosa. *American Journal of
Psychiatry*, 152(7), 1073-1074.

Swain-Campbell, N. R., Surgenon, L. J. & Snell, D. L. (2001). An analysis of consumer
perspectives following contact with an eating-disorders service. *Australian
and New Zealand Journal of Psychiatry*, 35, 99-103.

Swartz, M. S. & Swanson, J. W. (2004). Involuntary outpatient commitment,

community treatment orders, and assisted outpatient treatment: What's in the data? *Canadian Journal of Psychiatry*, 49(9), 585-591.

Tan, J. O., Stewart, A., Fitzpatrick, R. & Hope, T. (2010). Attitudes of patients with anorexia nervosa to compulsive treatment and coercion. *International Journal of Law Psychiatry*, 33, 13-19.

Tantillo, M. (2004). The therapist's use of self-disclosure in a relational therapy approach for eating disorders. *Eating Disorders*, 12(1), 51-73.

Tasca, G. A., Maxwell, H., Bone, M., Trinneer, A., Balfour, L., & Bissada, H. (2012). Purging disorder: Psychopathology and treatment outcomes. *International Journal of Eating Disorders*, 45(1), 36-42

Tassell, N., & Flett, R. (2011). Motivation in humanitarian health workers: A self-determination theory perspective. *Development in Practice*, 21(7), 959-973.

Tchanturia, K., Campbell, I. C., Morris, R., & Treasure, J. (2005). Neuropsychological studies in anorexia nervosa. *International Journal of Eating Disorders*, 37(S1), S72-S76.

Tchanturia, K., Davies, H. & Campbell, I. C. (2007). Cognitive remediation therapy for patients with anorexia nervosa: Preliminary findings. *Annals of General*

Psychiatry, 6(1), 14-19.

Tchanturia, K., Morris, R. G., Brecelj, A., Collier, D. A., Nikolaou, V. & Treasure, J. (2004). Set shifting in anorexia nervosa: an examination before and after weight gain, in full recovery and relationship to childhood and adult OCPD traits. *Journal of Psychiatric Research*, 38, 545-552.

Thaw, J. M., Williamson, D. A. & Martin, C. K. (2001). Impact of altering DSM-IV criteria for anorexia and bulimia nervosa on the base rates of eating disorder diagnoses. *Eating and Weight Disorders*, 6, 121-129.

Thomas, S. P., Shattell, M. & Martin, T. (2002). What's therapeutic about the therapeutic milieu? *Archives of Psychiatric Nursing*, 16(3), 99-107.

Treasure, J. L., Katzman, M., Schmidt, U., Troop, N., Todd, G. & de Silva, P. (1999). Engagement and outcome in the treatment of bulimia nervosa: First phase of a sequential design comparing motivation enhancement therapy and cognitive behavioural therapy. *Behaviour Research and Therapy*, 37, 405-418.

Treasure, J. & Schmidt, U. (2001). Ready, willing and able to change: Motivational aspects of the assessment and treatment of eating disorders. *European Eating Disorders Review*, 9, 4-18.

- Treasure, J., Schmidt, U. & Hugo, P. (2005). Mind the gap: service transition and interface problems for patients with eating disorders. *The British Journal of Psychiatry*, 187, 398-400.
- Treasure, J., & Ward, A. (1997). A practical guide to the use of motivational interviewing in anorexia nervosa. *European Eating Disorders Review*, 5(2), 102-114.
- Turnball, S., Ward, A., Treasure, J., Jick, H. & Derby, L. (1996). The demand for eating disorder care: An epidemiological study using the general practice research database. *British Journal of Psychiatry*, 169, 705-712.
- Turner, H. & Bryant-Waugh, R. (2004). Eating disorder not otherwise specified (EDNOS): Profiles of clients presenting at a community eating disorder service. *European Eating Disorders Review*, 12, 18-26.
- Vandereycken, W. (2006a). Denial of illness in anorexia nervosa – A conceptual review: Part 1 diagnostic significance and assessment. *European Eating Disorders Review*, 14, 341-351.
- Vandereycken, W. (2006b). Denial of illness in anorexia nervosa – A conceptual review: Part 2 different forms and meanings. *European Eating Disorders Review*, 14, 352-368.

- Vandereycken, W. & Van Humbeeck, I. (2008). Denial and concealment of eating disorders: A retrospective survey. *European Eating Disorders Review, 16*, 109-114.
- Vandereycken, W. & Vansteenkiste, M. (2009). Let eating disorder patients decide: Providing choice may reduce early dropout from inpatient treatment. *European Eating Disorders Review, 17*, 177-183.
- Vanderlinden, J., Buis, H., Pieters, G. & Probst, M. (2007). Which elements in the treatment of eating disorders are necessary ‘ingredients’ in the recovery process? – A comparison between the patient’s and therapist’s view. *European Eating Disorders Review, 15*, 357-365.
- Vansteenkiste, M. & Sheldon, K. M. (2006). There’s nothing more practical than a good theory: Integrating motivational interviewing and self-determination theory. *British Journal of Clinical Psychology, 45*, 63-82.
- Vansteenkiste, M., Soenens, B. & Vandereycken, W. (2005). Motivation to change in eating disorder patients: A conceptual clarification on the basis of self-determination theory. *International Journal of Eating Disorders, 37*(3), 207-219.
- van Son, G. E., van Hoeken, D., Bartelds, A. I., van Furth, E. F., & Hoek, H. W. (2006).

Time trends in the incidence of eating disorders: a primary care study in the Netherlands. *International Journal of Eating Disorders*, 39(7), 565-569.

Vitousek, K., Watson, S. & Wilson, G. T. (1998). Enhancing motivation for change in treatment-resistant eating disorders. *Clinical Psychology Review*, 18(4), 391-420.

Wade, T. D., Frayne, A., Edwards, S. Robertson, T. & Gilchrist, P. (2009). Motivational change in an inpatient anorexia nervosa population and implications for treatment. *Australasian Psychiatry*, 43(3), 235-243

Waller, G., Schmidt, U., Treasure, J., Murray, K., Aleyna, J., Emanuelli, F., Crockett, J. & Yeomans, M. (2009). Problems across care pathways in specialist adult eating disorder services. *Psychiatric Bulletin*, 33, 26-29.

Waller, G. (2012). The myths of motivation: Time for a fresh look at some received wisdom in the eating disorders? *International Journal of Eating Disorders*, 45, 1-16.

Walsh, J. M. E., Wheat, M. E. & Freund, K. (2000). Detection, evaluation and treatment of eating disorders: The role of the primary care physician. *Journal of General International Medicine*, 15, 577-590.

- Watson, T. L., Bowers, W. A. & Anderson, A. E. (2000). Involuntary treatment of eating disorders. *American Journal of Psychiatry*, *157*, 1806-1810.
- Wilfley, D. E., Bishop, M. E., Wilson, G. T. & Agras, W. S. (2007). Classification of eating disorders: Toward DSM-V. *International Journal of Eating Disorders*, *40*, S123-129.
- Wilfley, D. E., Welch, R. R., Stein, R. I., Spurrell, E. B., Cohen, L. R., Saelens, B. E., Douchis, Z. D., Frank, M. A., Wiseman, C. V. & Matt, G. E. (2002). A randomized comparison of group cognitive-behavioural therapy and group interpersonal psychotherapy for the treatment of overweight individuals with binge-eating disorder. *Archives of General Psychiatry*, *59*, 713-721.
- Williams, A. M. & Irurita, V. F. (2005). Enhancing the therapeutic potential of hospital environments by increasing the personal control and emotional comfort of hospitalised patients. *Applied Nursing Research*, *18*, 22-28.
- Williams, A. M., Dawson, S. & Kristjanson, L. J. (2008). Exploring the relationship between personal control and the hospital environment. *Journal of Clinical Nursing*, *17*, 1601-1609.
- Williams, G. C., McGregor, H. A., Sharp, D., Levesque, C., Kouides, R. W., Ryan, R.

- M. & Deci, E. L. (2006). Testing a self-determination theory intervention for motivating tobacco cessation: Supporting autonomy and competence in a clinical trial. *Health Psychology, 25*(1), 91-101.
- Williams, G. C., McGregor, H. A., Zeldman, A., Freedman, Z. R. & Deci, E. L. (2004). Testing a self-determination theory process model for promoting glycemic control through diabetes self-management. *Health Psychology, 23*(1), 58-66.
- Williams, S. & Reid, M. (2010). Understanding the experience of ambivalence in anorexia nervosa: The maintainer's perspective. *Psychology and Health, 25*(5), 551-567.
- Willig, C. (2008). *Introducing qualitative research in psychology*. Open University Press.
- Wilson, G. T. (2005). Psychological treatment of eating disorders. *Annual Revision of Clinical Psychology, 1*, 439-465.
- Wilson, G. T., Grilo, C. M., & Vitousek, K. M. (2007). Psychological treatment of eating disorders. *American Psychologist, 62*(3), 199.
- Wilson, G. T., & Shafran, R. (2005). Eating disorders guidelines from NICE. *The Lancet, 365*(9453), 79-81.

- Wilson, G. T. & Schlam, T. R. (2004). The transtheoretical model and motivational interviewing in the treatment of eating and weight disorders. *Clinical Psychology Review, 24*, 361-378.
- Woods, S. (2004). Untreated recovery from eating disorders. *Adolescence, 39*(154), 361-371.
- Wykes, T. & Callard, F. (2010). Diagnosis, diagnosis, diagnosis: Towards DSM-5. *Journal of Mental Health, 19*(4), 301-304.
- Zalta, A. K., & Keel, P. K. (2006). Peer influence on bulimic symptoms in college students. *Journal of Abnormal Psychology, 115*(1), 185.
- Zaifsoff, S. L. & Taylor, A. (2009). Factors related to motivation for change in Adolescents with eating disorders. *European Eating Disorders Review, 17*, 227-233.
- Zeldman, I. D., Ryan, R. M. & Fiscella, K. (2004). Client motivation, autonomy support and entity beliefs: Their role in methadone maintenance treatment. *Journal of Social and Clinical Psychology, 23*, 675-696.
- Zipfel, S., Löwe, B, Reas, D. L., Deter, H. C. & Herzog, W. (2000). Long-term

prognosis in anorexia nervosa: Lessons from a 21-year follow-up study. *Lancet*, 355, 721-722.

Zuroff, D. C., Koestner, R., Moskowitz, D. S., McBride, C., Bagby, M. & Marshall, M. (2007). Autonomous motivation for therapy: A new non-specific predictor of outcome in brief treatments of depression. *Psychotherapy Research*, 17, 137-148.

APPENDICES

APPENDICES

Appendix A: DSM-IV-TR Diagnostic Criteria and DSM-5 Proposed Modifications

DSM-IV-TR DIAGNOSTIC CRITERIA FOR EATING DISORDERS

DSM-IV-TR Diagnostic Criteria for Anorexia Nervosa

A. Refusal to maintain body weight at or above a minimally normal weight for age and height, for example, weight loss leading to maintenance of body weight less than 85% of that expected or failure to make expected weight gain during period of growth, leading to body weight less than 85% of that expected.

B. Intense fear of gaining weight or becoming fat, even though underweight.

C. Disturbance in the way one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the current low body weight.

D. In postmenarcheal females, amenorrhea, i.e. the absence of at least 3 consecutive menstrual cycles. A woman having periods only while on hormone medication (e.g. estrogen) still qualifies as having amenorrhea.

Type:

Restricting Type: During the current episode of Anorexia Nervosa, the person has not regularly engaged in binge-eating or purging behaviour (self-induced vomiting or misuse of laxatives, diuretics, or enemas)

Binge Eating/Purging Type: During the current episode of Anorexia Nervosa, the person has regularly engaged in binge-eating or purging behaviour.

DSM-IV-TR Diagnostic Criteria for Bulimia Nervosa

A Recurrent episodes of binge eating characterised by both,

1. Eating, in a discrete period of time (e.g. within any 2-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances)

2. A sense of lack of control over eating during the episode, (such as feeling that one cannot stop eating or control what or how much one is eating).
- B. Recurrent inappropriate compensatory behaviour to prevent weight gain, such as self-induced vomiting, misuse of laxatives, diuretics, enemas, or other medications, fasting, or excessive exercise.
- C. The binge eating and inappropriate compensatory behaviour both occur, on average, at least twice a week for 3 months.
- D. Self evaluation is unduly influenced by both body and weight.
- E. The disturbance does not occur exclusively during episodes of Anorexia Nervosa.

Type:

Purging Type: During the current episode of Bulimia Nervosa, the person has regularly engaged in self-induced vomiting or the misuse of laxatives, diuretics, or enemas.

Nonpurging Type: During the current episode of Bulimia Nervosa, the person has used other inappropriate compensatory behaviour but has not regularly engaged in self-induced vomiting or misused laxatives, diuretics, or enemas.

DSM-IV Diagnostic Criteria for Eating Disorder Not Otherwise Specified

This diagnosis includes disorders of eating that do not meet criteria for the above two eating disorder diagnoses. Examples include;

- 1 For female patients, all of the criteria for Anorexia Nervosa are met except that the patient has regular menses.
2. All of criteria for Anorexia Nervosa are met except that, despite significant weight loss, the patient's current weight is in the normal range.
3. All of the criteria for Bulimia Nervosa are met except that the binge eating and inappropriate compensatory mechanisms occur less than twice a week or for less than 3 months.
4. The patient has normal body weight and regularly uses inappropriate compensatory behaviour after eating small amounts of food (e.g. self-induced vomiting after consuming two cookies)

5. The patient engages in repeatedly chewing and spitting out, but not swallowing, large amounts of food.

6. Binge-eating disorder: recurrent episodes of binge eating in the absence of regular inappropriate compensatory behaviour characteristics of Bulimia Nervosa.

DSM-IV Diagnostic Criteria for Binge-Eating Disorder

A. Recurrent episodes of binge eating. An episode of binge eating is characterised by both of the following:

1. Eating, in a discrete period of time (e.g. within any 2-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances)

2. A sense of lack of control over eating during the episode, (such as feeling that one cannot stop eating or control what or how much one is eating).

B. The binge-eating episodes are associated with three (or more) of the following:

1. Eating much more rapidly than normal

2. Eating until feeling uncomfortably full

3. Eating large amounts of food when not feeling physically hungry

4. Eating alone because of being embarrassed by how much one is eating

5. Feeling disgusted with oneself, depressed, or very guilty after overeating

C. Marked distress regarding binge eating is present

D. The binge eating occurs, on average, at least 2 days a week for 6 months.

Note: The method of determining frequency differs from that used for bulimia

nervosa; future research should address whether the preferred method of setting a frequency threshold is counting the number of days on which binges occur or counting the number of episodes of binge eating.

E. The binge eating is not associated with the regular use of inappropriate compensatory behaviours (e.g., purging, fasting, excessive exercise) and does not occur exclusively during the course of anorexia nervosa or bulimia nervosa.

DSM-V PROPOSED DIAGNOSTIC CRITERIA FOR EATING DISORDERS

DSM-V Proposed Diagnostic Criteria for Anorexia Nervosa

- A. Restriction of energy intake relative to requirements leading to a significantly low body weight in the context of age, sex, developmental trajectory, and physical health. Significantly low weight is defined as a weight that is less than minimally normal, or, for children and adolescents, less than that minimally expected.
- B. Intense fear of gaining weight or becoming fat, or persistent behaviour that interferes with weight gain, even though at a significantly low weight.
- C. Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.

Specify current type:

Restricting Type: during the last three months, the person has not engaged in recurrent episodes of binge eating or purging behaviour (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas).

Binge-Eating/Purging Type: during the last three months, the person has engaged in recurrent episodes of binge eating or purging behaviour (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas).

DSM-V Proposed Diagnostic Criteria for Bulimia Nervosa

- A. Recurrent episodes of binge eating. An episode of binge eating is characterised by both of the following:
1. Eating, in a discrete period of time (e.g. within any 2-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances.
 2. A sense of lack of control over eating during the episode (e.g., a feeling that one cannot stop eating or control what or how much one is eating).
- B. Recurrent inappropriate compensatory behaviour in order to prevent weight gain, such as self-induced vomiting; misuse of laxatives, diuretics, or other medications, fasting; or excessive exercise.

C. The binge eating and inappropriate compensatory behaviours both occur, on average, at least once a week for 3 months.

D. Self-evaluation is unduly influenced by body shape and weight.

E. The disturbance does not occur exclusively during episodes of anorexia nervosa.

DSM-V Proposed Diagnostic Criteria for Binge Eating Disorder

A. Recurrent episodes of binge eating. An episode of binge eating is characterised by both of the following:

1. eating, in a discrete period of time (for example, within any 2-hour period), an amount of food that is definitely larger than most people would eat in a similar period of time under similar circumstances

2. a sense of lack of control over eating during the episode (e.g., a feeling that one cannot stop eating or control what or how much one is eating).

B. The binge-eating episodes are associated with three (or more) of the following:

1. eating much more rapidly than normal

2. eating until feeling uncomfortably full

3. eating large amounts of food when not feeling physically hungry

4. eating alone because of feeling embarrassed by how much one is eating

5. feeling disgusted with oneself, depressed, or very guilty afterwards

C. Marked distress regarding binge eating is present.

D. The binge eating occurs, on average, at least once a week for three months

E. The binge eating is not associated with the recurrent use of inappropriate compensatory behaviour (for example, purging) and does not occur exclusively during the course of bulimia nervosa or anorexia nervosa.

DSM-V Proposed Diagnostic Criteria for EDNOS

The Work Group has recommended that the category Eating Disorder Not Otherwise Specified be replaced by a section termed Feeding and Eating Conditions Not Elsewhere Classified. Brief descriptions of several conditions that may be listed in the DSM-V,

should sufficient data be available to justify them as designated disorders, have been included in the proposal:

Atypical Anorexia Nervosa

All of the criteria for Anorexia Nervosa are met, except that, despite significant weight loss, the individual's weight is within or above the normal range.

Subthreshold Bulimia Nervosa (low frequency or limited duration)

All of the criteria for Bulimia Nervosa are met, except that the binge eating and inappropriate compensatory behaviours occur, on average, less than once a week and/or for less than three months.

Subthreshold Binge Eating Disorder (low frequency or limited duration)

All of the criteria for Binge Eating Disorder are met, except that the binge eating occurs, on average, less than once a week and/or for less than three months

Purging Disorder

Recurrent purging behaviour to influence weight or shape, such as self-induced vomiting, misuse of laxatives, diuretics, or other medications, in the absence of binge eating. Self-evaluation is unduly influenced by body shape or weight or there is an intense fear of gaining weight or becoming fat.

Night Eating Syndrome

Recurrent episodes of night eating, as manifested by eating after awakening from sleep or excessive food consumption after the evening meal. There is awareness and recall of the eating. The night eating is not better accounted for by external influences such as changes in the individual's sleep/wake cycle or by local social norms. The night eating is associated with significant distress and/or impairment in functioning. The disordered pattern of eating is not better accounted for by Binge Eating Disorder, another psychiatric disorder, substance abuse or dependence, a general medical disorder, or an effect of medication.

Other Feeding or Eating Condition Not Elsewhere Classified

This is a residual category for clinically significant problems meeting the definition of a Feeding or Eating Disorder but not satisfying the criteria for any other Disorder or Condition.



Dear _____,

We are currently recruiting individuals to participate in a study exploring peoples' views and experiences of support services for Eating Disorders in Ireland. It is thought that the views of those who have had experience of the health care system for the treatment of eating disorders can provide valuable insight into the development and improvement of treatment pathways. Consequently your contact details were provided by XXXX [named clinician], XXXX [named treatment centre], who indicated that you may be interested in participating in this study.

This research project is a DCU initiative. The investigators involved in this project are Dr. Siobhain McArdle and Ms. Grace Sheridan, Dublin City University, and Dr. Paul Gaffney and Ms. Nuala Miles from the Health Service Executive. Also collaborating on this project are XXXX [named clinician] and XXXX [named clinician] of [named treatment centre] and XXXX [named clinician] of [named treatment centre].

The details of this research project are outlined in the enclosed documentation which includes an information sheet and a participant consent form. If after reading through the documentation you are willing to take part in this study please sign the consent form and send it back to (*the name of the relevant clinician to be inserted*) using the stamped envelope provided. Once (*the name of the relevant clinician to be inserted*) has received your consent form a member of the research team will be in contact with you with further details of the study. **If you have any questions regarding the study, please do not hesitate to contact Dr. Siobhain McArdle, Dublin City University on (01) 7007750 or siobhain.mcardle@dcu.ie. Alternatively, you can contact Grace Sheridan, Dublin City University on 087 9728163 or grace.sheridan9@mail.dcu.ie.** We thank you for taking the time to read through the information and would greatly appreciate your co-operation in our research endeavours.

Dr. Siobhain McArdle, MSc., PhD., PG Dip. Cognitive Psychotherapy
Dublin City University



Title of Study: *Experiences of Support Services for Eating Disorders in Ireland: An Exploratory Study.*

This research project is supported by Dublin City University. The principal investigators are Dr. Siobhain McArdle (contact telephone # 017007750) and Grace Sheridan (contact telephone # 087 9728163) from DCU, SCHOOL OF HEALTH AND HUMAN PERFORMANCE. Other investigators are Dr. Paul Gaffney and Ms. Nuala Miles from the Health Service Executive. Also collaborating on this project are XXXX [named clinician] and XXXX [named clinician] of [named treatment centre] and XXXX [named clinician] of [named treatment centre]. If you have any concerns or questions about this study please feel free to contact Siobhain McArdle or Grace Sheridan at any time.

The purpose of this study is to explore people's experiences of support services for Eating Disorders in Ireland. We are particularly interested in the experiences of females who are either currently receiving treatment or who have previously received treatment for an Eating Disorder and are now discharged from the treatment service and in recovery. For adolescents who choose to participate in our study, we are also interested in their parents' views and suggestions.

This study will require your participation in a one on one audio recorded interview of your experiences. The interview will last approximately 60 minutes and take place at the site where you are currently receiving treatment. As a follow-up to the interview you will be asked to read a summary of the interview and provide approval of the contents. A follow-up support session with _____ (the name of the relevant clinician will be inserted here) will also be available to you if the interview raises any issues you would further like to discuss.

The information you share with us will be kept in confidence. However, confidentiality of information provided is subject to legal limitations. You will be given an ID number under which all your personal information will be stored in a secure file and saved in a password protected file in a computer at DCU. The investigators are the only people who will have access to the data. All the data related to this study will be destroyed one year after the project has finished by Dr. Siobhain McArdle.

Taking part in this study involves no health risks and is completely voluntary. If you do agree to take part in this study you can say you do not want to be part of the study anymore at any point without penalty or negative implications for treatment and support services. It is hoped that the findings from this study will inform service provision for individuals with eating disorders in Ireland.

If you have concerns about this study and want to talk to somebody outside the research team, please contact:

The Secretary,
Dublin City University Research Ethics Committee,
c/o Office of the Vice-President for Research,
Dublin City University,
Dublin 9.
Tel 01-7008000.



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The purpose of this study is to explore people's experiences of support services for Eating Disorders in Ireland. We are particularly interested in the experiences of females who are either currently receiving treatment or who have previously received treatment for an Eating Disorder and are now discharged from the treatment service and in recovery. For adolescents who choose to participate in our study, we are also interested in their parents' views and suggestions.

This study will require your participation in a focus group discussion of your experiences. The focus group will consist of four to five participants and last approximately 60 to 90 minutes in length. The focus group discussion will be audio recorded and will take place at _____ (insert site name as appropriate). As a follow-up to the interview you will be asked to read a summary of the focus group discussion and provide approval of the contents. A follow-up support session with _____ (the name of the relevant clinician will be inserted here) will also be available to you if the interview raises any issues you would further like to discuss.

There are no potential health risks involved in participating in this study. It is hoped that the findings from this study will inform service provision for individuals with eating disorders in Ireland.

The information you share with us will be kept in confidence. However, confidentiality of information provided is subject to legal limitations. You will be given an ID number under which all your personal information will be stored in a secure file and saved in a password protected file in a computer at DCU. The investigators are the only people who will have access to the data. All the data related to this study will be destroyed one year after the project has finished by Dr. Siobhain McArdle

Taking part in this study involves no health risks and is completely voluntary. If you do agree to take part in this study you can say you do not want to be part of the study anymore at any point without any negative consequences for treatment or future support. It is hoped that the findings from this study will inform service provision for individuals with eating disorders in Ireland.

If you have concerns about this study and want to talk to somebody outside the research team, please contact:

The Secretary,
Dublin City University Research Ethics Committee,
c/o Office of the Vice-President for Research,
Dublin City University,
Dublin 9.
Tel 01-7008000.



Title of Study: *Experiences of Support Services for Eating Disorders in Ireland:
An Exploratory Study.*

This research project is supported by Dublin City University. The principal investigators are Dr. Siobhain McArdle and Grace Sheridan from DCU, SCHOOL OF HEALTH AND HUMAN PERFORMANCE. Other investigators are Dr. Paul Gaffney and Ms. Nuala Miles from the Health Service Executive. Also collaborating on this project are XXXX [named clinician] and XXXX [named clinician] of [named treatment centre] and XXXX [named clinician] of [named treatment centre].

The purpose of this study is to explore people's experiences of support services for Eating Disorders in Ireland.

This study will require your participation in a one to one audio recorded interview in which you will be asked questions relating to your experiences of support services for the treatment of eating disorders. The interview will last approximately 60 minutes. As a follow-up to the interview you will be asked to read a summary of the session and give your approval to its contents.

Please complete the following (Circle Yes or No for each question)

- I have read the Plain Language Statement. *Yes/No*
- I understand the information provided and I have received an explanation of the purpose, duration and nature of the study. *Yes/No*
- I have had an opportunity to ask questions and discuss this study *Yes/No*
- The researchers have answered my questions and concerns. *Yes/No*
- I am aware that my interview will be audio-taped *Yes/No*

I am aware that if I do agree to take part in this study, I can say I do not want to be part of the study anymore at any point without any negative consequences for treatment or future support. .

Dublin City University will protect all my personal information. However, confidentiality of information provided is subject to legal limitations. My identity and personal information will not be revealed in the results of the study. The study findings may be presented at scientific meetings or presented in scientific journals. Dr. Siobhain McArdle will delete all data files one year after the project has ended



I have read and understand the information in this form.

My questions and concerns have been answered by the researchers, and I have a copy of this consent form. I agree to take part in this research project and allow myself to be audio-recorded.

Participants Signature: _____

Name in Block Capitals: _____

Witness: _____

Date: _____



Title of Study: *Experiences of Support Services for Eating Disorders in Ireland:
An Exploratory Study.*

This research project is supported by Dublin City University. The principal investigators are Dr. Siobhain McArdle and Grace Sheridan from DCU, SCHOOL OF HEALTH AND HUMAN PERFORMANCE. Other investigators are Dr. Paul Gaffney and Ms. Nuala Miles from the Health Service Executive. Also collaborating on this project are XXXX [named clinician] and XXXX [named clinician] of [named treatment centre] and XXXX [named clinician] of [named treatment centre].

The purpose of this study is to explore people's experiences of support services for Eating Disorders in Ireland.

This study will require your participation in an audio recorded focus group discussion in which you will be asked questions relating to your experiences of support services for the treatment of eating disorders. The focus group will last approximately 60 to 90 minutes in length. As a follow-up to the interview you will be asked to read a summary of the session and give your approval to its contents.

Please complete the following (Circle Yes or No for each question)

- | | |
|--|---------------|
| • I have read the Plain Language Statement. | <i>Yes/No</i> |
| • I understand the information provided and I have received an explanation of the purpose, duration and nature of the study. | <i>Yes/No</i> |
| • I have had an opportunity to ask questions and discuss this study | <i>Yes/No</i> |
| • The researchers have answered my questions and concerns. | <i>Yes/No</i> |
| • I am aware that my interview will be audio-taped | <i>Yes/No</i> |

I am aware that if I do agree to take part in this study, I can say I do not want to be part of the study anymore at any point without any negative consequences for treatment or future support.

Dublin City University will protect all my personal information. However, confidentiality of information provided is subject to legal limitations. My identity and personal information will not be revealed in the results of the study. The study findings may be presented at scientific meetings or presented in scientific journals. Dr. Siobhain McArdle will delete all data files one year after the project has ended.



I have read and understand the information in this form. My questions and concerns have been answered by the researchers, and I have a copy of this consent form. I agree to take part in this research project and allow myself to be audio-recorded.

Participants Signature: _____

Name in Block Capitals: _____

Witness: _____

Date: _____

Appendix G Participant Profile/ Demographic Data (Current Patient)

We are interested in learning a little more about you. Please read the items below and respond to the questions honestly and carefully. There are no right or wrong answers.

1. Date of Birth _____

2. What level of education have you completed to date?

Please tick the appropriate answer

- a. Primary School _____
- b. Secondary School _____
- c. College/University _____
- d. Other (please specify) _____

3. At what age did you become aware that you had an eating disorder? _____

4. At present, would you classify your eating disorder as

- a) Anorexia Nervosa _____
- b) Bulimia Nervosa _____
- c) EDNOS (Eating Disorder Not Otherwise Specified) _____
- d) Other (please specify) _____

*If you are not sure how to answer the above question, do you give the researchers of this study permission to obtain this information from the coordinating clinician?

Please tick Yes or No Yes _____ No _____

5. Is the treatment you are currently receiving for your eating disorder,

- a) In-patient treatment _____
- b) Out-patient treatment _____
- c) Other (please specify) _____

6. Would you describe where you live as

- a) Urban _____
- b) Rural _____
- Other (please specify) _____

Appendix I

Interview Topic Guide – Current Patient

A

- Participants view on access to information sources for ED

What is your opinion on the accessibility of information sources for people seeking help for an eating disorder?

- Participants view on information they obtained

How would you describe the information/advice that you received when seeking help for your eating disorder?

B

- Perceptions of barriers to care

What do you consider the most significant barriers/factors that prevent people from seeking help for an eating disorder to be?

- Experiences of barriers to care

What were the main difficulties or barriers you encountered when seeking help for your eating disorder?

C

- Experiences of treatment

What has been your experience of treatment for eating disorders?

- Positive aspects of treatment

What aspects of your treatment did you find helpful? Why?

- Negative aspects of treatment

What aspects of your treatment did you find unhelpful? Why?

- Experience of fellow patients

What, if any, is your experience of fellow patients?

D

- Experience of therapists

What has been your experience of therapists?

- Receiving treatment from more than one therapist

Since you initially began receiving treatment for your eating disorder, have you seen more than one therapist? What is your experience of this/ how do you find this?

E

- Participants' views of first point of contact for treatment for their ED

Who did you expect your first point of contact for initial treatment for your eating disorder to be? What did you expect of them/what did you expect their role to be?

- Participants' experiences of first point of contact for treatment for their ED

Who was your first point of contact when you sought help for your eating disorder? What was your experience of this?

F

- Suggestions for change

What suggestions or advice do you have to improve treatment for people with eating disorders?

Appendix J

Interview Topic Guide – Discharged Patient

A

- Participants view on access to information sources for ED

What is your opinion on the accessibility of information sources for people seeking help for an eating disorder?

- Participants view on information they obtained

How would you describe the information/advice that you received when seeking help for your eating disorder?

B

- Perceptions of barriers to care

What do you consider the most significant barriers/factors that prevent people from seeking help for an eating disorder to be?

- Experiences of barriers to care

What were the main difficulties or barriers you encountered when seeking help for your eating disorder?

C

- Experiences of treatment

What has been your experience of treatment for eating disorders?

- Positive aspects of treatment

What aspects of your treatment did you find helpful? Why?

- Negative aspects of treatment

What aspects of your treatment did you find unhelpful? Why?

- Experience of fellow patients

What, if any, is your experience of fellow patients?

D

- Experience of therapists

What has been your experience of therapists?

- Receiving treatment from more than one therapist

When receiving treatment for your eating disorder, did you see more than one therapist?
What was your experience of this?

E

- Participants' views of first point of contact for treatment for their ED

Who did you expect your first point of contact for initial treatment for your eating disorder to be? What did you expect of them/what did you expect their role to be?

- Participants' experiences of first point of contact for treatment for their ED

Who was your first point of contact when you sought help for your eating disorder? What was your experience of this?

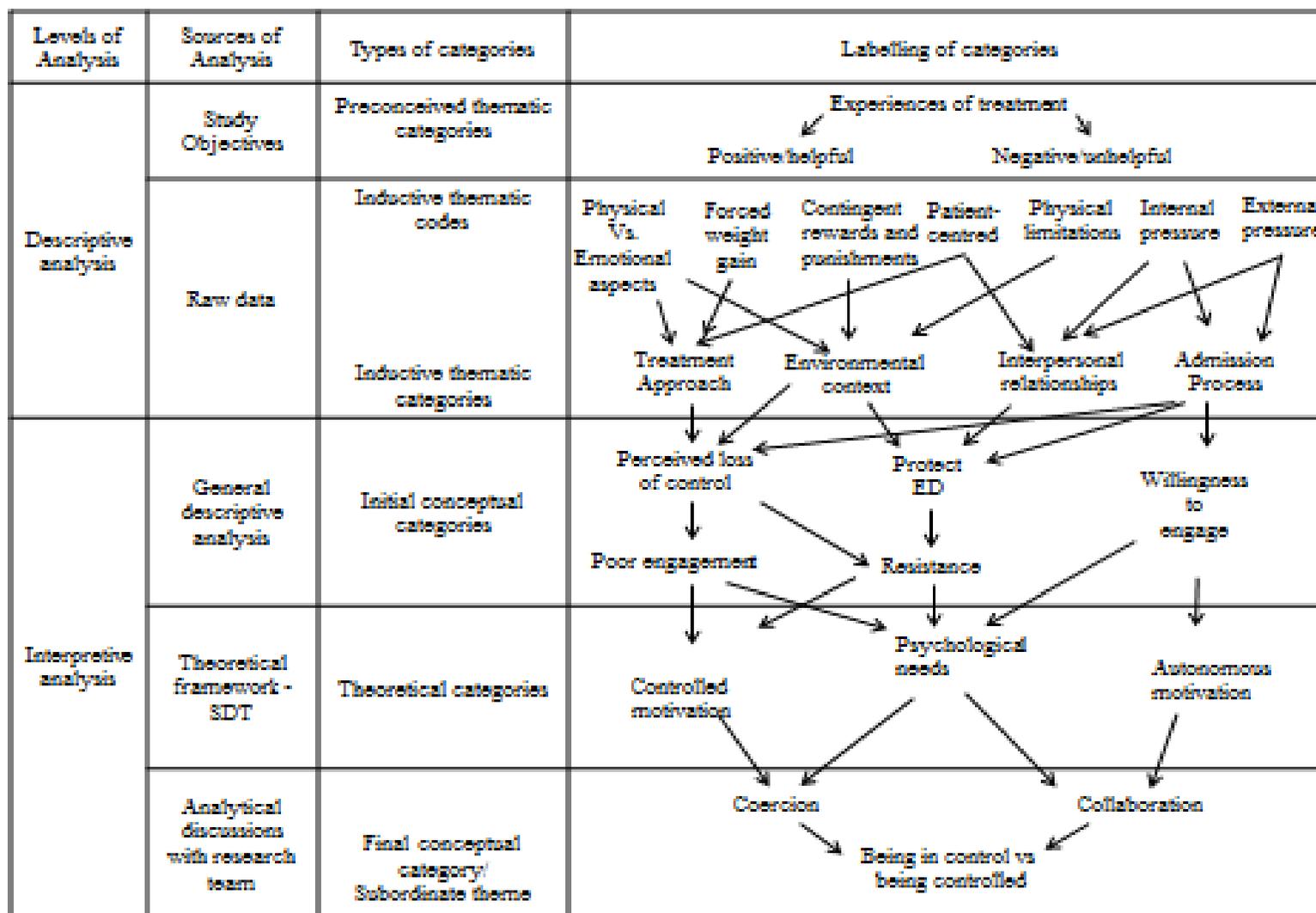
F

- Suggestions for change

What suggestions or advice do you have to improve treatment for people with eating disorders?

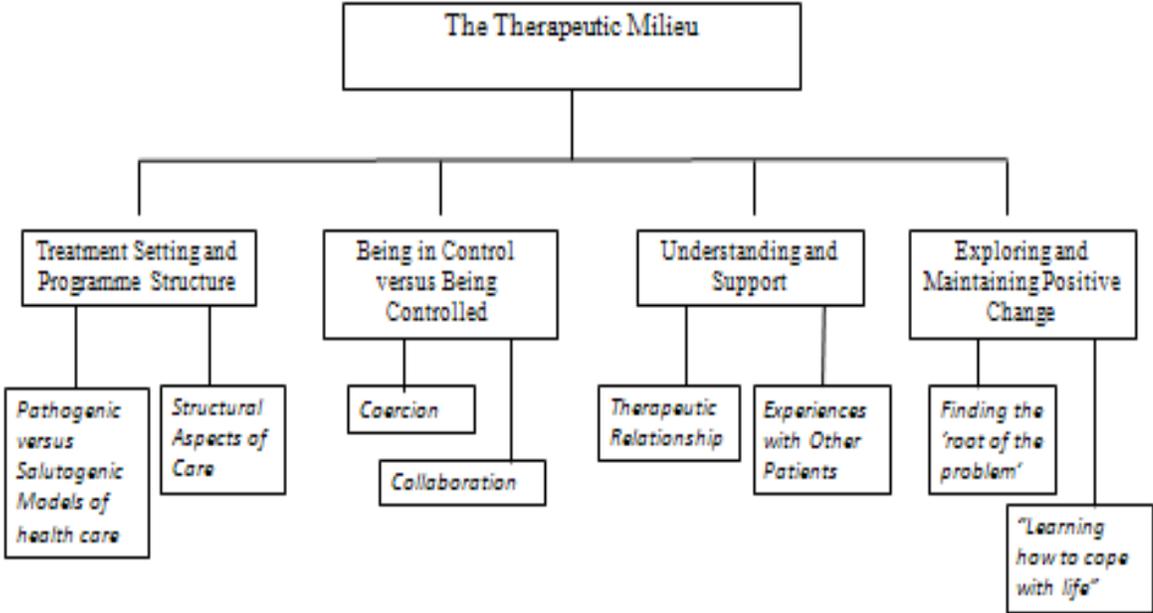
Appendix K

The analytical process of the subordinate theme of *Coercion and Collaboration*



Appendix L

Diagrammatic Representation of Overarching, Sub-ordinate and Lower-order themes



Facilitator: I suppose then Vicky we'll just begin at the beginning for you for you, and if you could give us a rough kind of overall sense of the different treatments you accessed from the beginning when you first began to look for help and access help to where you are today

Vicky: yea, em...I suppose, eh, I'm thirty one now. I am nearly a year and a half in recovery, and my last being XXXX [named treatment centre]. Em...my first treatment was when I was eighteen, I was in a general hospital, it's now XXXX [named general medical hospital]

Facilitator: oh XXXX [named area] is it?

Vicky: yea

Facilitator: alright

Vicky: sorry, I'm originally from XXXX [named area]. So, em, yea, I was in there when I was eighteen, em, and I was in the general ward for anorexia. Em...and I would have suffered with anorexia, bulimia then, just throughout the whole thing, it's very swing, swingish, I think, eh, the treatments go from anorexia to bulimia and I suppose here is the only one that kinda treated a combination of the two. Em...I then went into a, about, I'd say I was about twenty before I went into, god, let me think, sorry, around eighteen, nineteen, I was in XXXX [named treatment centre]. Em...and after that I was in XXXX [named treatment centre], em, both for anorexia. Em...I suppose the treatments like that wouldn't be my parents call cause they could only see underweight at that stage and there, there was no kind of, eh the bulimia wasn't as invasive as it got like. Em...after that, where...I was kinda doing outpatient and alternative treatments, art therapy, hypnotherapy, em, acupuncture, ah...god there was loads, I can't even think of all the different types of things I did but yea, I did alternative stuff and then at the age of about twenty/twenty-one I was in XXXX [named treatment centre]. It's an addiction treatment

centre in XXXX [named area]. It's the same as the XXXX [named treatment centre] in XXXX [named area] and they do deal with eating disorders so I was in, in there at twenty-one I'd say, em, for eh bulimia, cause they would deal with that addiction side to, you know, the overeating, binging and that behaviour. Em...after that I don't think I was in any other like treatments until I did XXXX [named treatment centre] again when I was twenty-three I'd say. Em...then I graduated to the...no, there must, there must have been something in between...I, sorry, after the, eh, XXXX [named treatment centre], the second time I did a, it's like a, a women's kinda project, it's called XXXX, it's in XXXX [named area]. It's where you will go from a treatment centre straight into, it's as intensive as a treatment centre and you're living there with other addicts and people suffering from the same sort of addictions. And em...and you get like the counselling, you would foster in the evening and I went from there to kinda like a halfway house idea so that between XXXX [named treatment centre] and that, that would have taken up a good year...year and a half. Em...so after that I went into XXXX [named treatment centre] with alcohol and...yea, I think it was just the alcohol and the bulimia at that stage. Em...and after I got out of the XXXX [named treatment centre] which was probably four years ago now, five years so I would have been twenty, twenty-eight I'd say. I got out of there and I stayed very sick for until, until I came to XXXX [named treatment centre]. The gaps got bigger like as my later teens moved on because I was so sick I didn't want help, I was more independent and my parents weren't calling the shots. Em...and I suppose, yea, I would've, I would've used a lot of things to kind of like hold me up, like alcohol, even here were detoxing me off eh...Nurofen, em, painkillers, eh tranqs and...there was something else I was using, alcohol. So I came in with those but along the way I would've been treated, kinda vaguely treated in treatments. Em...they, bringing it back to the HSE and stuff, I suppose my VHI covered all the anorexia treatments, the only bulimia treatments that they have available for bulimia would be XXXX [named treatment centre], XXXX [named treatment centre], more general wards, or psych wards. Em...I found both just absolutely, their approach to the whole thing is just backdated like, it's Dark Age. So I wasn't prepared to go there again. The treatment centres weren't meeting, em, the eating

disorders as a primary kind of, em, they'd, they'd sooner tackle drink and drugs and it was kind of like a third, something down the line with the eating disorders, em, which gave me too much of a kinda, a reign. Em...and then here really was the first place that I found that had like a happy medium of you do alternative therapies along with treating the anorexia, bulimia and they're not, I have done a lot of research so I knew that they had fresher ideas to their approach and I think that, well I remember reading...they said they didn't want to take your eating disorder off you, just help you give it up, so it would've been, that's totally not kinda how other institutes are, are, like treatments would kind of, em, go at it. But yea, sorry, I'm trying to keep it all in train with...

Facilitator: no, you're grand

Vicky: what's relevant. Em...the HSE covered my, or sorry, the VHI covered my inpatient treatments which would have been when I was eighteen, when I was in the general ward in, em, XXXX [named treatment centre], I said the second time I went in for alcohol as a primary cause they won't cover eating disorders on your VHI or via the HSE if you say that your addiction is bulimia even though all the symptoms are, would be the same, say the stealing, the lying, the over-usage and all that kinda stuff. So em they wouldn't cover it the first time, my parents paid out of pocket for XXXX [named treatment centre]. The second time...em, the VHI covered, em, me as alcohol being primary, em, which I did have a problem with at that stage. The, eh, the alternative treatments, they don't cover at all. They cover outpatient, I think VHI might subsidise, I don't know for sure cause they would have been earlier on as well. Em...but the HSE don't help you out with anything like that. Em...I think...so it was the XXXX [named treatment centre]...yea, I went in with alcohol as a primary in that because the VHI, well, I was detoxed in XXXX [named treatment centre] before going in there, off drink and drugs. And the VHI don't cover more than ninety days of treatment over the course of three or four years I think it is. So I wasn't covered for the, I ran out of days when I did go to try and get help again after the XXXX [named treatment centre]. I relapsed a week after coming out there and I spent the next five years really progressively ill, em, with eh on-going bulimia, chronic and the anorexia the whole time, kind of, threading

through it, the drink and the drugs and I wouldn't have been able to work in stages or do anything like that

(phone drops)

Vicky: oh, sorry

Facilitator: you're alright

Vicky: so they, they wouldn't cover anything so I couldn't get treatment when I did want to get treatment

Facilitator: and that was, sorry just, that was after XXXX [named treatment centre]?

Vicky: mmm hmm

Facilitator: yea, kinda five years before you came here?

Vicky: yea

Facilitator: so you couldn't get any...?

Vicky: I couldn't get any help from em...the HSE would only cover, em, pretty much the same as the VHI, general hospitals em...it's specifically geared at, like you're slotted into kind of a ward with people who most would be chronic cause that's why they're there. And...em, I mean, I wouldn't go in either because if you come out, if you go in you come out sicker. I always found anything like that geared, that were trying to claim you or like...treating an eating disorder, em, I would come out and I would be sick, very sick. Em...and worse with the treatment centres I got progressively sick kinda from the lesser evils first. Em...I paid for XXXX [named treatment centre] out of pocket, em, we couldn't afford it so we borrowed, em, like five hundred euros off em, about twenty of our friends, em, so we, we paid this treatment. Em...VHI or eh the HSE won't cover it and if the HSE do subsidise it, I believe that it takes so long to process and that they are able to come up with, as I've seen with dentists, any excuse under the sun. Em...my dental bills have been huge as well and I've had to go to pay out of pocket now cause of the effects of the eating disorder and all the drug-usage, I've lost a lot of

teeth like and they're rotting and I'm gonna lose some more but yea I'd have that from the osteoporosis and they won't, em, I've got a medical card but they won't cover anything. So I dunno is it HSE or VHI or is it just a general...what's available...?

Grace: yea, that's just really, we just want to get a general kind of sense em, I mean like, we have a little bit of information on it but nothing compared to this, what you can give us here today. Em...so just going back Vicky to when you said, em, when you were in XXXX [named general medical hospital] and was that like a general psychiatric ward or was that a ward specifically aimed at specialising in eating disorders?

Vicky: that was actually neither. I had a private room there. I remember the professor, XXXX was his name, he was a family friend, he would have been head of XXXX [named general medical hospital] medicine and he got me into where they wouldn't be treating...sort of on a psych ward, em, but general ward. I had a dietician. I basically got taken in, fed up, and left out with no clue, I mean I do wonder had that treatment been different how different things could have been cause it just...it intensified the problem. Em...I had no kind of psychiatric help or counselling after, I had a dietician and a room full of food, you know, that's the way I'd put that. That was a general, that was a general ward

Facilitator: and I noticed you said you didn't have any counselling, after did you have anything like that bar the dietician and a room full of food? Was there any other treatment you received?

Vicky: um...I had loads of counsellors, em, I've been going to see a lot, I, like there was just loads of different counsellors that we paid for like out of pocket, my parents. em...thy paid for a lot of treatments, em, mainly counsellors, weekly sessions. I didn't want to have anything to do with them. Em...and then I saw a lady, she was one of the first, XXXX [named health care professional] she specialised in eating disorders in XXXX [named general medical hospital] I think. So she was the only kind of in-between counsellor and specialist em, which again, they don't cover. Oh there was one other, sorry, it's all...

Facilitator: no, take your time, take your time

Vicky: in XXXX [named general medical hospital], what was she at that stage? Eh, there was another woman who was working with XXXX [named general medical hospital] and my mother brought me to her to ask her to write a letter on my, behalf of us, to claim off the VHI. She wouldn't, what wouldn't she write about me? She wouldn't, she wouldn't vouch for something, somebody with an eating disorder, politics basically and, em, if you don't get proper references and that would have been within the time of the Celtic Tiger so it wasn't the way the healthcare is now like. Em but back then if you can get proper references and all this kinda stuff, you can claim back a, a section of, you know. I can actually find out or even, em, or even just okay it with my mother to have a chat with you if, eh, if you wanted to know about that side of, kind of, they did all the real, kind of early days, kind of, financial and availability of like of places to go

Facilitator: was this, was this now before you went to XXXX [named general medical hospital]?

Vicky: in my, in my early teens, sorry, in my early twenties late-teens when it presented as a problem. Like I would have seen, kind of, psychologists/counsellors who would have been affiliated with eating disorder, you know, kind of institutes or XXXX [named general medical hospital] usually cause that's a hospital down there. Em...and you see most, all of that, kind of, what was available or what not or what we were entitled for, to, was dealt with by parents cause I was so young like. Em...probably from the age of about twenty-two I would have a bigger idea like of what I had to do to get in places like. Em, other than that, they did all that kind of ins and outs of the financial side of it

Facilitator: yea, when you were younger at that stage. Em, and when you were in the, am I right in saying the general hospital or general ward in XXXX [named general medical hospital] was kinda your first...when you were first admitted into somewhere?

Vicky: that was my first place. I think I was seven...seven...no I think I would have been eighteen then. And the, the hospital I went in to, I was still, I would have been

eighteen/nineteen, you know, it was probably a year later that I went into XXXX [named treatment centre].

Facilitator: okay

Vicky: em...yea

Facilitator: and what was that, your time in XXXX [named general medical hospital] like, the first time when you were eighteen?

Vicky: I just remember it being a completely, you see, cause I had the overeating and the bulimia, em, I appeared to be so underweight that when they said you're not getting out till you reach this weight I thought 'happy days' and I basically just binged my way out of there, you know? I remember him actually making a comment saying he'd never seen someone gain weight so fast and it had to have constipation or water retention or whatever, but it was literally I was left to my own devices in the room. Em...I was given a laxative to try and help on the toilets which were locked after mealtimes to prevent me getting sick. So I don't think they had any kinda clue of how to deal with it properly, you know. Em...so

Facilitator: in terms of the treatments and stuff bar the kind of trying to get you to reach a certain weight, was there any other kind of, did you receive any other treatment there in terms of...?

Vicky: just the dietician

Facilitator: just the dietician. Was there any counselling, was there any...?

Vicky: no

Facilitator: there was nothing like that?

Vicky: no. Even after I got out I wouldn't see the dietician, it was supposed to be weekly, em, but... I think I went into chronic bulimia after that cause I'd no take on how to tackle both of them that once it was uprooted, it's like addiction, once you start you

cannot stop, so I was after being let out and I couldn't stop eating so, em, I went on, straight back into the bulimia and I went up in weight and up

Facilitator: and what was the dietician like, I mean what information did she offer you or...?

Vicky: she basically just eh got me to keep a food diary and she would suggest things. Initially, I stayed in the anorexia, it was weird it was about maybe, maybe a month after I got out I stayed in, I went into, like a stretch of anorexia and then fell over into the bulimia and the overeating. But em she would have been trying to encourage me to eat more and more, em, and then I just stopped completely cause the bulimia is just unreliable, I suppose you just don't want to stop and you can't really. So, for a while so, I just stopped completely going to her when that hit

Facilitator: and then from there you, you were then admitted into XXXX [named treatment centre]

Vicky: yea

Facilitator: and what was that like, I'm not that familiar with their program or anything so maybe you can tell me a little bit more about that

Vicky: Oh Jesus. Em...they were a lot, I still talk about them, em, they would be classic, old-school, what everyone gets when they go for treatment. They have a three-stage program. XXXX [named therapist] is after telling me things have changed a bit since I was there but not a whole lot in the main game which is the three-stage program where they give you your three meals, three snacks and they, you are on very high calorie intake there. So if you, so food-phobic or everything like that, I just think it is just going to drive you over the edge because just the types of stuff they have, you have. Em...and then once you get into maybe stage two, is about a month there, or after you get there, you get weekend leave or day leave? Day leave I think it is which is maybe one day a week, someone gets to sign you out. Em...and then in stage three, which is probably the third month, you get weekend leave which is when you go home and puke your heart up and don't eat. And you come back Monday lighter which is, I mean...I'm saying you

because it's something that I would see in the other girls like, there was, well everyone's so afraid because the approach is so abrasive or invasive that everyone's petrified and looking after their own corner, cheating, so they don't, you know, it drive you into protecting or would drive everyone, by the looks of it, into protecting it rather than actually wanting to get well cause the techniques are that scary. I still wouldn't do it

Facilitator: the techniques that they use in XXXX [named treatment centre] you mean?

Vicky: yea which would be...I mean you're on a fry up and a bowl of cereal when you get up in the morning. The snack then of a meal supplement called Ensure, then you're on like your full dinner/lunch which is like your soup starters, your massive Sunday roast and then cream whatever for dessert. Two hours later you have another Ensure which is a meal supplement and teatime is the greasy spoon of, it was usually like chips and pie. Oh my god, even thinking about it now, I'd have a breakdown. Em...yea so I mean all that does in your head is put super, like, focused on the food, super afraid and like you're so freaked out you can't hear the type of help that's being talked to you, em, and anything that you're forced to do, in me, or in anyone with eating disorder that I see only creates a backlash. It's like the mother saying "don't go out with that guy", it's just, you know, that's the effect it has, two-fold, I've never seen anything else happen in all the treatments I've been in

Facilitator: so do you mean it kinda reinforces, is that what you're saying kinda?

Vicky: it, it's too much too soon and it has the backlash effect, I feel. I came out of there, I took up laxatives, I took up smoking, eh, and I took up some great weight losing techniques and really, I mean, I'm being smart like...just really sick behaviour. Because I got so afraid I was trying doubly hard to lose the weight put on plus more. Em...I think age as well has a huge factor in, em, recovery. It's so fine, the line is so fine. If you can get it, the younger the better. If you get it when they're set up in it in the late teens, they're more determined to stay, to kinda better eating disorder and in later stages you're so fucking sick of it and it's just harder to recover cause of the habitual effects, so there is a want but not, it's just too scary to stop the later it goes on. That's why most people

that you see who will survive it or even keep living in it or will be chronic, em, I guess I'd be considered, I, I was considered a write-off like before coming in. Em...I dunno, it's kind of a white knuckle effect at that stage but yea I can definitely say if I, had it been earlier it wouldn't have been this difficult

Facilitator: you mean if it had been earlier coming to XXXX [named treatment centre] or?

Vicky: ah...I don't know, I mean, to be honest, I don't know because here was like striking while the irons hot in a way but I can say as well I was up in that room thinking 'well, fuck this, I'm not fucking eating noodles, I'm going home' and Rory came out like and I was about to ditch like five grand of a deposit just to go home cause i didn't want noodles and I remember XXXX [named therapist] saying to me "give it a year and if you want to still go back", the only thing that kept me going then was thinking I could go back to it but where was I going with that point? I suppose that like I wasn't even sure when I came in here still but there was a want which wouldn't have been there in early teens, sorry, mid-teens. Early teens, I was loving the attention I was getting for this thing that I thought was terrible, at the start, it turned into...got its own face and legs and everything, personality and life, the eating disorder like. So it was great craic like, as painful as it was to go through, em, it got a lot of attention, it got a lot of people standing up to it so that's kinda in early-teens, teenagers want attention like. It can, it's such a fine line where it gets hit

Facilitator: so you think it's a critical time point, do you?

Vicky: yea, between twelve and yea, sorry, I didn't even say this. I suffered from bulimia just sporadically all through from the age of about nine, em, cause I was such a greedy kid like. I would've being overweight all my life and when I ate too much purely for, I don't know, I guess the discomfort of having binged or, you know, overeating, I'd make myself sick but it wasn't, it did get progressively more at twelve, thirteen, fourteen. But had someone stepped in around then I believe there wouldn't be the amount that there is today and the progression that happens, the sooner it's intervened

with, the better. And, then again, the anorexia and bulimia are, I mean they're totally different ballgames so it depends on what they're suffering from in the end. Anorexia, anorexic teens are probably a fucking nightmare, em...they, if you can get like up to the age of between twelve and sixteen like, anorexia, it would definitely be the best. After that, like I said, it's where you're engaging and you love this new figure and this new attention so you try to be sick. And, like, every time I'm saying you I'm thinking everyone in general. Em...from twenties onwards all I could see for myself and this is, it's unbearable but you can't see a way out cause it's too scary to stop. Late-twenties, you're fucking, you're wrecked from it, there is no way out. I actually stopped trying after, when I relapsed after the XXXX [named treatment centre], I didn't even want, that's the reason I didn't hope to get better or go for any type of help. Em...I, I just thought if I could, em, worked to make enough money to binge and get sick and drink until I died I'd be as, as least of a drain on like society and my family, but that would kinda be my option, I didn't see treatment as an option at that stage. But yea the progression to where you get treatment to bottom of the line is definitely brutal

Facilitator: so you're saying that when you went into XXXX [named treatment centre] that then you were nineteen and you were kinda bingeing on and off from when you were about nine, so when you were in XXXX [named treatment centre], it was anorexia you were getting treated for?

Vicky: eh XXXX [named treatment centre] anorexia, XXXX [named treatment centre] anorexia, yea

Facilitator: and XXXX [named treatment centre] was anorexia as well?

Vicky: mmm hmm

Facilitator: And apart from the, kind of, the food and the whole, eh, that process, what other treatments, um, you went on the three-stage process, I'm assuming that's an inpatient was it?

Vicky: yea

Facilitator: yea. What else was there treatment-wise, at that stage, did that program offer?

Vicky: em...outpatient which is you go out, you come back weekly for weigh-in. That's another thing, it's complete bullshit over this, you know the, they say that you need to recover but they're still holding scales as your deciding factor of you go back in or what happens you. So you get into the whole water-loading and all that, and that stuff, but that happens in the outpatient. You get weighed in weekly, em, you don't get counselling, that you have to pay for separately with a psychologist, if you wanted like additional counselling. There's more or less kinda like a dietician slash life coach I suppose? Em...and that will go on for...I ditched that after a month I think, I couldn't drink any more water but em (laughs)

Facilitator: it wasn't working for ya

Vicky: no, fuck that. I used to, I was telling XXXX [named therapist] there actually cause I said today that I just really felt like doing the same again, I have a bag with like two litres in it and I said to her "just even like automatic reaction is to go to like the bad stuff" and I showed her like the two litre bottles today cause I was being weighed in today which, again, is my choice but em yea, no, I stopped going to the aftercare cause you can't be up straight like that. Here, I've sat down and told her, em, all the shit that I would be actually doing that you've never felt. They make it so scary there that people don't want to engage with their recovery whereas here I've, I've definitely felt able to engage and I've seen others do the same as well. Em...and that is, that's how, you're just wasting money with XXXX [named treatment centre] basically I think, or general hospitals. I think working with someone if, if you could fund or help fund that, that's it. Em...just a want, even a small want and a bit of willingness and

Facilitator: a bit of willingness on their part or your part?

Vicky: both, both parts

Facilitator: both parts

Vicky: when I came here it was my thirtieth birthday and I left here feeling like somebody had actually, I didn't, I didn't think this was gonna make it better, usually going to treatment at the start at all 'oh this is it!', but I knew better at this stage. But I left feeling like there was a tiny bit of hope whereas anywhere else you'd be, you'd just feel like they're trying to haul it off you. I dunno, I'm just, I suppose this, it's so you can't keep it to a very smooth train of thought or anything like that with treatments. It has to come from both parties, that's all, you know, it has to. And if the parents fecking the kids for treatment against their will, you'll be guaranteed, I used to see that and not really understanding the younger ones when I was in XXXX [named treatment centre], watching like a sixteen, seventeen year old being, em, told what to do cause she couldn't sign herself in or out. I was eighteen like, I could do both, and being forced to get well, just wasn't going to work. Em...and I saw her get quite sick after as well

Facilitator: what in general was your experience of the patients in XXXX [named treatment centre]?

Vicky: I think, this sounds terrible, I think it's scarred me the most, em, cause I suppose that also that would have been my only experience with a specialised eating disorder unit, maybe that's what it was. Em...I was getting sick in the shower and I was doing the same as everyone else, em, you know hiding food, em, I was basically fighting the whole system the whole way through because everybody's in there to please someone, you know, parents, the husband, that was me, the parents as well. Em...I think unless, or they're chronic, at which stage they just have to sign themselves in as kind of 'see what you can do for me'. There's never anywhere that deals with a happy medium, like XXXX [named treatment centre] and, again, it's not been biased, I just know, I always had this in my head. The reason I agreed to come to XXXX [named treatment centre] as well cause I always had it in my head if I could set up a treatment geared at people with eating disorders it would be alternative therapies mixed with come on, you know, coaxing them basically. And all you need to add is a small bit of want on the other person's part, that's all you need like. Cause even in XXXX [named treatment centre] like I said, em, I had to be coaxed, a lot. And they, they, sorry

Facilitator: and, no, no, just saying that that's quite important

Vicky: and definitely work at giving it up rather than having it pulled out from under ya. Em...I will say this, in any treatments I went into after I started going looking for, from XXXX [named treatment centre] onwards, I never once got, made myself sick in treatment. Em...I suppose that, that isn't to me acceptable the way it would, it's more controllable once you can stop it, it's like if you take a drug addict and you detox them, if they go back and pick up the first fix, more fucking fool them and then after that, right then, goodbye, they're finished. But if they are struggling with, em, other things in their lives, they can be helped, if they pick up a fix they're gone. So, I suppose, in treatments it's the same, it's like once the behaviour is taken away, the help is available but if someone's getting sick in the bathrooms or they're not available for treatment...I dunno where I'm going with that, I suppose it does, it helps factors in it but if someone goes in somewhere and they're prepared, you know, prepared to stop getting sick, and they're still getting sick, they should be turfed back out again

Facilitator: yea, that's great. That's from your experience so...

Vicky: yea, it's very, I'm just trying to think of what, where that's all coming from, it is, it's like em I, I kind of, I let myself be coaxed by just managing to not, em, get sick and around all of that then I was able to be coaxed, you know

Facilitator: and going back then to, moving on then from XXXX [named treatment centre] Vicky, I suppose XXXX [named treatment centre] was then the next

Vicky: outpatient XXXX [named treatment centre]

Facilitator: outpatient, XXXX [named treatment centre]. What was that like?

Vicky: em...same thing, we had one family session which involved bringing your family who don't know what psychology is into a room and getting them to talk about their feelings. Em...so...they all...em are blaming the food and the weight and you've got the experts who know it's not about food and weight trying to get to family traumas. But it's not always about that, you know, so that didn't help personally. Em...I have to

say personally with that cause it may, it may benefit other people but only, again, teenagers. If you're not living with your parents there's no point in doing a family treatment program and also if there's not willingness on their part, same as the person with the eating disorder getting treatment, they're not willing to walk in and offer, you know, their help, em, it's just, it's just the same thing, it's not going to work. Em...I mean for a family who don't know about feelings, they can't help, you know, if they're still saying it's her food and her weight. So they're giving such a great form of treatment in a wrong way, does that make sense?

Facilitator: yea, that does make sense

Vicky: yea, that's my view on it, that, personal. Em...so we got one session of that and after that you have to pay for, everything's just paying through your nose when you have an eating disorder cause it's a middle-class disease, or a no-class disease or whatever they call it. Em...it's...em what else did I get? Em...the general nurse weighs you in once a week and the specialist sees you. Cause there's some specialist, at the head of every treatment, every unit, XXXX [named treatment centre], XXXX [named treatment centre], the specialist is running it but you are buying his time through your nose if you're talking to him. Em...

Facilitator: and is that one-on-one counselling or...?

Vicky: no, see that's why I don't understand about these specialists. XXXX [named health care professional] in XXXX [named treatment centre] has a team of people he calls, XXXX [named health care professional] is monitoring your recovery, the specialists are, you see there's no one combined, maybe that's what you need. I'm only getting my head straight as I'm talking

Facilitator: yea, I know, that, that's fine

Vicky: specialists, you'll get one dietician and then you'll get the feckin hippie counsellor over there so seriously you need, there's no collaboration or kind of, em, there's nothing combined

Facilitator: do you mean you'd prefer if it was kind of like the one person who was kind of giving the dietician kind of advice and information and also kind of acting as the, the counselling role?

Vicky: yea or maybe it's that they need to work really closely together cause even here, yea, you've separate counsellors to, XXXX [named therapist] would be the specialist and then you've the group sessions with someone else. I think they need to be on, that's what it is, the need to be on the same page working with a, a specific goal of combining the three rather than saying this is the program and this is my slot. It just seems like that maybe

Facilitator: it sounds like from your experience, from what you're saying from XXXX [named treatment centre] and XXXX [named treatment centre] that it wasn't something that you saw there

Vicky: they would have worked as a team but it's kinda like 'how's she doing with her food' and then you, there was such a huge gap cause there's no softies in between. There's the specialist that you get ten minutes with who...I don't know what the fuck he was doing there actually...he monitors you on how you feel like 'how do you feel about that?', cool, out the door. Em...and then the therapist, kind of, I don't even know what she was, a psychologist around the group which would be equivalent to XXXX [named therapist] and then you'd branch off into em...the alternative sort of, the other therapists on offer. But, yea, em...there's always the person who runs it and you can't...I don't know, see the ways I'm making, I'm referring to XXXX [named therapist] as the specialist and the therapist because yea she's taken the two major roles and then you've the counsellors, I think that's what you need. But this was like a specialist, a therapist, and then the break-off and there was no kind of communion between...

Facilitator: no communion, proper communication, is that what you mean?

Vicky: yea, yea I think so. It's so long ago, I'm here recapping going

Facilitator: it's fine, I know, I might be a bit difficult for ya to be able to think that far back and stuff and remember everything on the spot

Vicky: yea

Facilitator: so take your time.

Vicky: So yea, no but just she'd do all the weighing, the, em, group sessions

Facilitator: this is a general counsellor?

Vicky: she was, yea well I suppose there, no they're would be a nurse, I thought just there'd be, em, and they'd do all those kinda things. And then the specialists, they just like weigh you and ask you, you know 'how, how do you feel around that then?' and there's nothing really more than that said

Facilitator: do you mean that there's not enough depth in it?

Vicky: well there's no depth in it, whatsoever. I remember paying you man XXXX [named health care professional] in XXXX [named treatment centre], anytime you go in as an outpatient, seventy euros for ten minutes, it was absolutely, sorry pounds for ten minutes, it was crazy cause I remember my mom tearing her hair out in the waiting room going, saying 'that was ten minutes', 'yea, whatever I mean, don't know how long it was' but she was going mad over it. em...but yea, most places won't see you without, they do the diagnosis, d'ya know? And they are taking in big money for diagnoses but that's all...

Facilitator: is that kind of the initial assessment stage, is it?

Vicky: yea and most places, every place, won't take a look without an assessment

Facilitator: but how do you mean, they have their own assessment or if you're coming with a previous assessment, would they accept that?

Vicky: if you come with a previous assessment, you're going through for their assessment

Facilitator: oh okay, so to get in you have to go through their assessment?

Vicky: that's the way it worked mostly anyway. But shortly before going, when I'd decided I'd get treatment, I tried, before XXXX [named treatment centre], all around the same time now when I was thirty, I tried, em, XXXX [named treatment centre A], XXXX [named treatment centre B], XXXX [named treatment centre C], ...I didn't try any of the treatment centres again and then I looked, oh, oh I was going to just not go to any treatment cause they all...none of my VHI was going to cover them but they all actually, when, even if you're gonna pay out of pocket, they wanted a catchment area, they wanted, em, they didn't think I'd last, em, eh, sorry, I forgot this, my, the counsellor I was going to see and my partner didn't think I'd last over a month and neither did I so if I was going to get treatment so if I was going to get treatment it had to happen within a month. And, em, yea, they were giving me that time, they wanted me to do an outpatient program to be admitted and I said 'I've done every treatment under the sun' and she said are you sure you're bulimic and anorexic and I said 'told ya that' and she said 'you'll have to go onto our outpatients first', and I said 'I'm not, I'm at the stage where I cannot stop anything and if I did outpatient I'm telling you now I couldn't go away and not get sick for five hours, not to mind five days, or three months, you know'. Em...

Facilitator: and this was where sorry Vicky?

Vicky: that was XXXX [named treatment centre] actually, fucking laughed at me, no she sniggered and said that em, you know, good luck to me with the amounts of treatments, she went to recap on my treatments. This was... XXXX [named treatment centre], they were, they were the place now where I was saying

Facilitator: wanted you to attend on an outpatient basis before

Vicky: yea, yea

Facilitator: being admitted as an inpatient

Vicky: and I just said that 'I don't have time for that'. Em...yea cause I was, I was pretty chronic at that stage. Em...

Facilitator: so you felt that you needed to be admitted as an inpatient, you couldn't...?

Vicky: oh, definitely. Because I knew, I knew how outpatient would go, I'd be up on my own during the day, I had no control, I was, at that stage I would have been so bad that like I'd get up and I'd go straight for a binge or I could be bingeing for twenty four hours, like just between the toilet and the fridge and spend over a hundred euros that day on food. And I'd still go to bed at like four in the morning and get up for another binge and to vomit before going back, and I knew that I couldn't do three months if I couldn't manage two nights, even that. Em...it's kinda beyond your control, like with the drugs I'm saying, at that stage, em, but yea female anorexia came on at that so, yea I just knew during the day I just wouldn't eat and I was on laxatives and drinks and painkillers. And then during the night I would spend from about twelve onwards getting sick until four in the morning but at that stage I just knew that, em, they had to take me straight in

Facilitator: and do you feel that they recognised that you felt that your condition...?

Vicky: oh yea, I was, I was outside of work on the mobile and I just broke down crying when I realised these people can't help me. Em...the first one said "well, have you done treatment before?". That was XXXX [named treatment centre] I rang first and I said "yes", and she said could I take her through it and I gave her a brief list and she said "huh, that's quite an array you have there", she said and she said "well, I'm sorry now but you're not in our catchment area", she said and I said "if I pay for it by cash, would they consider taking me?". Em...basically told me I couldn't

Facilitator: and was his when you were looking for the inpatient treatment in XXXX [named treatment centre]?

Vicky: yea. So then when I went to XXXX [named treatment centre], they actually kept saying then "I'll take your details, em, and we'll get back to you", and by the time she got back to me it was a week, telling me that I'd have to, that was it, I'd have to go on a fucking waiting list to even do an outpatient program and I was like 'yea, you'll be digging me up from underneath", em, so I couldn't wait for any more follow-up on that, you know. Em...and where did I ring next? XXXX [named treatment centre], XXXX

[named treatment centre] and...there's one other place, XXXX [named treatment centre] which was the same story, you have to do an outpatient program, I was prepared to go back to XXXX [named treatment centre], I'm traumatised from the place but I'll still go back, but, em, you have to do an outpatient program there as well. All of them seem to have this thing of an outpatient program to, I don't know, I, I think there's a bit of money politics involved but, em, also yea there has to be a bit of genuine tracking of someone's behaviours and patters but there's no point when it's chronic. I know what you're going to do, groundhog day you do

Facilitator: so you feel that when you're at the stage that outpatient treatment is just not...?

Vicky: it was gonna be, it was going to bankrupt us like, em, sorry, I wouldn't have even found the means to be able to sustain an outpatient which isn't covered by any VHI or HSE. Sorry I don't know about the HSE but they don't get recognised unless you're inpatient, that's why I think it has got a little bit to do with money

Facilitator: and you've kinda, you've given us a good sense of the obstacles and things like that, did you find anything, any helpful aspects of the treatment in XXXX [named treatment centre] or the inpatient treatment in XXXX [named treatment centre] or the whole program in XXXX [named treatment centre], and kinda the outpatient in XXXX [named treatment centre]?

Vicky: em...again I'm trying to put my attitude now back when I had more of a teenager attitude, I'd say if I had, first of all, wanted to, there, there has to be that want cause if there's no want

Facilitator: to be given the choice, or do you mean actually motivated to want?

Vicky: motivated

Facilitator: motivated

Vicky: em...so yea, if I'd gone there and I'd wanted to get well, the weekly, you definitely need weekly help. The out, the after-care is vital for any recovery. I'm, em,

out since, eh...I'm out about a year and a few months and I still see XXXX [named therapist] weekly and a psychologist, XXXX [named health care professional], and I see him weekly as well. Em...actually no, I'm not, I'm like, I'm their pet case, they usually don't do that with inpatients but, em, yea, any other treatment, same thing, I would have said that was good, that they did follow-up and do eh aftercare. The inpatient...good out of that...em the structure around the idea was right to have to eat a template amount of, you know, nutrition every day. Em...and at regular times and to incorporate stuff like relaxation time, goal group, there all, I mean there's some things that you'd want to have to have all the time

Facilitator: alternative treatments as well

Vicky: yea

Facilitator: you need

Vicky: yea, but even like they all have good ideas behind their motives but they're only watery ideas. I researched treatment in, eh...eh...UK, Australia, and em, America before I came out here and they all seemed to go by that kind of an alternative self-help slash inpatient with, you know, the same type of thing here. So, em, sorry, my point being, they have a higher, em, higher, you know recovery rate than anywhere else, those three and their type of help is more alternative than the, and there's more help available

Facilitator: so do you find that they have kinda a different ethos, like what they're giving and what they offer?

Vicky: yea, you're just after reminding me of, I don't know how I forgot. I went to this place called XXXX [named treatment centre] which was actually really good, really good. Em, I went there from the age of twenty...I really wanted to get well. I was twenty-two maybe, I went till about twenty-six, I'm guessing. And that, that was the first time that they made me want to get better. Em, they would sit down and entice you because they invited you to engage in life and the living of it and, em, looking at nutrition and taking it in a respectful, healthy way, rather than stuffing you up for no reason. Understanding, working with, helping the patient understand what's happening

to them instead of, you know, just getting in there and wanting to stuff them up. They'd do nutrition workshops, em, they, I noticed that they holidays abroad, god, that's probably fecking disastrous probably but they do take them away on weekends, I'd say that's fun, oh god. Em...they did`...dance and stuff like that which is the same idea as they use here, just em stop focusing on the food, like mealtimes are there, they're set, you don't have to, and then around that, it's really about living life. Em...the joy

Facilitator: do you think that they bring enjoyment

Vicky: yea. cause in any eating disorder you've forgotten, you've lost all your friends and, I mean, in general, people have lost their friends, their, their hobbies, any activities, you'll always find that is gone, the further on it goes as well

Facilitator: they've lost a lot of interest in things like that?

Vicky: all interest yea. Em...yea, it's something I've had to, I suppose I still struggle with, em, it's what I'm working on

Facilitator: em...and then XXXX [named treatment centre], roughly kinda three to four years you were kinda there, was that on an outpatient basis Vicky?

Vicky: yea. They don't do inpatient

Facilitator: Oh, okay they don't do inpatient

Vicky: yea. So...em, they were fantastic, I dunno now how I forgot about them. Eh...they...they run under, again, a director and, em, she would kind of run all the workshops and then you each have your own counsellor but it's

(phone drops on the floor)

Vicky: fucking hell. I swear, XXXX's [named therapist] like you've got a mouth like a cesspit

Facilitator: (laughs)

Vicky: but em...she, eh...sorry what did you ask me there?

Facilitator: I can't even remember, I've completely forgotten (laughs)

Andrea: about the XXXX [named treatment centre], you were telling us how it worked with regards to counsellors and stuff

Facilitator: oh yea

Vicky: I was just testing your listening skills (laughs)

Andrea: oh right (laughs)

Facilitator: she passed, I failed (laughs)

Vicky: em, no the, the counsellors there, they all had to, em, or be involved with someone who had or they themselves would have been recovering, recovered from an eating disorder. And it's very interesting cause there's so much more compassion in there if they've gone through it. Em...and you can see it. There just, there has to be, it has to have that factor, that factor where you connect with something as well that wants to work with the therapist. Em...when I'd seen how fair XXXX [named treatment centre] could be, I began to trust someone when I came in and that's when I wanted to try, you know, stuff like that, I just can't see, there has to be a little spark there somewhere

Facilitator: so you're saying from your experience then that when you began to kind of trust Teresa a little bit that want in you became a little bit bigger?

Vicky: yea, yea. cause I actually aimed to, god I was devious, I decided I'd come in here and if I could get a month longer to live, like I just thought I'd probably get best, leave here and last a month I thought, you know, for the sake of the amount of money it was, I wasn't going to lose out on anything if it lasted me a month more. And then every time something happened to help me in here, em, I dared to actually think that I might be able to recover but that's how low I had gone. Whereas you take someone who, um, has like got a general eating disorder and a general want to get well, you see them totally engaging straightaway

Facilitator: em Vicky, you just said there, I noticed something that you said, that trust is a big thing for you, em, with XXXX [named therapist] and with therapists. Would you rate that as a, as an important thing to have in a therapist?

Vicky: hugely important

Facilitator: hugely important

Vicky: this, I actually had to tell a therapist in XXXX [named treatment centre]...there wasn't, she couldn't help me and it wasn't anything personal. Em...I told her that it was actually just a personal, there was no gel there. I'd talk to her but, em, I wouldn't divulge anything or there was no, there was nothing there, yea, and I was just saying "no, offence, you can't help me". Em...and that's when XXXX [named therapist] and XXXX [named health care professional] took over. Em...but they also did say that it was a fact that I'd been through so many counsellors and knew what boxes they wanted to tick and psychologists and god knows what. Em...it's kind of why...like I know I am a bit different that way so it's not really a general rule but there does have to be trust

Facilitator: what else would you say is, makes a good therapist?

Vicky: em...you do need to see that they have some sort of compassion, it's not advised, I know, but they would have to, as a general rule, counsellors aren't encouraged to get personally involved and I do know that in XXXX [named treatment centre] a few things that obviously grabbed me was she was quite, she would have given me her mobile number to call her if, you know, I needed to talk and that's too much invasive. But, whereas, em, you do need to see that the person cares. Like in XXXX [named treatment centre], I know XXXX [named therapist] cares but if a called and cancelled tomorrow she'd be like "well, your problem", but she does care, you know that kind of a way? Em...yea, I dunno

Facilitator: so the compassion and the trust, em, and in that relationship, as you said like, you gave us an example there of just the first, one of the first therapists you seen here, you knew instantly like on first impressions that it wasn't, you couldn't

Vicky: but it's like a shopkeeper. If you go to a shop and they're like on the phone talking and you're just like 'eh, screw you' and you're automatically not going to be exactly like 'hi', you know, and then if there's even a bit of friendliness or like, you know, chats going on when you're buying, you're like 'oh that person was really nice'. Same, you get more, you know, it works

Facilitator: you get more out of it. Em...and coming kinda back to XXXX [named treatment centre], what are the things that you find the most helpful aspects of the treatment here?

Vicky: with me...em, definitely, em, I wouldn't write this as a general rule but I was so unable to, em, kind of go straight into that, eh, they were flexible with me. Um, they'd let me away with a bit more than other people but because they saw I needed it. like I would refuse point blank to eat white bread and they'd actually allow me that when everyone else was sitting eating white bread. But they knew that like had they insisted, they know I'd be off out the door with my bags packed. Em...so they actually I suppose for me it was that they flexed just enough to not leave me too much reign but leave me breathing space and I guess that's even the whole idea of the place, is like they personalise it, yea, it was more personal. Um...and it's not like a general rule of you have to have this, this time, and you have to do that. They were able to see and in any places I've been the only effectiveness is when you're to look at the individual. Em...that's it really like

Facilitator: so do you mean more then, talking more in terms of individual needs and stuff like that?

Vicky: everything. All of us like, yea

Facilitator: and is there anything that you find, or you have found, in the past, unhelpful about the treatment in XXXX [named treatment centre]?

Vicky: I didn't think that they, huh, em, they weren't, you see, it was different cause when I went to XXXX [named treatment centre] they weren't prepared for a lot that, you know, when you're opening a new business, the unforeseen. I walked in one

morning and there was like, I don't sleep, I still don't really sleep but it was like about three in the morning, the kitchens opened and there's internet, laptop on the top and...to a person if you've got anorexia you're gonna go straight for the online if you've got an addiction to pro-ana sites. And a bulimic is just gonna like sweep out the presses and go to the nearest toilet...mostly. I didn't, as it happens, but stuff like that shouldn't have been an issue or they took on some general nurses which I don't think you can do, sorry, not general nurses, they were what looked to me to be like younger girls that had gone to college and studied some sort of psych care. They didn't have a fucking clue and they were dealing with...eating disorders are probably the most viscous people to work with cause they're so protective of their eating disorder. And eh,

(Alison catches a fly)

Vicky: did I get him? Yea

Facilitator: that's so annoying

Vicky: no way, I got him

Facilitator: did ya?

Vicky: he was in the kitchen for days, I picked up a two litre empty bottle of Pepsi, waited for him to land and I

Facilitator: (laughs)

Vicky: I was like no, no way! But em...yea, em, what was I saying?

Facilitator: em...the, the

Vicky: the general nurses

Facilitator: nurses, yea. They didn't have...

Vicky: yea, they just, they don't em, they took on people who just didn't have a fucking clue like and they were dealing with like really aggressive behaviour. No, not physically

like, just, em, me, for instance. I wouldn't talk to a few of them , I was, em, I wouldn't engage, in that kind of a, I wouldn't cooperate, you know

Facilitator: and did you feel that they weren't prepared for that?

Vicky: em...no, it wasn't fair on them, it really wasn't. Em...they were dealing with somebody who's thirty, eh, telling them, you know, being hostile, very hostile and still have, and they're young girls and they're going "will you eat your snack now please", and you're like "yea, when I'm ready, I said", you know that doesn't work

Facilitator: yea

Vicky: it's still someone, and they're thinking 'is it me, is it her eating disorder, is it her?', and they are unsure of their roles I guess. See, I'm only working this out as I was telling you like what

Facilitator: no, yea, you're doing a great job

Vicky: em yea, they're just, they're...they're too young and under-educated in the field they're working in. Looks like they got, to me, it looked like they got educated in college under a psych nurse and like the general things a psychos that'll do to you is an attitude like that. And then I'm guessing they got branched into eating disorders up to nursing homes or wherever the rest of them have gone and none of them a specif, it's just like wherever they got a job

Facilitator: oh so you mean, are you saying then Vicky, they didn't have any specialist, em, experience in eating disorders before they came to XXXX [named treatment centre]?

Vicky: yea, yea. They need to be trained in to work with someone with eating disorders and what they're to, like they didn't have a fucking clue that you've to lock bathrooms. They don't think about things the way eating disorder people would think like...

Facilitator: things like, for instance, practical things

Vicky: they'd go like 'fine', and you'd be ditching half the things in the bin, do you know, and bumping stuff up. I was getting up at six o'clock one day, a lot of days, watering down the milk and they would be in the bedroom and they wouldn't be aware that you can do these things, you know

Facilitator: so am I right in saying that you think they're inexperience just caused a lack of awareness?

Vicky: yea, you need to kind of know how, you know, I'm sure they've been educated on if they're in a psych unit how to handle a person who is having a psychotic episode or how they might lash out at you, so why not the same here or why not the same for a nursing home where they have different needs again, you know?

Facilitator: very good, and moving on then kinda back to, we haven't really discussed a lot about XXXX [named treatment centre] or XXXX [named treatment centre], em, and I noticed you said that XXXX [named treatment centre] I know that you went in for treatment for alcohol. With regards to the eating disorder in both XXXX [named treatment centre] and XXXX [named treatment centre], what was the treatment like that you received there?

Vicky: ...a lot more compassionate as well

Facilitator: more compassionate

Vicky: yea

Facilitator: you said that that was quite an important thing for you?

Vicky: big time. Em...they... XXXX [named treatment centre] were probably, you see it's very hard, I'm trying to differentiate between what my eating disorder preferred and what was best for me. Em...the XXXX [named treatment centre] wanted you to attend, it is an outpatient but it's like em...kind of groups that you go to, you could clock up a few brownie points you know to get you in there faster. And I was still chronic enough where I had to be detoxed in XXXX [named treatment centre] and kept there till I went in there, till I went into XXXX [named treatment centre] and I was inside in the alcohol

unit in XXXX [named treatment centre]. And I was inside in there, sitting on the bed bingeing all day and puking and they didn't say a word as long as I wasn't drinking, you know?

Facilitator: this was in where?

Vicky: XXXX [named treatment centre] being detoxed off the drink you see, and the drugs. And em...they said that they'd take me in if I could manage to detox off the drink and managed, they, they asked for you to be free from vomiting and laxative use I think it was a month but sure, Jesus, it was three days for me. And I remember I lasted two days and I lied about the third but, yea, they, they do ask that you do an outpatient program first. XXXX [named treatment centre] didn't, they took me straight in. that was the only difference between the two of them plus the XXXX [named treatment centre] is bigger with stricter rules like

Facilitator: and how did you find those then, what were they like, the most helpful aspects of the treatment?

Vicky: em...

Facilitator: in terms of for treating your eating disorder?

Vicky: well you're working...same as anything else like I mean XXXX [named treatment centre] aren't magic and they weren't going to be but they would be the same without the old-school kind of thinking. Em...you got say in your menu, em, group therapies and a bit of fun. So it was all in the right vein like, jus definitely not geared at like, see with bulimia there's so much insipid, em psychological working to be done. Sorry (to research assistant) I know I'm not looking at you as much but I can see you nodding along

Andrea: no, go on, you're grand

Vicky: I suppose I'm directing back my answers to whoever asked the questions but, em, it, yea, it's just, it's down to that really like

Facilitator: so you think that also the emotional and the psychological element needs to be addressed and although they did a good job of balancing the, you have a bit more choice in your meals and stuff and the compassion is there

Vicky: yea

Facilitator: the other side of things also needs to be addressed

Vicky: yea, I mean it is, it is really good for the drink and the drugs, it's em, the only thing I will say is the, I call bible bashing. They're very invasive on working around the twelve steps and it being God and a religion and...I wouldn't, I wouldn't be a great God kind of em believer but I would be of something spiritual maybe but that's not everyone's belief and so to kinda have it based on that is, I don't know where you'd go with that

Facilitator: it doesn't play on everybody's perceptions, is that what you're saying?

Vicky: yea

Facilitator: I noticed you saying, I remember at the start, now I'm not sure what centre or which one you were saying, but I remember you saying something like maybe it was the XXXX [named treatment centre] and it was kinda like you go in and they have the drugs and then maybe the alcohol and then the eating disorder treatments fall somewhere around that

Vicky: yea

Facilitator: is that something you felt in those centres?

Vicky: yea I remember getting asked, it was definitely because I remember even in the XXXX [named treatment centre], a guy asking me "so like what are you in here for?", do you know, it was the most, biggest kick in the stomach to be saying, like yea I know you don't really have a particular drugs, so what do you do? Em...because it's not highlighted, it's not, in a group therapy session, they'd nearly have you believe you're just fucking the junkie in there, as bad as everyone else whereas I felt like I, I had to

minimise my eating disorder and almost maximise painkiller addiction or my drink addiction, which wasn't the case

Facilitator: so do you mean, are you saying, and correct me if I'm wrong, are you saying that the eating disorder wasn't really given enough priority?

Vicky: no

Facilitator: in comparison to the drugs and the drink?

Vicky: big time, big time. Like there was a woman em XXXX, any who, she dealt with the eating disorder people separately because the groups are so focused on drink and drugs and that would have been once a week or was it twice a week? I can't remember, twice a week, which wasn't enough like. You dealing with something that you need to be tackling twenty-four seven in inpatient environment like. Em...so like...

Facilitator: that's good, we're getting a good sense of kind of from XXXX [named general medical hospital]kind of through the specialised treatments in XXXX [named treatment centre], XXXX [named treatment centre] to XXXX [named treatment centre] and XXXX [named treatment centre]..em...

Vicky: do you mind if I just pop to the loo first?

Facilitator: no, not at all

(break in audio)

Facilitator: Vicky, I'll suppose we'll kinda just, we'll move on then from the kind of, we've got a great overall sense the different treatments that you've accessed and both the helpful and unhelpful aspects of that and with regards to therapists as well, the important things you've noted for therapists. We kind of might move back a little bit to, em, just to finish things off, we'll look at when you were first accessing help, who was your first point of contact for that and what was your experience of it?

Vicky: you mean like with the family or the healthcare?

Facilitator: em...with before, I noticed that you, before you went into the general hospital in XXXX [named area], maybe you'd seen a doctor or I'm not quite sure who was the first professional you met, who kinda started getting the ball rolling on things, maybe it was a referral process, was there...?

Vicky: referral

Facilitator: it was a referral. And who was the main, who was the first person you saw with regards to kinda the treatments that you sort of

Vicky: you see that would have been like the first person was like a close friend of the family so he would've em...I remember he gave me a physical and em asked me about it. Em...but that would usually be the, the point of contact would be the GP

Facilitator: so it was the GP you had met?

Vicky: yea, yea

Facilitator: and what was that like? I mean did he offer you much information on the eating disorder?

Vicky: no, I wasn't educated at all on what anorexia or bulimia really was. I didn't even really know at that stage what was happening to me so I didn't, I wasn't able to make a call whether I wanted to get well. Em...I'm just trying to think even in general with people, em, people with eating disorders, they would, like the parents usually take them to the GP, the GP refers them to a counsellor who then, it usually would be the counsellor or therapist who would suggest that they go into a treatment. It's very rarely that you see someone come straight into a treatment, it's too much and too, em, in your face. Em...I think they're usually...

Facilitator: The GP is the first point of contact, you think. And did the GP recognise it was an eating disorder in your case?

Vicky: yea

Facilitator: he did

Vicky: yea

Facilitator: and he referred you on then to, I'm not quite sure, was it the general hospital in Cork?

Vicky: he admitted me

Facilitator: he admitted you into XXXX [named general medical hospital]. Em...when you said that you weren't educated on anything, was, did he give you any helpful advice or...?

Vicky: the dietician was able to. I think it was more they tried to just get you to eat normally, you know that kind of an attitude? And because I was suffering from a bout of anorexia then like the bulimia is and always will be the remaining underlying factor with me like and that wasn't tackled so...you can't take one and not the other

Facilitator: okay, and how did you find the GP was, how did you find, what was your experience with him about your eating disorder?

Vicky: oh he was very nice

Facilitator: very nice

Vicky: very kind, yea. And I did find that most GPs that I need to go to or do go to are very, em, understanding or even if they don't understand about it they'll always, they're general so they'll always refer you to a counsellor or some sort of a, some sort of a support who would have a knowledge of eating disorders

Facilitator: so you think that's quite good, that GPs would have say that, in general, then their, their kind of knowledge about referral pathways and about eating disorders is sufficient?

Vicky: they usually would look up a book, you know, and that is enough to give you a point of contact with someone who does know. They have free groups called Bodywhys, they're quite good even when I say I feel guilty cause I should probably go but, em, they're groups for the public who walk in and even if you don't know what's wrong

with you, you can sit and listen to other people and go “oh my god, that, how come they’re doing the same thing as me, they have what I have”. And even that, kind of, initial of what’s wrong can help you

Facilitator: somebody else experienced it as well

Vicky: yea or, like I said, an element of trust between a counsellor who does understand it or what’s happening them even from if they have no knowledge. But just someone who can, who can, who knows the disease, how it works and can voice that

Facilitator: and did you get any information leaving the GPs, like any, I don’t know, like even leaflets, any sort of that kind of information?

Vicky: no, no

Facilitator: do you think that something like that should be available from the GPs?

Vicky: I think there is nowadays

Facilitator: there is

Vicky: sorry, not in the waiting rooms and stuff I haven’t seen anything but then, like I said, could put you in contact with a name who will give you those. I mean there’s loads of book information and like specialists even if they’re not going to give you the help you need, they can give you information. And the internet and all that sort of stuff like I still need to refer to it and stuff like that to know what’s Vicky, what’s the eating disorder thinking, you know

Facilitator: and just moving on then to the information sources that are available in Ireland, so what is your opinion on them? That information that’s just available from the GP, information that’s available general

Vicky: em...it wouldn’t be great. I, like, if I wanted to know something about an eating disorder I’d like, go onto to Bodywhys or, like, we’re talking using Google, Bodywhys or what usually what I’ll be looking for will come up on a Canada or a US website

Facilitator: so would your preferred source of looking for information, would that be the internet?

Vicky: yea, I wouldn't ask a GP or anyone in a general eating disorder unit cause I do find they're still so old-school like. Em...yea, you need to, you, the only people that I know that have proper, em, kind of experience slash information on it would be XXXX [named treatment centre] or, em, XXXX [named treatment centre]. I'm just trying to think there, I don't know anybody else who's been able to give me any useful information, you know, bar the internet

Facilitator: bar the internet. So the information or advice that you received when you were first looking for help, what was that like?

Vicky: oh it wouldn't have been, it wouldn't have been great at all, em...the first place I saw that tackled behaviours I had were XXXX [named treatment centre]. So they have the information, it's just very dark age like and if, you see, cause I said this is such a complicated disease that they dealt with a general behavioural slash general thinking of it which, em, it just didn't cover it like

Facilitator: are you saying then, and correct me if I'm wrong, do you mean that not everybody has, fits that general criteria and that it's just not individualised enough

Vicky: it's that, that's it, yea. And I mean, when you are in like with Bodywhys they do keep it general but, you see, because you're getting a scope on (cough) I suppose the different possibilities of taking individuals into account. Like you can have a room full of people with anorexia right up to overeating. The person with the anorexia can even relate to the person with the overeating, you know, there's all crossways across there

Facilitator: and moving on then from the initial stage of, em, looking for information. Moving on from that to kind of to the next stage, looking for help, and the further stage, getting help, what do you think are the biggest problems that people come up against in Ireland when they're looking for help?

Vicky: funding

Facilitator: funding

Vicky: funding

Facilitator: so finances and that kinda thing

Vicky: if the willingness is there that you're saying, funding and...admission. The fucking loops you've to jump through if you do want to tackle something head on. They, some, quite, em often in teenagers, em, the symptoms present themselves so fast and they can be lifted quite fast so they will go in, they will be chronically underweight at the, you know, where they can do serious harm. To get them in somewhere faster then 'go on, try an old outpatient there', I think that they need access asap like

Facilitator: so you're saying that in that critical phase when adolescents are first presenting and because they, the symptoms kinda persist so and develop so quickly that problems like funding make it an even bigger problem when trying to access treatment and that just deteriorates the problem, is that...?

Vicky: em, if they could get the proper from of treatment fast

Facilitator: without problems like funding, is that what you're thinking?

Vicky: yea

Facilitator: it would be a lot better, the access

Vicky: big time, big time. Like it's so vital, I'm just thinking everything, like if they can get someone who understands and fast treatment, that's ninety per cent done with their ordeal

Facilitator: and is there anything else, em, other than the funding and the fast admission, is there anything else that you consider as barriers that are still preventing people from looking for help?

Vicky: education of the person offering help

Facilitator: and do you think they're problems, so when they're looking for help these are the problems they're facing. What about when they're, they're accessing help?

Vicky: how do you mean now when they're...?

Facilitator: do you mean kind of like, so somebody's in the real initial phase, the start looking for information then from that they're kinda, they're looking for the help, so you would kind of put down one of the problems would be funding, education of the person, em, offering the help. What about then when they're accessing it?

Vicky: em...that they just need to...it needs to be...like available to them, yea

Facilitator: and I noticed you put a lot of emphasis on the funding and fast admission. Were they kind of the biggest problems that you came up against when you were looking for help for your eating disorder?

Vicky: not personally

Facilitator: not personally

Vicky: not personally. And I suppose as well, like I said, things were bad in the economy and, em, I suppose because eating disorders weren't so, they're not great now, but they were terrible or maybe not as good as now then. So people would say 'put her in there', kind of, it was like a, a plaster

Facilitator: okay

Vicky: whereas now they seem to have more loopholes and more economic kind of things I guess so it just

Facilitator: do you mean just that they weren't recognised or there wasn't enough...?

Vicky: em...they're more recognised now but, em, but I don't know why, there's huge queues forming like, you know, and I wouldn't have need to queue to get into XXXX [named treatment centre] or the general hospital at the start and now it just seems to be a backlog, I don't know is it cause there's more eating disorders presenting themselves in

which case they should be younger anyway, you know, that would make it logistics like. Em...and we should make it more vital to give them fast access but people need to know what they're dealing with rather than going, putting all those people in the queue, into a number, you know what I mean? Em...but like it's just, it's just like that

Facilitator: so what then Vicky would have been the biggest problems and difficulties that you, that you came up against, em, when you were looking for help?

Vicky: (long pause) the eating disorder as a whole not being tackled as a whole with knowledge and education with me as well. Em...I suppose, yea, because you could tackle one and play down the other and I'd think 'oh yea, I'm fine', or I didn't know, em, just simple things that I wasn't educated enough on. I didn't know I can't leave somewhere and have a chocolate biscuit cause I'll have to have two packets. But no one says, "no, don't go doing this because it's so common that this happens", you know so

Facilitator: you mean the consequences of things kind of?

Vicky: yea, there was no one who was kind of educating me on that. For following up I need to have healthcare, I had taken on seriously, like in XXXX [named treatment centre] or whatever, em, and one thing actually, even with here, no fucking alcohol, no alcohol for anyone. It doesn't matter whether they're alcoholic or not, em, it's just like the amount of relapses I've seen due to alcohol. I mean even if you think that you don't have a problem the shit you do then, you've no defences against an eating disorder if you're drunk

Facilitator: very good. Em...going on then to kind of some suggestions or advice that you might have to improve treatments that are now in place, em, or for future treatments?

Vicky: copy the, the bigger countries

Facilitator: so do you mean like kinda like the UK and the US, the way systems are run there?

Vicky: um. Cause I just think, I don't know what factors would I give but it's just like anything else, where do all the big things come from that really kind of work. Everything down to TV is copied from the US and the UK, they do quite good programmes. Now I, like I said, there's loads of different factors in them to copy. I mean anytime Ireland goes out on a limb, Celebrity Bainisteoir

Facilitator: oh god (laughs)

Vicky: (laughs) need I say more? That's our treatment, that's the treatment, you can just bring it to eating disorder bainisteoir. Yea I mean they don't need to do their own research, they just need to look at what's fucking working like

Facilitator: elsewhere. And what about in terms of, em, therapists and things cause I noticed you said like trust is a big thing and you've had, from what sounds like, sometimes a negative experience with therapists. Could you offer any advice or suggestions that you have to improve working with therapists or therapists working with people with eating disorders?

Vicky: yea, no it, it's just so personal, I can't actually make a, kind of a, em, d'ya know, non-judgemental one on that cause I think it's down to the individual. But, yea, they have to, they have to have that compassion, they learn all that in Trinity or where not

Facilitator: and going on then from kind of like the information that's out there at the minute, em, I noticed you said that it's, it's still kind of not great and particularly when you were, when you were first looking for information there wasn't, you weren't educated, there wasn't much out there. Can you think of any ways to kinda improve, I suppose, awareness or what you can do with the information?

Vicky: no, you see, it's like with everything else, you pick up a leaflet, you know? They do have stuff in there, it's just like, it's just so, it's like everything else I was saying, it's so general. You can go through and pick up five leaflets and still, you know, it doesn't personalise it. I'm just thinking now what has made any one I've seen in all the years aware of something. A poster of a French model who was dying from anorexia, they put up a naked poster of her in, have you seen that?

Research Assistant: yea, I've seen it yea

Vicky: that fucking grabbed everyone's attention

Research Assistant: like a big billboard

Vicky: yea

Andrea: yea

Vicky: grabbed my attention as well actually but, em, stuff, yea, visual kind of more in your face things but I don't know, I'm not someone out of the media, I don't know how that works but media

Facilitator: so something that grabs your attention

Vicky: yea

Facilitator: em, very good, some great suggestions there. Em...I think we've kinda covered most things, the only thing I think we haven't kinda went into, I know when you where in XXXX [named treatment centre], you found their treatment very good, they were quite understanding, they had a better focus on nutrition, em, and things like that. Was there anything kinda that you found unhelpful about the treatment there?

Vicky: yea, you see because it was outpatient I was on my own reign but it does work. You see, outpatient for anorexia may stand more of a chance. They seemed to have more people with anorexia showing success there or maybe it was what I was seeing, I don't know, that could be biased. Em...I just think that the bulimia and overeating is too addictive to be able to handle

Facilitator: as an outpatient

Vicky: having said that so was the other, I still struggle with the anorexia

Facilitator: just from your personal experience you think that, or you feel that bulimia is more difficult to cope with and

Vicky: it's harder for people to see it as well. I did an interview with this woman for The Star and someone else, and the two of them, I was nearly totally ashamed telling them about it cause it's not, people don't have the foggiest in Ireland about the amount of people suffering from bulimia and, em, how you can like, any bulimic patch that I've gone through, I'd hold a size twelve, no one knows. It's all secretive so that can go, that can be as damaging and go unnoticed and un-helped and the person won't look for help for years like, you know. Em...so yea I suppose there's no awareness around that like, there is no, em, voluntary help kinda being offered cause if someone looks five stone, six stone, they're gonna be like 'oh no, let's get you in somewhere, so I suppose more of an education around that, for different types

Facilitator: so would I be right in saying that you kinda think that when people look at somebody's who's anorexic and they're, as you say, five stone, you think, whereas, the problem is with not recognising it in somebody who appears to look normal weight but they're actually suffering a lot of bulimic, bulimia

Vicky: yea

Facilitator: yea

Vicky: and they wouldn't feel okay asking for, I've told people before I'm bulimic "but you don't look it", cause I look quite healthy with, you know, the only give away would be, I'd have swollen glands but they wouldn't, they've no concept of what bulimia involves and all, you know, the addiction in there, they kinda think 'oh she pukes after meals, grand, yea, we'll get you some help'

Facilitator: they don't really understand it

Vicky: yea

Facilitator: very good. Well overall we got a really good sense of kinda the different treatments you've accessed, the helpful and unhelpful aspects, the same with therapists and you've kinda you've some opinions and your own experience as well accessing help, accessing information, accessing help, some things that might prevent that. So just

to kinda finish things off now, em, I'm just gonna give you a rough summary of what you've said and feel free to stop me at any time if I'm on the wrong track here cause that's important as well. So jus kinda when we began when you gave us a brief overview of the different, the hospitals, the treatments, em, both specialist places, so you went on from the XXXX [named general medical hospital], the general ward there to XXXX [named treatment centre] and XXXX [named treatment centre]. Em... after that there was like a few outpatient alternative treatments, em, to XXXX [named treatment centre] and then

Vicky: sorry XXXX [named treatment centre]

Facilitator: oh XXXX [named treatment centre] was there, sorry

Vicky: I left that out, it was in between

Facilitator: no you're grand, just we're on the right track

Vicky: before XXXX [named treatment centre] and after, with the alternatives, you can slot it in there

Facilitator: and then you had two stays in XXXX [named treatment centre]. After that there was like a renewal program in XXXX [named area] and from, you said after that it was like a halfway house, you were there a year, a year and a half after those, em, and then you went to XXXX [named treatment centre] for the alcohol and the, the binge, the bulimia, sorry. Em and then kinda for five years when you left there, there wasn't really much

Vicky: counselling

Facilitator: counselling until you went to XXXX [named treatment centre]. Em... you kinda then gave us a great sense of XXXX [named treatment centre] and a lot of the problems there was, I noticed you put a lot of emphasis on the food and the weight and things like that, that it didn't deal with other problems like the emotional, psychological side of things. Em... and you were quite young going in there at eighteen, you said. Em... XXXX [named treatment centre] was just an outpatient, you were admitted as an

outpatient but you felt that at that time, where you were, you badly needed inpatient treatment, the inpatient wasn't going to work for you. Em... XXXX [named treatment centre] you said was a fantastic program and that it was quite different to the other two, the people there had a better understanding and were more compassionate and they had a better approach to nutrition. As you say, it wasn't just chips and pie, or cream

Vicky: eat, as I said

Facilitator: eat. Em...and at the time you were an outpatient there as well, the only fault that you had there was that you thought you needed inpatient for where you were at the time and it was a problem that you see for a lot of outpatient treatments for bulimia. From your own experience, you feel that when you're at certain stages and you need help, em, it's inpatient help that you should get, not the outpatient

Vicky: and the chronic

Facilitator: and the chronic

Vicky: the chronic anorexic yea

Facilitator: the chronic anorexic. Em...you also said that, em, identifying as kinda two of the biggest problems to getting help would have been funding, and kinda the fast access and not being on waiting lists. Em...the education of the person offering help is important to you as well. A few different things that you said throughout, kind of, like, you even mentioned the general nurses here, they just, you said they didn't have the education for eating disorders specifically. And that would have been a problem in a few other places as well that didn't have specific specialised in eating disorders treatment

Vicky: yea

Facilitator: kinda moving on from that, I'll have a quick look at it here, my head is gone to mush (laughs)

Vicky: I know that's why, I'm here trying to catch up with you thinking 'yea'

Facilitator: (laughs), em...your GP was your first point of contact, you had an overall general positive experience of him, em, and you'd expect him to kinda refer you on to somebody else, which is what he did. Em...although he didn't give you any kind of education or information on the eating disorder you think that, in general, that's kinda changed over the years and that now it might be a different kind of thing. Then I noticed as well you said that, em, when I asked did you think leaflets should be given when you're leaving, you said that they did give you information whether it's referring you to the right person who has that information

Vicky: or a leaflet

Facilitator: or a leaflet, you'd come away with that information

Vicky: um

Facilitator: which is important. Em...

Vicky: you'd find it with the internet anyway, most people would like

Facilitator: yea the internet you said would be

Vicky: Googled it

Facilitator: your preferred source of

Vicky: most people as well though like even a parent when they go to see what's wrong, they can and do that quite a bit, you know

Facilitator: em...you identified the most important things in a therapist as the trust and compassion and you found that in XXXX [named treatment centre] that they had that understanding that they just didn't in the therapists in XXXX [named treatment centre] and XXXX [named treatment centre], you feel that they didn't have. Em...you spoke a lot about XXXX [named treatment centre], about how they, kind of, were a little bit flexible with you as well, they gave you a, I think you described it at one stage as a happy medium. Em...they know kinda how far they can let you go in one way, but then they know kinda how far kind of to be able to make, keep those decisions as well

Vicky: it's individualised, personalised

Facilitator: it's individualised, yea personalised is the word you used, yea. Em...and you said that the person has to, it gave you a little bit more of that want to get better

Vicky: yea

Facilitator: as well. Em...which would've, you kinda identified as important in treatments, treatments that motivate you to want to get better, to want to recover is quite important as well. Em...I think that's kind of, I hope we're not leaving out a lot here

Vicky: no

Facilitator: but I think that's

Vicky: here take my email here anyway and if you do feel that you're missing gaps or you want to know about anything you can send me an email and that

Facilitator: yea if you're comfortable with something like that?

Vicky: yea, it's XXXX

Facilitator: that's great, thank you very much

Vicky: you'll be on to my Facebook now, I gave away too much (laughs)

Facilitator: are you feeling alright after the interview?

Vicky: yea

Facilitator: yea, as I said at the beginning like the questions they weren't devised to be very invasive so I hope you don't feel that they were too invasive

Vicky: no, no, not at all

Facilitator: em...you gave us fantastic information, I could sit here and listen all day

Vicky: Jesus, I don't know about that (laughs)

Facilitator: no you gave us great information here and I've no doubt that it's gonna be so valuable to what we're doing

Vicky: cool

Facilitator: em...if it has raised a few issues for you kinda let me know and you know I can contact XXXX [named therapist] and she will give you the follow-up session obviously but...just once you feel alright after the interview, em, that's our main priority here really

Vicky: like I said if you would like me to contact either of my parents and ask them about the side, the initial phases, I'd be able to get a better view on that

Facilitator: that's very nice to offer that as well. Thanks so much for offering for offering that. Thanks so much for taking the time here today

Vicky: no problem, I don't mind at all, it kinda gave me a break in between

Facilitator: so Rachel we'll just start off then em maybe you can just tell us a little bit about kind of from the start, from the beginning when you were first looking for help, em, kind of the different treatments you experienced and things like that all the way up to where you are now, just even a brief overview so that we know

Rachel: em...like, kind of when I started it, where...

Facilitator: yea kind of even from when I suppose when you first, when you...

Rachel: realised? Em...I suppose it was kinda like in school, em, basically I don't really know what I, or how I realised I had one. It was kind of more like in school, kind of I was bullied for a while and then I was throwing out like food and stuff. I thought it was a game in my head. And the, em, like loads of people were really concerned about me but I didn't pass any remarks, sure I thought 'sure this is good craic like'. Didn't really pass any remarks. Then eh a teacher came to me one day in school and was kinda like em "Rachel I need to talk to ya", and I was kinda like "okay" and then she was like "Have you got, is something wrong like, why you're not eating and stuff?", but sure I obviously lied cause that's what you do, telling them different things. Em...and then nothing was really said for like two months after that and then my parents got a phone call and then they were like "there's something wrong". They kind of didn't really pass any remarks cause like I was kinda like chubby as it was in like sixth class and first year so I didn't think, didn't think anything of it but then it got to a stage where I just realised something was wrong. Em...basically they (parents) kinda went looking for help, didn't really know where to go and then they came to XXXX [named treatment centre]. We went to the GP and originally they said, they were like "ah no, it's just girls, just being a girl, probably hormonal and stuff", so I was delighted obviously. I knew they was something wrong at the time but I didn't really understand why and then that went on a few weeks later, we went to a different doctor and then they took me bloods and stuff and they were just "ah no, it's fine, it's fine, there's nothing wrong". And then about

three weeks later after that we went back to the other, my own GP and then they sent me, they referred me to XXXX [named health care professional] in XXXX [named general medical hospital] and then I seen him for a while and he kinda said, em, he kind of checked out medically and stuff and obviously I was given, he told me I had to put on weight in like two weeks or something and if I didn't something was gonna, like I was gonna have to go into hospital or something. Sure I didn't think anything of it, then he referred me to see XXXX [named therapist] here and I seen XXXX [named therapist] for a while and then I was put in to XXXX [named general medical hospital] because they, I think, in my head it was kinda like just to threaten me but it didn't really. It didn't bother me at all so then it was there where I actually kind of said "oh maybe there is something wrong cause they put food in front of me and I was like 'no way', I was like 'no', it was like growing in front of my face or something. There's something not right. and then I kinda just thought, I was in denial cause sure I was there "these are all just kinda saying things, that I did have an eating disorder", but then I didn't, I didn't really care. I was like, I was in a bad sate in my head where I just didn't want to be here so it didn't matter if I didn't eat. And then...I, what happened after, I was in the XXXX [named general medical hospital] for a while and then I got discharged to go on holidays cause I was rewarded cause I put on weight which was all false, it was all other things that I had on me to try to put on weight. And then I went on holidays, I lost a load of weight again, eh...and I was seeing XXXX [named therapist], I didn't see XXXX [named therapist] for two weeks that time I was on holidays and I came back and seen XXXX [named therapist] and she had me put back in. And then em...

Grace: this was in XXXX [named general medical hospital] was it?

Facilitator: back in to XXXX [named general medical hospital] yea. Em... and then I wasn't getting any better and then I was getting checked medically and weighed and all that kinda craic and that didn't, I knew I was losing weight but I couldn't help myself cause I was just like, I would describe it kinda like not me, it was kinda like maybe a possession or something in me, it was like another part of me that I didn't want to be there but it was there. And the, a few, I don't know whether it was weeks or months, I'm

not really sure and then I was sent to XXXX [named treatment centre] which was the best things that ever happened me, really. Em... and I was there for, like, I think it was fourteen, fifteen, maybe sixteen weeks and, em, that, they just helped me with the therapy and kind of group work and kind of craic like that, and then, see I had stopped seeing XXXX [named therapist] at that stage obviously cause I was in XXXX [named treatment centre] and then I kind of, when I was over there that was fine but when I was coming back and they were talking about aftercare I didn't want to see XXXX [named therapist] cause I blamed her for putting me over there in the first place cause even though the only reason I didn't get on with her, cause she was the first person that actually challenged me, and actually telling me there was something wrong. Cause otherwise, yea. So I came back and I went to XXXX [named health care professional] for a while and he worked in different parts of, not just about the eating disorder, he works on the other, kind of, emotions where I was bullied and stuff and reasons behind it rather than just the focusing on the eating disorder. And I seen some other lady in XXXX [named treatment centre], I don't know who she was, I can't remember what her name was...eh...

Facilitator: XXXX [named therapist]?

Rachel: I haven't a clue to be honest. Some other woman, I only seen her for a week though

Facilitator: was she a therapist or...?

Rachel: eh...she could have been. Em...I seen her for a while, eh...for a week I think it was and then I decided to go back to XXXX [named health care professional]. I stayed with XXXX [named health care professional] for a good while, he had me on other parts and then I went back to XXXX [named therapist] and ever since I've been with XXXX [named therapist] till today basically.

Facilitator: so you've had a few therapists Rachel?

Rachel: yea

Facilitator: yea, we'll get into that now in a wee while, that's very interesting so it is em...maybe just beginning back then at the start when you were looking for help, just going back to the, to kinda the information and thing that was available to ya

Rachel: eh...it was really limited like. Like it was more my parents that were looking for help. Like, I don't know, they didn't, like they rang other people that they knew might have eating disorders cause my friend, like she knows a girl who has eating disorders and then they kind of like, basically, Mam rang everyone and read books cause there was no other information where you can actually go to someone, I think there should be, like a group or like a helpline where parents can actually go to and ring and look for information cause there's actually nothing actually out there to be like 'oh yea, I need help', cause the GPs, they're not exactly specialised and they don't exactly have enough training in my opinion, I know that sounds like a strong opinion there

Facilitator: no, not at all

Rachel: em...they don't, I don't think like a lot of them, like even when I was there like three GPs just looked over us and thought nothing of it. They were just like, 'oh it's just being a girl, hormonal, whatever'. Didn't pass any remarks even though I was so underweight and everything, they were just kinda like 'ah, maybe she's juts skinny'. Even though that wasn't the way it was, that's why I think like GPs, I dunno there's something not right there, you either need to be trained or know, look out for symptoms and then like for parents to actually have a helpline or something like those whatever you call them, Samaritans and all them kinda thing. That there's actually a place, you know, for people, for parents cause they don't know where to go cause it's never the person with the eating disorder that wants to go anyway. They don't care. It's not exactly they admit they have one until they actually get to a certain stage, you know

Facilitator: so you say then with the GPs, they just didn't recognise that you had an eating disorder?

Rachel: no, not a clue. They really didn't, like they just thought nothing of it or, like obviously I hadn't been bad at that stage but I had lost about two stone, at that stage, in a

really short period of time. And they just, never looked over, didn't want to know about it, to be honest. Only that this other man wanted to, he knew there was something wrong. Like...

Facilitator: is that a GP that man?

Rachel: yea, he's... XXXX [named GP]

Facilitator: okay

Rachel: he was fine

Facilitator: so you saw your first GP was, was it your own GP?

Rachel: no, it was Mam's GP

Facilitator: it was your Mam's GP?

Rachel: yea

Facilitator: and...

Rachel: she looked over it and didn't think anything of it and then I went to a doctor in town just randomly because Mam didn't believe that something, everything was right. And she looked over it and then I went back to XXXX [named GP] and then he was like, you know, there's something wrong and then he referred me to XXXX [named health care professional] in the hospital so

Facilitator: oh okay, and you said at the time that XXXX [named GP] recognised it was something

Rachel: was wrong

Facilitator: something was wrong

Rachel: yea

Facilitator: did he recognise it was an eating disorder do you think?

Rachel: em...I reckon he did, he had a lot of experience like, he's old enough as it is now, on the way (laughs) but

Facilitator: he's pushing on!

Louise Rachel: either an eating disorder or something mental, something not right there, I knew, I knew in my heart and soul he caught on to me and I was raging. I was so thick. Coming out of that place I was like "no!", god

Facilitator: and so he then, sorry, he referred you on to XXXX [named health care professional] in the hospital?

Rachel: yea

Facilitator: and you went to the hospital to see XXXX [named health care professional]?

Rachel: yea

Facilitator: and what was that like? XXXX [named health care professional] not a GP, he's...

Rachel: no, I think he's a pediatric consultant or something

Facilitator: yea

Rachel: like that. Em...he knew that I had an eating disorder, even though he never said it straight out, I knew that he did know. And then he checked me out medically and stuff and he was the one who suggested for me to go into hospital because he kinda, he questioned me what I ate for lunch and stuff and he knew I was lying through my teeth because there's no way that all the stuff I named I was eating in the first place, he knew there was something wrong like and I didn't like him either, again cause he challenged me and he told me I had an eating disorder and I fought with him over it. I was like "no way". So yea...

Facilitator: and what about your parents in all of this, say your Mam or your Dad, how did they get on with the GPs and stuff and...?

Rachel: well Dad's quiet. Dad would kinda keep quiet about it whereas Mam would push you on and she was so determined to get me help cause she knew, in her heart and soul, obviously every Mother knows her own daughter, that there was something wrong. She said to the first two GPs that there was something wrong, like ye's are missing something but they fought with her saying no. XXXX [named GP] said yes and Mam agreed with him and then they, between the two of them, they kinda got me into XXXX [named health care professional] and Mam was always there and Mam was always kinda like "no, way". When I was told that they wanted to put me on antidepressants, Mam was like "no, she doesn't need anti-depressants. Only for Mam I probably would have been on antidepressants, that kinda stuff, Mam was very involved, Dad was always there but like Dad wouldn't be a talker so Mam did most of the work. But she was the one reading books and, left, right and centre basically everything she could find she did

Facilitator: and was there much information available to your Mother in terms of like from these professionals, from the GPs, from...?

Rachel: no, definitely not. They might hand them a leaflet that has been sitting there for the last thirty years which has never been updated or anything, it was ridiculous, just looking back on it now and just thinking 'how did she do it?'. Only that she went to the bother of ringing people in XXXX [named area] and like XXXX [named area], she rang people everywhere to talk to parents and stuff like obviously some people turn around and say they don't want to talk about it like, it's over, but then there's people that actually did. But there was never anyone there for the parents only XXXX [named therapist], the family therapist here. Before all that, cause it was me that suggested it at, to actually bring the family in to talk about, well, even though my brothers didn't want to be involved at all. But my parents, I thought, I could see them falling off the rope cause they were on their own. And they didn't really know where to go, it was, there was nowhere to go.

Facilitator: so am I right then in saying that, you Mam, it was mostly through like personal connections and people who knew people?

Rachel: yea

Facilitator: that that's how she got in contact with people that had had an eating disorder?

Rachel: yea

Facilitator: and that's where she got a lot of the information, between that and books and things?

Rachel: yea

Facilitator: em...in terms of you, I know you said Rachel that like for a long time you didn't kind of know you had an eating disorder and didn't kinda admit to having an eating disorder

Rachel: yea

Facilitator: when you did and you knew that you had an eating disorder did ever go and try and look for information or what was that like for you?

Rachel: em...well basically it was the day I was told I was going to XXXX [named treatment centre] in four hours, I was given a four hour deadline, told I was going to XXXX [named treatment centre]. I was let out of XXXX [named general medical hospital] to go home and pack my stuff and, well, I couldn't pack my stuff I was too weak at the time, I just sat on the bed. But I did, it wasn't, it was kinda more of a shock to the system at first, but after about a month in XXXX [named treatment centre] was when I started looking for information. They wouldn't give it to me obviously cause there were computers and stuff there but everything was blocked off, anything to do with eating disorders was, on the thing, cause everyone was trying to research stuff but everyone was trying to look for diets and all this kinda craic on the internet, whereas I wanted to look at stuff that I could actually do so I just read books and loads of books.

Obviously some things helped me and other things went the opposite way where I knew I could get away with things cause there's obviously helpful tips in those things for, well, anorexics do make them helpful even if they're not. So there was never really any, no one actually told me cause I was kinda, I felt like I was treated in XXXX [named general medical hospital], like in fairness, they did what they could but like some of the staff were so... "no way, you're not", like they couldn't have been arsed, like you're just there and they don't want to know ya and they don't want to know what's wrong with ya cause they've so many other jobs to do. They don't really care

Facilitator: dismissive

Rachel: yea, kinda, but like I asked them, there's only, there's one staff member I remember, she helped me, she sat beside me and she talked to me and things like, do you want like to use the laptop to look up stuff to try and help ya if you want. Whereas no one else would give me any information, it was like they didn't want to give it to me, they didn't care. So that's what I felt like as, kinda, turned an eye to it so

Facilitator: so that's going in to then the staff there in XXXX [named general medical hospital]. Em...so just kinda to clear it up then with the, there was just basically nothing for you?

Rachel: no, not at all

Facilitator: when you went looking, when you wanted to look for information to help yourself?

Rachel: yea

Facilitator: there was nothing and you said as well for parents it's pretty poor

Rachel: very poor for parents. I think family therapy is a huge key because it's not even just the person going through the eating disorder, the whole family's affected. And like if parents or groups of something like, even people going through it or if you had enough parents who have been through all of it that would actually be willing to talk to people, like actually have a group of people who say are all inpatients of the parents and

then people coming in and talking to them and showing their experiences. Like obviously no one can tell people what to do but like listen to their stories cause you can pick up on things and like “oh I never thought of doing that”, cause when they’re in their like state of mind where they think our son or daughter is in hospital or whoever it is, like, they’re all kind of lost and caught up in everything themselves like, they’re in the situation whereas someone who has been through it is out of it can look on to them and advise them, or whatever like. There’s nothing for parents at all, I just , it makes me so angry like just thinking about it, just so thick

Facilitator: yea so the parent support is definitely a big thing for ya then?

Rachel: yea

Facilitator: just not even like, just listening to someone who’s gone through the experience

Rachel: yea

Facilitator: em...for somebody, you think it is so important for somebody who’s going through at the minute

Rachel: and the fact that em people like say like when I had my eating disorder I was so manipulative. A lot of parents I see, like when I was in XXXX [named treatment centre] there was like, there was at least twenty of us on the unit but like, I see the parents, the girls are so manipulative to their parents, they’re just like “oh I don’t wanna distress them cause they’re gonna be, they’re not gonna eat then”, and it’s kinda like a dominos effect. Whereas if parents knew how to stand up for themselves an kinda like “oh yea” just agree with them at the stage, so then the parents then is thinking or on the same side but like really looking for help cause it’s so hard for parents as well. And you only realise that after you come out of the whole hurricane. Yea, I don’t know, I just think, family therapy, I just, even people to talk to for parents is a hugely helping someone in getting better at all

Facilitator: yea you seem to have like a great opinion of knowing that it's not just you that was affected by the eating disorder, it's the parents. You feel quite strongly Rachel about that

Rachel: yes

Facilitator: having support for parents that are out there, just seeing what your parents went through and the complete lack of support for them, complete lack of information, anything that was available to them. Em...moving on then kinda to like things that, first of all we speak about maybe thanks that prevented ya from looking for help and then from getting help, em and obviously lack of information was a big key for yourself and for your parents. Is there anything else that you can think of that, that em would be like a big obstacle or act as a big barrier?

Rachel: well obviously money, for a lot of parents, like we were okay because we got money from the HS, was it the HSE that does that gives those...?

Facilitator: the HSE funds yea

Rachel: yea, thank god at this time like if someone went to go for funding now, I wouldn't even say they'd get it cause of the state of the country like but money overall, XXXX [named treatment centre], could have been a grand a day, or a grand a week, or something like that and, oh yea, we got funding, we wouldn't have been able to have afford it at all. And like I see, em, there's girls that were in XXXX [named treatment centre] and lads obviously as well but they, they're parents could only put them in, for like, two weeks or something because that's all they could afford. There is no funding. The expense of the whole thing is ridiculous because they're so few eating disorder units at all that specialise in thing, that obviously their prices are gonna be huge and they all had to pay thing, like money is huge. Maybe not for me cause I got the funding as well but like for other families who are lower down, money would be huge and then like if it's, if they've loads of, there's no support there, again, for parents say if it's a single parent or whatever like when they have another child they can't exactly like leave that child and, d'ya know what I mean kind of? Em...what else would be kind of, money and

lack of support and lack of information. Em...I suppose, I think it all comes back to support cause a lot of parents would kinda keep it, don't want people knowing about it and brush it under the carpet and stuff. Whereas and then they've nowhere to go and talk about it to anybody else. That's yea, I think that's really....yea

Facilitator: that's very interesting Rachel, particularly on the finances. Your very valid point what you say about the price of it

Rachel: yea. It is ridiculous like cause there's like, and that fact that there's so many units and waiting lists which throw people off. They wanted to put me on a waiting list in XXXX [named treatment centre] at one stage, juts to put me on the tube cause I couldn't eat and that stage, waiting on a bed to go to, where was it, they wanted me to go to XXXX [named treatment centre] originally and then I was going to be waiting on bed lists so then they were like "no, she has to go somewhere else", and they got XXXX [named treatment centre], luckily enough, thank god. But your waiting lists as well throw parents off and you're having to pay on top of that to wait, on a list, which there's no eating disorder beds really which is ridiculous cause like if you see like the likes in XXXX [named treatment centre] they have so many units and they're huge and they all are so specialised whereas like here, you've absolutely nothing in Ireland. They really don't, like, mental health stuff is kinda like one of those things back in the day where they just 'if you have a problem, keep it quiet'. Whereas I'd a complete, you'll see me on the news one day campaigning or something, oh my god

Facilitator: (laughs)

Rachel: I'm telling ya, I'll set up a unit if I have to.

Facilitator: good woman. So ya think that kind of in Ireland that there kind of, would you say, that they just don't prioritise mental health?

Rachel: yea they don't understand. Obviously everyone know there has to be a budget in the country. It obviously hasn't worked cause the country's in recession but for mental health, it's something people shouldn't be taking money out of to put into roads or something like. All this country has to show for itself is roads and fro the mental

health you just see so many people who all they need is, like obviously some people work on outpatients, fair enough, they might not be gone past they stage where they didn't but people, where I was gone past the stage of being helped outside, I couldn't survive at all outside, I probably would have been dead at this stage, whereas for beds, waiting lists, XXXX [named treatment centre] and what other units are there in Ireland even, I can't even think of them. Like, there's , they don't understand how much of, like if they look at the percentages of how many eating disorders, I think it is like 9.6% of eating disorders and then like then there's a huge percentage that die because obviously they had no help, there's no beds, there's no one there. And then they have like, especially for eating disorders, they don't even have the right kind of therapists in there, there like psychiatric nurses and kinda things where the people are not specialised in eating disorders. They do not work, they do not combine together, there, like, the girls, we used to have a group in XXXX [named treatment centre] where we'd talk about like what helped us and what didn't help us and like for therapists and stuff, certain things, like the psychiatric, the psychiatrists, I don't think work for an eating disorder. And the rest of the girls agreed with me. Whereas like a psychologist would. But they all have like these new psychiatric nurses here and then they've a general nurse here, they don't understand, they have no training in this, the whole system. So it's kind of like you're not understood so you walk all over them because you have the eating disorder, you're the one going through it but they don't really understand. Yes they've read books, they've studied psychology but they don't understand the actual eating disorder of it. like in an inpatient, fair enough patient, but they might believe, whoever wants to work, they might understand and the might obviously give it a chance but like for those kind of like, for the fact there's so little beds and then putting general nurses into an eating disorder, just throwing them food and thinking about, all it is about food and they don't actually look behind the whole system of why they have an eating disorder. Again it comes down to finances and where the money goes in the country. It's not in the health system at all

Facilitator: so you would say it's kinda like finances, waiting lists, lack of information, particularly lack of support as well would be kinda the biggest things coming up, that

they would come up against when they're looking for help and when they're getting help. Em... and then in terms of like the biggest problems you faced, would they have been any, I know you said for you were lucky enough to get the

Rachel: funding

Facilitator: the funding from the HSE. Em... obviously lack of support for your parents

Rachel: yea

Facilitator: em...

Louise: at the time. Until XXXX [named therapist] decided to talk us for family therapy. But it was too late, at the time, when her and XXXX [named health care professional], XXXX [named therapist] and XXXX [named health care professional] decided to talk to Mam and Dad like later on in the system but they, I know by them they always thought that if they had a got it from way back, they would have been more prepared for the whole thing cause they, basically they were called in, told they had a bed in XXXX [named treatment centre], did they want to take it. Mam and Dad were so relieved but they were never kept updated at all. It was kinda like they just met the therapists and that was it and they were gone. Like obviously everyone knows people are busy and stuff but like, if you're gonna deal with a case, deal with it right and obviously that's why research is so important, to see how far you can come and change things.

Facilitator: yea, exactly. Em... moving on then Rachel to your kind of, you first, we talked about your first point of contact for treatment was the GP

Rachel: yea

Facilitator: when you knew that you were first going to be getting help for your eating disorder who did you think would be the first professional you would meet, did you think it would be the GP?

Rachel: em... yea well Mam kinda told me I was going to the GP, well the doctor is basically what she said and I was like “oh no”, yea I kind of did, but I knew they wouldn’t know

Facilitator: yea

Rachel: because I hadn’t gone past the stage where I wasn’t sane, I was still on the planet cause I still had weight on me when, even though I consider weight at the time, yea I probably did know I was going to a doctor first. But I never thought I would end up in hospital ever, or even land in XXXX [named treatment centre]. I, oh god, no way. I just thought I was going to be sent to the doctor, told to go home and that’s it, doors closed. Yea

Facilitator: so that, so you didn’t, am I right in saying there, you didn’t expect the GP to recognise that you had an eating disorder?

Rachel: yea but then the fact that the first two didn’t recognise that anything was wrong motivated me more cause then it was kinda like the voice in my head telling me that I, I was getting away with it. so keep going, why would you stop, no one’s looking at ya like, and you have all these little voices in your head telling you “oh they’re actually so stupid, they can’t even realise, like, that you’re not eating”, and then it’s kinda like “okay well I’ll just go home and not eat anymore and exercise like mad so”. Yea there’s things that motivate ya. When people don’t recognise things or if people are like, a lot of, I see people in England, there was some therapists over there and they’d actually get angry at the patients because they wouldn’t listen to them, or they’d look away from them or they’d do thing and they’d actually shout at them, which means they’re gonna get more angry and anxious and it’s like a vicious circle and then the anorexia, oh whenever we have, it keeps feeding ya, you’re feeding yourself by saying “don’t do it, you’re walking away from the situation”, kind of like. So that’s what I mean if they’re not actually trained in eating disorders, there’s things that people do, they don’t realise but they motivate ya even more to get worse, if you know what I mean.

Facilitator: so you nearly say that for the GPs like not only was there a lack of, the way that they didn't recognise you had an eating disorder, not only but did that kinda allow ya to keep going but it also motivated ya?

Rachel: yea. It does definitely motivate ya by people not having actual proper training at all

Facilitator: so that would, would that be the biggest thing you say and GPs in this country?

Rachel: yea, they don't, yes they deal with everything daily but for something like eating disorders there should be actually a trained eating disorder person to go to. Like obviously it's not exactly easy just to like go "yea she's a flu, give her a few antibiotics", like they should have actually training on symptoms or there should be people to go to for training in eating disorders and symptoms and knowing things around it, cause obviously everyone that just stops eating doesn't have an eating disorder but like, yea they're just, I don't think and they're so, I feel so bad saying this, inconsiderate and uncaring towards people with mental health issues, they really are. Like I don't think I've actually met a doctor who actually cares, it's their job, that's the way they kind of look at it and if there's something else wrong they refer you on to someone else. They just don't care

Facilitator: so would you feel that they were kinda like dismissive?

Rachel: yea definitely

Facilitator: em...and then I noticed you said that you kinda thought like 'oh I'll go to the GP, oh they'll not pick up on anything and I'll head off home', like, door closed, finished. Was that what you had expected from them all?

Rachel: no. I didn't think I was getting caught cause you think when, when you have, like, anorexia, you think by, like people, you don't think you'll ever get caught cause you're so sly, you don't even understand, it's so, it's such a sly and vicious illness that you think you get away with absolutely everything but when someone catches you it's

kinda like, like you start rushing again and you're like you have to do even more like in case they catch me again. It's yea, I don't know, it's really

Facilitator: and just you said that, so the first two GPs didn't pick up on it at all?

Rachel: no

Facilitator: just put it down to women problems

Rachel: yea

Facilitator: or something like that, and it was XXXX [named GP] who kinda copped that 'wait a minute'

Rachel: yea

Facilitator: 'that something's not right here', when you kinda, as you put it yourself, got caught, got caught out, what did you think then was gonna happen, what did you think that, what did you think XXXX's [named GP] role would be, what did you think he would do?

Rachel: eh...well I've known XXXX [named GP] a long time so I knew he was gonna do something, he wasn't gonna let it lie. Whereas the other two I could have walked on and they wouldn't have noticed anything. But, yea, I don't know, I thought he was gonna go and refer me to a therapist or else just leave me be but then I was kinda like "no, he's gonna do something about it". But I didn't know what, I didn't know what to expect cause it's so...numb in my head that I didn't really think of anything at the time. It was kinda like, okay, whatever, "I'll do whatever I have to do to keep them happy", walk back out, do it all again.

Facilitator: and then he sent you in contact with XXXX [named health care professional] in the hospital and from there you were admitted as an inpatient into XXXX [named general medical hospital]

Rachel: yea

Facilitator: yea. Em... I know XXXX [named general medical hospital] is not a specialist unit for eating disorders

Rachel: no

Facilitator: em...can you tell me a bit more about that and kinda what it was like there?

Rachel: em...I'd give them credit for they did what they could do, but they were very dismissive. They did not understand anything about eating disorders, really, like I would never send, like if I was a psychologist right now I'd never send anyone to XXXX [named general medical hospital] with an eating disorder or even just for the sake of putting them into it. They'd no training, they, they're busy, they have a job to do, they're general nurses or whatever they're doing like and there's different units and stuff. But putting, they don't, they're not trained basically and all they think about, a lot of nurses obviously don't know anything about eating disorders of they've never read anything, have never come into contact with people, they just think it's about food. All they think and tell you is to sit there and give you your dinner and lunch and whatever and just say "eat it, if you don't eat it, not my fault", weigh ya, that's it. You could get away with everything cause people, they didn't know when you get weighed you put batteries in, you drink loads of water, all these trick that you have, but they would never recognise it. I had a bed beside a sink and a toilet, could I be any happier really? And at one stage I was in, em, I was, I was obviously in a bed and then there was another boy that went in who was one of another patient, but he was in for the complete opposite reason, for overeating. So we used to swap plates, taking, but they didn't have a clue, not one of them had a clue. But then they sister out there that used to give out to XXXX [named therapist] if I lost weight, which would annoy me because at the time I kinda like XXXX [named therapist], in my head, because I was juts kinda like okay like, but then she'd give out to XXXX [named therapist] cause I lost weight and then, she didn't care, she was kinda like 'what is she doing on my unit?'. That was the way I felt like, I was so unwelcomed and it was just, it was horrible, it was really horrible. I would never, ever put anyone in XXXX [named general medical hospital] ever for an eating disorder.

Facilitator: so I noticed that you talked a lot about she was very focused on you losing weight and, and they'd weigh ya and give you your food

Rachel: yea, that's all they cared, they don't understand it's an illness in your head, it's not just about eating food

Facilitator: and had they focused on any kinda issues like that?

Rachel: not in XXXX [named general medical hospital]

Facilitator: no?

Rachel: no, no one talked to me in XXXX [named general medical hospital] at all like, every day they doctor would come round and be just taking blood pressure or something like that the nurse. But no one ever talked to me, sit down and talked to me about absolutely anything. At one stage I asked could I talk to someone, they were like "no, too busy, we don't care, you're just a patient, just stay on the bed". I was on bed sit basically, I wasn't allowed get off the bed. But sure I did even more work in the morning than I was meant to anyways cause that's what I did. But like no one talked to me, at all, except like one or two nurses that I knew from just home and stuff like so I was, kind of, yea it was lonely, really, just thinking about it

Facilitator: you were quite isolated, am I right in saying that?

Rachel: it makes you worse though cause when you're in a room full, like, of four walls, 24 hours a day, all you're doing is being thrown food, all you're doing is thinking about it, I don't know, getting sick or like hiding stuff, what's your next plan, what's your next like exercise you're gonna do. It's kind of, it's kinda like, institution, it's like you're being imprisoned in these four walls and it is disgusting and oh, no way would I do it

Facilitator: just didn't work for you at all anyway

Rachel: no

Facilitator: so from there then, you went, you went on holidays Rachel wasn't it?

Rachel: yea, I went on holidays

Facilitator: and then you came back from holidays and you were admitted to XXXX [named general medical hospital] again

Rachel: again

Facilitator: and what was it like, was it the same second time around?

Rachel: it was better for me because I was insane basically. I knew all the tricks of the trade. I knew every nurse that would be on, what to do, who to get away with. The fact that they weren't trained, I just took complete advantage of it. Like I knew when they were on duty, when they were off duty, when they went for their breaks, I nearly had, I was so insane that I was taking down like notes every day and watching the place. I was a freak. That's, you'd nearly get more like psycho, is what I call it, in the place because the second time around I knew absolutely everyone and everything that went on in that unit and if there was, like, cases, all the nurses run off to one of the hall so I was going to the other end of the hall so like yea. And at the time I, XXXX [named therapist] came in every week and me and XXXX [named therapist] fought for life, fought, we hated each other. Well she didn't hate me but I hated her because she used to bring in scones and stuff and I will never look at a scone the same way

Facilitator: (laughs)

Rachel: I laugh now about it cause I'm just like, oh god, the things I used to do, no, I just, the fact like, I'd nearly look forward to seeing XXXX [named therapist] every week because like she was the only person that ever talked to me the whole time. And yea, but at that time like, the program, she kinda had used, never worked. Never will work and she knows it never works so she changed after obviously I went through it cause I told her basically, straight up, what are you doing, that's not right cause it, yea, it was weird, cause I basically I worked on rewards. If I ate certain things I got rewards, and if I didn't I'd get things taken off me which was the biggest mistake. And, at the time, it was the only thing she could do cause she's so, limited things, she'd limited resources and she couldn't do anything. She couldn't, yea, I don't know.

Grace: and why do you feel it didn't work for you Louise?

Rachel: well basically because with anorexia I think people, yes you have to focus on the weight, at one stage, you have to be medically alive. Basically I thought that, at the time, it was too much weight focused and food focused whereas, and it was kinda like if I ate this I got, I got a school book cause I, I, like I love studying and stuff so I was kinda like "okay that's grand". At one stage I wasn't allowed to see my parents for two weeks, two weeks, there was no way that was happening, I tried to hop out windows, like tried to run out of the unit. Like, no way, this is not happening, that's why it made me even more angry. It fed my anorexia once again, made me more motivated, if I couldn't get things that I wasn't able to do, I was to do even more things. So at one stage I thought I gave on myself, I lay on the bed, I didn't move for, I'd say, about four days. I did not move for four days like, I didn't drink anything, I didn't eat anything, I just sat there thinking I'd rather die than be in here. I wasn't allowed do anything. I wasn't allowed get off the bed. If I got off the bed, they'd nearly put me back on the bed and I was kinda like fighting the whole time with someone that you didn't want to fight with. I didn't have the energy to fight with anyone but I had to because the anorexia was feeding myself, thinking 'you're full of energy, just get up and do it' and then, yea. I just didn't, the program just didn't work at all. And ever since like, she hasn't done it, like XXXX [named therapist has come so far. I'm so proud of her, like I feel like

Facilitator: (laughs)

Rachel: oh you're so nice like, so strong, ah god

Facilitator: so Rachel going on from your experience, you two experiences in XXXX [named general medical hospital], it was after that that

Rachel: I went to XXXX [named treatment centre]

Facilitator: you went to XXXX [named treatment centre]

Rachel: yea

Facilitator: tell us a bit more about XXXX [named treatment centre]

Rachel: XXXX [named treatment centre] is amazing, it is an amazing place for like eating disorders. It's just, it's so specialised. Like basically, there's like lots of different villas and the villa I was in was for eating disorders of adolescents. Adolescents never mixed like, adolescents and adults and all. The fact that helped me so much was that everyone's in the same boat, everyone had some sort of eating disorder or some sort of problem around food. Yes, at the beginning it was horrible because it was, I didn't want to be there but there was competition, there was always competition in the place like it was like getting up in the morning, seeing who's out walking first and laughing about it now cause I'm just like 'what extent did we go to'. But like, we had like, when I set up a group session in XXXX [named treatment centre], myself being, I kinda started copping on. It was only in XXXX [named treatment centre] that I realised there was one hundred per cent something wrong cause basically when I thought about it, once you go there, you sign paper that if you don't eat the food, well you'd three options, you could either eat the food, you drink Jevity, this like Ensure, it's kinda like those nutrient drinks, or else you get tubed and depending on, you also have the choice whether to sign the papers for tubing cause they can't do it otherwise without a parents signature and I sat and I bawled on the bed and I was like "Dad, sign it, if you don't sign it, I'm not gonna do it", because I knew that if there was no third option, that was me, I was gone. So they signed and like the fact that I knew, I didn't eat for four weeks, it was a joke like, I couldn't, it was just like there but then I knew there was the fear of like the Ensure coming my way as well and they used to be disgusting. Disgusting. They used to, at one stage they ran out of so much Jevity like from me, like, drinking it, that they had to actually get flavour juice in it and it was worse. I think I'd rather get tubed than do that. And the fact that the tube was there makes, you were gonna have to put it into your system, one way or another. Because, yes it's horrible thinking about it, but if you gave them the choice of eating, gave them like twenty minutes, if they didn't eat, you gave them Jevity, you gave them five minutes to start, if they didn't take that, you'd get tubed and that was the end of it. There was no putting up with shit, saying 'if you don't do that oh, like, feck it, you're alright like', leave them out cause they would have gotten away with it. And then the good thing I'm on about is every day at four o'clock I used to tell

the girls to our room together where we can talk. Obviously there had to be supervision there. And em we just used to all talk about it, what helped each other, what didn't help each other, and experiences and stuff. Obviously I went in there and I never spoke a word for I'd say about four weeks, I didn't even say hello to anyone, I was so scared and nervous and weak and frail. But with this group thing it was kind of everyone helped each other, we felt like we were a big family together and obviously there was people who were pulling other people down or other people motivating people. I'd seen other girls who were further on at this time, that they were, that there is hope. If you show people at weaker stages that there actually is hope and they want to get better then it motivates you on the other side. Yes it was tough work, people were pulling you either way but XXXX [named treatment centre], I don't know, they were so specialised, there were so caring, they wanted you to be there, even night staff, and the night staff in XXXX [named general medical hospital], I just wanted to shout every one of them, they were so horrible to me. They just didn't like me at all cause I was just so narky. But over there it was such, and it was so good because if you had, if you reached a certain weight in the week, you got to go swimming for like an hour with everyone else or you got different things. But it was always never that they took anything off ya. Like you had to be a certain weight, yes it was about weight over there as well but like, the therapy, we didn't really get much therapy sessions one-to-one, that wasn't really that good, but when we did it was good. And then we had OT as well which I thought was actually great, like art therapy as well which I thought was really good especially for people who were so creative. Like I couldn't get over some of these girls like, how things, we were told to paint a picture one day of what we thought our life was for the last while. I just got a lump of black paint and painted over a page and they were just like "what is that?". I couldn't talk about it, I couldn't say it out if I didn't have the picture if you know what I mean? Like there's so many other therapies that that they had in XXXX [named treatment centre]. Like OT was good actually as well and then the art therapy and we got to go to school every day. There was a school there and obviously they were all doing A-levels and GCSE's and craic like that but I got school work sent over. The school was

really good like that, some of the teachers were actually genuinely sent over my stuff. This is before my Junior Cert so I, like I wasn't

Facilitator: XXXX [named educational establishment] here was it?

Rachel: yes

Facilitator: oh

Rachel: I wasn't planning on sitting it, sitting on it, but then the doctor over there, XXXX [named health care professional], he was absolutely amazing, like he the person, one person that goes to me "do you want to sit your exams?", I goes "yea", he goes, and then, every other person is saying "no don't do them, you're gonna stress out, you're gonna, like you're doing well, just concentrate on yourself". And I was so, I'm so determined and stubborn and this joke like. I was like "I'm sitting my exams". I didn't go to school for, I wasn't, I was in school like three quarters of first year, I wasn't in school till the Junior Cert day, I didn't have mocks, I didn't do anything, I studied myself over there, people sent me over stuff and the teacher, XXXX, he used to help me so much cause like I used to be on my own again cause they were all XXXX [named nationality] so they didn't really know anything about my course but they all motivated me and find a strong point in me and passion to do well is what I'm trying to say. And I sat my Junior Cert and I got an A and six B's and I wasn't even in school and they were all higher level like it was a joke.

Facilitator: wow

Rachel: that made me so over the moon. I was just like "I am getting well, I am so doing my best, I don't care". Whereas some of the others like obviously there was a few other ones, narky ones that didn't really care, they'd put you down. But like I've, there was four girls in XXXX [named treatment centre] who did not wanna get well, they just wanted to die on the spot, trying to kill themselves and there was all things going on in the unit. But when I realised what someone else had done for me, I said to the girls "try and find strong points whether they were creative or sporty or something", and I'm trying to get them to focus on things. There was a girl who was so musical like she could

pick up anything and play it, instruments and stuff and like I think that helped so much there, the fact that we all were like, the family, someone would help me out, I'd help them and like, yea, it was extremely hard being away from my family like it killed me. The first day, I can still see the day where I was there and people had to hold me back from running outside cause my parents, the door closed and they were gone, gone like in a taxi and I didn't see them for a week. Like my parents were so good, they got to come over and back every single weekend but if I had been here I never would have got better, at all. I would have died, I literally would have died, I know I would have dies, I didn't really give a, I didn't care at the time I was so sick. But in XXXX [named treatment centre] it was a different setup. They were so specialised, they cared, they were interested in ya, there was people there to help, there was people there to always to talk to, if, even no matter what time of day it was, there's someone, there was always someone there to talk to ya. It was like a massive mansion of a house basically and there was a room you could just sit down in if you wanted and we'd Pilate's classes and we'd dance mats and stuff that we could do when we were a certain weight. And then there was like, oh the physio was really good actually as well, she used to give us massages and stuff like after like exercising and stuff cause there was so many girls with osteoporosis at that stage and she worked kind of, I don't know if she's a physio actually but she kinda worked on a basis of like she, the first day I went in she just goes like she gave me a piece of string and told me to like draw myself on the floor, and obviously I did the whole width of the room even though you could jump through it five million times but like, in your head you're that big. And like, I don't know, they were just so trained and specialised and I'm just like so wish there was a unit over here like that.it doesn't take that much money like to like, obviously it costs money but like that unit would save so many girls lives and boys lives and people's lives and make such a difference in the country to having, the XXXX [named treatment centre] system is amazing. Like is anyone asked me about the XXXX [named treatment centre] like I, just, I love it, obviously I was glad to get out of it but like at the time it just was the best thing for me because I felt if the situation got to a bad stage, yes my parents had to be there and take over everything, the control again after I came home, but like, that fact

like, I don't understand how people can get better like by going, staying at home and having an outpatient, like yes, it's only a bit, only here and not actually further down the line, yea, that's okay but living in the house, knowing the tricks of the house and places to hide, places to run, you know the kind of, you're in your own home setting. Whereas the fact that I was taken out of the house and then put back into the house after. I left for XXXX [named treatment centre], was the best thing that happened because it was, I wasn't in the same environment the whole time, if you know what I mean, you didn't go through a whole line, in a straight line. I'd probably describing this really awkward (laughs)

Facilitator: no you're not at all, it's fantastic, it's great. Em...so XXXX [named treatment centre] I noticed you described earlier it was the best thing that ever happened to ya?

Rachel: yea

Facilitator: and you said, you were saying yourself now that like you don't know where you'd be like from before it. Em... what would you describe as the most helpful aspect of it?

Rachel: em...I think it's just, there was so many of us in the same boat in, with eating disorders. Yea, as I said there was competition, big time and don't get me wrong, there was loads of competition, people were fighting and arguing or whatever but like knowing that there was other girls ahead of you get well and showing that people can actually get well, whereas if you're on your own in a room or kinda like in XXXX [named treatment centre] where it's just like, it's not a hospital environment, that's what I mean like. You have your bedroom like, a campus, it's like dorms, everyone has their own room, maybe there's one or two sharing and like there's the kitchen then and like a sitting room with, there was a telly and there's a garden outside, we obviously weren't allowed outside on your own and stuff but like it was like a, it was like a house, it wasn't like you were sitting in a hospital bed looking at the walls and how disgusting they look and stuff. That's, I think that's why it was so good, you had people there in the same

boat and then it was like a house and not like a hospital environment that you weren't sitting with blood pressure things everywhere and

Facilitator: so it sounds like, am I right in saying that it was kinda a bit more like normal life for you?

Rachel: yea, that's it

Facilitator: than being stuck in a hospital

Rachel: yea, exactly. That definitely would make a huge difference

Facilitator: and was there anything, any kind of unhelpful aspects for you about the treatment in XXXX [named treatment centre]?

Rachel: em...

Facilitator: I'm just gonna turn this (dictaphone) around a little bit...

Rachel: no, I wouldn't say, no, because everything about it was kind of so, it helped different parts of ya. Obviously it got, it kinda got boring during the day sometimes when we didn't have our group sessions and stuff. And it was really crappy when you didn't make your weight cause you nearly wanted to make your weight because you got to do, like, things and go outside and play rugby and there was sports days and it was normal life. well like, unhelpful...I don't really think there was, it was kinda, everything kinda made you more motivated, if you didn't get it this week and you seen all the rest of your friends going off, you'd be so mad at yourself you'd want to put on weight and you're kinda getting all excited thinking "oh I'm gonna put on weight so I can go and do this with these". And then the fact weigh-ins, weigh-ins were a pain cause you actually had to strip down to nothing and that was so annoying but, like, they did it at like six o'clock in the morning so then you couldn't go into the bathroom and load yourself and do everything else that you used to do. But, it was grand. There was one thing that was so unhelpful was that the girls, when there was a group of girls together they decided to put a diary into the, into the main living room and everyone would write things into it and do whatever. That was so unhelpful cause there was so many people bringing other

people down and kind of saying, like actually naming girls in the book, it was like a burn book, like of them yokes out of mean girls, it was ridiculous like. One of the staff, I told the staff about it cause I was just so thick with it, I was like...

Facilitator: and was that monitored by the staff?

Rachel: no, they didn't know about it

Facilitator: oh, okay so it was the patients themselves that

Rachel: yea see that's, that was probably the only unhelpful thing but in relation to like staff and stuff, no. They're all legends, they were just...and the fact that there was a mix of gender was good because if it was all girls, it would have, god, it'd be all really cause it'd be so bitchy

Facilitator: a bit of craic from lads

Rachel: yea at least you'd have someone to cheer you up cause there was an autistic boy there as well and he was hilarious, he used to just crack us up. He didn't have an eating disorder but he was autistic but he had eating problems and like obviously when you're anorexic you try and take everything that is zero calories and all this kinda craic and he used to sit down at the table and be like, he'd have a banana beside him and then he'd be like "god, I wouldn't mind a bit of that chocolate fudge cake", and then you'd be looking at them and then he'd be like "girls, don't eat that, you're fat, you'll be fat if you eat that". But like if it was anyone else they'd get shot but the fact that he was autistic as well and he was just, he brightened your day up. There used to be an upstairs and a downstairs and upstairs kitchen was kinda the ones, like the newer ones would come in and then you'd build yourself up and then you'd be able to eat downstairs in the main canteen where like visitors and stuff would come in and other units. There's secure units and that kinda craic there as well. So that helped but he, when you got put downstairs he was the person to go to like, he was hilarious, that's what like, and the mix of gender as well made it kinda a more homely environment and stuff. It was good, it was, yea, it was a nice place to be

Facilitator: so it gave you a bit of variety anyway?

Rachel: yea

Facilitator: so you said Rachel that, although there was a lot of competition among other patients you still feel that, am I right in saying that it was such a positive aspect of XXXX [named treatment centre] knowing other people were going through the same problems and, as you said yourself, if you didn't meet your target one week and you seen that your friends were going out and they were getting to do all these activities, it really acts as a motivator

Rachel: yea. A lot of people would say "well what happens if it goes the other way?, if they don't want to get well?". But the fact that you had the, you were gonna put on weight one way or another, you didn't have a choice like if you were gonna get tubed you were still gonna put on weight. Like it didn't actually matter whether you ate it whole or whether you, mushed up, or whatever like. So yea, it did. The fact that you knew that there was a load of people sitting in the same boat and you weren't sitting there on your own thinking "I'm on my own", cause like you're, you're in more denial when you're on your own. And in a hospital environment cause you think you're on your own and no one cares and everyone else is wrong and you're not wrong but in that kinda environment you realise, oh actually, there is other people like this and in the same boat and missing home and stuff so it's good in that kinda sense.

Facilitator: and just with the different parts of the treatment in XXXX [named treatment centre], so you said that not very often but sometimes you did have the one-on-one therapy and you had a bit of group therapy and you got to do like different activities say like swimming and things like that, provided you reached your target weight. Was there any other parts of the treatment, was there anything kind of aimed at families or parents?

Rachel: there was family therapy as well. I can't remember, he was coloured, but he was a ledge. He used to be so funny like he used, he was good, he was actually a deadly family therapist. My brothers only came once to visit me cause they didn't want to know

about anything at all and it just killed them cause my older brother got sick after I went over originally but they, when they came to the family therapy session and that really helped them as well. Cause when the parents, my parents used to come every week and they used to have family therapy every week, they'd come as well. So it was kinda good in a way cause then they got to talk and then, I talked first in the room cause if you're always in the room, they're not gonna say what they want to say cause they're just gonna feel like 'oh', and then the person feels like absolute crap like. So they talked with him for an hour or something and then I'd come into the room, talk for a half an hour and then everyone was, kind of, a bit more relaxed. If you know what I mean? Cause they actually did get support in XXXX [named treatment centre]. I can't fault XXXX [named treatment centre] at all, really I can't.

Facilitator: so family therapy was definitely, it was, it sounds like it was the first kind of level of support for your parents?

Rachel: yea definitely. Definitely it was because that was one of the first things that, when I was admitted, was the first thing, that we met the family therapist. So that was like kind of a relief to my parents. They didn't have, they were like "woah, like are you joking, like we're actually getting support right now over here?", so yea, it was good

Facilitator: so you had the family therapy, the one-on-one therapy,

Rachel: the group therapy, I set it up

Facilitator: the group therapy, very well done, a great idea and....

Rachel: like OT

Facilitator: OT sorry

Rachel: and art therapy as well

Facilitator: and art therapy. So quite extensive compared to, I know XXXX [named general medical hospital] wasn't a specialised unit or anything like that. Em...in terms of individual therapists over there how did you, you seem to have, on the whole...?

Rachel: yea, em...I had a lady but at the time there was kinda, like, job vacancies and she was only there for a while which kinda threw me off because after coming from here to telling my whole story with XXXX [named therapist] and XXXX [named health care professional] and that, I was kinda, like, “ah do I have to start again, please leave me alone”, like I didn’t want anything to do with a therapist originally when I went over there cause I was so sick but then after a while I talked to her and I kinda, like, was my own therapist, to be honest, at the time when I seen other people getting better and some of the girls were like. One-on-one therapy in XXXX [named treatment centre] was a bit...it wasn’t great to be honest. That actually probably was a fault of the place cause there wasn’t one exactly there the whole time. And it was, there was so many of us and there was one therapist between three units which was crap because there was our eating disorder unit, there was a secure unit and there was, what was the other unit, there was another unit for something else, it was a kinda like, what ya call it, an open units? Where people go in daily and if they have to stay in, for depression and stuff, they’d stay in

Facilitator: a day unit

Rachel: yea, like and it wasn’t great for that kinda sense but when you had, actually had therapy, the woman was really good so yea

Facilitator: so just kind of a little, am I right in saying, a little bit of inconsistency for ya?

Rachel: yea

Facilitator: yea. It’s definitely a problem. So overall, XXXX [named treatment centre], you can’t praise them enough

Rachel: no, really, I can’t. Like if you’d a unit like that in Ireland, you’d be fairly flying

Facilitator: and you, when you, how long did you spend in XXXX [named treatment centre] Rachel?

Rachel: I think it was about sixteen, sixteen to twenty weeks, I’m not sure

Facilitator: sixteen to twenty weeks and then you came back to XXXX [named area]?

Rachel: yea

Facilitator: em...and what was the plan when you were discharged from XXXX [named treatment centre]?

Rachel: to come back to XXXX [named therapist] and XXXX [named health care professional] and just aftercare here, just therapy like twice a week and stuff. And just living at home again.

Facilitator: and I think was it, was it XXXX [named health care professional] you saw first

Rachel: yea

Facilitator: or was it XXXX [named health care professional]?

Rachel: no I think it was XXXX [named health care professional]

Facilitator: and how did you get on with XXXX [named health care professional]?
What was that like?

Rachel: very weird because after coming, I don't know, it was just so weird cause he wouldn't be specialised in eating disorders, he'd be more on the other wavelength with OCD and all that kinda craic. But I needed to sort out other stuff in my life there, like looking around like bullying and kind of, other than just the eating disorder, cause everything else was so focused on the whole disorder whereas this kinda helped me, XXXX [named health care professional] helped me in other ways. Like I used to be a shy, timid girl and people would think 'oh she's so confident now'. I'm not exactly really confident in myself, I might come across like that but I'm not but XXXX [named health care professional] helped me to actually come out and be a person and not just be a number, you know what I mean? So that was really good but then I got to the stage where, at that stage I was sane again, I knew in my head and I wanted to get well, obviously there was still days, there's still days up to now like I'd struggle but XXXX

[named health care professional] thought me to get over that but then I recognised that like that a few weeks later that I wanted to go back to XXXX [named therapist] cause I, she was the one that challenged me, got me to XXXX [named treatment centre], even though I hadn't even really talked to her when I was over there but she was the one that challenged me and she was the one that I went back to in the end cause she was talking about the eating disorder and stuff so it helped me get on further over the finish line really, that's kinda how I look at it

Facilitator: so XXXX [named health care professional] focused on things that weren't about your eating disorder?

Rachel: yea, which helped

Facilitator: which helped, and as you say now, it even helps you to, to now, till today. So going on then to, to XXXX [named therapist]. Em...and you said at the beginning that you didn't like XXXX [named therapist] at all cause she was challenging you and you weren't ready to be challenged. Em...tell us a little bit about your experience with XXXX [named therapist] from the beginning to now?

Rachel: em...when I met XXXX [named therapist] originally I used to think she was my idol, "oh she's gorgeous, she's so skinny", and I was so raging with myself and then she challenged me and then I hated her. She went from being the nicest person to being a bitch. That's the way I look at it. but she, she challenged me and I hated coming to sessions and I tried not coming to sessions at all to see her because I wasn't ready at the stage where she thought I was. Like she thought I was at a certain stage but I wasn't really cause the way I look at it with XXXX [named therapist] at the time, I knew that there was something, she wasn't all there, where like she wasn't ready, she hadn't enough experience in my head. So I took advantage of that and I basically gave out to her and I was awful to her, I was so mean. But she challenged me, I didn't want to see her, she still came with her bag of scones and stuff and I was so...

Facilitator: (laughs), with a bag of scones

Rachel: she wouldn't listen to me, that's what I thought at the beginning cause she thought, cause she took everything to her heart cause she was too soft. She didn't have enough experience in the thing whereas now, she's amazing. She is one of the best therapists like I could ever say, like id' recommended anybody to go to XXXX [named therapist], she is class. She has so much experience, she's read so much more, she's learnt so much from me and my parents and she keeps, she'd always say that to me. But I've seen it in her, like she's grown so much, she knows what she's talking about now, she has experience, she didn't have experience back when originally I first came cause, I don't know, she was just, probably just not there at the time. She's, yea, she's just class

Facilitator: and what do you find are the most helpful parts of XXXX's [named therapist] therapy? Or therapy with her?

Rachel: she listens to ya, she doesn't tell ya how ya feel and she doesn't like kinda advise ya. Like if you, a lot of people think that going into therapy that she'd kinda say "oh yes, do this and do that", she'd listen to ya, she's helping you sort it out in your own head whereas you don't realise that until you actually don't really need therapy anymore. Where you actually think, 'oh yea, she actually did tell me what to do and she didn't advise me what to do', and in the sense where she's kinda telling ya, you know what I mean? Em...yea that, her CBT was really good as well. Em...what else, yea I just think, it felt more like I had a friend there than I was going to see someone. She made ya always feel that you could tell her anything and she wouldn't say anything unless obviously it was something suicidal or something that she would have to tell, in fairness. You always knew that everything was going to be confidential with her and she's a woman, like, I, like especially as a girl going to her, you talk about other things like and it wasn't just all about the eating disorder and she originally when I first went to her it was all about kinda weight, and around eating and stuff. But the, after a while, it was kinda like we didn't, like if I lost weight one week, she wouldn't make a big deal about it saying "oh god, what are you gonna do?", like originally she did. The first time I came, like this is before XXXX [named treatment centre]. But after XXXX [named treatment centre] like it was kinda like more, yea we'd talk about boys and we'd talk

about like friends and other stuff than the weight. She was there, she was a friend, she listened to ya, she didn't advise, she was just...someone there to talk to when you needed her, if you know what I mean. And if you had to cancel an appointment she wouldn't get mad like, whereas, I'd say other people probably would be thinking 'oh, waste of my time'. She genuinely cared, you'd know with her, she wanted to help ya. Kind of like some people just try to coach ya, you know what I mean?

Facilitator: so communication, I'm getting, for you is a big thing, she's a great listener, a very active listener

Rachel: yea

Facilitator: and something else that you said that was interesting as well, like she'd help ya, she would be helping ya and you wouldn't even know

Rachel: realise

Facilitator: notice or realise until you were better and you think 'oh my god, she was actually helping out a lot, I didn't even realise'

Rachel: yea

Facilitator: so nearly she was doing it so subtly

Rachel: yea, definitely

Facilitator: em...was there any kinda unhelpful aspects of the treatment with XXXX [named therapist]?

Rachel: just the original whole program, just didn't work, and I just thought she just didn't have enough experience at the time and, in fairness, she did what she could, she tried everything, really she did. But I wasn't ready in my own head, it was me, I wasn't ready in my own head to go but she thought I was, at that stage. The nurses in the XXXX [named general medical hospital] just gave out to her the whole, time, really, I don't know if I'm not allowed to say that, I don't know, I don't care

Facilitator: no, no

Rachel: they were horrible to her so she had no resources or anything to work with. There was no one out there who wanted to know, just as I said, they're so dismissive about eating disorders, they're kind of like 'oh you're taking up our bed', if there's people on trollies, 'oh she's taking up a bed, why is she here like'. And they even know, it's not her who just decided to put someone into XXXX [named general medical hospital] like unless they have to. Em...yea other than that, no

Facilitator: so you felt that XXXX [named therapist] didn't have much support?

Rachel: no, she didn't, at the time. She was kinda, she wasn't listened to cause I believe like she' so, she's a nurse, people, some of the other people on the team are, have higher up degrees or whatever they want to call themselves. Though I think they're not great at all, they didn't help XXXX [named general medical hospital] at all poor thing like. XXXX [named health care professional] is another man who I just have so much credit for what he does. Obviously, he's a top job now which is great for him, I'm so delighted for him as well. But XXXX [named therapist], he was the only one there for XXXX [named therapist], like if even some of the other doctors in the team and stuff though just cause she's a nurse, she doesn't have much experience, don't listen to her cause the psychiatrist is saying something else, or the psychologist is saying something else. Because she's a nurse, she wasn't looked at if you know what I mean. Even though like she could be a psychologist or a psychiatrist and she'd be twice as good as half the ones on the team. Like I know she would be. And she has more experience, you know she, you know she understands, she went through stuff, she never told me obviously but I know in my heart and soul that she has. She won't tell me obviously but I pick it up in her. Just lack of support for her as well just because she's a lower degree is stupid because she, she'll be on top of her game before she ends up retiring, she will, I know she will

Facilitator: yea, she is, she's great

Rachel: yea

Facilitator: so you kinda feel Rachel then that, em, even with a load of qualifications that doesn't necessarily make you a good therapist or a good psychologists of something?

Rachel: no. I always find the ones that have actually experienced things in their lives understand than people sitting there reading books. I sound so bad saying that but I don't care cause I believe in it so much because I've seen it, I've seen therapists in XXXX [named treatment centre], like, who had experience and people who didn't. They were complete opposites to each other like. Like there was a therapist over there who I wouldn't go to cause I knew, there was, I'd seen them reading books and books and I was like 'definitely haven't a clue, do not have a notion'. Yes, you can sit and ask people questions and follow all these guidelines in the books, these models and stuff, then this might work, this might work but like someone's whose had experience and they could have the lowest degree or someone could have the highest degrees, just cause they studied and have academic ability, but it doesn't mean they're better, they're better at their job like. Cause if you don't warm to someone and stuff, it's never gonna work, ever

Facilitator: so you feel that XXXX [named treatment centre], am I right in saying, it was important for you to be understood that rather somebody read a model in a paper or a book and apply that then. Would I be right in saying that?

Rachel: yea

Facilitator: do you think it's someone that can kinda understand you more?

Rachel: yea, and the fact that like she likes to tell me about things that she used to like have, like interviews and stuff like, and she was doing a model up and she was like lecturing at this and that. And you'd know that she was actually interested in like eating disorders and health and things like that and people, rather than someone just sitting there, right appointment, talk, see you later, not hearing one thing about them. Like the fact that I actually got to know her as a person as well, it was a two-way system, it

wasn't just like, oh this is my job, see you later, you know what I mean so it was kinda, like, yea

Facilitator: as you said earlier, she em, I know you said earlier that it was more like, it wasn't like coming in for therapy, it was more like having a chat with a friend

Rachel: a friend, yea, yea, definitely it was

Facilitator: which is a big thing for you as well?

Rachel: yea

Facilitator: em...what would you say is the biggest thing, the most important thing to have in a therapist?

Rachel: em...listening skills, trusting, knowing that things are gonna be confidential and guaranteed they're gonna be confidential. Em...that they're actually consistent with ya and you know they're interested, understanding the person, everything basically that describes XXXX [named therapist]. Basically, like, she has everything and people that have experience, like obviously that doesn't count on the job when you're going for the interview, whether you've experience or not but like, they have to understand and be interested in wanting to help ya and not just treating it as, going up blind really. Em...

Facilitator: no they're great suggestions. Em just going back again to when you came back here, I think, I might have heard you mention that you had family therapy with XXXX [named therapist]?

Rachel: yea

Facilitator: and what was that like?

Rachel: it was really good, it was really weird. It was hard on me, I think, more than because seeing my brothers, like my brothers used to come as well, they used to hate coming but they'd come, they'd be made come. But it kinda thought me that I had a family there, that's what i thought. I think it's really sad when people do not have like strong families or whatever cause I knew I had something to go home to and the family

therapy kinda like got everything out, like obviously there was shouting going on cause my brothers would shout at m and I'd shout at them and they'd be so mad at me because they think it would've been my fault, that I brought this on top of myself and stuff cause they didn't understand. But family therapy, although they didn't get one-to-one therapy, obviously, they kinda made them understand that their sister wasn't well, she had a problem, she needed help. Whereas like, if we didn't have that like, the family session, I don't know where we'd be like, yea, kind of, weird

Facilitator: so you find that like it was helpful more so for everyone else in the house apart from yourself?

Rachel: yea

Facilitator: particularly your brothers who you said, before this, didn't really understand

Rachel: yea, they didn't really have a clue

Facilitator: and what about for your parents, how was it

Rachel: I think it did really help them as well. Like obviously at the stage they were so anxious they didn't know what was happening or where I was in my head and stuff but it, it definitely did, but it came on too late. It happened too late, definitely, definitely did

Facilitator: was the first family therapy session you had, was it after you came home from XXXX [named treatment centre]?

Rachel: em...no, it was the second time I was in the hospital, in XXXX [named general medical hospital]

Facilitator: oh okay

Rachel: yea

Facilitator: so you feel that it should be there from the start?

Rachel: right from the start and like, obviously, it's hard to get appointments and stuff but like, if there is two parents or whatever, but like, it's no good if one of two parents comes on their own. I just think that's pointless unless they're actually a single parent, if you know what I mean and like they get brothers and sisters involved even though it's hard for that cause if everyone's not on the same wavelength, it's just kind of a mess. Like obviously people hate coming, like if people knew that they were going to therapy or something like that they'd probably freak and be like 'oh what's wrong with you family?, you are freaks'. But like it would definitely help, it definitely helps other members of the family to understand cause, as I said like, t's not just you going through yourself, everyone else is going through, and everyone else is affected in the house. So, yea, it definitely did help

Facilitator: em...so then, with your, your family therapy here and your one-on-one with XXXX [named therapist]. Was there any other treatment you got with the service here or was

Rachel: (nods)

Facilitator: that was it. And what was your experience of everything really, em...oh sorry, just going back to the XXXX [named treatment centre] actually and the family therapy there. How would you compare the family therapy in XXXX [named treatment centre] to the one here?

Rachel: em...completely different, really cause like they were dealing with a different situation in XXXX [named treatment centre] because I was over there and my parents came over every weekend and they'd just kinda talk about really home and stuff. I think I preferred it over there because we were out of the situation; we weren't like, living here so it, yea, I don't know. I just, personally, I thought it was better for my parent's sake. But I'd say the actual therapy end of it was better here cause XXXX [named therapist] is just amazing as well, she's, ah she's so good at her job and she's so there

Facilitator: so are you saying then in terms of, for the whole family, and therapy for the whole family, here is better but in terms of parental support like, kind of a net for your parents

Rachel: yea exactly

Facilitator: over there maybe

Rachel: yea

Facilitator: em...so kinda drawing on all the experiences of the few different treatments that you had from the beginning to now, what do you think is the most important part, the most important thing or element to have in a treatment?

Rachel: in like...what do ya mean?

Facilitator: em...like say you had, or not even the most important kind of, you'd family therapy, you had one-on-one individual therapy, you know you'd some group therapy over there, some art therapy, OT, em...is there anything else that you think is important to include in a treatment?

Rachel: em...nice staff. Understanding staff because, as I said, there's a lot of things that staff would kinda like get thick with you cause you've an eating disorder, even though it's not your fault. Nice staff to actually talk to and then all those other thing like therapies, one-on-one therapy is essential, family therapy is essential, a huge need to be looked after, parental support, a programme where weight, it's not all gonna be about weight. XXXX [named treatment centre] had it bang on. You had the weigh-ins on a certain things, at six o'clock in the morning; it was forgotten about for the day. Obviously if you've put on weight, you feel crap whatever but there was someone there to talk to. It wasn't like you were gonna be left on you own, sitting with your feelings and stuff for the day. Like, you were allowed go to school, make it as normal as you can, that's what I loved about the XXXX [named treatment centre] is that you had school, you had a garden, you had, like, your own room, your own bathrooms, like a kitchen, whatever. It was just normal things whereas in a hospital the environment's not great, at

all. It just completely wrong, I just don't believe in it at all. So treatment-wise, it's obviously a key to have a good family, if you've family support, cause if you think you're going back into a house where there's domestic violence, abuse, or something going on behind closed doors which I've seen by girls over in XXXX [named treatment centre] where they're going back to houses of domestic violence and stuff but they've never told anyone else. They're obviously not going to have the motivation to get better if you know what I mean, that's why I think family therapies huge. If they go into the system, they have to come for therapy. I just think it's wrong if they don't, or there should be something there that you have to, make them go cause there's always things' going on behind closed doors, it's never, you know that kinda way, yea

Facilitator: so would you rate individual therapy and family therapy as the two most important...

Rachel: yea, well as in family therapy as well with kinda parental support on top of that and not just therapy on their own, only. Yea those things, huge, keys

Facilitator: key parts for treatment. Em just kinda recapping a little bit there then, after you came home from XXXX [named treatment centre] and seen XXXX [named health care professional] for a few sessions and it was another lady you seen and we're not sure if it was XXXX [named health care professional], what was that like?

Rachel: I didn't like it cause I think she was a psychiatrist and I just, I didn't know, I didn't warm to, cause I was sick of seeing so many people at that stage, I was just kinda like 'oh please, just let me go back to someone that I know like XXXX [named health care professional] or XXXX [named therapist]', because I just didn't want to be there at all, I dunno, a different type of therapy altogether. Didn't like it, didn't think it worked for me at all. I dunno, ah, I dunno, it was just creepy or something, I dunno, I just didn't think it worked at all

Facilitator: so her therapy didn't work for ya at all, what about your relationship with the therapist?

Rachel: no, I didn't warm to her, I couldn't. She just seemed, she seemed like a person who kind of was there for the job but just blanked ya at the same time. Kinda just sitting there like, how do I describe it? It's kinda like they're there for a job, but they didn't really care. But she didn't seem like inconsiderate or anything, it's just kind of like, a blank face, a poker face just going 'alright, okay', and 'how do you feel today?', this kind of, I was like 'oh god', I can't sit here. I just didn't want to be in the room at all.

Facilitator: so it sounds like you felt that she was just...

Rachel: there

Facilitator: there, asking you the same questions but not getting to know you, am I right in saying that?

Rachel: yea, yea

Facilitator: em...and so, from the sounds of things, your relationship with XXXX [named therapist], even XXXX [named health care professional] and XXXX [named therapist] like, have been completely different

Rachel: yea, definitely

Facilitator: em...kinda going back then Rachel just gonna look here a few things. Em...I'll see if I've just missed out on anything here. (Long pause). Just in terms of just going back to the beginning then for the information sources and that. Em...do you think there should be more information available from the GPs to take away with ya?

Rachel: yea, definitely

Facilitator: and in terms of then like your preferred information sources, like the sources that you would prefer to get most of your information from, where would that be?

Rachel: probably a group that has been put together by people who have actually been through things or, yea basically, a group where people have actually gone through things and not books and internet and stuff cause there's so many people who have written

about these things but they're not actually there. If you actually get to talk to someone who's either been through it themselves or family has been through it or have had experience of it in their house is so much better, one hundred per cent like. And yes obviously it's going to be hard cause there's a lot of people don't wanna talk about it after years later, but like if there was a parent support group or a person to come in, a helpline that someone could talk to someone or something like that, like I dunno. I just think books, you actually have to do it for research and stuff but for experience and for looking for help and stuff, no.

Facilitator: yea from the sounds of things you say that like you'd rate experience as like one of the top things of, like, getting to actually know what's going on

Rachel: yea because there's so much reading you can do and there's so many different opinions and aspects to it and like if GPs aren't even updated themselves and they're throwing you a leaflet, another book, you're just gonna, like, that's just exactly what I just read but it's not actually there, it's not happening, it's kinda like writing on paper, you can chop it up and it's gone.

Facilitator: so apart from then the support groups for the parents and the support groups for the people who are going through eating disorders, through it themselves, em...just moving on then to the, kinda some suggestions that you, or advice that you would have to change the treatments that are now in place in Ireland like. Em...if you could sit down with somebody who was beginning a new service

Rachel: yea

Facilitator: what would you say? This is what you need to do this and you need to not do that. Em...basically I would basically try and say, try and build a place like XXXX [named treatment centre] where it's a homely environment, like you feel like you're at home, you, everyone has their own rooms, there's obviously like, there obviously has to be boundaries and stuff where they thing, make them have school, let them go to school, let them be like as if they're in a normal world, basically. Em...kind of employ psychologists, psychiatric nurses, not psychiatrists, not psychiatrists at all. Have people

trained in different types of therapy that have OT and art therapists there, have, like, a physio, beds there but not in a hospital environment at all. Like, have staff that actually have experience, but in eating disorders, or trained in eating disorders. Em...always have the threat of the tube, that sounds so bad, people that have eating disorders would kill me for saying that, but give them the option of eating. Those three, I think, those three steps, they killed me at the stage but they, they were the things that worked.

Facilitator: the three steps again were eat, don't eat?

Rachel: eat, you have like twenty minutes to eat, you have, you either drink Jevity or Ensure and then you get the tube if you don't. And yes, it was horrible, people pinning you down but they're keeping you alive, they're helping you and there's a certain stage where you just have to cop on like. And just everything, just for the people here, to actually cop on with mental disorders and stop putting it under the table. Get it out there, have an actual proper unit. Yes, XXXX [named treatment centre] and all that are there but in XXXX [named treatment centre] all they do is focus on weight restoration, it's not about weight and it's not about just eating. Yes, someone has to be at a certain level of weight to be seen, cause people can go, I was gone beyond being sane, I didn't have a clue what was going on, I might as well have not been on the planet. Whereas XXXX [named treatment centre], over in XXXX [named treatment centre], yes, they had to get my weight up to a certain extent, start the therapy, have the family therapy, all the different therapies, have rewards like all the, if you reach a certain weight you can go swimming, you can go to the sports day this day and have school. Just have everything in a normal environment except having the actual helpers there that who are actually gonna help the people rather than sitting there in a hospital bed, I just...

Facilitator: just keep it as normal as possible?

Rachel: yes and have group therapy. I just think groups in relation to people actually going through the thing help each other as well. Where they can actually talk and obviously it has to be supervised there or whatever but actually having people talking to each other. And even like if there was a unit like XXXX [named treatment centre], have,

like if the parents come in at the weekends, if there's certain hours they can come in then give them the option of actually going into the room, talking to each other and see how their experiences are going. What have they done to help them? What's unhelpful to them? That there's actually something there for them at the weekend or during the week, whatever day's people decide to have visiting and stuff, that it's not also limited like

Facilitator: something going on for the parents or for

Rachel: yea

Facilitator: another network of support there, em, bring it here. Em...and as well Rachel you said for yourself, you said in terms of information sources, have a group of people here who have been through it and who are going through it and you think that's the best support that could possibly...

Rachel: yes and to show other experiences cause I think it's absolutely ridiculous, people having to actually go to XXXX [named treatment centre] to get help when there is services here but they're not, they're not being funded, they're not being given money, there is no actual proper units, who...I knew a girl who had to wait a year to get a bed in Ireland, a year. She could have been dead in a year, you can die in like six months if you stopped eating and stopped drinking altogether, dehydration, everything like, the need to pit in money into this country, into the health system, into eating disorders specifically. Yes, there's psychiatric units and these people for depression and other things but, like, have a proper unit set up by people who actually want to help other people. It's so essential like, it's ridiculous like, I'd rather fundraise for the rest of my life and get this unit than actually do anything about it like

Facilitator: it's very important to you anyway. Em...so in terms of like education and information like, as in education about eating disorders

Rachel: yea

Facilitator: any advice for anything that that Louise?

Rachel: em...just kind of let the person with the eating disorder know that you care, they're gonna be in denial for the first while until they actually admit. The first step to getting well is admitting that you have a problem and understanding that you have a problem. Be there for support, like parents need to understand as well that, yes, they're gonna get angry with their kid or whoever it is but the thicker you get, the more motivated you're making your child and in relation to looking up stuff like I would kinda say try and talk to as many people as possible that have, went through it or people that actually went through it, not even parents. When it comes to their kid, basically I think yes obviously it's hard cause a lot of people don't want to talk about it, but I presume there's people out there that actually do want to talk about it and they're either in psychology or they're in something to do around that area so try and get to talk to those. That's why I think there should be a helpline or something so that they actually can go and get numbers for people to talk to

Facilitator: so you're saying that to educate parents is very important?

Rachel: huge. I think that's even more important than one-to-one therapy for a person with an eating disorder, really I do like cause of they haven't educated themselves how are they meant to know? They just think that it's just about food or whatever, they don't understand it's something else, the reason it's going on or why it started or what's making it or what's feeding the whole motivation about it so, yea, it is

Facilitator: so we've educating the parents, we have the group, the group support sessions, em, and the helpline for parents and that. Eh...I know that you said as well that during that you find it a little bit, you find it annoying, maybe that's not the word I'm looking for, the right word I'm using, correct me if I'm wrong, em, the way you seeing so many different therapists and you would have preferred to see the one

Rachel: yea...it, in a way, I mean in general the way I meant that was kinda like coming from XXXX [named treatment centre], from seeing like XXXX [named therapist] and XXXX [named health care professional] and that to go and the other lady, to going over to England to see a one-to-one therapist, another family therapist, it's kinda like having

to restart the whole story again but like it I was put in XXXX [named treatment centre] before I went to, if I was put in XXXX [named treatment centre] like when I started like, they wouldn't... it would've been stupid like. I wouldn't have lasted over there anyways, but it was kinda like having to get to know from one to one, where at least if you were like say if you were working with a support service, stop that completely, go to say the likes of XXXX [named treatment centre] or something like that, have your therapist there for the time you're there, stop that and go back. Like it's annoying having to go unless they can read notes or something. Like some of the therapists over there, they didn't have really a clue, there was so many patients but like yea, it is, it's annoying having loads of different therapists at the same time even though every bit, every bit help, like, you know what I mean, in a certain way so

Facilitator: yea you said as well when you were with XXXX [named health care professional] you were eager to get back to XXXX [named therapist]

Rachel: yea but I needed XXXX [named health care professional] at the time to sort out other things that was going on in my head rather than just the eating disorder. Cause if you keep talking about it, you're gonna want to keep going on it cause it's just like if someone tells you not to look out the window, you're gonna look out automatically, it's just a reflex thing. If you talk about like if someone just starts saying "oh don't talk about your eating disorder", you're gonna talk about it more. So it's the complete opposite but like I do think you have to have someone there when you come back to deal with the other stuff like, about bullying, or grieving, or bereavement, whatever, if it's kinda one of the reasons behind the whole thing and then go back to that but keep the whole eating disorder, when you come back from the after, after service, to a minimum. Talk about food and weighing stuff, like obviously you have to be weighed but like just leave it at the beginning of the session, do it, and then talk about whatever you have to talk about if you're, yea

Facilitator: yea, that's an important thing for treatment for you anyway. Em... we got a lot there Rachel so kind of give you a rough kind of em going over of what was kinda said. Sorry, just before we finish up then, just with regard and it'd be very fresh for ya

now, just with regard to discharge planning, em, planning you discharge and things like that, how did you find that?

Rachel: sad cause I feel like I've came on a journey with all of the people in this place like. It's weird because it was always a security net there cause I've been out of XXXX [named treatment centre] like months now so it's kinda always the security net now. I was discharged like today so it's kinda, it is, it's really sad to see. Obviously I'm gonna try and keep in contact and ring to say I'm getting on okay or whatever. It's gonna be hard but lie everyone has to move at some stage, has to break free. Yes I know like if things go wrong, I will still be able to, if they're only a phone call away to talk to. But, yea it is, it's really sad, it's, it's nerve-wracking but I know I'll be fine. Like they've actually got me to the stage like, usually after a certain stage you're meant to be like discharged or whatever like, I'd probably be here...I'm only ready to leave now but like a lot of people after they come home and they're after say, after service, after like that, they just kinda like discharge people. Like I've seen people be discharged, not in here, but in other places, they're not ready to go, they just relapse but at least here they've made sure that you're ready, you're standing on your own two feet. Then you're ready to move on. Yes, there will be days where I'll be so sad and stuff thinking 'oh why am I not there', but that's it. Life's a journey

Facilitator: like you said, you feel now that you're ready to....

Rachel: ready to go

Facilitator: move on

Rachel: yea

Facilitator: em...brilliant Rachel. We'll just recap then on...I'll give you a very, very rough and brief recap from what was said kind of and I'll hand you over to XXXX [research assistant] there for a little bit more then. Just kinda at the beginning, you kinda gave us a little bit of a background into the different treatments and your journey from the beginning to the end and a problem that you have with GPs is that you just don't think that they're trained at all, particularly seeing as out of the three GPs you seen, two

of them didn't even pick up that you had an eating disorder. They put it down to women's problems, or girl's problems, as you call them. Em...and it was the third GP that recognised something's not right and referred you on to, em, XXXX [named general medical hospital]. Em...in terms of the information that's out there you think it's particularly poor, particularly for parents, em, and you seen this first hand with your parents where it's just, particularly there's information whatsoever and, even more so, there's no support for them. Em...going on then through to some of the problems that you came up against or some of the problems that you think are huge, you think financially it's pretty difficult for a lot of people although you said in your, you got funding from the HSE, you were lucky to get the funding, that wasn't a problem for you but you can understand how it would be for other people who might only get a week or two in the service. Em...you said, particularly in this country, mental health problems are, as you said, brushed under the carpet, swept under the carpet and they need to be brought out, em, and spoken about. Em...and some of the other, sorry, em, just with, yea some of the other problems you had, financial problems, waiting lists was another one. You said that there was a girl that you know of that had to wait a year

Rachel: yea

Facilitator: to get into somewhere which you think is just ridiculous. Em...and the GPs and they didn't recognise. Em...you said particularly here in Ireland. There is no proper decent service here and something should be, from your experience in XXXX [named treatment centre], something should be built, purpose-built and with specialised staff in it, people who know what's going on, people who want to be there and care. Em...as well the environment sounds like it was important to you, em, something to kinda hold on to as much of normal life as possible. You had like a school, a kitchen, your own room and everything. And, as you say, compared to XXXX [named general medical hospital] where you're lying in a bed and left alone with your feelings, as you say. So that's something that's quite important to you. Moving on then to the treatment in XXXX [named treatment centre], you said it was the best thing that ever happened to you and you couldn't really fault it. Em...there's so much support, not only for you, for

your parents as well. Em...you found you had a lot of, you had the art therapy, the OT, em, you had individual and particularly the family sessions which you think are so important. Em...with regards to unhelpful, you didn't really have much to say in that, you said you couldn't really fault them. Maybe their individual sessions weren't great, just for you personally but, again, on the whole, fantastic service. Em...coming back here, em, when you first seen XXXX [named health care professional] it was, you said it was, I suppose what you describe, it was nearly like a break from your eating disorder. Would I be right in saying that?

Rachel: yea

Facilitator: and not kinda talking all about the eating disorder. And then you went into, you were able to get back to XXXX [named therapist] then and you just described your relationship with XXXX [named therapist] as brilliant. She really understands ya, somebody you can talk to, confide in and know it's not gonna be

Rachel: said

Facilitator: you know it's not gonna be said which was trust, is a very important thing for ya. Em...and as well which is something interesting is that you got to know XXXX [named therapist] as well as her knowing you, as you describe it, it's a two-way street. Em...you also, with XXXX [named therapist] found her very good as well. The only kind of poor, em, or weak therapy that you kind of, em, came up against or experienced was with the psychiatrist here which you just, the therapy wasn't for you, the therapist wasn't for you. Em...but, other than that, the rest of the team here you found were pretty good. Em...in terms of support for XXXX [named therapist], you thought it was quite poor. Em...

Rachel: yea, originally

Facilitator: originally quite poor compared to now. Em...and something that as well that was very interesting that you noticed was that, em, XXXX [named therapist] might not have as many qualifications or as many letters behind her name as other people but

she's streets ahead of everybody else. You think that she's, she's gonna be even, she's just gonna become so big

Rachel: yea

Facilitator: em...some of the suggestions you had then in terms of the education was for, education for parents is a huge thing, em, particularly at the beginning, and family support, you think should be there from the start. Em...information, you think that the main sources of information should be from a group, people who have experienced it before. Em...and parents need to get in contact even more so with young people who have gone through or people who have gone through the eating disorder, and not just parents. Em...em...a few things sorry, the helpline as well, you said was quite important and...there's was another few things that I can't just, not coming to mind at the minute but I know XXXX [named research assistant] will have, definitely written down. Am I on the right track here with you? Is that alright?

Rachel: yea

Facilitator: great

Research Assistant: okay just, em, from the start then, you were saying, at the start, you were bullied in school and you saw that people were concerned for yourself but you thought that nothing was wrong. You didn't know what they were talking about. Em...then, did you say that your parents were told something was wrong by someone in your school, was it?

Rachel: eh...the teacher

Research Assistant: the teacher rang. Then you went to the GP and they said it was just girl problems and you went to another GP and were told that it was fine. Then you went to, eh, XXXX [named GP] and you were referred to a doctor in XXXX [named general medical hospital]. So that's where you were told to put on weight in two weeks and if you didn't then you were going to be admitted

Rachel: yea

Research Assistant: so you were admitted into hospital, em, and then you kind of realised something was wrong when food was being put in front of ya

Rachel: yea

Research Assistant: and you just couldn't eat it. Em...then you went on holidays for two weeks, lost weight and went back to XXXX [named general medical hospital], wasn't getting any better at all. Then you went to XXXX [named treatment centre] and you were there for about sixteen to twenty weeks, you said. You said that XXXX [named therapist] was the first person that challenged ya and said, you know, "something is wrong here". Em...you went to XXXX [named health care professional] and he felt, you felt he dealt with your emotions, like the bullying and so on. Em...then you went back to XXXX [named therapist] and you've been with her ever since. Em...you were talking about information at the start, you described the information out there as limited, you said it was more so your parents that were looking for information at that time and you then said that there should be a group, em, session, group therapy and helpline for parents. You think GPs aren't specialised enough, or have enough training to deal with eating disorders. Em...you know, the GPs didn't recognise you had an eating disorder even though you'd lost two stone in such a short space of time. Em...then you were talking about that doctor, XXXX [named health care professional] and, who knew that you had an eating disorder and thought you should go into hospital. You said that your Mother was determined to get you help. Em...that your Dad was always there as well but it was mostly your Mother that was kinda pushing for

Rachel: yea, yea

Research Assistant: to get things going. Em...you said there wasn't any information out there for your Mother but your Mam rang people all over the country just to, basically to try and understand the disorder

Rachel: yea

Research Assistant: and how it worked. Em...so she used a lot of personal contacts. Em...then you talked about going over to England and that one month into being in

England you started to look for information, em, on eating disorders, on anorexia. You couldn't really get any cause everything was blocked but you started to read books, em, and you said that some of that kinda worked for ya and some against ya. Like you got some tips from certain books and so on that you could use that for yourself. Em...then you were talking about XXXX [named general medical hospital], you said that you felt they didn't care in there about you, you know, about your illness. Em...you think that family therapy is a huge element and that bringing a group of parents together who have been through having their child diagnosed and treated for an eating disorder would be a really good resource for newly-diagnosed parents. Em...then we were talking about barriers to treatment, em, you acknowledged money as a huge barrier to treatment and how lucky you were to get funding for your place in XXXX [named therapist], that there's a lack of support and also a lack of information there are also barriers to treatment. Then you were comparing services in XXXX [named area] to those in Ireland and how there's a serious lack of services in Ireland. Em...you think hospitals and you don't think therapists are specialised in eating disorders at all, that they don't understand the eating disorder and that this allows those with eating disorders to kinda walk all over therapists, in a way

Rachel: yea

Research Assistant: and manipulate them. Em...then you were talking about going to the GP as your first point of contact. You said that you never thought that you'd end up in hospital ever. Em...because you thought you were never going to get caught that they'd n ever catch you out. Em...and because of that you felt that they hadn't recognised it that, in turn, motivated your disorder, motivated you to keep going. Em...you thought that the doctors that you met, em, in your journey, well GPs mostly were inconsiderate and uncaring especially for those who have mental health illnesses

Rachel: yep

Research Assistant: in XXXX [named general medical hospital], you said they were dismissive in there, they didn't know anything about eating disorders. They did what they could though at the same time with what they had

Rachel: yea

Research Assistant: em...you could get away with having an eating disorder there cause no one really knew much about them. You said that you felt unwelcomed in there and that it was really horrible for you. Em...and that they didn't understand that it was an illness that was in your head, em, and you felt lonely cause no one talked to you there really and you felt like you were imprisoned. Em...then you said your second time being in XXXX [named general medical hospital], that it was better for you cause at that stage you said you knew all the tricks of that trade and that you could play everyone. Em...you said that you and XXXX [named therapist] used to fight a lot but then, at the same time, that XXXX [named therapist] was the only person that actually talked to you when you were in XXXX [named general medical hospital]. Em...then you were talking about how you told XXXX [named therapist] that the program that she was using, you know, wasn't working, didn't work for you, that it fed your anorexia. Em...you think XXXX [named therapist] has come so far especially where she is today. Then you started to talk about the XXXX [named treatment centre], how amazing it was and how, you know, everybody was in the same boat there regarding issues with food. It was horrible for ya at the start, there was a lot of competition. You realised over there that there was something seriously wrong. Then you talked about the food, drink and tubing experience and how you knew that if tubing wasn't an option for you that, you know, that, that could be the end. Em...then you were talking about the group therapy that you set up amongst the other patients and seeing other girls do well, this gave you a lot of hope. Em...than you were talking about studying in XXXX [named treatment centre], the teacher was brilliant. Em...you were just talking about XXXX [named treatment centre] mainly then and how it was so good for ya and how it was like a house, it was so normal. Em...then you talked about the different therapies you received, family therapies, OT, art therapy, group therapy. And then you were talking about XXXX

[named therapist], how you'd describe her as an amazing therapist now and then the most important things in a therapist, listening skills, confidentiality, em, being understandable. Family therapy was very important and then with regards to suggestions and advice. To try and build a unit that is a lot like the XXXX [named treatment centre], homely and with all those elements and that was pretty much it

Rachel: yea

Facilitator: I dunno if you're feeling alright after all that, probably knackered

Rachel: it's like dragging up the past but it's fine now

Facilitator: is it?

Rachel: discharge, interview, done

Facilitator: and do you feel alright leaving today after the interview?

Rachel: yea

Facilitator: did you feel alright talking about everything, all that with us?

Rachel: yea, it's tough, it is tough. It's hard going, your mind, cause you just think 'feck, I've come a long way but then I'm kinda just, I say to myself "I did it like, I'm still standing so I'm kinda proud of myself in a way", I'd never say that, I'd never compliment myself like that but like, yea, no I am. And if I can help someone else like that, just makes me even happier to show people actually can get better

Facilitator: you seem quite determined to

Rachel: I will, I'm climbing to the top, I don't care what happens

Facilitator: Rachel thank you so much for taking the time to come here today and share your experience with us.

