

**Reconstructing Livability: a grounded theory of
partners' experiences of living with someone
with an eating disorder**

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By

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DECLARATION

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Reconstructing Livability: a grounded theory of partners' experiences of living with someone with an eating disorder

SUMMARY

Background: It is estimated that 200,000 people in Ireland are experiencing an eating disorder (ED). Although EDs are primarily associated with adolescents and young adults, in recent years an increase in people of older ages, many of whom are in romantic relationships, has been documented in the literature. Research into family members' experiences of living with and supporting a person who is experiencing an ED has tended to focus on parents' perspectives, with the perspectives of partners being seriously neglected. What knowledge is available regarding partners' experiences is generally merged with other family members' experiences and their unique position as a partner is rarely accounted for. Approaches to care and support for partners are primarily based on interventions developed for parents, which in the context of the intimate relationship, are often not appropriate or useful for partners. Therefore, in light of the limited knowledge available to develop appropriate and useful interventions for partners living with a person with an ED, the current research was conducted.

Aim: The aim of the study was to develop a grounded theory of the personal lived experiences of intimate partners of people with an eating disorder.

Methodology: The theory of '*Reconstructing Livability*' was constructed using Classic Grounded Theory (CGT) methodology which was underpinned by a social constructionist epistemology. In-depth interviews were conducted with 18 partners of people with an eating disorder. Data were analysed using CGT principles, including concurrent data collection and analysis, theoretical sampling, constant comparative analysis and memo writing.

Results: Data analysis resulted in the development of a theory conceptualised as '*Reconstructing Livability*', where the primary concern for the participants was identified as '*Encountering and living within a disrupted relationship*'. The disruptions experienced by the participants are understood, by them, to come about as a result of their partner experiencing an ED, and as their partner experiences repeated ED setbacks, the related disruptions to the partner, the self and the relationship become increasingly evident. The theory of '*Reconstructing Livability*' represents the cyclical process undertaken by the participants to resolve their primary concern, which in the current theory is considered a

personal journey of recovery from the distress of living with the disruptions in their lives. A significant component of the participants' recovery is that they can remain committed to their intimate relationship, despite encountering ongoing ED disruptions to it.

Four stages in the cycle of '*Reconstructing Livability*' are identified in the theory, with each stage containing various strategies undertaken by the participants as they progress towards reconstructing the livability of their relationship and a recovery of the self. The first stage '*Encountering a disruption*', is concerned with participants becoming aware of the various aspects of their lived environment that become disrupted as a result of living with a partner with an ED to include disruptions to the partner, the self and the relationship. Once participants become aware of the disruptions they progress to the next stage of the process, '*Informed self*'. The strategies in this stage are focused on; developing a knowledge of the nature of ED, understanding what their partner may be going through and how best to support them and understanding the disruptions that have come about to their lived environment. However, becoming an '*Informed self*' is experienced both in a distressing and a positive way but despite the distress associated with knowing, all participants acknowledge a need to improve their knowledge and understanding of EDs. The third stage in the process, '*Countering the disruptions*' explains the strategies participants undertake to counter the disruptions to the partner, the self and the relationship. As a result of becoming an informed self, these strategies become more finely tuned with each cycle of '*Reconstructing Livability*' they experience. As participants gain an understanding of the cyclical nature of EDs and become aware of their limitations in preventing further ED setbacks from occurring, the strategies they engage become focused on recovery of the self within the intimate relationship. This is the fourth stage of the cycle conceptualised as '*Reclaimed livability*'. A period of stability is experienced at this stage in the process until their partner experiences an ED setback, and participants re-enter the cycle again at the stage of '*Encountering a disruption*'.

Conclusion: The theory of '*Reconstructing Livability*' represents a dynamic process of personal recovery, the findings of which not only add to what is already known about the phenomenon but provides new insights into the experience of partners living with a person with an ED. The theory provides a basis on which more appropriate approaches to care and support can be developed for partners of people experiencing an ED, and offers guidance on the future direction for education of professionals, for policy development and for further research in the substantive area.

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Chapter 1

INTRODUCTION

1.1 Introduction

This thesis presents the Classic Grounded Theory of '*Reconstructing Livability*', which is concerned with the substantive area of the experiences of partners who are living with a person with an eating disorder (ED). This chapter presents an overview of the thesis, providing the context within which the idea for the research was formulated to include both the theoretical and personal influences on its genesis. As part of the overview, a brief outline of the format of the thesis is provided, which illustrates the overarching framework within which the theory was developed.

1.2 Background to the study

EDs, as understood in contemporary medicalised constructions, are considered serious mental 'illnesses' where mortality is reported to be as high as 20% for those who experience the 'illness' over a prolonged period of time (Crisp 2006, Fichter *et al.* 2006). EDs are most commonly associated with young people, but recent studies report an increase in people of middle age presenting for treatment who are more likely to be married, have a longer duration of ED and have an older age of onset than their younger counterparts (Ackard *et al.* 2013). In addition, primarily because of a longer duration of ED, people of middle age presenting with an ED are reported as being more physically, psychologically, and socially compromised than younger people (Ackard *et al.* 2014).

Earlier literature suggests a traditional general belief, that few people experiencing EDs engaged in committed romantic relationships (Woodside *et al.* 1993). This belief, however, has been challenged by more recent literature indicating an increased number of married or cohabiting people experiencing EDs presenting for treatment (Van den Broucke *et al.* 1995a, Bulik *et al.* 2011, Bulik *et al.* 2012). One large multisite international study of women with and without a life time ED (n=2,096) reports that relationship status in women with EDs is comparable to those without an ED (Maxwell *et al.* 2011). Fichter *et al.* (2006) report a significant shift in the relationship status of women with AN (n=75) over the course of a

twelve year period of their study. The authors found that 9 (12%) people were co-habiting at the beginning of treatment; however, this figure rose to 29 (38.7%) at 12 year follow up. Although the statistics for those in relationships vary, interpersonal problems, fear of intimacy, communication difficulties and relationship dissatisfaction in romantic relationships, are consistently reported in the literature relating to people experiencing EDs (Pruitt *et al.* 1992, Van den Broucke *et al.* 1995a, Woodside *et al.* 2000, Evans & Wertheim 2005, 2010, Arcelus *et al.* 2012).

The majority of research in the area of EDs and intimate relationships is from the perspective of the person with the ED, much of which examines relationship functioning and the impact being in a close intimate relationship has on recovery from the ED (Van den Broucke *et al.* 1995b, Van den Broucke *et al.* 1997, Bussolotti *et al.* 2002, von Soest & Wichstrøm 2006). Literature and research that explores EDs and intimate relationships from the perspective of the partner not experiencing the ED is seriously lacking. In addition, the majority of research exploring family members' experiences of living with a person with an ED is primarily focused on parents as family members, where partners as family members are again neglected. Family members' experiences have been primarily framed in the context of providing care to their loved one, and thus are usually referred to as carers. In the research relating to family members as carers, the impact of living with and caring for someone with an ED is reported to impact on their psychological, social and physical functioning, giving rise to many unmet needs (Highet *et al.* 2005, Graap *et al.* 2008b, Martín *et al.* 2011, Coomber & King 2013). Family functioning is also reported to be affected, particularly where conflict exists around managing the ED behaviours and associated health risks (Treasure *et al.* 2003, Sim *et al.* 2009, Halvorsen *et al.* 2013).

In recognition of the importance of involving families in the treatment of people with EDs and of the impact caring has on family members and family functioning, various approaches to care involving family members have been developed (Lock *et al.* 2005, Treasure *et al.* 2007a, Fisher *et al.* 2010). Whilst involving family members in the treatment of adolescents and children with eating disorders is advocated in best practice guidelines (National Institute for Health and Clinical Excellence 2004), involving family members in the treatment of adults is a more contentious issue (Treasure *et al.* 2005). Unlike in the treatment of young people, there is a lack of empirical evidence pointing towards the

usefulness of involving families in the treatment of adults, and there is little information on the benefits of involving partners (Dimitropoulos *et al.* 2007). Furthermore, the differences in rights and responsibilities of adults experiencing EDs and the degree to which they are dependent on family members further complicates the issue of involving family members in treatment approaches for adults (Treasure *et al.* 2005). Despite the lack of evidence supporting the inclusion of partners in the treatment of their significant other, couples therapy approaches have been used for couples where one person has an ED (Belangee 2007, Bulik *et al.* 2012, Linville & Oleksak 2013). Although the use of couples based therapies have been reported as beneficial (Dick *et al.* 2013), for the most part they are aimed at improving outcomes for the person experiencing the ED, with minimal focus on the experience or outcome for the partner. This is problematic in the context of The National Carers Strategy (Government of Ireland 2012) which recognises the adverse impact that taking on a carer role has on family members' personal wellbeing. In recognition that carers often overlook their own needs, the strategy proposes to 'Promote the development of supports and services to protect the physical, mental and emotional health and wellbeing of carers' (Government of Ireland 2012, p. 14). Although this strategy can be applied to partners who are living with a person with an ED, focusing only on their carer role fails to take into account other types of support or services partners may require, such as relationship supports. Therefore, the position of partners as opposed to other family members needs to be explored in order to gain insight into what is different and distinct in relation to their own experiences.

1.3 Formulation of the research idea from a personal perspective

The origin of the study from a personal perspective transpired from my experiences stemming back over nearly three decades of working as a psychiatric nurse with people who experience EDs. I have had the opportunity over the years to work with families and specifically work with partners in the course of my practice, but this work was primarily focused on recovery for the person experiencing the ED. Several years ago when working with a particular couple, I was struck by the level of distress expressed by the partner not experiencing the ED. This went beyond the distress of not having information and guidance in relation to the ED that I was familiar with. This particular partner was desperate to re-experience life as a couple as it had been earlier in their married life, before the onset of

the ED. He expressed this in his desire to go shopping for clothes for his partner as they used to do, even commenting on a particular expensive piece of clothing he thought she would like. This really opened my eyes to look beyond the care and support a partner can provide to the person experiencing the ED and begin to look at both people in the context of the intimate relationship. The service I worked with routinely provided family support, education and therapy to families of adolescents experiencing EDs but very little was provided for partners. Filling this gap in the provision of services was something I felt very strongly about, particularly as I began to see a pattern in partners' distress when I knew what to look out for in subsequent couple sessions. I went in search of the literature and best practice guidelines in order to inform my practice so that I could work more effectively with the couples. It was then I became fully aware of the dearth of research relating to partners' experiences when living with a person with an eating disorder and realised this was an issue that needed to be addressed. Through the course of my work I spoke with colleagues from nursing and other disciplines and linked in with people working in nursing academia to discuss how I could move forward with my ideas. Initially I thought a smaller piece of research was a good starting point, but through my discussions with colleagues in nursing academia I was encouraged to take on a PhD as a way of addressing the problem. Although I had no previous experience in using a Grounded Theory (GT) approach, this option appealed to me based on my desire to address the gap in the literature by producing a model which could influence practice and approaches to care. In addition I had the opportunity to draw on experts in the field of GT who were more than willing to support me in achieving my goal.

1.4 Overview of the theory

This thesis presents a substantive Classic Grounded Theory (CGT) of the experience of partners who are living with a person experiencing an ED. The aim of the research was to gain an understanding of the lived experience from the perspective of partners, with a view to inform practice and policy in relation to the provision of appropriate supports and services to partners. Given the lack of research and theory in the substantive area and the need to build on the limited body of knowledge currently available, GT methodology was considered the most appropriate way in which to address the aim of the research. More specifically, the GT approach used in this research was that advocated by Glaser, namely

Classic Grounded Theory (Glaser & Strauss 1967, Glaser 1998, Cutcliffe 2005, Glaser 2013). I chose this method as my preference was to work with a more flexible research approach allowing the partners' main problems and the manner in which they addressed these problems to emerge from their own perspectives. Details of the theory, its development and the literature supporting the findings are presented in this thesis.

1.4.1 Format of the thesis

The thesis is divided into three distinct but interrelated sections, namely literature (chapter 2-3), methodology (chapters 4-5) and theory with discussion (chapters 6-11). Chapters 2 and 3 explore the literature relevant to the area under study. Two salient areas are discussed: eating disorder constructs and close intimate relationships. The first area in chapter 2 contextualises EDs by looking at the historical and contemporary meanings attributed to them. Firstly, the historical meanings of food and body image practices are explored in relation to the religious and cultural influences of the time and secondly, the meanings of food and body image practices are explored in relation to contemporary understandings and the resultant approaches to care. This chapter culminates with a review of the more recently developed recovery approach and its application in the field of EDs. To provide a context in which partners' experiences of living with a person with an ED can be understood, Chapter 3 explores the concept of close intimate relationships and discusses the aspects of intimacy, communication and love in terms of relationship functioning. This chapter concludes with a discussion on caring in intimate relationships and more specifically on caring in intimate relationships where one member has an ED.

Chapters 4 and 5 provide an account of the methodology and conduct of the research process undertaken in the study. Chapter 4 begins by examining the philosophical underpinnings of the study to include the epistemological, ontological, and methodological positions adopted by the researcher. GT methods are then discussed with a particular emphasis on CGT as this was the GT approach used in the study. Chapter 5 then discusses the application of CGT methods to the conduct of this study, culminating in a discussion on the ethical principles adhered to throughout the research process.

Chapters 6-10 present the theory of *'Reconstructing Livability'*. Chapters 6-9 explicate the findings of the study with each of these chapters representing a stage in the process of *'Reconstructing Livability'* which cumulatively explain the manner in which partners' address their main problem of *'Encountering and living in a disrupted relationship'*. These chapters are followed by a discussion in chapter 10, which addresses the salient issues emergent from the analysis and how these fit with and expand on what is already known in the substantive area under study. The final chapter discusses the limitations and quality considerations as they apply to this study. This chapter culminates with a discussion on the implications of the study and proposes recommendations for the provision of supports and services for partners of people experiencing an ED, for future research and for policy development.

Chapter 2

EATING DISORDER CONSTRUCTS

2.1 Introduction

In order to provide context in which the experiences of partners of people with eating disorders (EDs) can be understood, this first literature review chapter discusses the contemporary construction of EDs. These constructions are primarily situated within a medicalised framework and comprise of the sociocultural, biomedical, and psychological perspectives. Each of the three perspectives discussed provide a different lens in which the aetiology, approach to care and personal and family issues are considered, all of which can impact on a partner's experience of living with a person with an ED. As a basis to understanding the contemporary constructions of EDs, the historical beliefs around food weight and body image attitudes are first explored. The final section of this chapter then presents a newer approach to understanding and caring in mental 'illness', that of the recovery approach which, when applied to partners' experiences, can provide us with additional understanding from their perspective.

As this study uses Classic Grounded Theory (CGT) methodology to provide insights into the experiences of partners, the distinctive procedures required to conduct the literature review using this methodology are first presented.

2.2 Literature review in Grounded Theory

Particular procedures for the conduct of the literature review are required when using CGT methodology. The exact manner in which these procedures are carried out however, has provoked ongoing debate in the literature. This debate is primarily centred on the timing and extent of the literature review in the substantive area. On one hand, conducting a preliminary review of the relevant literature prior to data collection or analysis is considered helpful in sensitising the researcher to what is important in the data (Strauss 1987, Strauss & Corbin 2008). This is one aspect of the sensitising process inherent in CGT methodology and is referred to as 'developing theoretical sensitivity'. On the other hand,

having knowledge of the existing literature is considered to adversely influence the emerging theory, where the researcher might apply existing theoretical suppositions to the newly emerging theory (Glaser 1978). When this happens, the emerging theory may not reflect what is happening in the data and thus the findings may not be relevant to the substantive area under study.

Cutcliffe (2000) suggests, that although a literature review prior to analysis may be required for clarification and definition of concepts and terms, the depth and extent to which the review should be conducted confuses many researchers. He proposes that a first phase of the review is carried out for the purpose of supporting theoretical sensitivity, providing partial frameworks and for concept clarification. The timing of a second phase of the review he suggests, will depend on the form of Grounded Theory (GT) used. When using Glaser's CGT approach, the second review is only conducted when the theory is sufficiently developed and evidently grounded in the data (Glaser 1998). This is in contrast to a Straussian GT approach where the review is conducted at the concept development stage (Strauss & Corbin 1994b).

As this study uses a Glaserian CGT approach, the literature review process undertaken was the one advocated by Glaser (1978), who remains steadfast in his belief that reading in the substantive area be delayed until the theory is near completion. The main purposes for delaying this review are firstly to reduce the potential for the emerging concepts to be influenced by preconceived ideas obtained from the literature. Secondly, the purpose is to facilitate the researcher in remaining as open as possible to discovering what is going on in the data, which, as proposed by Urquhart (2001) supports an inductive approach to the analysis. Finally, Glaser (1998) suggests that doing a detailed review first is futile as the researcher will not know what the substantive area is prior to going into the field. He further adds, using the literature relevant to the study, which only becomes apparent as the grounded theory nears completion, will ultimately serve to delimit the literature review process.

Avoiding the influence of existing knowledge on the emerging theory, although remaining the ideal, is often problematic. This is because it is generally recognised that researchers do not enter the field with no prior knowledge in the substantive area (Morse 2001). In

addition, Glaser (1998) acknowledges the difficulties facing some researchers, where a detailed literature review is required for a dissertation proposal or grant application. In these situations Glaser (1998) suggests that the literature reviewed is used as a form of data and should be treated in the analytical process like other data. However, the advice remains that in-depth reading in the substantive area be avoided as far as possible (Cutcliffe 2000). The prior reading that is advocated when using a CGT approach is the preliminary reading outside the substantive area under study which according to Glaser (1978 p. 32), is concerned with 'Reading for ideas, style and support' (Glaser 1978, p. 32).

The literature review process undertaken for this study commenced with a very limited literature search in the area of partners' experiences of living with someone with an ED. This was to provide the researcher with information regarding the depth and scope of the knowledge currently available on partners' experiences and to identify gaps in that knowledge. Although limited, what was reviewed exposed a significant lack of research and theory in the substantive area of a partner's experiences. This finding supported the need to conduct the current research study with a focus on theory development rather than verifying an existing theory. The use of CGT methodology was considered appropriate as it provided the tools for developing such a theory that was grounded in the data provided by partners of people experiencing an ED.

A more detailed reading of the literature outside the substantive area was conducted in the initial stage of the research process which included the literature in two primary areas that could be related to the partners' experiences. This was to provide context in which the partners' experiences could be framed, and included the contemporary social construction of EDs and close intimate relationships. A more in-depth examination of the literature specifically relating to partners' experiences of living with a person with an ED was conducted when the theory was well advanced and the participants' main concern had been identified. This more in depth literature review was later added to the literature review chapter on intimate relationships, as it encompassed the aspect of caring in such relationships. The current chapter however, focuses on the first of the areas under review and discusses how contemporary understandings of EDs can influence a partner's experience.

2.3 Historical context of Eating Disorder

This section of the literature review examines some of the historical understandings of food and body practices, many of which are reflected in contemporary society. The meanings attributed to these practices differ according to the time in which they are experienced. For example, today, within a medicalised framework they are considered to be symptoms of an 'illness', but prior to the late seventeenth century and the medicalisation of EDs, food and body image related behaviours were often understood in terms of religious dedication. Most notably, various forms of food practices were recorded throughout religious histories and were often portrayed as both legitimate and acceptable for those times. In the fifth century BC, the practice of Pythagoreanism advocated dietary restrictions for ethical and ascetic reasons based on a belief that purity of body and spirit was achieved through abstinence from bodily pleasures. Similar ascetic practices relating to food and the body were documented in other ancient religious cultures such as Janism (Cort 2002). In an account of medieval women spiritualists, Walker-Bynum (1987) traces the development of fasting practices in Christian religions. These she suggests were modelled on Jewish traditions from the late first Century, where fasting was considered a powerful means of penance and renunciation of transgressions. Although asceticism was regularly practiced in this medieval era, it varied in intensity and outcome. In some cases it resulted in death, as in the case of Saint Catherine of Siena (1347-1380) who died in a state of malnutrition at the age of 33 years. The recognition of her devotion to a religious life rather than framing her asceticism within contemporary conceptualisations as disordered eating behaviour, resulted in her canonization in 1461.

There are close parallels between the accounts of food and body image related behaviours in historical times and current life stories of those who, in today's language and understandings, are considered to have an ED. Understanding the meaning of these activities for the individual however, requires situating their behaviours and beliefs in the context of the time in which they occur. As time has progressed modernisation and secularisation has brought with it a more medicalised approach to understanding and interpreting human behaviour. According to Conrad (2007), this is where problematic human behaviour is defined within a medical framework and the problems are considered a deviance from normal life occurrences. In terms of the medicalisation of food and body

problems, in contemporary society they are primarily understood as a pathological state and have acquired the label of 'Eating Disorders' (American Psychiatric Association 2013). It is within this understanding therefore, that society generally situates the experiences of partners and other family members of people experiencing an ED.

The progression of the medicalised view of EDs has developed over time with the body of knowledge growing as a result of reported case studies, empirical evidence and theoretical conjecture. The first account of Anorexia Nervosa (AN) is credited to Morton (1720), who provides a description of an 'illness' characterised by weight loss not attributable to any systemic disease. Although there were various case reports of anorexic type illnesses in the intervening years, it was not until 1874 that William Gull first named the issue as 'Anorexia Nervosa' (Gull 1874); the use of the term 'nervosa' implies its presentation is that of a mental state rather than a gastrointestinal disease (Silverman 1997). In a search of the literature for early references and indications of Bulimia Nervosa (BN), Parry-Jones & Parry-Jones (1991) identified 12 case accounts ranging from 1678 to 1897. This provides evidence for the existence of various positions on BN throughout the centuries. It was finally defined and named 'Bulimia Nervosa' by Russell (1979), who views it as a variant of AN. Binge Eating Disorder (BED), the most recently classified ED (American Psychiatric Association 2013), was first described by Stunkard (1959) and is reported to account for 40%-60% of people presenting for treatment for EDs (Machado *et al.* 2012).

2.3.1 Classification systems and their critique

Contemporary constructs of EDs are primarily situated within the illness/disease related classification frameworks. The main contemporary classification frameworks are the Diagnostic and Statistical Manual of Mental Disorders or DSM-5 (American Psychiatric Association 2013) and the International Classification of Diseases or ICD 10 (World Health Organisation 1992). Although both are similar in their diagnostic criteria for EDs, DSM-5 is the classification system referred to in this thesis as it is the one most recently updated. DSM-5 distinguishes between the subgroups of EDs to include AN, BN, BED and Other Specified Feeding and Eating disorders (OSFED).

AN is characterised by an intense fear of weight gain, body image distortion and weight controlling behaviours that result in significant weight loss. BN is characterised by episodes

of binge eating followed by compensatory behaviours such as vomiting or laxative abuse. BED is similar to BN but the binge episodes are not followed by compensatory behaviours and thus result in significant weight gain for the person. The term OSFED applies to those individuals whose ED behaviours or cognitions do not fully meet the criteria for AN, BN or BED. (More detail on the classification of EDs is provided in Appendix 1). Some authors support this distinction of subgroups, whilst others consider EDs as one syndrome with various manifestations of symptomatology (Van der Ham *et al.* 1997). Despite different manifestations however, the underlying core symptoms of food and weight preoccupation coupled with body dissatisfaction are considered relevant to them all (Polivy & Herman 2002).

The suitability and relevance of using a classification system for mental illness has long been debated in the literature and its application to the area of EDs has also been included in these debates. The usefulness of applying such a framework is generally centred around clinical practice and research, and includes the following; i) The use of a classification framework provides an empirically based system to standardise the definition of EDs and their subgroups and scientifically measure the efficacy of interventions (Wonderlich *et al.* 2007, Peterson *et al.* 2011); ii) It provides a basis for conducting research (Treasure *et al.* 2010); iii) is user friendly in primary care setting (Goyal *et al.* 2012) and; iv) is useful for meaningful communication between clinicians working in different services or countries (Halmi 1983). In respect of the person with the ED, using a classification framework is considered helpful in guiding treatment options (Kaye *et al.* 2005, Mitchell *et al.* 2013) and useful for the person when accessing illness specific medical and social benefits (Rössler 2013).

Using a classification system however, has also been met with medical and person centred concerns. Goyal *et al.* (2012) argue that the rigid application of the DSM-5 criteria hinders a complete examination of the full spectrum and variations of ED's. This supports Ackard *et al.* (2007) who do not dispute the usefulness of diagnostic classifications, but suggest the variety of presentations and the experiences of people seen in epidemiological populations is not appreciated when such criteria are applied. In particular, difficulties arise in the provision of care and treatment for those who do not fully meet the criteria specific to each subgroup of ED. Wildes and Marcus (2013) advise that using a multi-dimensional approach

to classification of EDs which includes neurobiology and co-morbid psychopathology, would go some way towards alleviating this concern. In respect of issues relating to the person experiencing the 'illness', diagnostic labelling is linked with stigma which has been shown to negatively impact on both the life of the person with the mental 'illness' and on family members (Ben-Zeev *et al.* 2010). The primary stigmatising perceptions society has towards those experiencing the ED are that they are attention seeking, they lack personal responsibility and are personally to blame for the 'illness' (Stewart *et al.* 2006, Crisafulli *et al.* 2008, Griffiths *et al.* 2015). Stigmatising perceptions towards family members are also blame related, where family members are often perceived as causing the ED because of poor parenting or inadequate provision of support to the 'ill' relative (Stewart *et al.* 2006, Dimitropoulos *et al.* 2015).

Regardless of the arguments for and against the use of classification systems, the dominant understanding of EDs in contemporary society is influenced by medicalised thinking (Mayes 2014). This has important implications for both the person with the ED and family members where the ED is defined as a mental 'illness', and where behaviours and thinking patterns are seen as symptoms and an expression of that illness. The use of classification systems within the medicalised approach define people by their symptoms and determine the approaches to care, where the clinician is seen as the expert. It is the clinician who prescribes the interventions based on the aetiological assumptions inherent in the ED construct within which they practice. Although the person experiencing the ED and their families can be included in treatment and care decisions, the hierarchical power relationship seen in the medicalised approach positions the clinician in a more powerful position with regard to decision making. In contrast, Ryan *et al.* (2008) suggest that, in order to improve outcomes for those in treatment, the focus needs to be on the person's own experience, their autonomy, their decision making and motivation for change. Vandereycken and Vansteenkiste (2009) further add that the lack of autonomy and choice in treatment options for people with EDs results in high levels of premature drop-out from treatment. They propose that this is often viewed by the 'experts' as non-compliance, resistance to change, or is related to the personality of the person experiencing the ED. In this situation little consideration is given to the therapeutic relationship or the treatment characteristics that may or may not fit with the subjective experience for the person with the ED and their partners. The authors further advise that allowing the person with the ED

to exercise autonomous decision making with regard to their treatment will foster a positive engagement in treatment. This is in keeping with a more recent recovery approach (Mental Health Commission 2008) that focuses on the human experience from the perspective of the person experiencing the ED and their partners¹.

2.3.2 Epidemiology of EDs

Although information regarding the epidemiology of EDs in Ireland is limited, it is estimated that approximately 200,000 people in Ireland experience some form of an ED (Government of Ireland 2006, Government of Ireland 2014). Reported estimated international figures for the prevalence of AN are between 0.37-1.3%, with an average age of onset between 15 and 19 years (Bulik *et al.* 2005). The estimated prevalence for full and partial BN syndrome is 1%- 5.4% (Shapiro *et al.* 2007), with an average age of onset of 20 years (Hudson *et al.* 2007). Prevalence rates for BED are estimated at between 0.7% and 3.0%, with a typical age of onset from late adolescence to early 20's (Brownley *et al.* 2007). Bramon-Bosh (2000) points to the marked distorted gender distribution of EDs, where only 5-11% of those presenting with an ED are reported to be male (Kjelsås *et al.* 2004, Button *et al.* 2008); however similarities of core psychopathology and comorbid illnesses have been identified in both genders (Bruch 1974, Braun & Sunday 1999, Geist *et al.* 1999). Adding to the complexity of EDs is the high prevalence of psychiatric comorbidity including anxiety, depression, substance misuse and obsessional compulsive disorders (Hudson *et al.* 2007, Treasure *et al.* 2010). The presence of comorbid 'illness' is reported to further impact on family members' experiences. For example, in a questionnaire study of people with EDs (n=84) and their caregivers (n=143), González *et al.* (2012) found that the perceived burden of care for carers improved when the person with the ED had lower levels of anxiety and depression.

EDs are considered to be a serious mental 'illness' (Klump *et al.* 2009), with a mortality rate in one subtype, that of AN, as high as 20% in cases of a prolonged illness of 20 years or more (Agras *et al.* 2004, Birmingham *et al.* 2005, Crisp 2006, Fichter *et al.* 2006). Care, treatment and recovery from an ED is often associated with a relapsing and remitting course over a number of years (Fairburn & Harrison 2003, McFarlane *et al.* 2008, Bohon *et*

¹ The recovery approach will be discussed in greater detail in section 2.6 at the end of this chapter

al. 2009) and as it advances all aspects of a person's life are affected. Not only is the person with the ED physically compromised (Lock *et al.* 2001, Mehler & Krantz 2003, Mehler *et al.* 2004), but there is also a marked deterioration in emotional, social, economic and interpersonal functioning (De la Rie *et al.* 2007, Crow *et al.* 2009, Klump *et al.* 2009, Treasure *et al.* 2012a, Downs & Blow 2013). Therefore, it is understood that the ED can have an effect on the wider community, and in particular on those individuals who are closest to the person with the ED, including partners (Perkins *et al.* 2004, Hillege *et al.* 2006, Whitney *et al.* 2007, Downs & Blow 2013).

2.4 Contemporary constructions of EDs

Although the onset and development of an ED is considered multifactorial in nature (Steiger *et al.* 1990, Garner 1993, Cooper 1995, Kaye *et al.* 2000, Morais 2002), there are several dominant contemporary constructs that explain the ED and provide various guidelines in the approach to care. These perspectives are discussed here under the headings of the sociocultural, biomedical and psychological constructs. People living with an ED and their partners will encounter professionals and non-professionals alike, whose thinking will be influenced by one or more of these perspectives. This may influence their own personal understanding of EDs and subsequently impact on the way in which they behaviourally and cognitively react to the presence of the ED in their lives. Therefore, understanding how the ED is framed within each construct can provide context in which the partner's experiences can be given meaning.

2.4.1 A Sociocultural construction of EDs

Examining EDs from a sociocultural perspective is concerned with how the social norms and expectations of the society in which a person lives influences their thinking and behaviours in relation to the development and maintenance of the ED. The consideration that EDs are a culturally bound syndrome has been posited from the outset of its emergence as an 'illness', when industrial capitalism brought with it changing attitudes in society (Brumberg 1998). In these earlier times, prior to the development of societal preoccupation with food and weight, the 'illness' was primarily associated with middle class females who used the ED as a way in which to define themselves and control their environment (Brumberg 1998, Lelwica 1999). Although these associations remain the same

in contemporary thinking (Soh *et al.* 2006), shifts in cultural norms have resulted in the inclusion of body shape and weight as aspects pertinent to understanding the meaning of EDs today.

Tracing the history of desirable body shape and weight through the arts, Raphael & Lacey (1994) point out how female body shapes have changed over time. The changes they suggest, have gone from the plump and muscular figures of the seventeenth century to the current emaciated frames where the unattainable ideal of slenderness gives rise to body image dissatisfaction. Body image dissatisfaction is the subjective negative appraisal of one's body that is linked to various forms of mental distress including EDs, low self-esteem and depression (Presnell *et al.* 2004, Clay *et al.* 2005). This is in part a culturally driven phenomenon where the social meanings assigned to the female body imply that thinness is equated with positive self-esteem and happiness and fatness is equated with low self-esteem and body disgust (Kadish 2012).

Body image dissatisfaction is a prevalent occurrence in western and more affluent societies (Holmqvist & Frisén 2010), and is reported to affect more women than men (Miller & Pumariega 2001). In one study of female (n=60) and male (n=50) college students, Stanford and McCabe (2002) report gender differences in the nature of body image dissatisfaction. The authors found that men face dichotomous cultural standards of both muscular and lean bodies whereas women's cultural standards are singularly concerned with smallness. In addition, the authors identify opposite sex peer influences as important to both males and females but more marked in females. In another more recent study using body shape visual aids, body dissatisfaction and the drive for muscularity was measured in men (n=226) between the ages of 18-67 years (Bucchianeri *et al.* 2014). The authors found body dissatisfaction and appearance based social comparison to be more markedly experienced by early adult men. This results in a stronger drive to engage in compensatory muscle building behaviours for these young men. Empirical evidence therefore indicates that men also have concerns and issues with body image, resulting in body changing behaviours and negative self-evaluation.

Holmqvist and Frisén (2010) attribute the rise in body image dissatisfaction in western societies to an increase in exposure to body related information in an economic

environment, where people have the resources to access body changing products and procedures. This is in contrast to findings from a literature review by Soh *et al.* (2006), who report low levels of EDs in non-Western societies. Although they suggest that this arises as a result of different cultural values regarding body shape and size, they further add that higher socio economic status is positively correlated with an increased risk of ED regardless of cultural background. Hesse-Biber *et al.* (2006) further the sociocultural discussion regarding EDs, suggesting that EDs are a consequence of individual psychology in a socially problematic world. They suggest the impact of media and other industries in promoting a cultural ideal of thinness, reinforced by family, friends and colleagues within their social world, increase the likelihood of vulnerable persons developing an ED.

As part of the debate around the impact family factors have on the development and maintenance of ED cognitions, the impact of romantic partners' attitudes on body image satisfaction for those with an ED has been modestly examined. In a quantitative study, Markey *et al.* (2004) examined married couples (n=172), to determine the role husbands' attitudes played in relation to the body image satisfaction of their wives. They found that wives overestimate their husband's dissatisfaction with their bodies, which impacts on how they feel about their bodies. This is similar to the findings in Pole *et al.* (2004), whose questionnaire study of married couples (n=77) also found that wives perceptions of negative body evaluation and critical comments from their husbands has a significant impact on their body dissatisfaction². The authors relate these findings to poor marital communication and they suggest that this could be targeted in couple's therapy with an aim to improve marital satisfaction, reduce body image dissatisfaction and improve other ED related behaviours and cognitions.

Orbach (1993) posits women's difficulties with body shape and their relationship with food goes beyond the pressures to conform to cultural ideals of thinness and should be seen as a symbolic struggle for autonomy. This opinion is echoed within feminist thinking where reducing the understanding of women's distress to culturally driven body ideals is at the expense of understanding what that distress is really about (Thompson 1994). Katzman and Lee (1997) suggest, within a world of social change, food and weight can be seen as the

² No studies were identified that explored the impact of female partners' attitudes on their significant other's body image dissatisfaction.

product of women's struggles with disconnection, transition and oppression. They conclude that recovery for those with EDs should be focused on defining oneself beyond body shape and weight and on developing effective interpersonal relating.

Treatment and care guidelines stemming from the sociocultural construction of EDs target both the individual psychology of the person experiencing the ED and the broader social attitudes and perceptions in relation to mental 'illness'. Various types of individual psychotherapeutic interventions such as cognitive behavioural therapy or interpersonal psychotherapy are considered helpful in enhancing positive self-worth, improving interpersonal skills and fostering change in ED related cognitions and behaviours including body image related distress (Farrell *et al.* 2006, Glauert *et al.* 2009). In order to be useful, these interventions need to be provided in a culturally sensitive manner that respects cultural and religious beliefs (Miller & Pumariega 2001). Interventions at a broader social level are concerned with prevention and education, targeting public policy and community attitudes around such things as body image, that serve to exacerbate some of the problem associated with EDs (Levine & Piran 2004).

Although considering EDs within the sociocultural construct provides us with a rich context for understanding them, using this construct in isolation is problematic. Firstly, it fails to explain why some individuals are more susceptible to developing an ED than others (Tozzi *et al.* 2003). Secondly, it limits the opportunity to identify an ED problem; for example Räsänen and Hunt (2014) suggest the cultural construction of EDs as a female 'illness' means that men fail to recognise if they are experiencing an ED. Thirdly, empirical evidence provided by Crisafulli *et al.* (2008) suggests that viewing the aetiology of EDs within this construct alone generates a blaming milieu in which an individual is seen to succumb to cultural pressures to attain perfection with the perfect body. Blaming can also be extended to family and significant others where their perceived critical comments or lack of support is seen as a significant part of the onset and/or maintenance of the ED. Bearing these critiques in mind, some authors suggest that the aetiology of EDs should include a combined sociocultural and biomedical perspective in order to provide a more holistic understanding and a more informed approach to providing care for those with EDs and their families (Morais 2002, Bulik 2005, Crisafulli *et al.* 2008). The next section therefore will explore the construction of EDs from a biomedical perspective.

2.4.2 A biomedical construction of EDs

Examining EDs from a biomedical perspective is concerned with the role genetic and neuroendocrine factors play in relation to the development and maintenance of the ED for a person. Regarding the genetic factors, family studies report a higher frequency of full and partial ED syndromes in first degree relatives of someone with an ED in comparison to the general population (Lilenfeld *et al.* 1998, Strober *et al.* 2000). Familial studies however, do not delineate between family environment and genetic susceptibility. Twin studies go some way to solving this problem whereby environmental factors to which only one twin has been exposed to are accounted for (Bulik 2005). Some of these twin studies report heritability estimates ranging from 50% to 90%, with concordance rates reported to be significantly higher for monozygotic twins than dizygotic twins (Strober 1995, Treasure *et al.* 2010). More recent studies have shown an increasing emphasis on genetics and EDs, suggesting genetics may account for why some people are more vulnerable to sociocultural influences in developing an ED than others (Bulik 2005). However, this research is still in its infancy and any conclusions based on current hypotheses would require more studies using larger sample sizes (Culbert *et al.* 2015).

Neuroendocrine factors are concerned with changes in brain functioning such as altered neurochemical activity, brain structure and brain metabolism and can be seen in various endocrine disorders and metabolic disturbances. Due to methodological difficulties associated with premorbid detection of the development of EDs, determining if neuroendocrine factors are a cause or a consequence of the ED is problematic. What is evidenced, however, is that serum abnormalities including hormone and enzyme levels are particularly evident in those with EDs when malnutrition is severe (Montagnese *et al.* 2007, Saito *et al.* 2007). Studies have also reported that improvement in these abnormalities is associated with weight gain (Nakazato *et al.* 2009, Treasure *et al.* 2010), supporting the treatment focus of nutritional rehabilitation advocated in this construct.

Treatment and care guidelines in the context of the biomedical construction of EDs are primarily centred on nutritional rehabilitation for the person and the use of pharmacotherapy. The aims of nutritional rehabilitation are to affect weight gain, improve eating habits and reduce the metabolic effects of starvation, thereby improving physical

and psychological functioning (Golden & Meyer 2004). The aim of pharmacotherapy is also to improve both physical and mental health. In terms of physical health, drug treatment is used for the purposes of supporting nutritional rehabilitation and to counteract the physical complications of malnutrition or other ED related compensatory behaviours such as purging. Mental health improvement, on the other hand, is associated with the use of psychotropic medication particularly when treating comorbid psychiatric conditions such as depression and anxiety. For example, some antidepressants have been found to be helpful in treating binge eating behaviours in BN and BED (Wilcox 1990), but there is limited empirical evidence supporting the use of psychotropic medication for those with AN (National Institute for Health and Clinical Excellence 2004, Mitchell *et al.* 2013).

Using a biomedical approach is useful in both safeguarding against the medical risks associated with EDs, such as cardiac or respiratory collapse, and the psychological risks associated with comorbid mental health issues, such as depression and self-harm. Using this approach in isolation from psychological interventions however, has consistently been reported as a negative experience for those accessing treatment (Bell 2003, De la Rie *et al.* 2006). This is reflected in the findings from a randomised prospective study where Halmi *et al.* (2005) report a low rate of acceptance of treatment in those with EDs when medication was used as a stand-alone treatment intervention. A negative experience of using psychotropic medication for the person requiring the treatment is generally associated with side effects of the medication (Hamer & Haddad 2007, Moncrieff *et al.* 2013). The experience for family members is reported to be influenced by what they perceive to be the costs, such as expense or side effects, and the benefits, such as improved health of their relative taking the medication (Grover *et al.* 2014). In the absence of research examining family attitudes to psychotropic medication use in those experiencing an ED, caution is required when making inferences based on findings from other areas.

In the context of close intimate relationships, the impact of psychotropic medication on sexual functioning and sexual interest is also an important issue for consideration. Other causes of sexual functioning difficulties in people with EDs such as nutritional deficits or body image dissatisfaction have been reported (Pinheiro *et al.* 2010, Castellini *et al.* 2012); however, the effect of using psychotropic medication on sexual functioning in people experiencing EDs has not been researched. General reports however, suggest that these

medications can interfere with normal sexual functioning in terms of decreased sex drive, anorgasmia or delayed ejaculation (Gitlin 2003, Stimmel & Gutierrez 2006) and can thus impact on intimate relationship satisfaction.

Although framing the ED within a biomedical construct is reported to reduce blaming and stigma (Crisafulli *et al.* 2008), a challenge highlighted within the sociocultural construct above, it limits the exploration of any underlying psychological issues the person may be experiencing. Therefore, the general advice is that psychological therapies are provided alongside the medical management of someone with an ED (National Institute for Health and Clinical Excellence 2004, American Psychiatric Association 2006). In discussing the psychological construction of EDs, three main psychological perspectives reported in the literature and these will be presented in the next section in terms of how each perspective explains the nature of the ED and how each influence care, treatment and partner involvement.

2.4.3 The psychological construction of EDs

Examining EDs from a psychological perspective is concerned with understanding a person's ED thoughts and behaviours as a reflection of their mental processes. The three main approaches within the psychological construction of EDs discussed in this section are the cognitive behavioural, psychodynamic and family systems perspectives. Although there is some overlap in their philosophies, discussing the aetiology of ED and the care approach of each provides differing perspectives on understanding the psychological meaning of the ED for the person and the impact this may have on family carers and partners.

Cognitive-behavioural perspective: This psychological approach to understanding EDs considers the interaction of cognitive biases with behavioural disturbances as the maintaining and self-perpetuating factors for people with EDs. Cognitive bias refers to thinking errors which are based on one's subjective interpretation of experiences. These occur at a subconscious level, are felt to be real and are not usually in keeping with other people's interpretations (Williamson *et al.* 2004). Those with EDs demonstrate their biases by their over concern in relation to food and weight (Polivy & Herman 2002). Body shape, weight and food, and the person's inability to control them, become a dysfunctional way

in which the person with the ED self-evaluates (Fairburn & Harrison 2003). Negative self-evaluation coupled with activating events in the environment further intensify the cognitive biases resulting in heightened body image distress and low mood (Altabe & Thompson 1996, Williamson *et al.* 2004). Engaging in ED behaviours is understood to relieve the anxieties and distress associated with the negative self-evaluation and body image distress (Benas & Gibb 2011).

Treatment and care guidelines provided from this perspective primarily focus on the thought and behavioural processes serving to maintain the ED (Fairburn *et al.* 2013). Empirical research has shown that earlier models of cognitive behavioural therapy (CBT) have been effective in the treatment of BN and BED (Agras *et al.* 2000, Waller *et al.* 2014). In a review of treatment outcome measures however, Lundgren *et al.* (2004) found that although CBT interventions affect a reduction in ED symptomatology post treatment, symptoms such as dietary restraint, body image concerns and self-esteem are rarely within a normative range. In the absence of the effectiveness of CBT in the treatment of people presenting with EDs within the other subgroups of EDs, such as AN, a trans-diagnostic model of CBT referred to as enhanced CBT (CBT-E), has subsequently been developed (Fairburn *et al.* 2003, Waller *et al.* 2007). This treatment is delivered using evidenced based manuals (Fairburn *et al.* 2008) aimed at normalising eating and weight controlling behaviours while challenging maladaptive cognitions and emotions (Turner *et al.* 2015). In a study to measure the recovery outcomes using CBT-E for those with AN (n= 99), Fairburn *et al.* (2013) report that for the two thirds of people who completed the treatment there was a substantial improvement in body weight, ED cognitions and behaviours. Watson *et al.* (2012) suggest, in addition to improving ED symptoms, CBT-E also has a positive impact on quality of life for the person. In a later review of the empirical research on outcomes for CBT-E, Groff (2015) also found that using CBT-E is generally effective, however she points out that empirical testing of this model is only in its infancy and caution is required when interpreting the findings.

Although the use of CBT-E has been shown to affect change in behaviours and cognitions for those with EDs, little attention has been given to the perspectives of family members within this model. Only one paper was found where partners were involved in their spouses' treatment when a CBT approach was used. In a quantitative study, Gorin *et al.*

(2003) randomly assigned women with BED (n=94) to a standard CBT group, a CBT group with spouse involvement or a waiting list control group. They found that, although both groups participating in the CBT groups made significant improvements in comparison to the control group, CBT with spousal involvement showed no additional benefit. This study did not examine the experience from the perspective of the partner; rather, the focus was on the experience for the person with the ED.

The cognitive behavioural perspective of EDs provides little by way of aetiological explanations, however it provides insights into how the ED is maintained and as discussed above, offers treatment strategies based on these insights (De Silva 1995). Other psychological perspectives, considering both the aetiological and maintaining factors of EDs, provide alternative ways of considering EDs. These perspectives include the psychodynamic and family systems, presented in the next two subsections.

Psychodynamic perspective: This psychological approach to understanding EDs, the origins of which are found in the Freudian theories of the unconscious and drive conflicts, consider ED symptoms as an unconscious expression of psychological conflict (Caparrotta & Ghaffari 2006). A dominant theoretical perspective in psychodynamic thinking and EDs is attachment theory, where early life experiences are seen to impact on maturation and relationship functioning in adulthood. When an individual has good experiences in childhood, they are able to engage in intimate relationships in a loving and supportive way without undue anxiety or concern (Tasca & Balfour 2014). In contrast however, where early parental interactions with the child are disrupted, the child becomes insecurely attached and fails to adequately separate and develop autonomy as they mature (Bruch 1973).

The primary manifestations of insecure attachment reported in people with EDs are either an avoidant attachment style or an anxious attachment style. The former avoidant attachment is characterised by diminished emotional connections and moderated emotional expression (Tasca & Balfour 2014). The latter anxious attachment is characterised by an individual using another to maintain their sense of security. When security and safety are disrupted, resulting in heightened feelings of anxiety and fear, the individual's behavioural system is activated and they seek a secure closeness to their attachment figure (Armstrong & Roth 1989). Zachrisson & Skårderud (2010) suggest

attachment figures in childhood and adolescence tend to be parental but in later years this shifts to peers and romantic partners. In a randomised controlled study of people with an ED (n=127) and people without an ED (n=80), Ward *et al.* (2000) found that both styles of insecure attachment were seen across all ED subtypes. In addition, they found that often contradictory attachment styles, that is both anxious and avoidant types were experienced simultaneously. They discuss these findings in relation to the contradictory messages of wanting to be left alone and needing closeness, this in turn elicits frustrated and helpless responses in clinicians. In light of this finding it would be important to examine the effect that simultaneous contradictory attachment styles would have on partners and how that might impact on relationship functioning.

Although the understanding of attachment theory in EDs primarily focuses on the struggle to achieve autonomy, Wechselblatt *et al.* (2000) suggest that this focus diverts attention from the bigger picture of the role that relationships and relatedness play for the individual as they mature. They suggest difficulties in engaging and maintaining relationships occur when the need for autonomy is in conflict with the need for relatedness. Fishler (1990) considers the integration of attachment and object relations theories as the solution to understanding relationships and relatedness, while object relations theory is concerned with the development of one's relationship with the self and with others. This integrated approach considers the need for independence for the person while they continue to need connections and attachments with others (Flanagan 2011). An understanding of the link between maladaptive attachment and disrupted object relations in those with EDs is provided by Caglar-Nazali *et al.* (2014). They suggest, in addition to experiencing low levels of control and self-esteem the person with the ED has difficulties identifying their own and other's emotions. This, they consider, leads to persistent social difficulties that affect most aspects of social and relationship functioning.

The majority of the literature on attachment theory and EDs is concerned with psychopathology and risk factors for developing an ED and is primarily considered in relation to adolescents. Evans & Wertheim (2005) however, use an attachment framework to explore the intimate relationships in women with BN (n=55), women with subclinical EDs (n=42), women with depression (n=44) and a control group with no eating disorder or depression (n=80). Their findings suggest the women with BN present with anxiety and

avoidant attachment responses, whereby intimacy and closeness with their partner is avoided. In addition, they report the women with BN expressed more negative feelings relating to openness, responsiveness, caring and affection towards their partners than the control groups. This they suggest, results in problematic relationship functioning.

Treatment and care guidelines from a psychodynamic perspective are primarily concerned with individual therapy. This focusses on the subjective experience for the person with the ED where treatment can last from 1-4 years. The relationship with the therapist is the mechanism whereby the interpersonal and intrapsychic problems are worked through (Zerbe 2010). Family members and carers are not usually involved in the therapy but can be offered support and education as an adjunct to the individual therapy; however exclusion from, or only limited involvement in, treatment interventions has been reported as problematic for partners. In a qualitative study of the experience of family carers in ED (n=20), 5 (25%) of which are partners, Winn *et al.* (2004) report partners understanding of their lack of involvement in the treatment process as being related to confidentiality issues. As a result the partners report feeling far less informed than parents as carers, and identify the need for more information as an important issue.

In contrast, involving family carers in the treatment of those with EDs is considered a central component in the family systems perspective. Although this approach to care is primarily advocated for children and adolescents, recent developments in family involvement in psychotherapeutic inputs for those with EDs consider the inclusion of partners (Bulik *et al.* 2011). It is in light of these developments that understanding the ED from a family systems perspective is discussed.

A Family systems perspective: A family systems approach to understanding EDs is concerned with the development and maintenance of EDs in the context of family structures, relationships and interactions. The theoretical propositions range from the viewpoint where family functioning is considered dysfunctional and seen as a cause and maintaining factor of EDs (Minuchin *et al.* 1978), to more current thinking where there is a reorganisation of family life because of the ED (Whitney & Eisler 2005). A primary concern regarding the former consideration is the implicit understanding that families are to blame. This can significantly interfere with families engagement in the treatment process (Røijen

2000). In contrast, the latter considers the ED as a central organising component of family life which serves to facilitate the elimination of blame (Downs & Blow 2013). The reorganisation model understands that family life and family interactions become reorganised in a way that is thought by the family to be helpful to the person with the ED, but ultimately it accommodates the ED behaviours. For example conflict avoidance, employed for many reasons including concern for the health of the ill person, reduces the opportunity to challenge ED behaviours resulting in an escalation of those behaviours (Eisler 2005).

Understanding EDs from current family systems perspectives not only acknowledges the difficulties for the person with the ED, but also acknowledges the impact it has on the family members themselves. Much of this research, although primarily concerned with the unhelpful interaction styles that arise from the difficulties associated with living with someone with an ED, also identifies the needs of the family members. These include needing more support and information, improved access to treatments and the need for practical advice (Winn *et al.* 2004, Highet *et al.* 2005). These findings have been integrated into family therapy approaches which are the primary treatment and care guidelines found within this construct (Treasure *et al.* 2007a, Sepulveda *et al.* 2010, Treasure *et al.* 2012b).

Family therapy, as recommended in various clinical guidelines (National Institute for Health and Clinical Excellence 2004, American Psychiatric Association 2006), however, is primarily intended for adolescents and children. In the absence of empirical evidence, the appropriateness and usefulness of involving families/partners in the treatment of adults with EDs is not so clear (Eisler 2005, Treasure *et al.* 2005, Downs & Blow 2013). In addition to couple counselling (Dick *et al.* 2013), some interventions for partners have been reported (Leichner *et al.* 1985, Bulik *et al.* 2011, Gísladóttir & Svavarsdóttir 2011). All of these interventions are primarily aimed at enabling families and partners to support the person experiencing the ED through their recovery³.

Evaluating the benefits of a particular approach to treatment and care is usually measured in terms of recovery (Williams *et al.* 2012) but this has proved problematic for several

³ This aspect of the literature will be explored in greater detail in section 3.7 'Caring in close intimate relationships'

reasons. Firstly, there is no consensus across the approaches on specific criteria for recovery from EDs (Noordenbos & Seubring 2006). Secondly, although there is general agreement that recovery comprises of physical, psychological, social and interpersonal elements, these are not consistently included in studies on recovery in EDs (Pettersen *et al.* 2012). Thirdly, the majority of the research fails to include opinions on recovery from the perspective of the person with the ED (Vanderlinden *et al.* 2007). However, a new recovery orientated approach in Irish mental health services goes some way to filling this gap (Mental Health Commission 2008). This approach is discussed in more detail in the next section.

2.5 Recovery perspectives: Clinical recovery versus personal recovery

Two perspectives on recovery are explored in this section. The first looks at the meaning of recovery from a clinical perspective, and the second examines the meaning of recovery from the perspective of the person experiencing a mental 'illness'. From a clinical perspective and situated within the medicalised construct, the meaning of recovery in mental health is traditionally framed as the clinical absence of symptoms and a resumption of pre illness levels of functioning (Davidson & Roe 2007). Although several criteria for the clinical recovery of people who are experiencing an ED have been posited in the literature, no uniform definition has been established. In an examination of the literature to evaluate recovery from AN and BN, Jarman and Walsh (1999), who acknowledge the absence of the service user's view on recovery, identify physical, psychological and social dimensions as salient issues in their discussions on clinical recovery. This is reflected in later studies examining recovery in EDs; for example, when measuring the efficacy of psychological therapies for adults with AN, Dare *et al.* (2001) propose criteria that measure various grades of recovery. The authors consider recovery criteria are related to weight, menstruation and eating behaviours that are graded as recovered, significantly improved, improved or poor. Vrabell *et al.* (2008) subsequently used some of these criteria as a guideline to measure the recovery trajectory for adults with EDs for longer than 7 years. Their criteria for recovery however, did not include factors relating to menstruation as they argue there are many other reasons apart from the ED that can account for irregular menstruation. The lack of consensus on what constitutes clinical recovery goes some way

towards explaining the variability in recovery rates across the research findings ranging from 30-75% for those with AN to 50-70% for those with BN (Vrabel *et al.* 2008).

Prognosis for recovery from an ED within the medicalised construct is reported to be linked to the severity of the ED. Defining severity of illness is measured, among other things, by the length of time the person has the ED, the number of hospital admissions, other co-existing psychological difficulties and illness specific markers such as amount of weight lost (Berkman *et al.* 2007, Fichter *et al.* 2008). Prognosis is also linked to a protracted recovery trajectory, where outcome studies report that at least 30% of people with AN continue to have ED symptoms after 10 years (Kaplan & Strasburg 2009, Keel & Brown 2010). A protracted recovery trajectory is often viewed within the medicalised construct as 'chronic and enduring'. Wonderlich *et al.* (2012), among others, (Strober 2004, Tierney & Fox 2009), suggest there is no definitive criteria to determine the boundaries of 'chronicity' in EDs; however, Noordenbos *et al.* (1998, 2002), drawing on previous follow-up studies, consider an ED as 'chronic', where duration of illness is 10 or more years.

As demonstrated in a research study conducted by Noordenbos *et al.* (1998), the use of the term 'chronic and enduring' can be problematic for the person experiencing a mental 'illness' and also for their family members. In this study the authors analysed letters written by people who had been previously treated for an ED (n=369). They found, when long-term EDs are framed as incurable by the person with the ED, their family members and/or clinicians, it creates a negative environment where people lose faith in the possibility of improvement. The authors further add, where recovery is problematic for the person experiencing the ED, the focus should be on improving their quality of life. This is in keeping with Treasure *et al.* (2005) who, drawing on their experience of working with families of adults with AN, suggest that in the case where a person has a more severe form of the ED and complete recovery is problematic, improvement should focus on quality of life rather than failure of recovery. The authors do acknowledge however, that this particular focus from the family members' perspectives can be difficult as often complete recovery is what the family desire the most. When the family members' ideals and goals of recovery are in conflict with the realities around a full recovery, it can significantly affect the environment within which they live. The general wellbeing of both the person with the ED and their family members are affected as family members experience disappointment and

apprehension when a full recovery is not achieved (Treasure *et al.* 2005). A further complication of the ED being framed as 'chronic and enduring' is the effect this has on the attitude of clinicians who often view a person with a longstanding ED as being resistant to treatment and subsequently the clinicians report finding the work challenging (Geller *et al.* 2001, Strober 2004). Overall, therefore, the implications of the ED being labelled 'chronic and enduring' impact on a person's identity, interpersonal relationships, life opportunities and treatment experiences (Manderson & Smith-Morris 2010).

In a more recently developed recovery approach, recovery is considered an individual process, concerned with the personal journey for the individual, the outcome of which is determined by their own wishes, capabilities and goals (Mental Health Commission 2008, Higgins & McGowan 2014). Personal, as opposed to clinical recovery, provides us with a deeper understanding of what is personally important to the person for their own recovery. The research exploring this perspective of recovery primarily uses qualitative research methods, capturing the subjective experiences and understandings that extend beyond the dimensions of measurement used in the medicalised interpretations of recovery. These subjective experiences provide a basis on which commonalities are identified and person centred theoretical frameworks can be developed (Jarman & Walsh 1999). In a systematic review and modified narrative synthesis, Lemay *et al.* (2011) developed a conceptual framework of people's personal experiences of recovery, consisting of the recovery process and the characteristics and stages of this process. They suggest the recovery process is centred on connectedness, hope for the future, identity, having meaning in one's life and empowerment.

Several studies explore the subjective meaning of recovery from the perspective of the person with an ED. The focus of most of these studies is on what people found helpful or not helpful in their own journey of recovery (Bell 2003, Tozzi *et al.* 2003, Keski-Rahkonen & Tozzi 2005). Psychotherapeutic interventions, empathic relationships and support are among those issues people found helpful whereas medical intervention and a focus on weight were identified as not helpful (Bell 2003). However, from the findings in a doctoral study examining recovery for women with an ED (n=12) Oberlin (2013) suggests a combined medical and person centred approach to care is beneficial where both medical risks and self-discovery for the person are attended to.

How people consider themselves as recovered from an ED has also been examined in the literature. Following the analysis of letters (n=369) written by people with EDs, Noordenbos *et al.* (1998) report various ways in which the people considered they had improved or recovered from their ED. For some, it was about the absence of bingeing or being able to enjoy a meal out socially; for others, it was about having the energy to do other things, being able to manage anxiety and depression or having ownership of their body. In the context of self-acceptance, recovery meant having a purpose in life and being able to express oneself emotionally. The authors found that, despite experiencing various levels of ongoing ED symptoms, the women in the study defined themselves as recovered. Similar findings are reported by Pettersen and Rosenvinge (2002) who, in a mixed method approach, examined the concept of recovery for women with EDs (n=48). The authors found that an absence of ED behaviours and thoughts are meaningless as the only criterion for recovery. They suggest recovery for the person experiencing the ED is an ongoing subjective process that includes such issues as satisfactory social functioning, acceptance of oneself and their body and having a purpose in life. Federici and Kaplan (2008) also suggest that recovery for women with an ED is an ongoing process requiring motivation, self-belief, expression of emotion and the capacity to develop trust in others. They conclude that exploring the experiences of those who have an ED is important for developing more individually tailored and effective interventions that promote personal recovery.

Topor *et al.* (2006) posit that others, including family members, also have a journey of recovery to make. This recovery journey is concerned with learning to relinquish their various caring roles as their relative reclaims their independence. In a systematic review of the literature, Reupert *et al.* (2015) concur with this concept of family members' recovery. They suggest, while remaining connected to the person who is overcoming the mental 'illness', family members' recovery is associated with accepting a level of separation from and an acceptance of a renewed autonomy in their relative. Machin and Repper (2013) further add, as the recovery journey is concerned with self-discovery and growth, then family members and carers are also taking that journey for themselves. Although this literature considers recovery for family members in general, no studies examining this journey for partners and more specifically for partners of people with EDs, was identified.

Adopting a recovery approach to mental 'illness' has not been without its challenges and criticisms. The subjective meaning of recovery for each individual makes it a difficult concept to define, generating problems in the standardisation of recovery practices (Davidson *et al.* 2005, Collier 2010). Harper and Speed (2012) suggest the biomedical influences on recovery and resilience discourses, limit the way in which a persons' emotional distress can be understood and usually the distress is framed in the context of deficits, such as poor quality of life. The authors further argue that current recovery approaches are individualistic in nature, and that responsibility for recovery lies with the person experiencing the mental distress. As pointed out by Rose (2014), this is problematic in the context of the social world within which people live, where a focus on individualism excludes the importance of social relations. Haper and Speed (2012) therefore, advocate for a balanced approach to recovery to include personal, social and political practice. Criticisms of the recovery approach have also been voiced by people experiencing mental 'illness', who have set up an online group (Recovery In The Bin 2014). They believe the concept of recovery has increasingly been influenced by neoliberalism and colonised by professionals. This they suggest, has undermined the central principles of autonomy and self-determination inherent in the recovery approach. In consideration of this criticism, Higgins and McGowan (2014) reflect on the need for the recovery approach to be rescued from professional colonization.

Regarding the practical challenges to implementing a recovery approach, Shera and Ramon (2013) highlight the need for an organisational culture that supports this approach but suggest changes in practice can be a difficult undertaking for professionals. Davidson *et al.* (2006) identify risk and resources as the overarching problems for its implementation where risks are seen in the context of harm coming to the person or others when the person experiences impaired judgement as a result of their mental 'illness'. Resource problems on the other hand, are primarily about funding a new developing recovery approach with supports, staffing and training. Encapsulating these challenges is a comment from McDaid (2013b p. 22), who states: 'Staff must operate in an environment that facilitates recovery, including having a legal framework that promotes choice, autonomy, de-institutionalisation and positive risk taking, adequate staffing of multidisciplinary teams and appropriate, modern facilities'.

The literature reviewed herein supports adopting a recovery approach to understanding the experiences of people with EDs and their partners, as doing so provides a broader perspective of their lived experience where the focus is not restricted to symptoms and diagnosis. Instead, it incorporates all aspects of the persons' life including the lived environment of the intimate relationship.

2.6 Summary

The various ways in which EDs are constructed in contemporary society have been presented in this chapter. Traditionally these include the sociocultural, biomedical and psychological perspectives in which the aetiology, approach to care and family involvement have been discussed. The person who is experiencing the ED and their partners can encounter any one or a combination of these approaches on their journey of recovery, which can ultimately impact on how they experience that journey. Despite the various theoretical propositions in each construct, no single approach to understanding and treating EDs is endorsed. Rather, in order to embrace the associated medical, psychological and sociocultural issues, a combination of approaches is advocated. However, similar to international developments (U.S. Department of Health and Human Services 2006, Ramon *et al.* 2007, Department of Health and Ageing 2009), contemporary developments within Irish mental health services advocate a personal recovery approach to care and treatment of people with mental 'illness'. This approach focuses on the subjective experiences of the person who is experiencing the mental 'illness', where the provision of care and support is guided by that person's goals and wishes. This is applicable not only to a person experiencing an ED but also to their partners where, according to Noordenbos (1998), failing to consider the person's perspective of recovery reduces the identification and mobilisation of their personal resources, thus limiting their treatment options.

Having examined the contemporary constructs of EDs, which provides insight into the various understandings of EDs, the approaches to care, and the potential impact on experiences for those with an ED and their partners, the focus in the next chapter moves to close intimate relationship functioning. This is to provide a further context in which the current research is situated, whereby the experiences of the participants, who are intimate partners of the person experiencing an ED, are explored.

Chapter 3

CLOSE INTIMATE RELATIONSHIPS

3.1 Introduction

The previous chapter explored the literature in relation to contemporary constructions of eating disorders (EDs), where each construct provides a framework in which a partner can give meaning to their experience of living with someone with an ED. However, the importance of situating a partner's experience within a close intimate relationship setting became evident as the study and theory developed. Therefore the focus of the literature review expanded to include both theoretical perspectives and empirical findings concerning relationship functioning in close intimate relationships. Furthermore, as is applicable to the current study, the exploration is extended to include more detailed information on relationship functioning in couples where one person is experiencing an ED.

3.2 Defining close intimate relationships

There are many ways in which adult couple relationships are referred to across the literature. These include romantic (Oyamot *et al.* 2010, Arcelus *et al.* 2012), intimate (Overall *et al.* 2009, Miller 2012), close (Kelley *et al.* 1983, Fincham & Bradbury 1987), dyadic (Levkovitz *et al.* 2000) and marital (Fincham & Bradbury 1992). Many of the components in each concept overlap and generally conform at some level to the definition of intimate relationships provided by Kelley *et al.* (1983). This definition states that 'The close relationship is one of strong, frequent and diverse interdependence that lasts over a considerable period of time' (Kelley 1983 p. 38). The authors include the relationships of marriage, close friendships and parental/child dyads as examples of close relationships. Birnie-Porter and Lydon (2013) however, suggest sexual intimacy and desire are usually what separate romantic relationships from more platonic or other family relationship types. The social exchange theory of interdependence (Thibaut & Kelley 1956, Kelley & Thibaut 1978) provides an appropriate framework in which intimate relationship functioning can be examined. This framework is concerned with interpersonal interactions within the couple dyad which consider the effect of the cognitions, behaviours and

emotions of one person on the cognitions, behaviours and emotions of the other (Cook & Kenny 2005). It is within this framework of intimate interacting to include sexual intimacy, love, communication and caring, that the experiences of the partners living in a close intimate relationship with a person with an ED will be explored.

3.3 Intimacy: exploration of the concept and its development

Defining intimacy is a difficult task as it is conceptualised in many different ways in the literature. These conceptualisations include relationship interactions where self-disclosure from one partner is validated and reciprocated by the other (Clark & Reis 1988). From an emotional investment perspective, intimacy is understood as the quality of feelings and connectedness in a relationship (Prager 1995, Knobloch & Solomon 2004), the mutual sharing of a person's innermost thoughts (Armstrong 2006) and the communication of commitment and love (Miller 2012). Birnie-Porter and Lydon (2013) consider the experience of intimacy in relation to the physical connectedness of sexual activity.

Van den Broucke *et al.* (1995c) consider intimacy as a dyadic phenomenon incorporating cognitive, behavioural and emotional components, the intensity of which is contingent on the degree of interdependence and connectedness between the couple. Their model comprises three interconnecting levels: the individual, the dyadic and the social level. The individual level comprises of the need to be oneself and the readiness for self-disclosure. The dyadic level is concerned with the couple interactions and behaviours as a relationship unit. The third, social level, acknowledges the relationship in the broader context of larger groups such as family or friendship networks, which incorporate features of exclusiveness as a couple. More recently, Prager's (2014) theoretical perspective posits that intimacy is concerned with verbal and non-verbal interactions, self-disclosures, positive involvement with ones' partner and the sharing of mutual understandings. She suggests intimacy involves the reciprocal extensive sharing of ones most private aspects of the self which is accepted by the other with respect and understanding. Regardless of how intimacy is conceptualised however, satisfactory relationship intimacy is generally considered to have a positive influence on the self and on the dyadic relationship (Hinchliff & Gott 2004, Sprecher & Cate 2004, Birnie-Porter & Lydon 2013).

Intimacy in a relationship is not static; rather it changes and develops as the relationship progresses and the lives of the couple become more intertwined. The 'I' becomes 'we' as the individuals begin to include the other in their cognitive representations of themselves and independence transforms into mutuality and interdependence (Williams-Baucom *et al.* 2010, Miller 2012). Prager (2014) suggests becoming 'we' in intimate relating needs careful negotiation in order to achieve a balance between the need for autonomy and the need for connectedness. The level of intimacy negotiated and realised is different for each couple and is influenced by many factors. Miller (2012) considers these factors to include cultural standards, the history and past experiences brought by each individual to the relationship and the personal characteristics and traits of each person. The level of intimacy also changes in response to relationship uncertainty or critical relationship events such as conflict, physical separation or environmental changes (Knobloch & Solomon 2004). Included in the literature on changes to relationship intimacy is the event of one partner experiencing an ED.

3.3.1 Intimacy in couples where one partner has an ED

Reports in the literature suggest that the lived relationships of those experiencing an ED exhibit low levels of intimate interacting (Pruitt *et al.* 1992, Ghizzani & Montomoli 2000, Newton *et al.* 2005, Arcelus *et al.* 2012), which is thought to contribute to relationship distress and dissatisfaction for the couple (Van den Broucke *et al.* 1997). The aspects of intimacy generally referred to in the studies on intimacy and couples where one member has an ED, include communication, trust, commitment and sexual intimacy.

In a questionnaire study of couples (n=25), Van den Broucke & Vadereycken (1989) compared the marital relationship of couples where one person had an ED (n=12) with couples where one person had either depression or anxiety (n=13). The researchers also compared the scores with normal controls that were retrieved from previous publications utilising the same questionnaires they used in this study. No further information on the normal controls is provided. They found that both groups of participants experience significant dissatisfaction with sexual and marital functioning, and this dissatisfaction is greater than that of the normal controls. In relation to the couples where one member experiences an ED, the authors report that the quality of interacting is rated more negatively by the spouses without the ED who report their wives as having a more

unfriendly attitude towards them than they have towards their wives. The authors suggest that these difficulties in interacting result in marital dissatisfaction which can escalate as the ED persists.

In a later study, Van den Broucke *et al.* (1995b) compared marital intimacy in couples where one member had an ED (n=21) with maritally distressed couples (n=21) who were on a waiting list for marital therapy and with non-distressed couples (n=21). All of the couples where one member had an ED were in heterosexual relationships and all of those experiencing the ED were female. They used the Marital Intimacy Questionnaire (MIQ) to measure five dimensions of intimacy including lack of intimacy, cognitive aspects of intimacy, being open with a partner, affect and commitment. Their findings report that couples living with an ED experience lower levels of intimacy in comparison to the non-distressed control group, particularly around being open with each other, but experience higher levels of intimacy than the maritally distressed couples.

Woodside *et al.* (2000) also investigated marital intimacy as an aspect of marital satisfaction in couples where one member had an ED (n=22). The Waring Intimacy Questionnaire (WIQ) was administered before and 14 weeks after a 5 day intensive day hospital treatment intervention for the couples. The WIQ is an empirically validated tool used to measure the following eight components of marital intimacy; conflict resolution, identity, sexuality, affection, cohesion, compatibility, expressiveness and autonomy (Waring & Reddon 1983). The authors found, the 5 day intensive day hospital treatment intervention resulted in an improvement in overall intimacy scores from the perspective of the person with the ED. However, the partners, who scored satisfactory ratings at baseline, showed no change in their scores at follow up. On completion of the programme both members of the couple reported persistent difficulties with sexual intimacy. The authors suggest that ongoing sexual intimacy difficulties may be as a result of the person with the ED not having fully adjusted to a new body weight and shape at the time of the follow-up rating. The research on intimacy in couples where one person has an ED demonstrates therefore, that living with an ED can impact on intimate relationship functioning and satisfaction.

In order to provide a more in depth understanding of the individual elements of intimacy namely sexual intimacy, love and communication within couples where one person is experiencing an ED, each element will be explored separately, both from a general and ED specific perspective.

3.4 Sexual intimacy and relationship functioning

Armstrong (2006, p. 283) defines sexual intimacy as ‘an expression of love and a meaningful connection that is fuelled by emotional intimacy and physical tenderness’. She considers that ideally emotional intimacy should be the foundation on which sexual intimacy develops. Reciprocal sharing of personal thoughts and experiences allows one partner to come to know the other as a sexual being in a trusting and validating environment. Sexual intimacy is understood to play an important role in satisfactory relationship functioning and stability, which is facilitated by satisfying sexual activity (Yeh *et al.* 2006). Miller (2012) suggests that sexual activity is most rewarding when the need for both autonomy and connectedness are met in a loving and respectful way. However, maintaining a favourable level of sexual intimacy for a couple can be impeded by relational uncertainty or alteration in personal sexual functioning. According to Knobloch and Solomon (2002), relationship uncertainty arises when a person is uncertain about their own or their partner’s involvement in the relationship or uncertain about the future of the relationship. Alterations in personal sexual functioning are attributed to many factors both internal and external to the person and can be categorised under a variety of interrelated cultural, physiological and psychological factors.

In relation to the impact of cultural factors on sexual functioning, Armstrong (2006) proposes that media driven ideals of sexual activity are primarily based on performance, with minimal consideration given to feelings and emotions. These ideals and expectations around performance can negatively impact on sexual development, sexual activity and relationship satisfaction. Physiological factors such as physical changes, ageing, illness or the side effects of a variety of medication are also reported to affect sexual functioning (Kautz 2007, Chisholm *et al.* 2012, Wiederman 2012, Karraker & DeLamater 2013). The psychological factors of negative self-perception, low self-esteem, loss of mastery of one’s life and living with mental distress are all reported to impact on the ability to effectively

engage in sexual activity or experience sexual intimacy (Higgins *et al.* 2008, Bonfils *et al.* 2015, Sharabi *et al.* 2016). In the context of the mental distress experienced by those with an ED, the dimension of body image distress is particularly pronounced, and this is reported to have a significant impact on sexual functioning and sexual intimacy (Newton *et al.* 2006, Bulik *et al.* 2011). As the Classic Grounded Theory (CGT) presented in this thesis explores the experiences of partners living with a person with an ED, the following section will explore the general links made between body image and sexual intimacy followed by a more specific discussion on sexual intimacy in couples where one member has an ED.

3.4.1 Body image and sexual intimacy

Body image is defined as the attitudes and perception a person has in relation to their physical characteristics (Cash & Fleming 2002). It is considered to be a two dimensional construct involving body satisfaction which is concerned with affect, cognitions and behaviours in relation to perceptions of appearance, and body size perception which is concerned with the subjective estimation of body size (Carr-Nangle *et al.* 1994, Sands 2000). Research findings and theoretical conjectures point to a general link between body image and sexual activity, sexual satisfaction and sexual intimacy. In a magazine survey to assess the relationship between body image and sexual behaviours in women (n=3,627), Ackard *et al.* (2000) found that the interconnecting concepts of self-image and body image are significant predictors of sexual activity. The authors suggest that a positive self-image can result in a decrease in body concerns; however, a negative body image can negatively influence both self-image and self-worth. The authors further report that women with a positive body image engage in more sexual activity. Using an internet survey in a community study of women between the ages of 18-49 years (n=154), Pujols *et al.* (2010) examine the link between body image concerns and sexual satisfaction. They understand sexual satisfaction as a fulfilling personal and interpersonal sexual relationship with low distress in relation to sexual activity. They found that body image issues such as weight concerns, sexual attractiveness and thoughts about one's body during sexual activity are strong predictors of sexual satisfaction in women. Although the majority of research on body image and sexual satisfaction is primarily focused on women (Wiederman 2012), studies examining the phenomenon in men also report that body image concerns impact negatively on sexual satisfaction (Holt & Lyness 2007, Milhausen *et al.* 2015). In general

however, body image concerns are reported to be more prevalent in women (Davison & McCabe 2005).

Factors affecting body image are multifactorial, with negative influences causing body image disturbances. Body image disturbance is characterised by a dysfunction in the cognitive, behavioural, perceptual and/or affective attitudes relating to one's weight and shape (Pimenta *et al.* 2009). This leads to a variety of health problems such as mental distress, depression, low self-esteem and disordered eating patterns (Levine & Piran 2004). Stormer and Thompson (1996) identify social comparisons and negative verbal commentaries about one's shape and weight as contributing factors to body image disturbance. Furthermore, Posavac and Posavac (2002) suggest the impact of media driven ideals of attractiveness on a person who has low self-esteem is likely to trigger body image disturbances.

3.4.2 Sexual intimacy and couples where one partner has an ED

The research specifically relating to sexual intimacy in close relationships where one partner has an ED reports that many couples are dissatisfied with sexual intimacy, and this in turn can negatively influence relationship satisfaction. From the perspective of the person with the ED, sexual dysfunction is a commonly reported phenomenon regardless of the subtype of ED the person experiences (Pinheiro *et al.* 2010), and is characterised by significant disruptions to cognitions and behaviours relating to sexual activity. Body image disturbance and poor physical status are proposed as primary reasons for such difficulties. In a phenomenological study exploring intimacy for women with Anorexia Nervosa (AN)(n=11), Newton *et al.* (2006) identify physical closeness, including sexual and non-sexual activities, as a component of intimacy important to the person with the ED; however, the ED is consistently identified as a barrier to developing or maintaining sexual closeness. The main ED related difficulties impeding sexual closeness identified by the authors are the lack of sexual desire and body image difficulties for the person experiencing the ED. For those people who are unable to engage in sexual activity however, hugging and cuddling are reported as an important way of being physically connected to their partner.

In a comparative study of women with EDs (n=242) and a normative sample of women without EDs (n= 202), Pinheiro *et al.* (2010) investigated the sexual functioning variables of intimacy. Their findings suggest that women with EDs report higher levels of relationship and sexual difficulties than the comparison group. The difficulties include loss of sex drive, sexual anxiety and relationships without sexual intercourse. In addition they found that people experiencing AN had higher rates of loss of sex drive than those experiencing Bulimia Nervosa (BN) or Binge Eating Disorder (BED). This is explained in part by a lower life time body mass index in those experiencing AN, which is associated with impaired physiological functioning of the sexual organs. The authors further add this can also be as a result of marked body dissatisfaction and discomfort with physical closeness. In a later study, Castellini *et al.* (2012) used a series of questionnaires to evaluate sexual functioning in people experiencing AN (n=44), BN (n=44) and a normative control group (n=72) recruited from a General Practitioner. They report that both groups of people experiencing an ED show significant difficulties in sexual functioning to include arousal, orgasm and satisfaction. These difficulties were higher than the sexual difficulties reported by the control group. The authors propose the difficulties in sexual functioning for the people experiencing the ED are associated with body concerns for those experiencing restricting AN, and with emotional eating for those experiencing binge/purging AN and BN.

The research on sexual intimacy in intimate relationships where one person has an ED is predominantly from the perspective of the person experiencing the ED, all of whom are women. The reports on sexual intimacy experiences for partners of people experiencing an ED are usually as a part of larger studies examining general relationship functioning. In one study using Interpretative Phenomenological Analysis to explore the general experiences of male partners living with someone with BN (n=8), Huke & Slade (2006) report on the aspect of sexual intimacy. The authors posit that partner's feel the ED places a strain on the sexual intimacy within the relationship. In particular, the partners identify body image concerns for the person with the ED and their own difficulties with some ED behaviours, such as vomiting, as barriers to sexual intimacy. In another earlier study exploring the romantic relationships where one person was experiencing an ED (n=13) compared to those relationships where one person was experiencing neurosis (n=13), Van den Broucke & Vandereycken (1989) also report findings in relation to sexual intimacy. They found that there is a significant level of dissatisfaction with sexual relationships in both groups of

couples. They propose that sexual dissatisfaction in partners of people with ED reflect clinical impressions that partners generally become more dissatisfied with the relationship as the ED persists. No further detail regarding sexual intimacy is provided in this paper. As part of a larger qualitative study examining the impact of living and caring for someone experiencing an ED, Highet *et al.* (2005) also report on sexual intimacy for partners. In this study the experience of carers of people with EDs (n=24) is explored. The majority of carers are parents, but some are siblings and partners. However no percentages or figures of relationship type are provided in the study details. The partners in this study are reported to experience the ED as a threat to sexual intimacy which subsequently results in them questioning the viability of their relationship.

The studies both from the perspective of the person with the ED and the partners' perspective provide evidence suggesting intimacy and sexual intimacy within the intimate relationship is disrupted as result of the ED. In the context of the importance of intimacy for personal and relationship satisfaction, relationship stability and personal well-being for either partner can be placed at risk (Van den Broucke *et al.* 1995c, Highet *et al.* 2005). Fehr *et al.* (2014) however, suggest where compassionate loving is present in a relationship it supports the stability and quality of that relationship, improving relationship satisfaction and personal wellbeing. The concept of love and intimate relationships therefore will now be explored.

3.5 Love and intimate relationships

The conceptualisations of love are as varied as the different types of relationships that love attends to (Berscheid & Meyers 1996, Regan 2006, Graham 2011, Fehr *et al.* 2014). As such, love is a difficult concept to define as different characteristics apply to each type (Hegi & Bergner 2010). The most commonly agreed forms of love are passionate, companionate and compassionate loving which, according to Berscheid (2010) are sensitive to changes in partner attitudes and general relationship changes that occur over time.

Passionate love is a highly emotional state concerned with strong attraction and intense longing for another (Sheets 2014). It comprises of physiological arousal and associated cognitions towards another person where the emotions can range from elation and

tenderness to anxiety and pain. The physiological state incorporates three components, namely lust, attraction and attachment that, in part, facilitate successful reproduction. The cognitive states are the thoughts, feelings and judgements that account for sexual arousal (Miller 2012). Companionate love on the other hand is concerned with a profound attachment to a person that incorporates more ordered emotions including intimacy, affection, trust and commitment (Hatfield & Walster 1978, Regan 2006). Companionate love is based on a deep committed friendship developed over time and is positively correlated with reported marital satisfaction (Miller 2012). Close relationships can comprise of both passionate and companionate elements at the same time, but according to Miller (2012), passionate love tends to decrease over the life span of a relationship and companionate love grows.

Particularly relevant to this study because of its caregiving properties such as helpfulness, empathy, providing social support and the selfless giving of the self for the good of another person, is the third form of love, compassionate love (Sprecher & Fehr 2005, Oman 2011, Miller 2012). In the context of close intimate relationships, Berscheid (2006, 2010) frames compassionate love as one partner's acknowledgement of the others' distress and the capacity to respond to that distress. Many authors view compassionate love as a form of altruistic love (Sprecher & Fehr 2005, Hegi & Bergner 2010, Collins *et al.* 2014, Reis *et al.* 2014), but Underwood (2009) argues that it extends beyond altruism on the grounds that individuals have freedom in choosing to exercise compassionate love. The interactional dynamics of compassionate love are based on communally responsive relationships, defined by a partner responding to the needs and welfare of their significant other in a way that maximises both the psychosocial and physical health of that person (Monin *et al.* 2008, Berscheid 2010). Although not contingent on reciprocity, the provider of compassionate loving gives with a confidence that their own needs will be met when required (Clark & Monin 2006, Berscheid 2010). The strength of communal responsiveness is influenced by the level of confidence a person has on the certainty and closeness of their relationship, and the degree to which they feel responsible for the other (Mills *et al.* 2004, Clark & Monin 2006, Monin *et al.* 2008). When a person has a high level of confidence in their relationship this promotes compassionate loving interactions that in turn provide a safe and secure environment where partners find it easier to open up to each other and make their needs known (Sternberg 2014).

Generally, as evidenced in the following example, compassionate loving is recognised as promoting quality, satisfaction and stability in close intimate relationships. In a study of introductory psychology students involved in romantic relationships (n=115), Fehr *et al.* (2014) found those engaging in compassionate loving towards their partner operated in a prosocial relationship manner by providing caregiving and self-sacrificing support to that partner. Self-sacrificing support in compassionate love has been defined as the situation in which ‘individuals give up some immediate desire in the interest of bettering their relationship or benefitting the partner’ (Whitton *et al.* 2002, p. 159). Fehr *et al.* (2014) also report that the more everyday compassionate acts there are in a relationship the more satisfied the couple are with the relationship. However, in contrast, in a research study of older married couples (n=64) with an average age of 71 years, Rauer *et al.* (2014) found that engaging in compassionate loving can be also associated with some potentially harmful consequences. They suggest that, in addition to compassionate burnout for the provider, the need for compassionate loving can generate fears of dependency and loss of autonomy for the partner requiring the compassionate loving. This, they consider, can create an inferior-superior dyadic relationship where the inability of the recipient to reciprocate compassionate loving creates for them feelings of inequity and indebtedness. The authors further add that in cases where prolonged compassionate loving is required, the recipient can perceive themselves as a burden to their partner. Berscheid (2010) also identifies problems when considering compassionate loving from the perspective of the provider. She suggests that providing compassionate love over a protracted period of time, where one partner is found to be in a long-term state of distress, is problematic as it requires long term self-sacrificing from the provider. She, among others (Rauer *et al.* 2014) acknowledge the dearth of research in this area, where maintaining compassionate loving over a protracted period of times is poorly understood.

3.5.1 Compassionate love and ED couples

No studies were found specifically examining compassionate loving in the intimate relationship where one person is experiencing an ED; however, some studies report that supportive relationships including a supportive relationship with a partner, promote recovery for the person experiencing the ED (Hsu *et al.* 1992, Tozzi *et al.* 2003). The supportive elements in these relationships, as identified by the person experiencing the ED,

incorporate elements of what Underwood (2009) suggests are factors of compassionate loving. These elements include having needs and feelings understood, being respectfully valued, being accepted and being provided with emotional support. However, Dick *et al.* (2013) point out, the ability of a partner to provide this support is influenced by the partner's emotional state at a given time. In the situation where emotional distress related to the ED is heightened for the person experiencing the ED, responding to the other's needs is more difficult. This in turn, the authors suggest, impacts on relationship functioning.

Taking into consideration the literature on compassionate love as presented above, several issues pertinent to the experience of partners living with someone with an ED need to be reflected on. Firstly, in relation to the long term recovery trajectory frequently associated with EDs (Fichter *et al.* 2006, Berkman *et al.* 2007), long-term self-sacrificing in the form of compassionate loving for the partner not experiencing the ED could be problematic. Secondly, if a partner is experiencing emotional distress particularly in relation to the ED, the ability to provide compassionate support to their partner can be problematic. Thirdly, in the presence of a lack of understanding or knowledge in relation to EDs as reported by partners (Leichner *et al.* 1985, Huke & Slade 2006), the ability to recognise the ED related distress in the person with the ED can be hindered. This may reduce the ability to respond to their partner's distress with appropriate levels of compassionate loving. In the context of not knowing or understanding, compassionate loving is replaced with less constructive communication interactions such as high levels of expressed emotions (Kyriacou *et al.* 2008a). These, less supportive communication interactions, are reported to reflect feelings of overburden, self-blame and helplessness in family members (Szmukler *et al.* 1985, Whitney & Eisler 2005) and are reported to have a negative impact on interpersonal relationships and relationship satisfaction (Treasure *et al.* 2007a). In this context, the following section will discuss communication and more specifically the communication interactions for a couple where one person has an ED.

3.6 Communication in intimate relationships

The interdependence theory of communication is concerned with the growth of interpersonal interconnections between individuals as encounters become more frequent and diverse. The interconnections are concerned with multiple modes of interactions in the

form of either verbal or nonverbal exchanges of information, with the goal of co-creating meaning (Guerrero *et al.* 2014). Nonverbal communication encompasses all overt and covert interactional behaviours, excluding those that employ language. Verbal communication is concerned with language behaviour, the self-disclosing element of which is considered an integral part of interdependent intimacy development (Miller 2012, Prager 2014). Self-disclosure, the sharing of personal information about one's self, expands in breadth and depth as a relationship progresses from initial superficial verbal interactions to later more meaningful revelations about the self (Miller 2012). Self-disclosure behaviour is influenced by many factors including personality characteristics, mental health, cognitive ability, past experiences and attachment styles (Mikulincer & Nachshon 1991, Omarzu 2000, Forgas 2011, Lemay & Melville 2014). Disclosure reciprocity also impacts on the capacity for ongoing self-disclosure where shared information about the self is matched with the level of openness of a partner (Miller 2012).

Self-disclosure is primarily goal driven and incorporates both rewards and risks for the self-discloser. The desired rewards are variable, but usually include being understood, having needs met, feeling safe and secure and increasing intimacy (Laurenceau *et al.* 1998, Forgas 2011, Guerrero *et al.* 2014). The risks are concerned with rejection, hurt and embarrassment, loss of personal control and loss of autonomy and integrity (Omarzu 2000). In the interest of self-protection or protection of the other, where the perceived risks are seen to outweigh the rewards, silence and secrecy can replace self-disclosure. Although self-disclosure, in contrast to silence and secrecy, is considered to promote positive relationship functioning, Finkenauer & Hazam (2000) argue that in certain circumstances, particularly where protection of the other is prioritised, secret keeping can be regarded as beneficial. Keeping secrets around personal illness is concerned with protecting the other person from the worry or anxiety that might arise if they are informed about the illness. The aim of keeping secrets, therefore, is often to reduce the burden of knowing for the other person (Rosenblatt & Wieling 2013). This however interferes with the process of problem solving as a couple, as critical information around issues that need to be resolved are withheld. Communication thus becomes strained, and the relationship can be experienced in an untrustworthy way (Imber-Black 2014).

Regardless of the motives for the keeping of secrets, it is experienced differently for the person keeping the secret and their partner. The former can understand and justify their own secret behaviours but the latter can feel resentment and rejection in light of not knowing (Finkenauer & Hazam 2000). Finkenauer & Pollmann (2009) frame the partner's experience of not knowing in the context of social exclusion, where concealment is seen as a separation and exclusion from the person keeping the secret. The authors postulate that this can be experienced in a threatening way by the partner as they can perceive the concealment as a reflection of their own undesirability and untrustworthiness. This, the authors suggest, is incompatible with the interdependent elements of trust, love and intimacy required in close relationships. In the limited research regarding couple communication where one partner has an eating disorder, poor self-disclosure or secrecy, interchangeable terms used in the ED literature, is identified as an unhelpful communication style (Dick *et al.* 2013). This can contribute to the lack of understanding around the ED from the perspective of the partner not experiencing the ED which can impact negatively on relationship functioning.

3.6.1 Non-disclosure in ED couples

Non-disclosure is a well-documented communication style for people with EDs (Fairburn & Cooper 1982, Dalzell 2000, Basile 2004, Vandereycken 2006). Basile (2004) suggests that people with a lower body mass index (BMI) and higher ED symptomatology, exhibit lower rates of self-disclosure. The non-disclosure is generally concerned with the negative feelings relating to the ED, with difficulties around self-expression, or with the person being in denial. These are presented in examples of the literature below.

The ED related negative feelings of shame and guilt are associated with loss of control, particularly where binge eating and purging are frequent patterns of behaviour (Woodside *et al.* 1993). In a systematic review of qualitative studies relating to non-disclosure and shame and guilt in those experiencing EDs, Oluyori (2013) considers shame and guilt as separate but interconnecting emotional concepts. The author suggests that shame, which is linked to the severity of ED symptomatology, is related to both the stigma of having a mental 'illness' and the ED behaviours (such as restricting, thinking about food, overeating and loss of control) that the person is unable to overcome. Guilt for the person, on the

other hand, solely arises as a consequence of experiencing the ED where the person feels they have failed to live up to their own and other people's expectations.

In a detailed review of the literature, Vandereycken (2006) frames non-disclosure for people experiencing an ED as a denial of the 'illness'. The author identifies two primary causations for the denial; impaired self-awareness and a deliberate denial of the ED behaviours or cognitions. The former impaired self-awareness is concerned with a cognitive or neurobiological impairment which the authors consider is possibly due to the effects of starvation on the brain. This results in distorted information processing with regard to body shape and size and food intake. The latter deliberate denial of ED behaviours and cognitions, is purposefully employed by a person in order to either portray a positive image of the self to other people or to defend against unwanted interference from other people, such as health professionals. In a later, retrospective, internet study of people with an ED (n=401), Vandereycken and Van Humbeeck (2008) report similar findings in relation to denial of 'illness' suggesting that those in the earlier phases of the ED showed a higher reluctance to self-disclose.

There are other conceptualisations of difficulties with self disclosure and self-expression in the literature for people experiencing an ED. Beales and Dolton (2000) frame the difficulties with self-expression as alexithymia, the inability to identify and communicate emotion. The authors further consider the ED symptoms as a physical expression of internal conflict. Nordbø *et al.* (2006) also report that the ED is a non-verbal way of communicating distress, where the person with the ED does not feel understood by other people. Meyer *et al.* (2010) frame it in the context of emotional control where those with eating disorders consider emotional expression as a sign of weakness that could lead to rejection by others. Geller *et al.* (2000) also examined inhibited expression of negative emotion in women with AN (n=35), women with a variety of other psychiatric diagnosis (n=39) and women with no psychiatric diagnosis (n=34). The authors report significantly higher levels of inhibited self-expression in those with AN compared to those women with both other psychiatric diagnosis and no psychiatric diagnosis. This they consider, is concerned with relationship preservation where the person with the ED suppresses negative feelings and minimises personal needs in order to avoid the disruptive effects of conflict on their intimate relationship.

Van den Broucke *et al.*'s. (1995a) findings challenge the understanding that there is limited self-disclosure in couples where one member has an ED. In a controlled observational study of couples with an ED (n=21), maritally distressed (MD) couples (n=21) and non-distressed (ND) couples (n=21), the authors found the ED couples engaged in self-disclosure more than the ND couples. The authors suggest that this may be needs driven, where couples experiencing high levels of personal or relational distress need to verbally self-disclose. In addition they found ED couples used less criticism and disagreement when communicating than the MD couples.

There is limited research reporting on the experience of living with secrecy and non-disclosure from the partner's perspective. In an internet survey of male partners of someone with an ED (n=23), Alexakos (2004) found that partners were aware of the ED cognitions and behaviours despite the denial from the person with the ED. Although the majority of the partners in this study knew about the ED at the beginning or in the early stages of the relationship, 1 (4%) partner reported only being informed prior to getting married and expressed anger at not having been told sooner. In a more recent study of ED couples (n=17), Linville *et al.* (2016) also found the majority of people had disclosed about their ED prior to committing to the relationship. The one partner who had not been informed prior to commitment, viewed the secrecy as a betrayal. As part of a study exploring the experiences of living with a partner with BN, Huke & Slade (2006) suggest the partners found secrecy a hurtful experience that made understanding the struggles of their ill partner more difficult and disrupted the trust in the relationship. All of the research in relation to non-disclosure in couples where one member has an ED is concerned with the difficulties the person experiencing the ED has with self-disclosure and all are women. Non-disclosure and/or secrecy operated by the partner without the ED has not been investigated.

A further aspect to communication disruption in family members where a person has an ED is in relation to the high expressed emotion arising in the context of living with and caring for a person with an 'illness' over a protracted period of time (Kyriacou *et al.* 2008a). This issue will be discussed in more detail in the following section exploring the issue of caring in close intimate relationships.

3.7 Caring in close intimate relationships

Intimate relationship functioning can become disrupted as a result of critical relationship events (Knobloch & Solomon 2002) which, in the case of illness or disability, challenge the normative rules and boundaries of the relationship (Rolland 1994). In terms of a long term 'illness', Berg and Upchurch (2007) suggest that a period of adjustment and distress is experienced by both members of the couple, where couple interacting and coping behaviours vary at different phases of the 'illness'. Much of the literature relating to long term 'illness' in intimate relationships frames partners' experiences in the context of providing care for their significant other and examines the impact that being a carer has on the care provider's wellbeing (Fadden *et al.* 1987, Cheung & Hocking 2004, Eriksson & Svedlund 2006, Ribeiro *et al.* 2007).

A carer is defined as 'Someone who is providing an ongoing significant level of care to a person who is in need of that care in the home due to illness or disability or frailty' (Government of Ireland 2012, p. 8). In a recent discussion paper on defining carers, Care Alliance Ireland (2015) conducted a survey with people who were caring for a family member (n=789). They report 12% (n=94) of people are caring for a spouse and separately report that 1.27% (n=10) of people are caring for someone with an ED however, they do not identify the relationship of the carer to the person with the ED. The National Carers Strategy (Government of Ireland 2012), acknowledges the difference between the natural caring roles families, relatives and friends engage in on a daily basis and the more intense, ongoing level of caring required where someone in the relationship is unwell over a protracted period of time.

The experience of caring for a person with a longstanding 'illness' is documented across all domains of 'illness'. The field of mental health is well represented in this literature, and the research has explored the experiences of families caring for people with a diagnosis of schizophrenia, psychosis, mood disorders and dementia (Goldstein *et al.* 2002, Jungbauer *et al.* 2004, Van der Voort *et al.* 2009, O'Dwyer *et al.* 2013). Much of the literature relating to family members as carers who are living with a person with a mental 'illness', refers to the interlinking concepts of psychological distress, expressed emotion and carer burden as key elements in family members' experiences (Sczufca & Kuipers 1996, Heru 2000,

Goldstein *et al.* 2002, Shah *et al.* 2010). These concepts are also discussed in relation to family members' experiences of living with a person with an ED, some of which include the experiences specific to partners (Van den Broucke *et al.* 1994, Santonastaso *et al.* 1997, Kyriacou *et al.* 2008a, Coomber & King 2013).

The concept of Psychological distress is framed by Kyriacou *et al.*(2008b) as the accumulation of adverse psychological effects, primarily anxiety and depression, a person experiences while caring for a family member who is unwell over a protracted period of time. Although the authors acknowledge that contributing factors to this distress are unclear, they suggest challenges such as poor access to treatment, lack of information and poor social support contribute to its development. In a cross sectional study of family carers of people with an ED (n=115), Whitney *et al.* (2007) also found dependency of the person with the ED, the stigma associated with the 'illness' and concern around the consequences of the ED are major predictors of psychological distress.

The concept of Expressed Emotion (EE) refers to the family members' interactions, behaviours and attitudes towards the person who has the 'illness' (Hoste & le Grange 2008). Much of the original work on EE was done in relation to family members living with a person experiencing schizophrenia (Brown *et al.* 1958, Vaughn & Leff 1981), but this has since been extended into other areas of family carer enquiry, including that of families where there is a person with an ED. Due to the negative impact on remission, EE is primarily linked with the more unhelpful interactions such as family members being over protective, hostile, or even highly critical of the person who has the 'illness' (Sepulveda *et al.* 2010). How EE develops in family carers of people with ED is not fully understood but many contributing factors have been posited in the literature. Szmukler *et al.* (1985) suggest it is related to feeling over-burdened and not supported, while Whitney *et al.* (2005) consider that high EE is associated with family carers feeling helpless and self-blaming. In the context of adults with EDs, Treasure *et al.* (2007a) posit, the high levels of distress that arise in the context of being excluded from their loved ones' care decisions with professionals, lack of information regarding EDs and lack of support for their caring role, contribute to high levels of EE in the family carers.

The concept of burden of care refers to the impact on the life of the family carer when the needs and wishes of the person who is considered unwell are required to be put before the

needs of the carer (Baronet 1999). The two distinct facets to burden of care identified in the literature are objective and subjective burden. Objective burden is concerned with the observable costs to the carer arising as a direct result of the unwell person's problems (Maurin & Boyd 1990). Subjective burden, on the other hand, is related to the perceived burden and associated feelings that the carers experience as a result of caring for the person who is 'ill' (Jungbauer *et al.* 2004). Treasure *et al.* (2001) and more recently Graap *et al.* (2008a) compared the experience of caregiving burden in families where a person has an ED and families where a person has other long-term mental 'illnesses'. In the former, a mixed methods approach was used to examine the experiences of carers of people who had AN (n=71), and carers of people who had a psychosis (n=68). Carers from both groups reported similar experiences regarding the difficulties encountered in their caring role with a similarity in both the subjective and objective burden of care (Treasure *et al.* 2001). Also, using a mixed method approach, Graap *et al.* (2008a) compared the levels of distress and burden in carers of people experiencing an ED (n=32) with the carers of people experiencing schizophrenia (n=30). They report similar experiences of burden in carers in both groups. They identify worry for the future of the person with the illness, particularly where the illness is experienced over a protracted period of time, as a major area of contribution to carer burden.

3.7.1 Partners' experiences of living with and supporting the person with the ED

The literature specific to partners' experiences of living with a person with an ED is very limited but what is there can be divided into three categories. The first category includes studies that incorporate partners' experiences as part of the total carer population; the second explores the lived experience from both of the partners' perspectives; and the third explores experiences only from the perspective of the partner without the ED. These will be discussed below, according to these categorisations.

A number of studies, using qualitative, quantitative or mixed methods that explore caring for someone with an ED, include partners as a subset of the total carer population (Haigh & Treasure 2003, Perkins *et al.* 2004, Winn *et al.* 2004, De La Rie *et al.* 2005, Highet *et al.* 2005, Winn *et al.* 2007, Graap *et al.* 2008a, González *et al.* 2012, Raenker *et al.* 2012, Coomber & King 2013, Padierna *et al.* 2013). In this body of research, the percentage of the

study population that are partners range from 7.7% (Winn *et al.* 2007) to 34% (Graap *et al.* 2008b). The majority of these studies discuss the themes of psychological distress, burden of care, expressed emotion and unmet needs of the carers; however in most of the studies the authors tend to treat all participants as a homogenous group, and do not indicate if there are any different, distinct or separate issues for partners as opposed to other family members. In those studies that do make reference specifically to partners, they report that these partners exhibit similar levels of distress, burden and dependency as experienced by the mothers of people with EDs (Perkins *et al.* 2004, Martín *et al.* 2011, Raenker *et al.* 2012). Some of these studies also report on the unmet needs as identified by the partners which are primarily related to the need for support, information and good communication with the healthcare provider (Winn *et al.* 2004, Raenker *et al.* 2012).

The second group of studies that examine relationship functioning and psychological distress include the perspectives of both the partner and the person with the ED. Van Buren and Williamson (1988) examine the marital relationships and conflict resolution style in couples where one person has BN. Couples experiencing BN (n=12) were compared with couples who were maritally distressed (n=14) and a normal control couple group (n=15). The authors report that spouses of people with BN were more dissatisfied with their intimate relationship than the control group but not as dissatisfied as the distressed couples, and conflict resolution styles were similar for spouses across all three groups. Van den Broucke *et al.* (1994) explored the concept of psychological distress in husbands living with a person with an ED. Using a marital functioning questionnaire (MMQ) and a psychiatric symptoms questionnaire (SCL-90), they examined couples (n=21) where one member had an ED. The couples were demographically matched with maritally distressed couples (n=21) who were on a waiting list for marital therapy, and with non-maritally distressed couples (n=21). They aimed to test the hypothesis that partners of people with an ED would have significantly more symptoms of psychological distress than the control groups and that partners' psychological distress symptoms would match that of their wives. However, contrary to other research findings and their own hypothesis, the authors found that the husbands of ED patients reported similar levels of psychological distress to non-maritally distressed husbands and this was significantly lower than the psychological distress reported in the maritally distressed couples. In addition, they did not find that the partners' distress corresponded with their wives levels of distress. The authors suggest the

contradictory findings may be as a result of the small sample size or that perhaps, in order to protect their partner, the husbands answered with 'fake good' responses. More recently Fischer *et al.* (2015), using a cross sectional design with couples where one member had AN (n=16), examined partners' distress when living with a person with an ED. Partners' distress was measured over the domains of caregiver distress, negative feelings and emotions and relationship satisfaction. The authors found that partners experience lower levels of distress and more satisfactory relationship functioning when their efforts at supporting the person with the ED to change the ED behaviours are matched with the persons' motivation to change their ED behaviours.

The third category explores the experience of living with someone with an ED from the partner's perspective only. Interestingly, only two studies in this category were identified in the literature (Alexakos 2004, Huke & Slade 2006). Using phenomenological analysis, Huke & Slade (2006) explored the partner's (n=8) experience of living with someone with BN. All relationships were heterosexual of which 7 (87.5%) participants were male and 1 (12.5%) was female. 5 (62.5%) of the participants were aware that the person had an ED prior to co-habitation. The authors identify five primary interconnecting themes; i) communication difficulties, primarily secrecy and deception in relation to the ED. This subsequently led to poor levels of trust and difficulties in knowing what was happening to their partner. Secrecy was also a difficulty experienced in the context of not knowing if others should be informed; ii) not understanding and wanting to have more information. In particular the partners were looking for reasons why the ED had happened and to make sense of it; iii) trying to help the partner with the ED, afraid of getting it wrong and feeling powerless in the face of the ED; iv) living with and developing an acceptance of the ED while maintaining a hope that their partner would improve; v) acknowledging the strains in the relationship as a result of the ED. The partners also acknowledge the strengths in the relationship, such as wanting to be there for the person and respecting them for the efforts they make to overcome the ED. Due to the diverse experiences identified, the authors suggest individual assessment of needs is crucial in order to provide an appropriate level of support and education, identified as a primary need, for the partners.

In a Doctoral thesis Alexakos (2004) explored the experience of male partners (n=23) who were in a heterosexual relationship with someone with an ED. A questionnaire requesting

demographic information and containing a number of open ended semi-structured questions relating to their relationship was delivered via the internet. Similar to Huke and Slade (2006), she found partners wanted to gain a better understanding of the ED and be able to support the other person. The author notes that those with a more limited knowledge of the ED tended to be more hopeless about recovery and the continuance of their relationship.

In summary, the literature relating to partners' experiences of living in an intimate relationship where one person is experiencing an ED identifies that partners experience various levels of psychological distress and disruptions to relationship functioning. The need for information to make sense of the disruptions and to assist in providing effective support for their partner are among the partner's needs identified in this literature. Having some understanding of the partner's support needs has informed the development of some interventions for couples in this area.

Interventions for couples where one member has an ED

Several therapeutic interventions specifically devised for couples where one person is experiencing an ED have been developed. Leichner *et al.* (1985) give an account of a support and information group set up for spouses of women with AN and BN (n=6). They devised these sessions in response to requests from the people experiencing an ED who were looking for education and support for their husbands. The authors suggest that the sessions provided a forum where the partners could ventilate their feelings, identify with others and access ED related information. The group intervention was reported to have a positive impact on spouses' levels of distress and guilt, and was found to be a helpful adjunct in the treatment interventions for the person with the ED. In a later study, Gisladdottir & Svavarsdottir (2011) developed an educational and support nursing intervention for carers of people with EDs (N=21), which included 3 partners (14%). The three week programme was based on the Calgary Family Intervention Model (Wright & Leahey 2009) and was aimed at improving carers' abilities to support the person with the ED. The results of the pilot study indicated that providing education for the carer resulted in a significant improvement in the understanding of EDs but only a slight improvement in high expressed emotional interactions; however, in this study, partners' experiences of the intervention were not distinguished from other family members' experiences.

More recently Bulik *et al.* (2011) developed a couple based intervention for AN focusing on the couple working together to address the AN behaviours and cognitions. In contrast to many approaches for adolescent families, this intervention does not require the partner without the ED to take control of the feeding and eating aspects of care as they suggest this can contribute to an unhelpful imbalance of power within the relationship. As part of a multi-disciplinary treatment, the intervention provides psychoeducation and assists in the development of good communication skills between the couple. The overall aim is to improve relationship functioning and improve the AN behaviours and cognitions in the person experiencing the ED. This intervention is currently undergoing clinical evaluation.

Although partners can benefit from these interventions, for example where their need for information and support are met, or where intimate relationship functioning improves, the primary aim of the interventions is to support the person with the ED through their own recovery. There is little focus on the partner's own need to recover from the distress of living with an intimate partner who is experiencing an ED. The current study goes some way towards addressing this need by exploring the experience of living with a person with an ED, specifically from a partners' perspective.

3.8 Summary

This chapter considered close intimate relationship functioning in the context of intimate interacting. In particular the literature in relation to sexual intimacy, communication and compassionate love as part of relationship functioning in couples where one member has an ED was explored. The psychological effects of malnutrition and the cognitive processes of body image dissatisfaction and body shame for the person experiencing the ED are reported to impact on sexual intimacy and difficulties with self disclosure are reported to effect communication within the couple dyad. Although the concept of compassionate love and couples living with an ED is not specifically examined in the literature, it was explored in this chapter because of its caregiving properties. The potential difficulties facing partners in providing compassionate love to the person experiencing the ED were discussed in relation to a partner's lack of knowledge of EDs, the problem of self-sacrificing associated with providing compassionate love over a protracted period of time and distress experienced by the partner not experiencing the ED.

The final section in this chapter explored the concept of 'illness' related caring in the intimate relationship. In particular, it examined the literature in relation to the impact of ED related caring on the partner providing that care, and on relationship functioning. Needs of partners are identified in some of this literature and these have informed the development of therapeutic interventions; however, these interventions are primarily focused on supporting the person experiencing the ED with little attention given to a partner's need to recover from the distress of living with an ED in their lives. The current study addresses this gap in the current knowledge where, by using a Classic Grounded Theory (CGT) approach, the experiences of living with an ED from a partner's perspective are explored and conceptualised. The next chapter therefore will present the methodological approach of CGT that was used in the current study.

Chapter 4

RESEARCH METHODOLOGY

4.1 Introduction

When a researcher engages in social research, the process of data collection, analysis and dissemination of findings are laden with theoretical issues (Schwandt 2000). These issues are primarily concerned with the philosophical assumptions of the nature of reality and the nature of knowing. It is widely understood that in order to conduct good research, the underlying assumptions inherent in a study should be made known to the reader as it makes visible the beliefs, choices and actions undertaken by the researcher in the conduct of the study (Norton 1999, Creswell 2007). This chapter therefore presents the philosophical underpinnings that include, the epistemological, ontological and methodological concerns, relating to this study.

As Classic Grounded Theory (CGT) is the methodology used in this study, I will begin by tracing the development and modification of Grounded Theory (GT) over time. This provides an understanding of the philosophical complexities associated with using this methodology. Then, in discussing my own philosophical beliefs, I explain how these fit with a CGT approach. The chapter culminates with a detailed discussion on the research process and procedures that are inherent in a CGT approach.

4.2 Philosophical underpinnings of Grounded Theory

The most fundamental level on which a research study can be examined and described is at a philosophical level. This provides insights into the implicit assumptions of reality, knowledge, reason and proof supposed by the researcher and inherent in a study (Clark 1998, Vasilachis de Gialdino 2009). The core assumptions at a philosophical level of any given study include the epistemological, ontological and methodological positions adopted by the researcher (Guba 1990). Epistemology is concerned with the nature of knowledge and relates to issues around how we can know reality (Vasilachis de Gialdino 2009). Ontology is concerned with the nature and form of reality and what can be known about

it, ranging from the existence of an external reality independent of human thought to a reality created by human consciousness (Norton 1999). Methodology emerges from the ontological and epistemological position adopted by the researcher and provides the explanation and justification of the methods that are employed in the study (Kaplan 1964, Morrow 2007). All three assumptions are considered to be interlinked, in that the researcher's assumptions regarding reality and knowledge will ultimately justify the particular choice of methodology (Crotty 1998). As Grix (2004) suggests, once the ontological stance is identified and understood there follows a logical progression of a corresponding epistemological and methodological framework. Asserting the philosophical assumptions of a research study serves three main purposes. They will support the researcher in defending their position (Grix 2004), they will demonstrate the congruence of the chosen methodology (Annells 1997), and they will also have implications for the rigor of the study (Norton 1999). In relation to a grounded theory methodology as is applicable to this study, Birks & Mills (2011) advise that reflecting on personal philosophical beliefs will facilitate the researcher in making methodological decisions and will ultimately influence the GT approach that the researcher chooses for the study.

Although explicating the philosophical assumptions of a research study is ardently advocated by many writers, in practice many researchers do not think too closely about reality and knowledge, choosing the methodology they feel most comfortable with. According to Milliken and Schreiber (2012), this concern is extended to include GT researchers who regularly neglect the philosophical considerations and use the methodology primarily as a data analysis technique. The authors further add that this leads to the researcher minimising the complexity of the research process and the epistemological assumptions which are central to the data collection and analysis are lost. Therefore as a foundation to this study the various philosophical positions applicable to GT methodology as it has evolved will be discussed, followed by the personal philosophical stance of this researcher.

4.2.1 The Emergence of GT

Grounded theory methodology has been aligned with a variety of philosophical assumptions that range from postpositivist to constructivist positions (Annells 1996). This can be confusing for the novice GT researcher who has to grapple with the array of

arguments and justifications posited by scholars and academics alike (Bryant & Charmaz 2010). In order to provide some clarification on the philosophical assumptions inherent in this GT study therefore, I will begin by tracing the different philosophical understandings associated with GT methodology as it has developed over time.

GT as a methodology, primarily concerned with qualitative data (Boychuk Duchscher & Morgan 2004, Walker & Myrick 2006), was developed from the experience of two sociologists, Barney Glaser and Anselm Strauss when studying the experience of dying patients in hospital (Glaser & Strauss 1965, 1967). This resulted in the amalgamation of two schools of thought; Glaser's quantitative considerations from Columbia University and Strauss's qualitative influence from the University of Chicago. The principles and practices of the constant comparative method that were generated when doing this research were subsequently formalised into a methodology. This was formally introduced in 1967 and named Grounded Theory (Glaser & Strauss 1967). The aim of the methodology was to generate a theory that accounted for the underlying, often invisible, patterns of behaviour used by the participants in resolving their main concern (Glaser 1998).

When GT was first introduced, positivism, although subject to challenges from alternative post positivist perspectives such as critical realist thinking, was the dominant orientation within which social science research was conducted (Tolhurst 2012, Hall *et al.* 2013). The philosophical assumptions of ontological realism and epistemological objectivism are the orientations primarily associated with this paradigm of inquiry, where research activities are concerned with the search for an accurate knowledge and truth of the world (Crotty 1998). Although positivism is generally aligned with quantitative research, Crotty (1998) suggests it can also be applicable for use with qualitative methods. It is therefore reasonable to place GT methodology within a positivist position where the analytical procedures developed from the different schools of thought of Glaser and Strauss can incorporate the merits of quantitative methods into qualitative approaches (Walker & Myrick 2006).

4.2.2 Positivist and postpositivist positions in GT

Ontological naïve realism associated with a positivist position, commits to the belief of the existence of an objective world that is independent of human beliefs, language or experience, and the belief that objects in the world truthfully exist as they are perceived to

exist (Madill 2008, Sankey & Ginev 2011). The aim of science in this position is to discover truth through the human senses rather than construct it through human interpretation. Discovery is by way of the scientific method of logic and mathematics using causal logic to generate contextually free universal laws. Through scientific research, naïve realism asserts that truth can be known and understood with certainty and accuracy (Crotty 1998). However, challenges to this understanding, particularly where objects in the world are not directly observable, have resulted in the emergence of a range of realisms. The discovery of truth in a positivist position therefore, ranges from the understanding that objects in the world exist independent of human consciousness to an understanding that, although objects exist, human interpretations lend meaning to these objects (Madill 2008).

Embedded in a positivist position is an objectivist epistemology, where knowledge acquisition is based on direct sensory experience providing theory neutral observations (Holloway & Wheeler 2010). Consistent with and correlated to a realist ontology (Ratner 2008) where objects in the world possess intrinsic meaning, the researcher's position is to discover that meaning free of any human consciousness or subjective bias. It is understood that the researcher can remain independent of that which is being researched and therefore the knowledge gained is not contaminated by his or her beliefs or values (Norton 1999). In positivist research the objective impartiality supposed by the researcher is primarily achieved through the application of scientific methods of enquiry and research is understood to realise pragmatic verifiable knowledge. Objectivity remains an ideal standard in research conducted in this tradition and measures to control researcher bias, particularly where qualitative methods are utilised, are vital in demonstrating the accuracy, repeatability and dependability of the study (Madill *et al.* 2000, Miller 2008). To achieve absolute objectivity however, has been a frequently debated philosophical issue (Eisner 1992, Madill *et al.* 2000). The challenges are particularly evident in the domain of qualitative research (Strauss 1987, Madill *et al.* 2000, Charmaz 2006) where the relationship between the researcher and the phenomenon under study is concerned with perception, understanding, meaning making and representation. These challenges, in conjunction with criticisms aimed at naïve realism, have resulted in the emergence of the postpositivist sciences.

Although GT emerged in the positivist era, many authors position the original form of GT within a postpositivist paradigm of enquiry (Annells 1996, Ghezeljeh & Emami 2009, Birks & Mills 2011, Levers 2013). Postpositive thinking provides a modified understanding of the philosophical assumptions found in the positivist position. The three primary modifications are; i) a shift from certainty to uncertainty of knowledge claims; ii) the challenging of naïve realist thinking and; iii) a repositioning of verification to justification of scientific findings, where knowledge claims are defensible by supporting evidence (Schumacher & Gortner 1992). The ontological modification from naïve realist thinking to critical realism provides a critical realist perspective of science. From this perspective an understanding of the existence of a real world independent of human knowledge remains intact; however, what is understood to be real in the world is the partial or uncertain human representations of it (Murphy 1990). The 'real' to which critical realists refer is not to claim absolute knowledge of reality rather, it refers to a natural or social reality regardless of whether it is observable or one has an adequate understanding of the nature of it (Sayer 2000). In this position therefore, reality can never be fully understood or known and relative statements replace objective certainty (Crotty 1998).

In contrast to the epistemological dualist stance inherent in positivism, postpositivist thinking acknowledges the impossibility of absolute objectivity; however, objectivity remains a guiding ideal (Guba & Lincoln 1994). This is pursued in part by challenging the research process and findings with critical thinking. Crotty (1998) suggests that knowledge acquisition in this position is considered an approximation of truth, on the basis that it is contextually situated and researcher influenced. Guba & Lincoln (1994) further suggest that replication of findings can be deemed probably true but, with evidence inconsistent with the findings, they can be proven false. Uncertainty and probability are important factors in understanding phenomena in the postpositivist position. Uncertainty is influenced by the context under which the phenomenon is studied, and by the scientists' biases which are shaped by cultural experiences and the models of theory they adopt. Findings are probable, or provisionally correct, only for as long as they have not been proven false (Della Porta & Keating 2008). Popper (1959) viewed the advancement of science, not through empirical verification, but through the process of falsification. In challenging the fallibility of scientific findings, he advises seeking evidence to falsify or refute a hypothesis rather than seeking empirical evidence to support or confirm it. He believed that no matter how many instances

are used to corroborate a theory or principle it can never be proven as absolute fact. However, findings could be proven false by locating just one instance that will refute it (Crotty 1998).

The use of qualitative methods in the postpositivist position comprises a cycle of interrelated logical steps with rigorous collection and analysis of the data where the researcher embraces multiple perspectives from participants (Creswell 2007). Tolhurst (2012) suggests that the procedures and techniques, if correctly employed in the analysis, imply that objective facts about the world can be realised and that these facts are realised in a trustworthy and valid way.

4.2.3 Interpretivist position in GT

Although positivist and postpositivist approaches provide us with critical and essential understandings of the world, these understandings are far removed from the day to day lived experience of human beings (Crotty 1998). Through their systematic rigid application of laws, these approaches fail to consider the reality of an ever changing uncertain world that people live in. In response to these deficiencies in the traditional approaches, and in acknowledgement of the fact that social and cultural sciences differed from the natural sciences, interpretivism became an alternative approach to enquiry (Schwandt 1994).

The understanding nature of interpretivism, a major departure from the explanatory nature of positivist and postpositivist positions, suggests that knowledge acquisition is culturally and historically situated (Crotty 1998). The philosophical assumptions primarily associated with this position are ontological relativism and epistemological subjectivism (Levers 2013). The aim of inquiry in this position is to seek to understand phenomena by interpreting their meaning in the context within which they are located (Fay 1996). The examination, clarification and understanding of the systems of meaning in interpretive research involves both the researcher and the subject researched as the main characters involved (Pressler & Dasilva 1996). The methods of investigation require the researcher to take an active role in the process whereby the researcher, using methods such as observation, interviewing and text analysis, becomes immersed in the setting in order to gain an in depth understanding of the phenomena under study. Construction of a

meaningful reality is achieved through a collaborative relationship between the researcher and the researched.

Contained within the interpretive sciences is the social psychological theory of symbolic interactionism (Schwandt 1994, Pressler & Dasilva 1996); a theory from which many authors suggest GT methodologies have stemmed (Annells 1996, Cutcliffe 2000, Mills *et al.* 2007, Aldiabat & Le Navenec 2011, Milliken & Schreiber 2012). Symbolic interactionism (SI), arising from the work and teachings of pragmatist George Herbert Mead, holds that things or objects in the world have no fundamental meaning in themselves (Chenitz & Swanson 1986, Given 2008). The self is an active participant in constructing the meaning for these objects through social interaction using shared symbols such as language, signals and artefacts (Cutcliffe 2000, Fassinger 2005). Modifications in meaning making, and the resultant behaviours engaged in by people, occur as people continuously interact with each other and engage in self-reflection (Crooks 2001). According to SI thinking, meaning making is one of the central elements in human behaviour and social processes. In order to comprehend fully what is going on, the researcher needs to focus on the individual's lived experience and understand meaning and perception from the participants view point (Jeon 2004).

The understanding among those authors who suggest the roots of GT are founded on SI thinking is based on the premise that GT seeks to explain how people define reality through interaction of shared symbols, artefacts and meanings in their social world (Cutcliffe 2000, Charmaz 2006, Milliken & Schreiber 2012). Therefore, fundamental to the methodology is the need for the researcher to fully explore the participants' experiences by interpreting the meanings they, rather than the researcher, attribute to the words they use (Milliken & Schreiber 2012). Glaser (2005b) argues against the claim that SI is intrinsic to GT research on the grounds that GT is a general inductive method that can be used on all data types and used with any theoretical perspective. He suggests the impact of SI on GT has remodelled GT, where this imposed theoretical framework ultimately diminishes the power of the general inductive method. Holton (2009) also challenges the use of SI as a theoretical lens, as it places constraints on what and how data is collected and further limits researcher creativity in analysing and conceptualising the data. In response however, Milliken & Schreiber (2012) argue that, rather than constraining the processes of data

collection and analysis, if understood accurately SI can provide the initial lens through which the phenomenon can be viewed. This they suggest, serves to expand the applicability and scope of appropriate theoretical codes that can be used. The primary argument put forward by Glaser (2005b) and Holton (2008, 2009) against using SI as a preconceived theoretical framework in GT is not to deny the appropriate use of theoretical codes rather, they argue against restricting oneself to a preconceived framework or code. In the context of the general methodology offered by GT, they advocate for the adoption of the most appropriate theoretical code(s) for the study.

Bryant & Charmaz (2010) acknowledging these disputes, suggest that SI and GT are consistent on several levels. Firstly they both attend to processes, the former interactional the latter underlying latent behaviours. Secondly, they both use empirical observations in the development of theories and thirdly, both perspectives posit that people act both individually and collectively. The major inconsistency, the authors suggest, is concerned with meaning making and the epistemological position of the researcher in the research process. On the one hand the researcher is viewed as an objective observer and reporter, which they suggest is consistent with Glaser's (1978, 1992b, 1998, 2001, 2005a) and Glaser and Strauss's (1967) CGT approach. On the other hand and more evident in Strauss and Corbin's (1994a, 2008) approach and Charmaz's (2000, 2006) constructivist approach, meaning making is constructed by the participant and the researcher.

4.3 Constructionism

Constructionism, a form of epistemology associated with those positions other than positive and postpositive positions (Crotty 1998), is concerned with understanding the world from the perspective of the person experiencing it. Constructionism claims reality and knowledge are constructed, rather than created, as human beings engage in the world (Schwandt 1994, Hua Liu & Matthews 2005). Crotty (1998) suggests constructionism brings objectivity and subjectivity together where objects exist in the world that are charged with meaning, but only become meaningful when the subjective mind comes in contact with them. Therefore, it is with the interaction between the object and subject that meaning is constructed. Although there are many varieties of constructionism, two broad classifications are commonly made in the literature. Firstly, the understanding of

knowledge construction as a cognitively constructed reality, referred to here as constructivism, and secondly, as a socially constructed reality, referred to here as social constructionism (Phillips 1995, Crotty 1998, Hua Liu & Matthews 2005, Lektorskii 2010). Burr (2003) differentiates between these two understandings, whereby the former depends on the extent to which the individual cognitively controls knowledge construction and the latter, the extent to which social influences, such as shared language, control it.

Constructivism, influenced by the work of Jean Piaget and his theory of cognitive development, posits that biological and psychological mechanisms influence knowledge acquisition (Piaget 1971, Phillips 1995). This approach views knowledge as constructed from an intrapersonal, cognitive perspective, where meaning making is dependent on the interplay between objects in the world and the individual mind. However, Heap (1995) suggests construction of meaning in this position is dependent on, and constrained by, an individual's cognitive architecture and representations with no consideration given to the sociocultural aspects of human life. A social constructionist position on the other hand, views the acquisition and understanding of the nature of knowledge in a broader context, extending beyond the scope of individual cognitions to embrace wider determinants and influences on an individual's understanding of the world in which they live.

Raskin (2008) understands relationships rather than individual constructions as central to social constructionism where meaning making is contingent on the collective rather than the individual. Crotty (1998) suggests 'social' in the context of social constructionism is concerned with the manner in which meaning is generated rather than the type of object that has meaning. Therefore, a social constructionist view postulates the construction of knowledge from an interpersonal perspective where social contexts and shared meanings, historical influences and language are crucial in determining what constitutes reality. I concur with Raskin (2008) and Heap (1995) who suggest constructivism and social constructionism are inextricably interlinked, where there is a coordination of activities between cognizing individuals in the context of systems of shared meaning.

Burr (2003) suggests knowledge construction arises from the social interaction of people on a daily basis and what is regarded as truth and reality will be the existing understanding of the world at that time. Berger and Luckman (1967) identify numerous experiences

influencing day to day social reality including; i) influences from the past, where the customs and cultures established and evolved by our ancestors over time are still practiced in the present; ii) the present, incorporating every day encounters and interactions between people and; iii) the future, where current interactions with others are made in consideration of future generations. Gergen (1985) also acknowledges these numerous influences when he suggests enquiry in constructionism seeks to elucidate shared understanding as having existed in the past, the present and those that might exist in the future.

Charmaz (2006, 2008) proposes that all GT methodologies assume a social constructionist approach in gaining an understanding of the world, but suggests CGT uses the approach in a more limited way. Referring to CGT as an objectivist version, she suggests it supposes an objectivist epistemology where objective impartiality is assumed by the researcher and therefore researcher influence is not attended to in the research process. Annells (1996) also highlights the objectivist stance taken in CGT which she suggests uses a modified objectivist approach. She posits the researcher functions independently of the method where the procedural directions are designed for the purpose of achieving objectivity. Glaser (1998) however, acknowledges the potential for researcher influences and biases which he refers to as forcing the data. This, he suggests, is a normal process that arises as a result of preconceived ideas and cultural influences. He warns the researcher to be aware of and to manage the issue of forcing through reflexivity, suspending the literature review of the substantive area until after the main concern is identified, constantly comparing the data throughout the analysis and using passive non-structured interviewing and listening procedures in data collection (Glaser 1998, 2002). He further directs the researcher to begin with a complete description and, as the analysis progresses, to become more conceptual. It is the conceptualisation of the data rather than accurate description that renders it abstract of time, place and people biases (Glaser 1998).

In addition to her criticisms relating to research influences in using a CGT approach, Charmaz (2006, 2008) also criticises CGT on the grounds that it fails to consider social contexts. Holton (2009) argues against this criticism suggesting that social context is simply considered another variable in the data which may or may not be relevant in explaining the theory. Holton (2009) further suggests the relevance of social context will become evident

in the method of constant comparative analysis and hence will earn its way into the theory. However, in response to what are perceived as deficits in the methodology, Charmaz (2000, 2006, 2008) developed a constructivist approach to GT methodology which embraces an interpretative depiction of reality rather than a mirror image of it.

4.4 Relativism

As constructionism is primarily concerned with epistemology, explaining the way in which people account for the world within which they live, it generally does not subscribe to any particular ontological premise (Gergen 1985, Schwandt 2000). Barkin (2003) suggests its alliance can range from a neoclassical belief that reality exists and can be known through empirical research to a postmodernist view that questions the existence of a reality independent of our observation or our representations of it. However, with an emphasis on the construction as opposed to the discovery of meaning and truth seen in realist ontologies, constructionism is often accused of relativism (Raskin 2001). Although many theorists view constructionist and realist thinking as occupying opposing positions (Al-Amoudi & Willmott 2011), Crotty (1998, p. 63) suggests 'social constructionism is at once realist and relativist.' This is based on the understanding that it does not dispute the existence of a world outside human observable experience; however, that world is meaningfully constructed by humans within a historical and cultural context.

From a social constructionist perspective, Berger & Luckman (1967) suggest that truth about the world holds no absolute right or wrong, and is unpredictable and unstable because the social contexts within which they are experienced are constantly changing. In everyday life the constructions are modified and tested in response to new experiences (Schwandt 2000). The research activities in constructionist approaches to enquiry therefore acknowledge different interpretations and perspectives producing multiple changeable realities where all claims to truth are as good as each other (Hua Liu & Matthews 2005). This view has received much criticism in philosophical circles (Raskin 2001, Appleton & King 2002) and is considered by Phillips (1995) to be the bad side of constructionist thinking. Lomborg & Kirkevoid (2003) suggest, if knowledge claims are equal and valid then researchers, depending on their own constructions of reality, can advocate whatever theory they prefer which can have little or even a misleading influence on science. Raskin

(2001) points out that a relativist position is often depicted by scholars as an anything goes philosophy ranging from solipsism as a best outcome to destructiveness as the worst. However, Gergen (1985) argues that relativistic thinking does not indicate that 'anything goes', as the normative rules governing the sharing of meaning in societies apply to enquiries under the constructionist umbrella. The knowledge acquired therefore does not necessarily correspond with a single objective reality; rather it corresponds with the participants lived experience within the context of social norms (Glaserfeld 2007), and is the best fit at a given time (Rolfe 2006a).

Reality is relative to time and context, is subject to change, and does not correspond to a single objective truth; therefore relativist thinking posits major challenges in assessing the validity of research findings. The challenges vary depending on where beliefs lie on the ontological monist-dualist continuum. Rolfe (2006a) differentiates between judgemental relativism and ironist relativism in this regard. Since an objective world is disputed and knowledge is individual, subjective and varied, he suggests that the concept of a shared agreement of validity has little relevance for the judgemental relativists. The ironists however, whilst not denying an objective reality, acknowledge that the findings can never be fully justified, but believe that they are the best findings for a given time and context. Therefore, it is the truth-value that is of concern. In relation to the instability of time and social contexts, Rolfe (2006a) further posits that no situation repeats itself and therefore the validity of the study is in the interpretation and is presented in the writing rather than in the method itself. Angen (2000) also suggests, because of this instability, regardless of how rigorously the method is applied a certain objective truth cannot be realised. She states that due to the underlying philosophical assumptions, using an interpretive approach 'is to risk certainty but this loss is mitigated by what we stand to gain in moral and practical relevance' (Angen 2000, p. 380)⁴

4.5 The philosophical underpinnings in this study

As this thesis is situated in the context of the social and cultural lives of the participants, it is underpinned by social constructionist thinking. This is in keeping with my understanding

⁴ The consideration of trustworthiness with regard to the study presented here will be discussed in depth in chapter 11

that knowledge and meaningful reality arise from human interaction within a social context (Crotty 1998) and this social context is influenced by the cultural and historical norms within which it operates. Human interactions are conducted within relationships which vary in their degree of interdependence, producing knowledge that invariably influences actions and choice (Parton 2003). The normative actions and choices become absorbed into the history and culture within which they occur, as new meanings are constructed that bring about change. Through this process of knowing people define themselves and their experiences.

My understanding therefore is that reality is not constant, will be time dependant and vary from culture to culture and society to society. In addition, it is my understanding there is an objective physical world out there, but that world cannot be fully realised; however, what can be realised is garnered from the coordination of activities between cognizing individuals in the context of systems of shared meaning. As a result, since reality is constructed by people in various life contexts, there will be multiple meanings idiosyncratic to the society in which they are constructed. This thinking does not equate to an 'anything goes' philosophy however, based on the premise of common experiences and shared understandings in societies, the knowledge that is constructed is recognisable and applicable to the society in which it is constructed at a given time. Therefore, the knowledge gained from conducting this study will be applicable to the participants and to others who live in their cultural and social world.

In keeping with constructionist thinking, I consider the process of acquiring knowledge in social research to be a negotiation between the participant and the researcher where both actively engage in constructing a version of an experience that is meaningful to the participant. In-depth interviewing, as is employed in this study, provides a milieu in which the participants' interpretations of their experiences are elicited. I concur with Charmaz (2006), who suggests that the flexibility and control afforded by this method of data collection supports the researcher in ascertaining meaning from the participant's point of view. However, attentive to Glaser's warnings (1998), I remained mindful of the issue of researcher bias and its influence on the emerging theory.⁵

⁵ The issue of researcher bias in relation to the current theory is discussed in more detail in chapter 11

4.6 Classic Grounded Theory

CGT 'is the discovery of theory from data systematically obtained from social research' (Glaser & Strauss 1967, p. 2). It does not attempt to test or verify an existing hypothesis; rather it seeks to generate a theory from data collected in the research field. CGT is based on the assumption that individuals in the context of group and social interactions attribute meaning to events. These meanings define situations for an individual on which common patterns of behaviour are unconsciously established (McCallin 2003). The goal of a CGT study is to generate a theory that accounts for these unconscious patterns of behaviour, making them visible in a way that is immediately recognisable to both the reader and the participants.

The purpose of entering the research field in a CGT study is to discover the participant's main concern in a substantive area and to gain an understanding of how they continually and unconsciously resolve this concern. Rather than predetermining what the main concern might be, or framing it within a pre-existing theory, CGT methods provide an analytical structure in which the main concern emerges directly from the participant's own narrated experience. Glaser (1998) suggests that the methodology is primarily considered an inductive practice where the systematic analysis of the data moves from specific observations to more generalised ideas and theories. He acknowledges that there are elements of deduction in the form of theoretical sampling (discussed below); however, he recommends that the association of CGT with deduction is kept to a minimum as it implies forcing of the data. Charmaz (2006) also acknowledges the practice of inductive and deductive reasoning in CGT which she frames as an abductive method, where reasoning begins with the data and culminates with a hypothesis. All possible hypotheses or theoretical explanations are then examined by revisiting the data for the best fit.

CGT methods can produce both formal and substantive theories. Substantive theories focus on a particular contextual setting (Creswell 2007) and can either produce a discrete theory in its own right or can be further developed into a formal theory (Lempert 2007). Formal theories emerge from the examination of social phenomena in a variety of situations and, although they can be generated directly from data, they are usually generated as an extension of a substantive theory (Glaser & Strauss 1967). The study

presented in this thesis aimed to produce a substantive CGT on the experiences of partners living with someone with an eating disorder. To this end, data was acquired primarily from interviewing participants who had experience in the substantive area. The analysis employed the core characteristics of CGT to include coding, constant comparative analysis, theoretical sampling, memo writing and theoretical sensitivity. A detailed discussion of these characteristics is included in the next section.

4.6.1 Core characteristics of CGT

Charmaz (2006, p. 2) states, 'grounded theory methods consist of systematic, yet flexible guidelines for collecting and analysing qualitative data to construct theories "grounded" in the data'. Glaser (1998) frames the methods as a package, in that each step in the process is done systematically. The objective of using this systematic approach is to allow the participants' main concern, and the underlying behaviours they engage in to resolve this concern, to emerge directly from the data (Glaser 1978). In addition, the systematic procedures employed in conducting a CGT study also serve to demonstrate the credibility and trustworthiness of the study and ensure the theory is relevant to the substantive area (Glaser & Strauss 1967, Glaser 1998, Birks *et al.* 2006).⁶

Glaser (1978 p. 16) describes the systematic process of CGT as 'a set of double-back steps' of which no step can be missed. The researcher moves forward in the process through the steps of data collection, coding, theoretical sampling, memoing and constant comparison of the data, as described in the next few subsections. In doing so the researcher also continually moves back to previous steps, all the while focusing on the participants' main concern. As the researcher revisits the data and continues to code, the focus of the analysis shifts to saturating the researcher's ideas and memos (where no further data can be found to expand on the ideas or memos). As the memos become more conceptualised, the process shifts to sorting these memos into theoretical frameworks which become the basis for the write up of the theory (Glaser 1978).

⁶ The systematic procedures in relation to the rigor of the current study will be discussed in greater detail in chapter 11.

4.6.2 Coding in Grounded Theory

Coding is the first step in the analysis that sets about defining what the data contains (Charmaz 2006). Through this process of coding data is developed into categories with their associated properties and dimensions (Categories are high level concepts that are grouped together based on similarities (Corbin & Strauss 2008)). Two primary phases of coding are engaged in CGT; substantive, subdivided into open and selective coding, and theoretical coding (Holton 2007). The aim of substantive coding is to fracture the data into incidents that reflect the empirical substance of the data, all the while moving from a descriptive level to a more conceptual level (Glaser 1978, Holton 2007). This is initially achieved through open coding, involving an in-depth examination of the data. The data is broken down into segments, line by line or incident by incident and labelled in a way that explains and summarises what is happening in the data (Charmaz 2006). Data can be labelled either by in vivo codes or sociological constructs (Hernandez 2009). In the former, phrases or words are taken directly from the words used by participants ensuring concepts stay as close as possible to the data. The latter are constructs named by the researcher in a way that best categorises an incident arising in the data. Open coding is applied to all the data such as interviews, memos, observations and field notes used in the study, and this continues until a core category becomes apparent. The core category 'accounts for most of the variation in a pattern of behaviour' (Glaser 1978, p. 93) and the majority of other categories are related to it.

Selective coding is more focused and conceptual than open coding (Charmaz 2006). Only when a potential core category is identified is selective coding employed (Holton 2007). Data collection, by way of theoretical sampling in conjunction with selective coding, is focused on saturating the core category where no new information can be found in the data to develop it further (Creswell 2007). In the interest of saturation, coding at this level is carried out not only on new incoming data, but also on previously collected data that is revisited (Scott 2009). The process of selective coding serves to delimit data collection to that data which is only relevant to the emerging core variable and related categories (Holton 2007).

Theoretical coding is employed in the final stage of analysis. The aim of such coding is to reassemble the fractured story back together at a conceptual level (Glaser 1978). Theoretical codes provide a conceptual framework in which the substantive codes are understood to relate to each other when integrating into the theory (Holton 2007). Glaser (1998) suggests that there are a wide range of theoretical coding families on which to draw from but the most appropriate one applied to any CGT study must earn its way into the theory through the analysis. He warns against the use of preconceived theoretical codes, as forcing will undermine the theory. A comprehensive study of the coding families in conjunction with a broad reading of the literature provides a milieu in which the researcher can develop theoretical coding sensitivity (Glaser 2005a, Holton 2007). Throughout the CGT research process, several theoretical codes can emerge as relevant but the one eventually chosen will have the best overall fit regarding the relationship between the core category and related categories and concepts (Hernandez 2009).

4.6.3 Constant comparative method

The constant comparative method (CCM), developed by Glaser & Strauss (1967), is an analytical tool employed in social science research to facilitate coding and comparison and in the context of grounded theory, theory development. As a general research method, Glaser & Strauss (1967) suggest it is appropriate for use in data groups of any size. Although this analytic method is used in many approaches to social science, its application and purpose differ in CGT. Firstly, it is used in the context of simultaneous data collection and analysis. This supports the emergence of the main concern throughout the analysis rather than preconceived at the outset of the study. Secondly, in contrast to other research approaches where it is used for description and verification, CCM supports the conceptualisation of data (Jeon 2004).

Glaser (1998) suggests CCM was borne out of the quantitative methods of index formation; however, rather than the summing up of the aggregate values, the meanings attached to the incidences occurring in the data go through a process of comparison. Empirical data is raised to conceptual level coding using a concept-indicator model. In CGT this is based on CCM, where comparisons between indicators identify degrees of similarities, differences and variation of meaning. This results in the development of properties and dimensions in the emerging coded categories. Through this method, the concepts and categories earn

their way into the developing theory as they have been systematically generated from the data. The primary purpose of CCM in CGT therefore is the systematic generation of a theory that is grounded in the data.

Glaser and Strauss (1967) detail the process of CCM as a constantly developing method where the stages are both successive and cyclical in manner. From the outset of the analysis the researcher codes incidents or indicators into as many categories as is appropriate. Initially when coding an indicator for a category, the differences and similarities of that indicator are compared to other indicators that have been assigned to the same category. Through ongoing comparisons of indicators, theoretical properties of the categories begin to emerge accounting for all possible dimensions and properties to that category. Ultimately this achieves theoretical saturation, elaboration and verification of the concepts (Glaser & Holton 2004). Corbin and Strauss (2008), suggest that the properties and dimensions of a category transcend the specific situation and allow us to think about concrete indicators in an abstract way. As the analysis progresses, integration of categories is facilitated by the constant comparison of the properties and dimensions of categories with other categories to establish the best fit with the emerging hypothesis that will eventually integrate with the theory. The CCM contributes to the generalisation and conceptualisation of empirical data, thus serving to delimit the boundaries of the emerging theory. Although not the primary concern, CCM plays an important role in supporting the quality and trustworthiness of a study. This is in the form of the validation of initial facts and findings through replication with comparative evidence from sources internal and/or external to the study. However, Glaser and Strauss (1967) point out that because of the nature of abstraction in higher level concepts, accuracy and verification are not crucial in the development of the theory.

4.6.4 Theoretical sampling

Theoretical sampling combined with the CCM is a key research strategy in the development of a grounded theory. Theoretical sampling is the procedure of collecting additional data specifically in response to, and in support of, emerging categories their dimensions and properties. The aim of theoretical sampling is to collect relevant data that will lend itself to the development of the theory in which the categories are subsumed. Rather than working

from a preconceived theoretical framework, the basis of the initial sampling in CGT is directed by a general sociological problem area (Glaser 1978) or, as suggested by Chenitz & Swanson (1986), the sample is sought from where the phenomenon under study exists. Subsequent data collection or theoretical sampling based on theoretical purpose (Glaser & Strauss 1967) is guided by the gaps identified through the CCM. Data sources are chosen as the need arises rather than predetermined as such at the beginning of the research process (Glaser 1992a). Theoretical sampling therefore can be viewed as a purposeful selection to accommodate theory emergence (Coyne 1997). Glaser (1978) advises the researcher to pace themselves in the field, as data collection and analysis must be done simultaneous in order to determine the theoretical direction of subsequent data collection. In addition he suggests that the researcher should stay open to new and additional information until the saturation of all operational categories has occurred.

4.6.5 Theoretical saturation

Theoretical saturation is said to be achieved when, through collection and constant comparison of data, no additional information is forthcoming to further develop the properties of a category. This is not to be confused with description of concrete repetition of stories or events rather, it is when the conceptualisation of incidences is saturated (Charmaz 2006). Saturation in CGT means that the categories are fully developed, variability is identified and explained and the relationships between them are understood and validated (O'Reilly & Parker 2013). The theoretical conceptualisations are then subsumed into the emerging theory. In order to ensure saturation, Glaser & Strauss (1967, p. 61) suggest the researcher pursue all possibilities to 'stretch the diversity of data as far as possible'. They further advise however, as categories range in relevance to the theory, that the depth of sampling for each one will be different. Those categories with the most explanatory power in relation to the emerging theory need in-depth enquiry, saturating them as far as is possible.

Charmaz (2006) suggests that data completeness is not determined by the length or number of interviews; therefore defining or ensuring full saturation can be problematic. She further suggests that data saturation can be incorrectly assumed when the initial research question is limited thus limiting the development of categories. Premature

saturation may also occur where there is limited or uncritical analytical treatment of the data, leading to a very descriptive study and a lack of integration of the various categories. Strauss and Corbin (1998) suggest complete saturation is never usually achieved but sufficient sampling will have occurred when the core category explains the phenomenon in depth and the relationships between the other categories are well defined. Bowen (2008) highlights the importance of transparency and thoroughness, emphasising the need for the researcher to support their claims of saturation by providing explanation and evidence of how this has transpired throughout the study.

4.6.6 Memoing

Throughout the course of the research project the researcher makes written records, referred to as memos, of the analytical processes that eventually serve to support and evidence the developing theory. They are instrumental in capturing and elucidating the rationale behind the researcher's analytical processes (Charmaz 2006). Chenitz & Swanson (1986) advise that memo writing is the only way the researcher can keep track of the emerging theory and inadequate memoing produces a superficial or incorrect theory. Glaser (1978) suggests the length of the memo is irrelevant once it captures, in total, the researchers thoughts and is valuable in directing theoretical sampling.

Strauss and Corbin (1998) propose that memos should be used in a flexible way rather than in a structured manner and they should be applied to data exploration, developing properties and categories, exploring and elaborating relationships within the data and developing the story. Glaser (1978) advises that the memos should initially be sourced from the process of constant comparison of indicators and concepts. As the research project progresses however, they can be sourced at every level of the analysis including from the sorting of the memos themselves to the writing up of the report. Lempert (2007) asserts memos are not intended for descriptive purposes; rather, through their interpretive nature, they facilitate the conceptualisation of the data. They provide the researcher with a means to explore, formulate, expand, or renounce emerging analytical ideas and in the process locate themselves as a social being within the research. As the memos develop and mature, the researcher can trace the saturation of categories and theoretical completeness. Confirmation of the core category and how the participants resolve the

main concern, which are key objectives of a grounded theory study, will be consistently repeated in the memos (Glaser 1998).

4.6.7 Theoretical sensitivity

The final core element of CGT is theoretical sensitivity, a researcher skill essential in the course of a CGT study (Glaser 1978). Theoretical sensitivity is the 'ability to have theoretical insight into his area of research, combined with an ability to make something of his insights' (Glaser & Strauss 1967, p. 46). According to Hall and Callery (2001), theoretical sensitivity supports the researcher in using their experience and literature in examining the data from different viewpoints, broadening the potential for developing the theory. Holton (2007) suggests an analytic temperament in the researcher is an important prerequisite for developing sensitivity where the researcher can stand back from the data, tolerate confusion, conceptually examine the data, and be analytically competent. Glaser (1978) advises that the first step in building theoretical sensitivity is to have as few preconceived ideas as possible about the substantive area when first entering the research field, leaving the researcher as open as possible to what might emerge in the data. Theoretical sensitivity is achieved with rigorous reading in a wide variety of fields (Glaser 1978), with emersion in the data (Strauss & Corbin 1998), with the researchers professional experience (Holloway & Wheeler 2010), and from personal and research experience (Strauss & Corbin 1994a).

4.7 Rationale for using CGT

The aim of this study was to develop a CGT that accounts for the latent patterns of behaviour employed by partners living with someone with an eating disorder. In doing so I wished to build on the limited literature relating to partners' experiences in this respect (Van den Broucke *et al.* 1997, Evans & Wertheim 2005, Huke & Slade 2006). CGT as a methodology initially appealed to me as, from my understanding, it is an appropriate methodology to use where there is little existing knowledge about a particular phenomenon (Stern 1980, Chenitz & Swanson 1986, Holloway & Wheeler 2010). CGT is used across many disciplines but is particularly prevalent in nursing research where, according to Birks *et al.* (2006) it provides a framework for enquiry into human conditions. It provides a means to explore the lived experiences of people in the context of social and human interactions, leading to the discovery of the main concern and the manner in which

the main concern is resolved (Glaser 1998, McCallin 2003). CGT methodology therefore fits with the aim of this study, to generate a theory based on the subjective meaning that the partners of people experiencing an eating disorder attribute to their experiences (Creswell 2007). As CGT is regarded as a general methodology, providing the tools for analysis and theory development, it is not confined to any particular ontological or epistemological assumptions; rather, it can be used with any philosophical perspective adopted by the researcher (Holton 2008). It is a suitable methodology therefore to use in conjunction with my own philosophical beliefs which come under the constructionist umbrella as discussed above.

As a novice grounded theorist there was much deliberation and grappling with the various approaches to GT before I finally chose which approach to use. Choosing a CGT approach (Glaser 1978, 1998, 2001, Glaser 2005a) appealed to me as I was particularly interested in allowing the main concern to emerge from the participants' perspective. This is in contrast to determining the research question based on what is known about the phenomenon, as in Strauss and Corbin's (Strauss & Corbin 1994a, Corbin & Strauss 2008) approach, which would have predetermined what to look for, thereby influencing the data (Heath & Cowley 2004). In addition, my preference was to work with a more flexible approach when following emerging ideas, as found in CGT, rather than a more structured technical approach described in later GT approaches. Finally, as recommended by McCallin (2003), I had the opportunity to work with experienced classic grounded theorists who were in a position to guide and mentor me throughout the research study.

4.8 Summary

Based on the recommendations from many writers, I have approached this chapter with an aim to explicate the philosophical assumptions inherent in this CGT study. In this chapter the complexity and myriad of positions associated with CGT, as discussed in the literature were presented. These discussions suggest CGT is not aligned with any specific philosophical position other than that which the researcher prefers (Glaser 2005b, Holton 2008), or is aligned with many different philosophical positions as it diversified over time (Norton 1999, Charmaz 2000, Birks & Mills 2011). This study however is guided by Charmaz's (2008) suggestion that all CGT studies assume a social constructionist approach.

This is in keeping with my own philosophical beliefs and in keeping with this research as it seeks to explore the world of lived experience (Schwandt 1994); that is, the lived experience of partners living with a person with an eating disorder. I have discussed my preference in choosing a CGT approach and in doing so have identified the theoretical procedures and issues relating to this approach. The following chapter expands on this by detailing how the methodology was applied to the development of the CGT that accounted for the concerns of partners living with someone with an eating disorder.

Chapter 5

RESEARCH METHODS

5.1 Introduction

Creswell (2007) explains the methods of a study as the procedures and techniques employed by the researcher in gathering and analysing data that is relevant to a research question or hypothesis. The current chapter details the procedures and techniques used in this study, which are the methods inherent in Classic Grounded Theory (CGT) methodology, the methodology underpinning the study. I begin by providing the background of how the study was conceived, and follow this with the purpose and aims of the study. The methods of data collection, the application of the core concepts of CGT methodology used in the development of the theory and the conceptualisation of the basic social process of '*Reconstructing Livability*' are then discussed. I finish the methods discussion by considering the ethical issues applicable to qualitative research with a particular emphasis on how these considerations were managed in this study. In this chapter, it is my intent to present my own methodological journey through the process, giving insights into the issues and challenges I encountered along the way.

5.2 Background to and purpose of the study

Working with people with eating disorders (ED) throughout my nursing career and specialising in this particular field through education and clinical work, I am privileged to meet and engage with family members and carers over the course of my daily work. As part of a multidisciplinary team we draw on available theoretical frameworks to provide evidence based, best practice services for the service users and their families (Treasure *et al.* 2003, Beumont *et al.* 2004, National Institute for Health and Clinical Excellence 2004, American Psychiatric Association 2006, Treasure *et al.* 2007b, Gísladóttir & Svavarsdóttir 2011, Treasure *et al.* 2012b). Although the family members I encounter are, for the most part, parents of those who experience an eating disorder, the service I work with also provides treatment and care for service users who no longer live with parents but are living with a partner in romantic partnerships. In the absence of adequate guiding frameworks

for developing and implementing appropriate and effective interventions for couples who are living with an ED, existing guiding principles are used. Although use of these guiding principles are essential and valuable, they do not adequately meet partners' needs or needs that may arise in the context of the intimate relationship. The purpose of this study therefore was to gain an in depth understanding from the perspective of partners who are living with someone with an ED, to give them a voice and to inform the development of a theoretical framework appropriate for their concerns and needs.

5.3 The aim of the study

The aim of the study was to gain an understanding of how living with a person with an ED impacts on the lived environment of partners, and as a result, to develop a substantive theory based on partners' experiences.

5.4 Objectives

Predefining objectives in CGT is a contradiction to the methodology, as predefined problems are usually a reflection of professional interests and assumptions and have little or no relevance to the participants in the substantive area (Glaser 1998). Defining objectives for this study however, was a requirement for registration as part of the research proposal and a requirement for ethical approval. Therefore the following provisional objectives were set out at the very early stages of the study:

1. To explore the partners' understanding of the relationship from a communication, commitment and intimacy perspective.
2. To examine how the ED has impacted on the partners' lives not only from a caring perspective but also in the context of other relationships in their lives, in their day to day functioning and on their mental and physical health.
3. To examine the strategies and interactions used by partners to help them cope with their partner's ED.
4. To explore what strategies they found most helpful in managing their relationship and what was not helpful, particularly in more acute phases of the illness.

On reflection, most of the objectives identified at that time, although they were areas of relevance, were not specific to the emerging theory. As the theory unfolded, I appreciated

Glaser's (1998) discussions on forcing the data with preconceived ideas. My experience of data collection and analysis reflected his suggestion that participants' main concern will prevail regardless of the researcher or dissertation committee expectations.

5.5 Access and Recruitment

Access to participants for this study was through various services nationally, including voluntary groups, outpatient treatment centres, community based programmes and hospital based services. For ethical reasons I did not access participants from my own clinical area of practice as there was a considerable possibility I would be working with them in a therapeutic capacity at some stage during their partner's treatment.

Following ethical approval (Appendix 2), access to the population was sought through advertising in the form of posters and leaflets (Appendix 3) in the participating venues. In response to the advertising, potential participants contacted me by phone or by email indicating their interest and/or to seek further information. An information pack containing a letter of invitation (Appendix 4) and an information leaflet (Appendix 5) was sent out to all those individuals who were interested in participating and who met the inclusion criteria. Only one person who contacted me did not meet the criteria. This person was the mother of young woman who had an ED. I explained the nature and context of the study to her, and gave her information in relation to appropriate services she could access. She offered me assistance in the future if I was to do further research in the area of parents' experiences. A few participants sought further clarification regarding the study by way of email or a phone call. All those who had indicated their interest at the beginning of the process agreed to take part in the study and I arranged a suitable date and time for the interview.

Eighteen participants in total were recruited, all of whom were interviewed once. The demographic details of these participants are provided in the table 5.1 below;

Table 5.1 Demographic Details of Participants:

Gender	Male	16
	Female	2
Age	25-35 years	11
	36-45 years	6
	> 45 years	1
Relationship type	Male same sex relationship	1
	Female same sex relationship	1
	Heterosexual relationship	16
Relationship status	Married	7
	Co habiting	11
Duration of relationship	<1 year	1
	Between 1-5 years	6
	Between 5-10 years	8
	>10 years	3
Onset of ED	ED onset prior to relationship	13
	ED onset after commencement of relationship	5
Children	No Children	13
	1 child	3
	3 children	2
Attending support group		None

5.5.1 Sampling

Initially data collection in this study was by way of purposeful sampling, where participants are selected for the study 'because they can purposefully inform an understanding of the research problem and central phenomenon in the study' (Creswell 2007, p. 125). The participants in this study were chosen based on their experience of living with a partner with an ED, in accordance with the inclusion/exclusion criteria devised for the study (Appendix 6). Initially I thought snowball sampling was an appropriate way in which to access the population. However, it was not feasible to apply this method of recruitment as the majority of participants did not have contact with or know of other partners living with someone with an ED. Only one participant knew another partner in a similar position but he was reluctant to put this person's name forward as he felt the other person was very private and did not like to talk about his partner experiencing an ED.

Following analysis of the initial interviews, codes and categories were generated. Theoretical sampling (Chapter 4.6.4) then replaced purposeful sampling as these codes and categories served to guide the collection of further data. The aim of theoretical sampling at this stage of the analysis was to develop the depth and breadth of the codes and categories to facilitate the emergence of the theory. Given the limited accessibility of participants who had appropriate knowledge and experience for the substantive area under study, I was not in a position to theoretically sample the population. The participants interviewed throughout the research process therefore, continued to be guided by the inclusion/exclusion criteria as set out at the beginning of the study. Theoretical sampling was employed subsequently as a way of sampling the data. Although there was no clearly defined interview guide at the outset of the study, once the categories began to emerge I developed more specific theoretical questions that were used in subsequent interviews in order to develop and saturate those categories (Coyne 1997). In addition, as codes and categories emerged, I returned to previous interviews to theoretically sample the data for the incidents occurring in these categories.

Theoretical sampling continued until all the relevant categories were saturated as far as was possible, that is until no additional data was found to further augment the categories (Glaser & Strauss 1967) and the incidences arising in new data reflected those already

detailed. The sample size was not predetermined at the outset of the study primarily for this reason. As stated by Glaser (1998, p. 159), 'data completeness is based only on theoretical completeness not on numbers or lengths of interviews'. It was not possible to anticipate how much data was needed to, firstly, identify all the relevant categories and secondly, to collect all the relevant information in saturating those categories. After 16 interviews were completed, I was of the opinion saturation had been achieved. However, I interviewed 2 further participants to ensure that this was the case. In keeping with Glaser's (1978) concept of pacing oneself between field work and analysis, these interviews were conducted over a period of 3 years.

5.6 Data collection

Creswell (2007), identifies four main categories of qualitative data collection methods under which most forms of data can be considered. These are interviews, observations, audio-visual and documents. I focus below on interviewing as this was the primary method of data collection in this study.

The use of interviewing for data collection covers a wide variety of practices. These range from highly structured, predetermined, standardised questions to an open ended unstructured format, considered by Rubin & Rubin (2005) as a conversation that is guided by the researcher. Although there are many data collection methods appropriate for CGT studies (Backman & Kyngas 1999), Creswell (2007) suggests interviewing is a key approach and the other methods such as participant observation or researcher memos are primarily applied in the development of the theory. Unstructured interviewing is the most commonly used interviewing technique in CGT (Chenitz & Swanson 1986, Duffy *et al.* 2004), the purpose of which is to gain an in-depth understanding of the lived experience of people and the manner in which they make sense of that experience (Seidman 2013). Thus, I believed the unstructured interviewing was a relevant and prudent method by which I would gain an understanding of what it is experienced by partners living with someone with an ED.

Jones (1985) suggests a completely unstructured interview is a misnomer, in that researchers are continuously making choices based on what participant information they

want to pursue and what information they choose to dismiss. He proposes, in preparation for the initial interviews, the researcher enters the research field with some well-considered broad questions, as this will serve to reduce participant ambiguity and hence improve access to good data. Charmaz (2006) also advocates the use of carefully chosen open ended questions that are appropriate to the research question and participant experiences. This functions to stimulate participant narratives and reflections. In particular, she suggests having an interview guide incorporating some helpful probes, can support the novice CGT researcher, giving them the freedom to concentrate on what the participant is saying. Although I initially entered the interview field with a loose interview guide, I was mindful of Glaser's (1998) suggestion that preconceived questions are rendered irrelevant if they do not fit with the participants' concerns as the participants will ultimately only discuss issues of concern relevant to themselves.

Corbin and Morse (2003) provide a four phase unstructured interview framework to include the pre-interview phase, the tentative phase, the immersion phase and the emergence phase, which I found helpful when conducting the interviews and use here to discuss the interview process I engaged in. Although ethical considerations relating to the current study are not discussed in detail until the end of the chapter, in order to provide a comprehensive account of the interview process many of the ethical issues are included in the following account.

5.6.1 The Interview process

The pre-interview phase: This phase begins from when the first contact is made with the participant up to the beginning of the interview. This time is used to ensure the participant is fully informed of all aspects of the research study and process. It can also be used as a time to develop a rapport between the researcher and participant. Developing a rapport with the participants was considered by me to be an essential part of the research process, not only in the interest of gathering quality data, but from a compassionate perspective. It was important that the participant felt at ease during the process, and felt heard and valued in presenting their own experiences.

All but four interviews took place in my workplace as this suited the participants. I would meet them at the front door and walk with them to my office at the far end of the building. That walk to the office became an important time for engaging in an initial conversation about many different topics; even talking about the weather seemed to put some participants at ease. One participant was interviewed in his own work place, one at a treatment clinic his wife was attending, one by video link and one at a community mental health facility. The initial conversations I had with these participants were of similar content but shorter in duration. Prior to commencing the interview, an explanation of the study was given including the aims, methods and procedures of data collection. I discussed the issues around consent and confidentiality, the details of which are provided below under ethical considerations. After giving the participants an opportunity to ask any questions, the consent form (Appendix 7) was signed by both the participant and by me, marking the end of this phase.

The tentative phase: This phase refers to the beginning stage of the interview where the participants may not feel fully at ease. This was reflected in my own experiences where most of the participants began the interview in a tentative manner. Their sense of hesitancy and uncertainty was marked by them asking for direction on to how to proceed. Sometimes they suggested they were afraid they would not give me the information I wanted. I reassured them there was no right or wrong information once they were telling me about their own experience. Inviting them to tell me how they met their partner was often a way for them to begin to talk about their relationship. As the interview progressed and the participants began to talk about their experiences in a more engaged and animated manner, they rarely looked for further direction from me.

The immersion phase: The immersion phase refers to that stage of the interview where both the participant and researcher are immersed in the story. A primary aspect of becoming immersed in the story is that it can evoke powerful emotional responses in the participants. In order to safeguard them from the harmful effects of difficult emotions and to preserve their dignity, the researcher needs to be able to support and empathise with them in working through the distress (Corbin & Morse 2003). I encountered such distress in the very first interview. The participant was very distressed and tearful when talking about how his partner had become ill again after a period of remission. He looked for a

tissue and I asked him if I would turn off the recorder. He responded with 'No, no, I'm grand, I get like this even if I'm watching Coronation Street on television'. Although he attempted to manage his distress with humour, I was mindful of how difficult this was for him, both talking about it and reliving it through the conversation. Though there were further episodes of upset for him throughout the immersion phase, he insisted on not taking a break, suggesting that getting emotional was helpful for him. Although I encountered different levels of distress and upset in other interviews, not one of the participants wanted me to turn the recorder off. Some even suggested they needed the emotions to be recorded so I would get a sense of how emotionally difficult it was for them at times. The immersion phase also impacted on me as a researcher in that I was listening to some very harrowing and distressing stories. I would often think about those stories sometimes at unexpected times when I wasn't working on the research, wondering how the participants were doing. I was thankful for my supervision, where talking about my experience was cathartic.

The Emergence Phase: The emergence phase marks the ending of the interview where the focus can shift back to the researcher, often by way of conversation. I was mindful of Clark's (2006) assertion that participants often volunteered for a study with their own agenda in mind, whether consciously or otherwise. I experienced this with many of the participants whose agenda included looking for information, someone to talk to, my opinion, therapy, personal validation, or to help the researcher help others in the same position. I learned after the first few interviews that I needed to sensitively hold fast to my position as researcher rather than therapist (this issue is discussed in more detail in section 5.6.5 below). I decided to provide this type of information and support after the interview was over and the recorder was turned off. I discussed this arrangement with the participants before the interview began. In the event an issue arose during the interview, I made known to the participant that I would come back to it at the end. The emergence phase culminated in a discussion with the participants on consent to use the information they had provided in the interview and this is discussed in more detail in the section on ethical considerations below. In addition, all participants were asked if they wanted a copy of the transcript of the interview and if I could contact them again if I needed clarification or further information. All participants agreed I could contact them and all but two of them

did not want a copy of the transcript, preferring instead to read the finished report. The participants were then accompanied by me to the front door of the building.

5.6.2 Pilot interview

Although initially I considered conducting pilot interviews with the targeted sample, I decided against it primarily for two reasons. Firstly, I was concerned I would experience difficulties accessing a sufficiently large sample size for theoretical saturation. This was because through my clinical work, I had experienced a reluctance on the part of the person with the eating disorder to involve their partners and a reluctance on the part of the partners themselves to engage with services. I therefore considered it essential to include all interviews in the study. Secondly, I personally felt it was unethical not to include all interviews from participants in the main study, as they were so generous in the giving of their time and experience with an expectation of inclusion.

I subsequently decided to conduct three test interviews with colleagues; a nurse, a psychotherapist and an occupational therapist, all very experienced in working with people with eating disorders and at various levels, experienced in working with client's families. Initially, I was particularly anxious as I thought my interview style and ability were under scrutiny by three professionals. However, I invited scrutiny and critical feedback on my techniques and approach as it made me reflect on what I brought to the interview and how I elicited information from the participant. This was invaluable knowledge for me when I began my interviews in the research field. Two very important issues were highlighted to me in this process.

Firstly, my experience of working with clients in a psychotherapeutic way was reflected in my interview style. At one level was helpful, particularly in developing a rapport or in allowing the participant to explore areas of concern. On the other hand, I needed to be mindful that the aim of therapy and the aim of the research interview were significantly different and I had to be careful not to digress into the therapist role while conducting the interviews. I was faced with this dilemma in the very first interview and this recurred in subsequent interviews where the participant was attending the interview with their own agenda, to get advice, support or even some therapy. Since this researcher/therapist issue had arisen during the test interviews I had prepared somewhat for this problem. As

discussed in the section above, I had decided to remain focused on the research aim during the interview and allocate time after the interview to provide the participants with information on supports they may have required. I made the participant aware of this decision before the interview began. Secondly, the pilot interviews made me very aware of the preconceptions I, and indeed my colleagues, had in terms of what the partners might consider as major issues and concerns. In particular, control as an assumed issue for the participants as partners emerged in all pilot interviews and this reinforced my own pre-conceived ideas of what might be a main concern for them; however, our interpretation of what concerned the participants did not reflect the participants views and I was very surprised when control did not come up at all in the first interview. Occasionally control was mentioned in subsequent interviews, but the participants were not framing it as a significant concern.

5.6.3 Interview procedure: topic guide and its development

For this study, a broad interview guide consisting of open ended questions was developed prior to entering the research field, primarily as a prerequisite for the research proposal and ethical approval. In the interviews I did not explicitly follow this guide; rather, I opened the interview with a broad question inviting the participant who, as advised by Jones (1985) had been informed of the aim of the research project, to talk freely about their experience of living with a partner with an eating disorder. As the interview progressed subsequent explorative questions were asked in response to the narratives provided by the participant. This was mainly used to seek clarification, expansion or exploration of issues raised by the participant.

As categories were developed through ongoing collection and data analysis, a more focused interviewing style was introduced in the form of theoretical sampling (Chapter 4.6.4). The questions having theoretical relevance and purpose were tailored in response to the emerging theory (Glaser & Strauss 1967). Although the participants continued to talk about their lived experience in general, I approached the interview with more specific questions in order to achieve the depth of information required for saturation of the emerging categories and concepts.

The length of interviews, determined by the participant, ranged from one to one and a half hours. At its conclusion I summarised the main points discussed in the interview, giving an opportunity for the participant to seek or make any clarifications. I asked if they were happy for me to use the interview in the research, and all participants responded in the affirmative. After turning off the recorder we had the opportunity to engage in a more general and/or supportive conversation and I thanked them for taking the time to participate and for sharing their story with me. Once the interview was over, I took some time out to reflect on and make some notes about the interview and my own subjective experience. I incorporated these into my memos which were instrumental in explicating my influences and biases on the analysis and development of the theory.

5.6.4 Recording the interviews

Glaser (1998) advises against the recording of interviews on the grounds one is not looking for descriptive completeness. He suggests it is a time intensive activity that serves to inhibit delimiting of theoretical sampling and stifles researcher creativity. He proposes, notes taken after interviews and later used with the constant comparative method are sufficient for theoretical saturation. He further suggests, relevant information omitted when note taking will be remembered through the constant comparative method. I would agree with Glaser regarding the time demands of transcribing and analysis of interviews, some of which were around 90 minutes long, and the fact having copious amounts of data delays delimitation. As a novice grounded theory researcher however, I wanted to be sure I did not omit any relevant information as I was not sure I could rely on memory to recall clearly what the participant was saying or that my own biases would affect what I recalled. In addition, having the recordings allowed me to listen back for clarification purposes and to interpret nonverbal content in context such as, silences, sighs, laughter, intonation and hesitations.

However, this issue was discussed at length at a Grounded Theory seminar, led by Barney Glaser, which I attended after completing 11 interviews. The debate around recording culminated in specific guidance for those too afraid not to record the interviews. The suggestion was to record the interviews but instead of transcribing verbatim, the researcher would make field notes when listening back over the recordings. This for me

served to delimit the data whilst providing me with the security of having a recording to listen back on when needed.

5.6.5 Reflections on Therapeutic Vs research interviewing

'Both a therapeutic and a research interview may lead to increased understanding and change, but the emphasis is on knowledge production in a research interview and on personal change in a therapeutic interview (Kvale & Brinkmann 2009, p. 41). I considered my clinical experience of working psychotherapeutically both in group and individual settings with clients with eating disorders as advantageous to me in conducting the research interviews; however, I was also very mindful of how that experience could in fact hinder the process. Laliberte-Rudman & Moll (2001) suggest shifting from therapist to researcher can be difficult to negotiate primarily because of power differential. They suggest in the therapist role the interviewer (therapist) is in the power position, whereas in the research interview the interviewee (participant) is the authority on the research subject. I was mindful of the participant as expert throughout the study. The participant had invaluable information which they were willing to share in the interest of me gaining a better understanding of their main concern. Laliberte-Rudman & Moll (2001) further point out that the participant may also struggle with their position as expert, seeing the researcher as a clinician rather than a learner. Although I would have experienced this difficulty with many of the participants at the beginning of the interview, when they became comfortable telling their story, they became accustomed to viewing me as the listener and learner. In addition, the authors also suggest that the process of the interviews are different in that a therapist guides the process in the context of information gathering specific to the needs of the client, whereas the researcher focus is broader, with an aim to determine how the participant's experiences fit within an overall understanding of the phenomenon.

Research interviewing is considered by Seidman (2013) as both a methodology and a socially contextual relationship that must be nurtured, supported and ended properly. He warns against an over familiarity in the relationship, highlighting the importance of establishing an appropriate rapport. I was mindful of Smith's (1992) advice of researcher as investigator, not researcher as counsellor, where developing a rapport was about

encouraging interaction while maintaining objectivity as far as possible. This did not stop me, however, from listening to the partners' concerns as this may have had some therapeutic benefits for them.

Endings also differ between both types of interviews. In therapy, endings typically begin long before the therapy actually finishes allowing the client, over a period of time, to work through issues and separation in an appropriate way (Subrin 2010). In the researcher interview endings are more abrupt, leaving the participant with strong emotional feelings or feelings of emptiness (Laliberte-Rudman & Moll 2001). This was not something that was evident in the interviews I conducted as, although many of the participants found the interviews cathartic, they commented on how helpful the experience was. Seidman (2013) suggests there is a significant shift in the relationship when a research interview is completed, with the relationship becoming more detached. He suggests the relationship established with the participant during the interview must reflect the expected post interview relationship. I saw this as a key element in avoiding confusion for both participant and myself the researcher, in the matter of endings. I was not in a position to change from researcher to therapist just because the recorder was turned off or the interview was officially terminated. As described in the emergence phase of the interview process, while not moving into the therapist stance I was still able to listen with empathy offering information or referral material where appropriate.

5.7 Data analysis

The analytical procedures undertaken in this study were informed by CGT, as described in the seminal work of Glaser and Strauss (1967) and further developed by Glaser (1965, 1992b, 1998). The process of theory generation entailed the simultaneous collection and analysis of data using coding, constant comparative analysis and theoretical sampling throughout. Although CGT is described as a package that leads the researcher from knowing nothing to becoming an expert in the substantive area (Glaser 1998), it was far from a linear orderly process. My experience of the process fits with Glaser's (1998, p. 15) suggestion that the research may progress as a 'cycle in circles' where the stages may all occur at one time, with the emphasis shifting from one stage to another and back again. Early in the research process this left me feeling very confused and frustrated. A primary

difficulty for me was my need to understand something in order for me to do it 'right' but, as a novice CGT researcher, I had to embark on the process of analysis and theory development before I could really understand the process. This meant I was often grappling around in the dark and with no clear delineation between stages, was left very unsure of what I was doing or where to go next. However, with the support of supervisors who were very experienced in CGT methodology, reading and rereading the CGT literature in conjunction with the 'doing' of the CGT methodology, clarity began to replace the confusion. At all times I kept returning to the questions; i) what is the participant's main concern? And; ii) how are they continuously trying to resolve that concern? These questions kept me focused and were particularly helpful when the confusion was intense.

The first 11 interviews were transcribed verbatim by me. I used the NVivo 10 software package (QSR International Pty Ltd 2012) to facilitate management and organisation of the data, and used it from the outset with open coding. Listening to the recordings of the transcripts facilitated an engagement and immersion in the data for me. I marked each transcript at 5 minute intervals to allow easy access to specific sections of the recordings in the event I needed clarification on what was being said or needed to get a sense of the non-verbal cues contained in the interview. Following Glaser's advice on recording (1998), in subsequent interviews I made field notes of the recordings. I transcribed only that information I required for the purpose of saturation and clarification of the developing concepts. I made short reference notes regarding information of lesser significance, and continued to mark the interviews at 5 minute intervals for easy access if needed at a later date. This was in part a reflection on my own self-doubt as I was afraid to discount any information but, as the analysis progressed, I rarely needed to go back to information deemed to be of lesser significance to the core category or the emergent theory.

5.7.1 Open coding

Initial open coding commenced when the first interview was completed. This entailed examining the transcript line by line and coding for incidents which were labelled either using the participant's words (in vivo codes) or using labels I thought best categorised the incidents. Glaser (1998) suggests the incidents are found in a line, phrase or a few sentences and rarely needs a paragraph to be recognised. However, I struggled not to over

fracture the data when I was examining it line by line. The amount of codes were multiplying very quickly and I knew I had a problem when, after only four interviews, I had amassed nearly 120 codes. Mindful of Glaser's (1998, p. 140) comment that 'coding does not go with holistic reading of an interview or field note for the "overall" conceptual impression', I found Silverman's (2011, p. 63) suggestion to 'at least try to retain the immediate surroundings of whatever data you are analysing', helpful. By doing this I could keep the contextual aspect of the code in mind and understand the codes in a more meaningful way. Open coding was performed in a progressively abstract way and code names were reworked and developed with the merging of new data and ongoing analysis of previous concepts (Wasserman *et al.* 2009). Table 2.2 below provides some examples of initial open coding, but a more extensive list is found in Appendix 8(a), with an example of open codes grouped together based on similarity, in Appendix 8(b).

Table 5.2 Open Codes

Participant ID	Open code	Interview excerpt
<u>003</u>	Coming into hospital Being left with junior staff Being himself Wanting to help Seeking advice Not getting answers Encountering professional inexperience Expecting better	I remember the admission thing, crickey... they were all lovely people but I ended up talking to a student nurse and being the person I am I said ' and what can I do to help?' There was no answer. I'm sorry but let's, let's ... the experience, no answer no such a thing as 'hey you know what, there's a book called the golden cage go read that'but that whole admission thing and what every guys, you've got to do better than this

5.7.2 Memoing

Memos document the researcher's analytical processes by recording how ideas about codes are developed and how interconnections of these codes are made (Montgomery &

Bailey 2007). The recording of memos in this study provided me with a forum in which ideas and insights around the analysis were collected, revised and amalgamated for use in the development of the theory (Glaser 2013). I began memoing with the coding and analysis of the first interview. Initially, the memos were relatively short and quite descriptive, providing me with an understanding of how and why I was linking and developing the codes. Over time, however, as the analysis progressed, they became more abstract and varied in length. For me memoing was one of the easiest parts of the research process and the idea that they were private as advised by Glaser (1998) gave me a freedom to record my thinking in whatever way worked for me at the time. Often I had flashes of ideas that, unless I grabbed them and wrote them down, would disappear. At other times vague ideas or insights taunted me with a meaning I could not quite grasp but by memoing them, adding to them over time and comparing them to other data, they usually began to take shape. Sometimes when I felt stuck, reading over previously recorded memos or writing about a code or concept often helped me become unstuck, or, when I needed clarification on where a particular concept was originating from or leading to, the memos were revisited.

The memos were stored in NVivo 10 where they were sorted by labelling, referencing and linking them to the various codes, categories and field notes as appropriate. Each memo was added to over time if new thoughts or insights arose during the analysis. In the early stages of the analysis, the memos were disjointed, jumbled and often descriptive. However, they developed into becoming more contained, directed and increasingly conceptual as the study progressed. Although memos were sorted in terms of labelling and linking at the time of their writing, I continuously returned to them, comparing and resorting them with each other and the categories and concepts when I had new data or new insights. In essence, the memos became a further form of data which were integrated into the developing theory. Despite the fact that memos are considered private (Glaser 2013), in the interest of demonstrating how they supported conceptualisation and theory development some examples have been provided in Appendices 9(a) and 9(b).

5.7.3 Identifying the main concern and core category

Through the process of open coding and constantly comparing the data, initially code to code and then, as categories were developed, category to category, the properties and

dimensions to the categories began to emerge. I had some difficulties moving from description to conceptualisation of the patterns of behaviour that were emerging in the data and, early on, even when I was thinking in a conceptual way I was not fully aware I was doing so. It was through discussing my work with supervisors and colleagues and reflecting on these conversations, I realised conceptualisation was developing as the analysis progressed. A frequent difficulty I had however, was naming what was going on in the data in a conceptualised way. Sometimes I used neologisms that although made sense to me, when I discussed them with my supervisors they did not make sense to them. For example when using the word 'Acceptabilising' to reflect the participants desire for their relationship to be acceptable to the self and to others in their wider social world, my supervisors suggested I write down everything I wanted the concept to capture and think about naming it in a way that could be understood by the reader. Although the word 'Acceptabilising' was deemed redundant, what it was trying to capture was ultimately incorporated into the category 'Countering the disruption.'

In the earlier stages of the analysis the participants' main concern was not clear and I grappled with several ideas including, '*learning to live with the ED in their lives*'. In hindsight however, it was evident I did not have enough data to identify the main recurring concern for the participants that could account for the majority of their underlying behaviours. With further data collection, analysis and memo writing, the main concern emerged as '*Encountering and living in a disrupted relationship*'. As the analysis became more conceptual the developing categories, '*Encountering a disruption*', '*Informed self*', '*Countering the disruptions*' and '*Reclaimed livability*' became part of the process the participants engaged in to resolve their main concern.

Identifying the main concern facilitated me in naming the core category into which the developing categories would fit. Again however, mindful of Glaser's (2001, p. 10) comment that, 'the pattern is named by constantly trying to fit words to best capture its imageric meaning' with ongoing analysis, identifying the core category was a process of naming and renaming it until I thought I had got it right. I brought my provisional core category '*Reconstructing normality in context*' (context referring to living with the ED in their lives) to a CGT seminar led by Barney Glaser in Stockholm early 2014. Through in-depth discussion with the group I reconsidered the name on the grounds that 'normality' was an

over-used term. As a result I renamed the core category '*Reconstructing Livability*.' Although the wording was changed the meaning remained the same, so it had changed in name rather than nature; therefore, it continued to account for the categories of the emerging theory and also fit with the participants' main concern of '*Encountering and living in a disrupted relationship*'.

5.7.4 Selective coding

Selective coding commenced when the core category of '*Reconstructing Livability*' was identified. Coding became limited to those variables that were concerned with the core and emergent related categories. Selective data analysis in conjunction with theoretical sampling, serves to saturate the significant categories while facilitating the delimiting of data collection. In practice, however, I struggled to collect only the data that was relevant to the emerging theory. I continued to allow the participant to tell his/her story in total, as ethically I understood this was only fair to the participant who often came to me with that exact purpose; however, as part of power sharing in the interview, I also pursued my own agenda of looking for data that could saturate the categories. Delimiting was by way selective coding and theoretically sampling the data as described above. I simultaneously continued to compare incidents, categories and concepts with each other to develop their dimensions and properties and identify conceptual gaps that required further theoretical sampling. These were then carefully examined to identify links and interconnections with other categories.

5.7.5 Theoretical coding

Theoretical coding is a higher level coding that provides a framework in which the substantive codes are related to each other as they are integrated into the theory (Charmaz 2006). Glaser (1998) suggests the researcher familiarise themselves with the many theoretical codes and coding families before identifying the one most suited to their data. I found the volume of theoretical codes overwhelming, often finding it difficult to make sense of their applicability and meaning. I had to shelve my investigation of them until the theory was nearing theoretical saturation. Identifying the core category as a cyclical basic social process (BSP), was the theoretical code that emerged as the most applicable for use in this study as the properties of the theory corresponded with the properties associated

with a BSP. The properties identified by Glaser (1978) suggest a BSP has a minimum of two stages which are variably time limited. It accommodates changes over time while not losing sight of the overall process, and transition from stage to stage and is marked by one or more events. This fitted well with the process the participants engaged in when attempting to resolve their main concern of *'Encountering and living in a disrupted relationship'*. The identified categories *'Encountering a disruption'*, *'Informed self'*, *'Countering the disruptions'* and *'Reclaimed livability'* became the four stages of the process that participants progressed through. Each of the stages were time limited with the end of each cycle being marked by an event such as, becoming aware of a disruption led to the need to be informed and becoming an *'informed self'* led to developing strategies to counter the disruptions. In addition, the nature of the stages changed in each cycle as the participants built on the strategies they had engaged in earlier cycles as they worked towards resolving the main concern of *'Encountering and living within a disrupted relationship.'*

5.8 Ethical considerations

'Ethics refers to that complex of ideals showing how individuals should relate to one another in particular situations, to principles of conduct guiding those relationships, and to the kind of reasoning one engages in when thinking about such ideals and principles' (Smith 1990, p. 141). Although ethical issues in research can be applied to many aspects of the research process, usually the focus of ethical consideration is on the power differential between the participant and researcher and the possibility for exploitation of the former (Lincoln & Guba 2003). The ethical principles used to guide the conduct of this study were the guidelines as set out by Nursing and Midwifery Board of Ireland (2015), the regulatory body for the nursing profession in Ireland and the professional body relevant to the researcher. The ethical considerations therefore included respect for the participant's autonomy and informed consent, non-maleficence and beneficence, justice and fairness, and confidentiality.

5.8.1 Autonomy and Informed consent

Autonomy for the participant intimates the research is conducted *with* participants rather than *on* them (Hammersley & Traianou 2014). The participant has the freedom to decide on getting involved in the research with an understanding of what that will entail, and have

the right to be influential on the decisions made in respect of the information they have shared with the researcher. A primary issue in respecting autonomy is concerned with the participant's ability to give true informed consent (Nursing and Midwifery Board of Ireland 2015).

Informed consent provides a means of protecting the rights of the participant (Smith 1992), allows participants to make autonomous informed decisions and is seen as a means of equalising the power differential between researcher and participant (Chenitz & Swanson 1986). Oliver (2010) advises for a participant to be as fully informed as possible, any information pertinent to the decision to participate must be given to him/her. Furthermore, the researcher cannot assume the participant will be able to foresee issues that might arise from participating; thus the researcher must, as far as possible, anticipate and make known any possible areas of difficulty that might arise. The subjective nature of informed consent makes it a difficult task to accomplish effectively, as the required information needed to make a decision to partake in the study can vary from participant to participant. Standardisation of information and consent forms does not always meet the needs of informed consent; rather, a dialogue between the researcher and participant is advocated in order to address specific issues of concern (Brody *et al.* 1997).

The Nursing and Midwifery Board of Ireland (2015) suggest obtaining informed consent is of primary ethical importance and, drawing on the edicts of Beauchamp and Childress (2001) advise; i) disclosure of information; ii) comprehension; iii) competency; and iv) voluntariness as the primary elements required for the consent to be valid. The information must detail all aspects of the research including participant's rights, risks and benefits, in a manner that is understandable from the participant's perspective. From the outset, there must be an ongoing opportunity for participants to seek clarification or ask questions of the research. Consent must be voluntary, free from intimidation or inducement, with the provision to withdraw from the study without any repercussions.

Ensuring informed consent was ethically and truthfully obtained was an ongoing activity from the outset of my contact with the participants. All potential participants received a written copy of the consent form which outlined the procedures, benefits, risks, exclusion criteria and confidentiality relating to the interview and study (Appendix 7). On meeting

with the participants I went through the consent form in detail, and in particular drew attention to the request to record the interview. I described the procedures I had in place for protecting their identity, discussed the potential benefits and harm of being involved in the study and stressed their right to withdraw from the study at any time during or after the interview. I encouraged the participants to ask any questions or seek clarification on any aspect of the study. All the participants agreed to their interview being recorded and the consent form was then signed by both the participant and me. The unstructured nature of the interview implied an uncertainty around issues that may have emerged during the process. I believed therefore that informed consent to use the data collected in the interview also needed to be given retrospectively. Once again, at the end of the interview I asked the participant to consent to use the information, shared with me in the interview, for the purpose of the study. All participants agreed and signed the consent form a second time.

5.8.2 Non-maleficence and beneficence

The principles of non-maleficence and beneficence are concerned with preventing harm and acting in the best interest of the participants, respectively. The potential risks to participants associated with the conduct of a study can occur in many different ways. Fatigue, discomfort, emotional distress and/or grief can be experienced as part of the recounting and sharing of personal memories and experiences. Although determining exact risks for participants at the outset of a research study can be difficult, Houghton et al (2010) advocate for the calculation of the risks and benefits of the study as far as is possible. The researcher needs to act in the best interest of the participant to ensure a balance between the risks and benefits is achieved. In addition, the participant must be aware that the benefits of the study may not apply to themselves but will apply to others in the future (The Royal College of Nursing 2003). My role as researcher in respect of the risk and benefits was to inform and protect the participant, as far as was possible. As discussed in section 5.6.1 above, the potential for the participant to experience emotional distress was discussed prior to commencing the interviews, and the participants were informed the interview could be stopped at any time without any negative consequences. The participants were aware that if they became distressed, I could turn off the audio recorder; in the cases where this occurred, the participants were reminded that this was an option.

In addition to experiencing distress recounting their experiences, there were other issues some of the participants found embarrassing or difficult to talk about. In these situations, I was guided by how the participants approached the issue or responded to questions I might have had about them. For example, in one interview I asked two questions relating to intimacy to which the participant simply answered 'No' on both occasions. The participant had had no difficulties elaborating on other issues in their relationship, so I believed either intimacy was not an area of concern for him or he was uncomfortable talking about it. I did not pursue the issue for two reasons. Firstly, guided by Glaser (1998), I was mindful of not looking for something that was not there just because I expected it to be there. Secondly, I believed the participant had the right to choose to speak or not to speak about any issue. Signing a consent form to participate in the study did not oblige him or any of the other participants to talk about things they did not want to talk about or provide me with the right to pursue such issues.

In the interest of the principles of justice and fairness, Christians (2003) advises the burdens and benefits of the research be justly and consistently distributed. In addition, the participants are required to be treated fairly and equitably throughout the whole process (Nursing and Midwifery Board of Ireland 2015). My role as researcher was to ensure all participants were treated with respect and all had the same level of inputs and access to information for understanding the research project. All participants were made aware that the benefits of the study would be realised at a later date and may not be applicable to them personally. However, some of the participants found they benefitted from participating in the study by simply having the opportunity to talk about their experiences or to get information from the researcher.

5.8.3 Confidentiality and Privacy

The very nature of exploration in social science inquiry threatens a participant's privacy in a way that is considered to be a potential source of harm (Christians 2003). Information on personal and private experiences is sought by the researcher and the participant ultimately relinquishes control over the representation of that information (Baez 2002). In addition, Hammersley & Atkinson (1995) discuss the concept of privacy in the context of distinguishing what is public information from what is private. They suggest the notion of

private information will depend on the view point taken by those involved. Moor (1990) views privacy as the control of information whereby the owners of that information, referred to as participants in this study, determine what information is passed onto others and how this is done so. Having respect for the participant, their autonomy and for the information they impart plays an integral role in maintaining their privacy.

Although the concepts of confidentiality and anonymity are interlinked, Baez (2002) differentiates between them stating that the former is related to personal information and the right to privacy while the latter relates to the right of the participant to remain unidentified. Effective in supporting the concept of confidentiality, safeguarding the anonymity for participants requires the researcher to remove any identifying information such as participant or third party names or information from the research site (Tilley & Woodthorpe 2011). When altering the descriptive elements of the study for the purpose of protecting the participant, the researcher needs to be careful not to alter the meaning of the story (Haverkamp 2005). Anonymity is not always a requirement however, there are cases in which participants wish to be identified in the research and they have the right for their contribution to be recognised (Walford 2005). This was not the case in the current study however, as all participants wanted to maintain their anonymity. In short, Baez (2002) suggests assurances of privacy, confidentiality and anonymity enhance the participants ability to be open and honest in the information they impart therefore supporting the integrity of the study. However, I was aware that the participants were not anonymous to me and that this fact might have altered the nature of the information they shared with me. In addition, I was aware of my professional obligation to break confidentiality particularly in relation to risk, either directly concerning the participant or concerning others. Prior to the participants signing the consent form I explained in detail these obligations and provided them with the opportunity to seek clarification on this.

In keeping with the principles of confidentiality and anonymity, all data was stored in accordance with the Data Protection Act (Government of Ireland 1988, 2003). To facilitate the protection of the data the following safeguards were put in place. Following each interview the recordings were given a code number. The person's name and corresponding code number were kept in separate, secure locations. The recordings and written transcripts were also kept separate; the former in a locked cabinet in my workplace and

the latter on a password protected computer, both of which only I had access to. The record of consent was also stored in a secure press away from the recordings, in a locked cabinet in my home. All transcriptions were conducted by the researcher, and during this process all names of persons or places disclosed in the interview were omitted. The participants were given assurances that the recordings would be destroyed once the study was completed.

In order to protect the identity of the participants, the code numbers applied were used in the interim and final reports. Careful attention was given to ensure that all other information such as biographical data or names of services attended were not used in the reports; therefore participants or the services involved in the study were not identifiable as far as was possible. In consultation with the participants, and in an ongoing effort to protect their privacy, due consideration was given to the location of the interviews. Only one participant chose to be interviewed in his workplace when all but one of the staff were attending an external training day, one participant, who was abroad, was interviewed by video link and all other interviews were conducted in a clinical setting.

5.9 Summary

The methodological procedures undertaken in this study were informed by Glaser & Strauss's (1967) and Glaser's (1978, 1992b, 1998, 2001) CGT approach. This chapter details the manner in which the CGT method was applied throughout the research process, with particular emphasis on how the core characteristics of coding, CCM, theoretical sampling, memoing and theoretical sensitivity were operationalised. I have discussed the manner in which the analysis progressed from description to conceptualisation as the theory developed. In addition, I have discussed the challenges, constraints, ethical considerations and progress I made along the journey. This journey culminated with the identification of the core category of '*Reconstructing Livability*' which was the way in which the participants continuously resolved their main concern of '*Encountering and living in a disrupted relationship*'. What follows in next four chapters is more detail on how the substantive theory of '*Reconstructing Livability*' was developed.

Chapter 6

RECONSTRUCTING LIVABILITY

6.1 Introduction

The substantive theory of *'Reconstructing Livability'* describes the process the participants undertake to address their main concern of, *'Encountering and living within a disrupted relationship'*. This and the following three chapters present an account of the theory. This chapter begins with a brief overview of the theory and describes the four distinct but interlinked stages of the process namely, *'Encountering a disruption'*, *'Informed self'*, *'Countering the disruption'* and *'Reclaimed livability'*. Following this, the remainder of the chapter presents in more detail the first stage, *'Encountering a disruption'*.

For clarity purposes, in the presentation of the theory the term partner is used for the person experiencing the eating disorder (ED) and the term participant is used for the person who participated in the research. In order to demonstrate how and why categories were developed, supporting evidence in the form of in vivo extracts from the data is included. Each in vivo extract is labelled in accordance to the identifying code number given to each participant, e.g. the first participant has the code number **Interview 001**.

6.2 Overview of the theory of *'Reconstructing Livability'*

The theory of *'Reconstructing Livability'* refers to the basic social process engaged in by the participants in response to encountering disruptions to their intimate relationship, that are perceived by them to come about as a result of their partner experiencing an ED. The disruptions are experienced by the participants as a change to the order and balance of the intimate relationship that had previously been established within the couple dyad. These disruptions occur over a protracted period of time as their partner experiences ED behaviours and cognitions⁷ with each ED setback⁸ they live through. The data demonstrates

⁷ ED related behaviours include food restriction, binge eating, purging behaviours and over exercising. ED related cognitions include dysfunctional thoughts in relation to self-esteem, body image, food and eating.

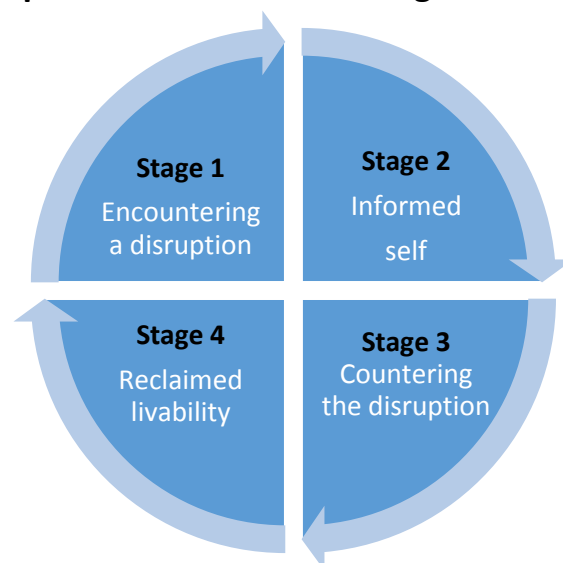
⁸ An ED setback as it applies to the current theory refers to the partners experiencing an escalation in, or a re-emergence of ED related behaviours and cognitions.

that the majority of the participants are living with a partner who experiences repeated ED setbacks:

'I was hoping that history wouldn't repeat itself but it is doing that...very quickly things just repeated itself all over again.' **Interview 005**

The theory of *'Reconstructing Livability'* is centred on a process participants go through in order to reclaim the livability of their life and the relationship. This process is a journey of recovery requiring each participant to engage in a personal recovery from the distress of living with ED related disruptions⁹ so that they can remain committed to the relationship and experience it and life in a satisfying way. The theory of *'Reconstructing Livability'* is a four stage process that is cyclical in nature, as participants repeatedly cycle and re-cycle through the stages. Each stage represents a category of the theory and the four stages are conceptualised as *'Encountering a disruption'*, *'Informed self'*, *'Countering the disruption'* and *'Reclaimed livability'*. Figure 6.1 below demonstrates one cycle in the process of *'Reconstructing Livability'*:

6.1 One cycle in the process of *'Reconstructing Livability'*



The cycle commences each time the participants encounter a disruption to their lived environment¹⁰ as a result of their partner experiencing an ED setback. The first stage in the

⁹ ED related disruptions refer to the disruptions that are directly attributed to living with an ED. In the remainder of the theory chapters, when I am talking about disruptions it will be specifically relating to the ED disruptions unless otherwise stated.

¹⁰ The concept of the lived environment as it applies to the current theory refers to the psychosocial environment, including that of the intimate relationship, within which each participant lives.

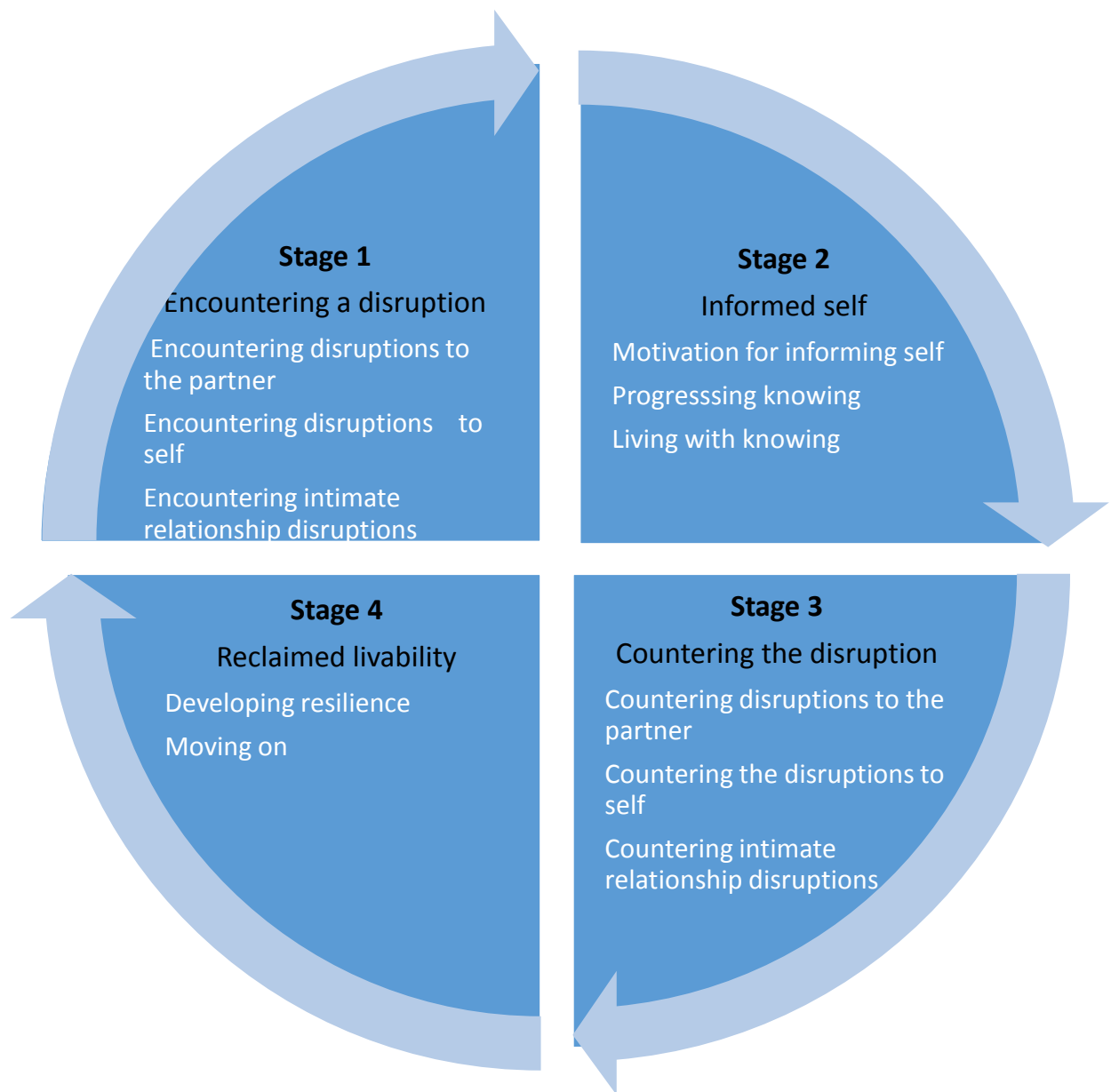
cycle is conceptualised as **'Encountering a disruption'** where the participants become aware of a disruption to their lived environment. This category consists of three subcategories conceptualised as *'Encountering disruptions to the partner'*, *'Encountering disruptions to self'* and *'Encountering intimate relationship disruption'*, each representing an aspect of the lived environment that has become disrupted.

The second stage in the cycle of *'Reconstructing Livability'* is **'Informed self'**. The subcategories in this stage represent the strategies undertaken by participants to help them understand the ED and make sense of the disruptions to their lived environment. The subcategories in this stage are conceptualised as *'Motivation for informing self'*, *'Progressing knowing'* and *'Living with knowing'*. Becoming an informed self is instrumental in guiding the strategies in the third stage, **'Countering the disruption.'** The subcategories in this third stage namely, *'Countering disruptions to the partner'*, *'Countering the disruption to self'* and *'Countering intimate relationship disruptions'* represent the strategies undertaken by the participants in responding to and managing the disruptions. These strategies are focused on recovering a lived environment where life and the relationship can be experienced in a satisfactory way.

Once participants have engaged the countering strategies, they move into the fourth stage of the process conceptualised as **'Reclaimed livability'**. This stage is concerned with the participants recovering their own lives, so they can remain committed to the relationship despite continuing to live with disruptions. The subcategories in this stage namely, *'Developing resilience'* and *'Moving on'*, represent the strategies undertaken by the participants to improve personal wellbeing so they can reclaim the livability of their relationship and lives.

The participants experience a period of stability within the lived environment at the end of each cycle of *'Reconstructing Livability'*, however, in the event their partner experiences a further ED setback they re-enter a new cycle at the first stage of the process, *'Encountering a disruption'*. Thereafter, reflecting the dynamic nature of the process, the participants once again move through the subsequent stages of the cycle. Figure 6.2 below provides a diagrammatic account of the process, detailing the categories (stages) and subcategories (strategies) contained in the process of *'Reconstructing Livability'*:

Figure 6.2 ‘Reconstructing Livability’: Categories and subcategories of the process



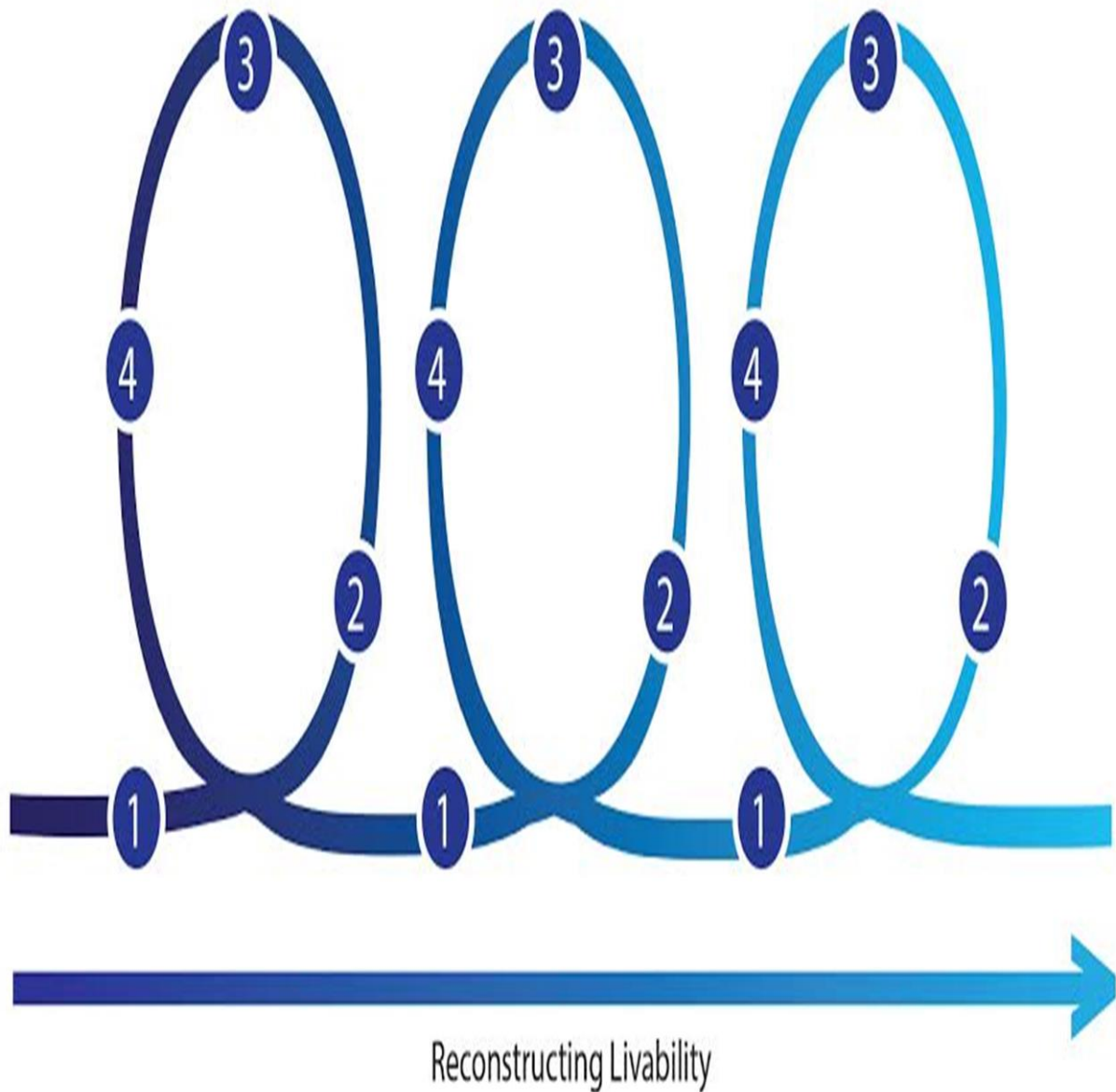
The rate at which the participants move through each stage during each cycle is mainly influenced by two factors. The first is related to the intensity of the ED behaviours and cognitions experienced by their partner. For example, the third stage '*Countering the disruption*' is prolonged for participants when their partner's ED setback is of a more severe intensity, as progression through this stage is in part reliant on a reduction or resolution of the ED related health risks¹¹ to the partner. The second factor influencing participants' rate of progression relates to their own mental and cognitive ability to work through the stages. For example, when participants experience heightened levels of distress or low mood they often find it difficult to progress through a stage. In addition to factors influencing the rate of progression through a stage, the rate at which participants work through the first three stages of the process is influenced by the number of times they have completed the full cycle, with the transition time involved decreasing as they enter successive cycles of '*Reconstructing Livability*'. The fourth stage, that of '*Reclaimed livability*' however, becomes more prolonged as the participants enter successive cycles. This occurs because the participants begin to focus more on reconstructing the self within the relationship, in order to be able to remain committed to and experience the relationship in a satisfying way.

The full process although cyclical is not a mirrored repeat of a previous cycle, as the nature of the strategies employed by participants change in each cycle as a result of participants learning from previous experiences and developing an understanding of their partners' ED and related disruptions. Neither does the repeat process follow a linear path of progression through the four stages, as sometimes the participants experience a doubling back or merging of the stages in a cycle. With each reliving of a cycle however, the participants move forward on their own recovery journey, and move closer to establishing a lived environment that is conducive to achieving personal and intimate relational growth and satisfaction, even if only minimally. To reflect a progression towards personal recovery where the participants reclaim the livability of the intimate relationship the shading in figure 6.3, depicting the theory of '*Reconstructing Livability*', gets progressively lighter.

¹¹ Health risks associated with EDs include such things as, dehydration, muscle weakness, osteoporosis, low blood pressure slow pulse, abnormal blood profile, kidney failure, heart failure and cardiac arrest

Figure 6.3 The theory of 'Reconstructing Livability'

Encountering And Living Within A Disrupted Relationship



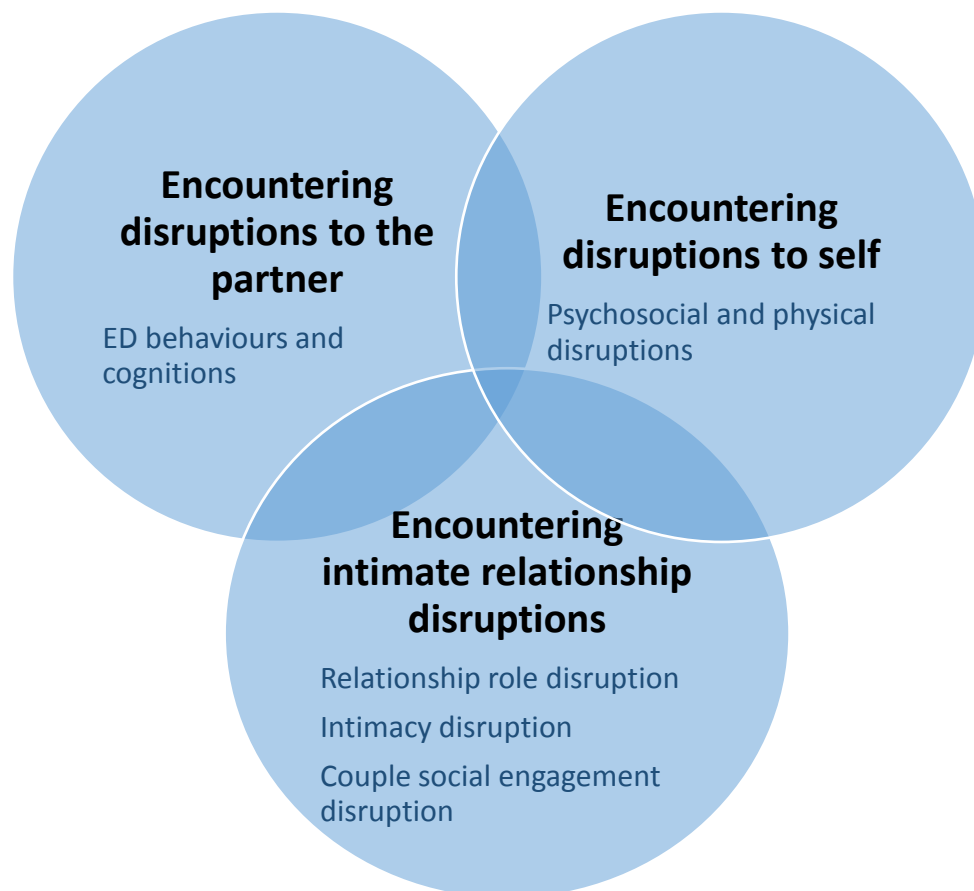
- 1 Encountering A Disruption
- 2 Informed Self
- 3 Countering The Disruption
- 4 Reclaimed Livability

As order and balance in an intimate relationship are unique to each couple dyad (Kelley *et al.* 1983) and is neither right or wrong, normal or abnormal, it is important to clarify that the nature of the order and balance within the participants' relationships is not the focus of the current theory. Rather, the focus of the theory is on the way in which the disruptions are experienced and the resultant underlying stages and strategies the participants engage in order to resolve their main concern of *'Encountering and living within a disrupted relationship'*.

6.3 Encountering a disruption

'Encountering a disruption' is the first stage of the cycle of *'Reconstructing Livability'*. In this stage various elements of the lived environment become disrupted, which impacts on the order and balance of the intimate relationship that has been established prior to a partner experiencing an ED or an ED setback. The interconnecting elements of the lived environment that become disrupted are; to the partner, the self of participant and the intimate relationship, which are depicted in figure 6.3 below:

Figure 6.4 Encountering a disruption



6.4 Encountering disruptions to the partner

The first indicator that a disruption to the lived environment is occurring is usually when participants encounter their partner's ED behaviours and cognitions. The ED behaviours and cognitions are not always easily observable however, particularly in earlier cycles of *'Reconstructing Livability'*, when participants do not have adequate knowledge of EDs and their partner does not talk to them about the ED difficulties they are having. Many participants' experiences suggest a significant length of time elapses from when a disruption to their partner begins to when they become aware of that disruption, as demonstrated in the following extracts:

'She was bingeing and purging then [Two years after they met, 30 years ago] but I did not know about that until about 10 years ago. She kept it a secret from everyone and it was hard to spot.' **Interview 015**

'She had an eating disorder when we met first. She had bulimia but I didn't know for a long time, she wouldn't tell me.' **Interview 017**

Becoming aware that a disruption to their partner is occurring usually starts with the more noticeable signs of the ED behaviours and the physical effects such as weight loss. In the earlier cycles of *'Reconstructing Livability'*, the participants find it difficult to make sense of the changes in their partner, which they often interpret as a medical issue. When their partner encounters repeated ED setbacks however, and participants become more familiar with the ED, they begin to associate the behavioural and physical changes with the ED:

'...and I said, "what's going on here", as I didn't know, but we didn't know at the time what it [weight loss, tiredness and headaches] was...maybe it was a virus, maybe thyroid...' **Interview 001**

'In terms of her physical appearance she has relapsed, she has gone back like she was, like there are bones poking out and you can see her ribs, you can see her spine, her breasts are tiny, her legs are like sticks, she doesn't really have a bottom anymore.' **Interview 005**

As participants live through successive cycles of *'Reconstructing Livability'*, their partner's reluctance to talk about their ED difficulties persist and so they continue to rely on the observable signs to indicate that an ED setback is occurring. With experience and the accumulated knowledge gained in each cycle, participants become more attuned to the

disruptions and use strategies of deduction, vigilance and instinct to identify a disruption, even when the signs are not so observable, as demonstrated below:

'I could see certain signs and, you just couldn't put your finger on it...because I knew there was just too many things adding up that was pointing towards the eating disorder.' **Interview 011**

'I know she is still throwing up when I am not there...if she tries to dodge the truth I will know by her, because she is not a good liar...I know now what is going on for her a bit and so I can keep an eye on things.' **Interview 018**

The ED related psychological disruptions experienced by their partner such as low mood or low self-esteem are more difficult for participants to make sense of, particularly when they have limited knowledge of EDs. When ED disruptions are a new experience the participants frame the psychological difficulties as low mood or anxiety and do not link them with the ED. It appears that framing the psychological distress as low mood or anxiety is because they are the first thing participants see, they are easier concepts for them to understand than the ED and they are perceived by participants as easier difficulties they can support their partner through. With experience of living through repeated cycles of *'Reconstructing Livability'* however, the participants begin to link their partner's psychological distress with experiencing the ED, which subsequently often become the indicator that an ED setback is occurring:

'I suppose, the, the biggest thing is, her mood can change you know, and it's usually a sign that the eating disorder is bothering her.' **Interview 004**

'It still hadn't dawned on me that oh well it's anorexia, I was still kind of thinking well maybe it is more depression so I booked a holiday away then for us...to cheer her up and give her something to look forward to.' **Interview 009**

As their partner experiences repeated ED setbacks, the participants begin to acknowledge the cyclical nature of the ED. This is an important development for participants' understanding of the ED and the long term impacts repeated setbacks may have on their partner, the self and the relationship. Seeing the cyclical nature of ED influences the expectations that participants have for their partner's recovery, where they begin to consider the ED will always be a part of their lives. Although this realisation can be distressing for the participants, in the long term it helps them to develop more realistic and

beneficial strategies to support their partner and counter the disruptions to the self and the relationship (discussed in the next chapter). Examples of the participants' awareness and acknowledgement that the ED will return are provided below:

'...and everything was going back perfect and she was nearly the nine stone again, and then she went off again, but they [ED behaviours] still kept going back then again, to square one again, and you wonder will it ever go away.' **Interview 001**

'I knew she would come out [of hospital] and then keep it [recovery] up for a while but then it was still, it is hard to see how, I never saw it [hospital] as a fix completely you know.' **Interview 006**

Although the disruptions are initially recognised in the form of their partner's ED behaviours and cognitions, with further ED setbacks experienced the participants also become aware of disruptions to themselves.

6.5 Encountering disruptions to self

Disruptions to self arise as the participant's encounter ED related changes to their lived environment that impact on their own psychosocial and physical wellbeing. The disruptions to psychological wellbeing evidenced in the data are consistent with the concept of psychological distress found in the literature on family member's experiences of living with a person with a mental 'illness'¹². The initial experiences of distress arise in the context of the worry and concern the participants have for the health and wellbeing of their partner. This persists throughout the entire process of '*Reconstructing Livability*', but is intensified in times when their partner is experiencing an ED setback. Although participants have a wide range of concerns for their partner's health, including osteoporosis, fatigue, fainting or low mood, a dominant distressing concern for the majority of participants is that their partner will die as a result of the ED, as demonstrated below:

'My main worry I believe, I could be wrong, I believe I will find her dropped dead any day now or she will drive the car and she will crash the car with the kids in it. But that is where I believe she is at. If I heard tomorrow she had a heart attack walking down the road I wouldn't be surprised.' **Interview 015**

¹² Refer to the forefronting literature in subsection 3.7 on '*Caring in close intimate relationships*' chapter 3

'It's Scary to think if she starts again [not eating], like reliving that all over again only it will be worse the next time, she will kill herself, it will go that far. Her body is damaged, her throat, her teeth. It's frightening to think if she goes over the edge I will never get her back.' **Interview 017**

Although the distress of worrying for their partner continues with each cycle of 'Reconstructing Livability' experienced, this distress is reflected in many other emotions. As participants live through repeated ED setbacks and encounter further disruptions to the lived environment that do not seem to be resolving, they experience emotions such as anger, frustration and disappointment. Examples of these are provided in the following extracts:

'It's more, actually at this stage, I kind of, as well as being worried a lot the time I'm angry and fed up.' **Interview 005**

'She can be well for an awful long time her body is very resilient...and then it comes to a head every now and again usually once a year or once every two years, it is becoming more frequent it has been becoming more frequent the older she gets and that's very frustrating.' **Interview 007**

For some participants, encountering disruptions to the lived environment impacts on their mood and peace of mind. However, as evidenced in the narratives, the participants are reluctant to frame these experiences in medicalised terms such as depression and anxiety. When they use these terms to explain how they feel, they are used in a cautious way, or the feelings are framed as feeling down, sad, fearful or stressed as demonstrated here:

'I'm quite down a lot of the time as I have to say.' **Interview 005**

'And I think I probably suffer from a little bit of depression now a small bit...I wouldn't classify it as anything major if you know what I mean, but I do get down, a lot of people get down as well.' **Interview 007**

As evidenced in the following extracts, participants also link their psychological distress with not knowing how to support their partner effectively. The distress at seeing a further ED setback, despite their efforts to support their partner through recovery, leaves the participants feeling lost and often hopeless for their partner. Over time this hopelessness can extend to the relationship where the participants question their ability to remain

committed, because they feel unable to provide a support that positively impacts on or makes a difference to their partner's recovery:

'I actually feel I have done all I can. I've tried throwing money at it, called in favours, getting my sister involved, you eventually run out of avenues...Unless I'm missing a trick I just don't know where to turn.' **Interview 015**

'When you actually feel like "I can't do this anymore, I can't be in this relationship, it's never going to go back to the way it was", you nearly feel, you feel a little bit trapped.' **Interview 009**

The distress of not knowing how to support their partner effectively is further added to when participants feel excluded from the professional inputs provided to their partner. Although the participants understand this in the context of confidentiality for their partner, they find the lack of information on their partner's progress or lack of guidance on how to support them disempowering:

'The one thing that used to get to me was when I was going over to the specialist with X [partner] I would sit in the waiting room while she was in talking and I never knew what was going on in there, so I never knew what to do when she came out.' **Interview 011**

'The problem is I only know what she tells me so if she comes back from her hours session and I ask her, "Oh it was great we had a good chat I feel I'm making progress baby steps", and she'll throw a few technical words at me. And that is me boxed off for a week. I feel I have let her off the hook.' **Interview 015**

Psychological distress also arises as a result of participants' perceived understanding of other people's attitudes and perceptions about them living with a partner with an ED. The participants worry that other people judge or blame them for their partners ED or an ED setback. When they perceive others to think they are not able to support their partner effectively, it impacts on their self-efficacy and confidence in relation to supporting their partner. In addition, many participants experience the judgements of other people who do not understand the ED, as stigmatising. Examples demonstrating the concerns regarding other people's perceptions are provided below:

'I worry about how they see me treating it that kind of way or if they think I'm treating it right or wrong.' **Interview 006**

'His family are very mixed up, I see that as the whole problem to start with, so when they start telling me what I should and shouldn't be doing it drives me crazy...I know they blame me for him not getting better.' **Interview 013**

'The stigma of mental illness is a very difficult thing to live with and people do not really understand...they can be very judgemental.' **Interview 016**

The participants' concern for how other people judge them goes some way towards explaining the disruptions to social functioning they experience, however this extends to include the participants' concerns about how others judge both their partner and the relationship. It is in the context of protecting their partner and relationship from others' judgement that the participants do not want to share personal ED information. As a result they often avoid social situations where they think other people will be looking for information, as demonstrated by the following participant:

'I don't mind going out with my old friends as they don't be asking questions about X [partner] and if they do they are only trying to help, but I have to say there are certain people I avoid going out with because all they want is the information, the run down on what X [partner] is doing, and personally it is none of their business.' **Interview 012**

Whilst limiting social engagement is considered a protective strategy, like a double edged sword, it results in the participants changing the way they engage with other people in the wider social world. Consequently, they may become 'silent', more distant and isolated from others, which is often experienced by them as feeling alone. As time progresses, their silence has a significant negative impact on their ability to access social supports for themselves, as demonstrated below:

'Knowing she was getting slowly worse made me feel lonely, alone and overwhelmed it was tough. I didn't like to talk to my friends about it [ED], I talked to X [partner], we're each other's support. That's why it was lonely when she wasn't there [when partner was in hospital] no one was there.' **Interview 010**

In addition, limiting social engagement adds a further layer of pressure to participants, as access to social supports for their partner is also limited, resulting in participants becoming the main and potentially sole source of support for their partner. Being the only support

for their partner can be an overwhelming and lonely experience for the participants as they feel they are responsible for their partners' recovery, as demonstrated below:

'She doesn't really have much of a social life to be honest with you, she wouldn't have many, many close friends at all. She would not have many friends at all, I'm kind of it.' **Interview 005**

'I would say I would worry more, like yes, because beforehand I think if she was at home her parents would make sure she was eating or, but here it's knowing myself she's not eating lunch or breakfast at whatever time and she is having no lunch. I feel responsible, before it was her parents' responsibility.' **Interview 006**

'It's difficult being the main person, there is no break from it, but you have to take your lumps. There are days when you feel it more keenly than others but that's what you sign up for.' **Interview 014**

A further cause of the disruption to social functioning is the impact of participants' psychological distress has on their motivation or ability to interact with other people. This can extend to include missing work, where the participants are afraid to leave their partner out of concern for their health, or the distress leaves them unable to concentrate at work:

'I'm so much quieter and, withdrawn I suppose would be the right word. So, if it has been a bad week and I am stressed, I suppose I would be quiet and I don't say much. If anything goes wrong I'm not one to, to talk to people and I want to bottle it up and not be with people...' **Interview 005**

'She wakes up at night crying, she thinks she is dying with heart palpitations. This really frightens me. I know she is sick when she tells me she is afraid, that happens about twice a year. It has an awful effect on me, I'm even afraid to go to work.' **Interview 015**

In addition, living with the ED related psychosocial distress also impacts on participants' physical health. In an attempt to cope with the distress, many of the participants use strategies such as overeating, drinking alcohol to excess, or ignoring their own needs when caring for their partner takes precedence. These strategies have long-term negative consequences for the participants' physical wellbeing, as demonstrated in the examples below:

'I was drinking too much, not in a sort of an alcoholic way, it's just in the sense that I was drinking and it was affecting my ability to get up early in the morning and to go to work.' **Interview 007**

'I found ways of coping when I wasn't talking to someone, I developed an interesting way, eating a block of ice cream a night. I still do. I developed a slight overeating disorder a couple years ago. When things were stressful I had to get out of the house, walk to shop for a block of ice cream. Then I did it every night to get out.' **Interview 017**

A distinct feature of the psychosocial and physical disruptions participants experience is the manner in which these are paralleled with the ED setbacks experienced by their partner. The disruptions to self are experienced more when their partner is experiencing an ED setback, were the participants distress levels increase initially as a result of the health concerns they have for their partner. When their partner is experiencing an improvement in the ED, improvements in disruptions to self also occur, such as a reduced worry for their partner's health or an improvement in concentration in work:

'...but once she gets stressed, I think she goes back to not eating properly and then I get stressed out again too.' **Interview 006**

In addition to encountering disruptions to the self, with each cycle that the participants live through an awareness of the impact of the disruptions is extended to include the intimate relationship.

6.6 Encountering intimate relationship disruptions

As a result of encountering disruptions to their partner and the self, participants also experience disruptions to intimate relationship functioning. An awareness of the disruptions to the intimate relationship is a gradual process which develops as the partner experiences further ED setbacks and the ED related changes in relationship functioning become more evident. Three distinct but interlinking subcomponents to intimate relationship disruptions are encountered namely, relationship role disruptions, intimacy disruptions and couple social engagement disruptions. Due of the significance of these three subcomponents to the theory each one will be discussed separately.

6.6.1 Relationship role disruptions

The relationship roles that have previously been established within the couple dyad change in response to the partners repeated experiences of ED setbacks. Most noticeable is the

caring role the participants take on as they begin to recognise an escalation or change in the nature of their partners' ED related needs. These changes in the caring role extend beyond what participants consider to be the normal couple caring already established in the relationship, which are required to be provided over a protracted period of time. The ED related caring includes the physical, psychological and social dimensions of their partner's needs arising from experiencing an ED. For example, the impact of the ED on a partner's wellbeing often requires the participant to take over the self-care needs of their partner or additional daily living tasks:

'Apart from the fact that she, you know, the illness has taken over, taken her over so much that she sometimes can't feed herself and I have to help her with that.'
Interview 003

'I do it [housework] because physically she is not the best to be running around hoovering I think anyway she would still do it if I didn't do it so I wouldn't be too happy about it.'
Interview 007

Generally the participants take on this aspect of caring for their partner willingly. However, in times when the ED behaviours and cognitions are perceived to significantly interfere with their partner's ability to care for themselves, the caring role the participants take on are perceived by them to be similar to that of a parent/child dyad:

'I was more like emm a father figure, or a Guardian, than the husband.'
Interview 001

Taking on a parental role is not something the participants are happy to do as it often results in them engaging in hyper-vigilant behaviours or highly emotionally charged interactions which they perceive impact on the way the relationship functions:

'Because that's what it became like, life as a couple became, you know, I became the parent and then she became afraid of me...'
Interview 003

'Then daily she was still vomiting and doing whatever she was doing and it came, a row would start then. I'd bring it up but it would just be, it would just end in an argument.'
Interview 004

'I came from work and snuck in the door...I sat at the bottom of the stairs. I knew where she was, I waited at the end of the stairs and I could hear her [the participant makes a vomiting noise] and I can hear her and hear her.'
Interview 015

Linked with disruptions to personal social functioning as discussed in the previous section, taking on the role of vigilant parent further impacts on the participant's opportunities for social engagement. Generally this happens because the participants feel that the need to be in close proximity in order to support their partner is more important than the need to engage in their own life activities, as demonstrated by this participant:

'I have started just coming home rather than staying at work and studying. When I come home at least I would be with her at dinnertime.' **Interview 009**

Even though participants acknowledge a change to their role within the relationship and willingly respond to their partner's caring needs, they are reluctant to frame themselves as being their partner's carer; although, they perceive that other people in their wider social world consider them to be so, as suggested below:

'The hard part is when my family, although they are well meaning, ask me how am I coping with caring for X [partner with the ED], for God's sake it's not like he is a complete invalid or 90 years of age I hate it when they see it that way, it's all wrong.' **Interview 013**

'I never wanted to become her carer but sometimes it feels that way, and other people certainly see me as her carer especially the kids, when they see the things I have to do for her.' **Interview 016**

'I don't see myself as a carer, and I wouldn't like it to come to that.' **Interview 018**

Although the participants do not want to become a carer to their partner, relinquishing some aspects of the caring role can be difficult for them. Even in times when the ED is less problematic for their partner, participants remain vigilant and provide aspects of ED caring such as support at meal times. This is due to their understanding of the cyclical nature of the ED, where the participants want to help prevent further ED setbacks from occurring, as evidenced in the following comments:

'From my point of view, I don't think I missed one day in two years, going home at 4:30 and have the dinner at 5:20 because she would be home by that time and I knew if I was later she would, I, I think, I didn't give her the chance to miss it. That was for two years, I'd say.' **Interview 001**

'Although she [partner], doesn't say very much about what is going on for her, I now have more of an idea and can bring it up in conversations. I can keep a discrete eye on what she is doing and call her on it before it gets out of hand.' **Interview 016**

The participants acknowledge that taking on ED related caring disrupts the equilibrium of the intimate relationship where interdependent functioning changes as their partner become increasingly dependent on them. This reaches a point where participants become concerned about their partner's ability to function independently and have an independent life, as suggested below:

'If I was to die tomorrow, I don't know how she would cope. First of all I really don't know, I dread what would happen, what she would do. She is not in that mental state or anything like it, I really don't know what she would do because I do everything for her anyway.' **Interview 003**

'She does say now, if I ever died if I ever left her that she would kill herself. she doesn't say it as a threat, it is more of a how "would I do without you" sort of stuff which is a double edged sword that someone loves you so much that they rely on you.' **Interview 007**

Striking a balance between their partner being able to function independently and providing the partner with adequate support, without generating dependency, is a difficult path for the participants to negotiate. This is difficult for three main reasons, the first of which as discussed above is the participant's need to remain vigilant for ED setbacks. Secondly, in light of the understanding that social functioning for their partner is seen to be disrupted, many of the participants find they become the sole source of support for their partner. Thirdly, over time the changes to the relationship such as the changed roles, become absorbed into how the relationship functions and become the norm. In addition to the changes in relationship roles, the participants also encounter disruptions to other aspects of relationship functioning, including disruptions to intimacy which is discussed in the next section.

6.6.2 Encountering intimacy disruptions

Encountering intimacy disruptions refers to the changes in intimate interacting within the relationship. The participants speak of several salient elements of intimate interacting that become disrupted as a result of the ED, namely communication, trust and sexual intimacy. ED related changes in communication within the couple dyad emerge in the context of

what is conceptualised in the current theory as *'Encountering silence'*. In contrast to other issues that the couple continue to communicate about, *'Encountering silence'* is concerned with both people within the relationship dyad not sharing ED related distress, concerns or difficulties with the other. The participants perceive their partner's silence as a way of concealing the ED behaviours and cognitions, but this silence leaves them distressed as they do not know what is happening for their partner as evidenced in the following extracts:

'She would convince me she had it under control, but I could see before my very eyes what was going on. It really affected my concentration you see, I wasn't sleeping, I was so worried.' **Interview 016**

'We had the big fight after she told me [about ED]. I didn't know what it was, I didn't know she was going into the toilet and throwing her guts up. She told me she had it for years, I hadn't a clue. We were married a year or 2 at this stage...I was annoyed, really angry, she hadn't said it before that and that was what the fight was over...It was hard not knowing something was wrong but knowing something was not right, not knowing what it was, not knowing anything about it, then being landed with it.' **Interview 017**

Participants also acknowledge their own engagement in ED related silence, explaining it as a way of protecting their partner from blaming themselves for the participant's distress or from becoming distressed if the ED is spoken about. ED related silence is also seen by the participants as a way of protecting the relationship from conflict. However, although they achieve the goal of protecting their partner and the relationship by keeping silent, this can be considered as a missed opportunity to access ED related support from their partner or a missed opportunity to challenge their partners' ED behaviours. These issues regarding the need to protect are illustrated by the following comments:

'So how do you break that cycle [the cycle of ED behaviours and cognitions], without hurting and destroying and making life further stressful for the person, that is the trouble.' **Interview 003**

'I'm not sure and I don't really want to bring it [ED behaviours], up because we would only start arguing. She can be very defensive about it [ED behaviours] and about her ways, now and then, it would all start an argument if I, I brought it up now.' **Interview 006**

'I told her that I always had mood issues as I think she probably said at one stage, no she's always saying it you know, that she is to blame for my mood.' **Interview 007**

The impact of not sharing ED related information within the couple dyad creates a sense of mistrust which is directed not only towards their partner but towards the self of participant. In the context of not knowing what is going on for their partner and subsequently not knowing how to support them effectively, the participants begin to mistrust their ability to do right by their partner, as illustrated by the following participants:

'Getting it right isn't easy, it's a bit of trial and error to be honest, but I began to see more the things I was doing wrong than the things I was doing right.' **Interview 013**

'I am not sure I trust her, although of course I trust her it is just I don't know if I trust myself now, you know, by doing the right thing.' **Interview 018**

Disruptions to intimate communication are also reflected in a change in communication style which is linked with the sense of mistrust and linked with '*Relationship role disruption*', such as being a vigilant parent. A combination of concern for the partner's wellbeing, frustration, anger or disappointment at living with ongoing ED setbacks or living with mistrust can often result in high expressed emotional interactions between the couple, as demonstrated below:

'But probably the most frustrating thing is there is no noticeable difference and, so you know, so there would be times when you would love to just say it, and sometimes I end up losing it with her.' **Interview 002**

'I said to her "I hate it", I can't make it "I hate you". It's about a year since that has happened to me. I just hate it. I [swear word], hate it on every level. She cried.' **Interview 015**

In addition to encountering communication disruption, participants also encounter disruptions to sexual intimacy and physical closeness, where the intensity and frequency of sexual intimacy gradually diminishes over the course of repeated ED setbacks. The reduction in physical and sexual contact is explained by the participants firstly, as a result of their own reactions and discomfort with the ED related physical changes in their partner, as evidenced in the following extracts:

'We used to always cuddle on you know in the evening times and I was finding it very hard then, to cuddle on, like just touching ribs I couldn't cuddle on, do you know? Because I couldn't feel comfortable cause I knew it [partner getting better], wasn't working and I can't encourage her by me being alright, because I'm not

alright. **Interview 001**

'What goes with that when she [partner] goes through those cycles [cycles of vomiting], is she would go to bed and not have washed her teeth. She would go to kiss me and I would be thinking oh [swear word]...I use the words in my own head, "she's dirty", so that effects our relationship because I don't want to be intimate with her. As far as I'm concerned she's dirty.' **Interview 015**

Secondly, the participants often attribute difficulties in sexual intimacy to challenges their partner experience around body image, poor self-esteem or low mood. For those participants who have lived through many cycles of 'Reconstructing Livability', and have gained some understanding of EDs, they understand their partners' sexual intimacy difficulties as complex, involving many other issues, as demonstrated below:

'I know she does have the body image issues, she hates her stomach, always, like if I ever tried to hug her and tried to put my hands anywhere near her stomach she's 'get your hands away you know I hate it.' **Interview 005**

'Normal sex life is not happening it's partly to do with a degree of dysmorphia but more to do with OCD [Obsessive Compulsive Disorder], there is stuff happening on many levels, things feeding into each other into a vicious circle, it's very complex.' **Interview 014**

Despite engaging strategies to counter the disruptions to the intimate relationship, as will be discussed in the next section, sexual intimacy often continues to be disrupted, which is perceived by the participants to be a long term consequence of their partner experiencing an ED, as suggested below:

'We stay away from sex or all of that no, no, that's very much non-existent. I would say after, say the last four or five years you know, prior to that, on and off you know, but after that no, not. I'd certainly say that some of this is down to that [ED], over the years, going back, around the eating disorder probably a lot of it was around the eating disorder.' **Interview 003**

With the exception of sexual intimacy, disruptions to intimate interacting occur in line with the pattern of ED setbacks or improvements experienced by the partner. For example, interactions become less highly emotionally charged when the participants are less worried for their partners' health. Equally, when there is an improvement in the ED behaviours and

cognitions, the focus of verbal communication shifts from those that are ED based to more 'normalised' interactions, as demonstrated below:

'It, [talking about normal things], sometimes it stops, there's a lot around eating disorder, and other things just sort of stops, communication for a while, and then something will come up that we start talking again and things get better for a while, but then it stops again...' **Interview 006**

However, each time the partner encounters further ED setbacks disruptions to intimate interacting become more evident. As the participants live through successive cycles of '*Reconstructing Livability*', they begin to work around the silence and manage the high emotionally charged interactions in a different way, so that the disruptions to communication are less distressing for them. This will be discussed in more detail in chapter 8, '*Countering the disruptions*'.

In addition to encountering disruptions to intimate relating, disruptions in relating to other people in their wider social world are also experienced by the participants to include family, friends and colleagues. This is conceptualised in the current theory as '*Encountering social engagement disruption*', and is discussed further in this next section.

6.6.3 Encountering disruptions to couple social engagement

Encountering disruptions to couple social engagement extends the idea of disruptions to personal social functioning as discussed in the subcategory '*Encountering disruptions to self*', to include disruptions to social engagement specifically relating to the couple. Disruption to couple social engagement is perceived by participants to be the result of difficulties experienced by their partner in relation to food and body image. Consequently couple social engagement becomes limited, particularly when socialising is centred on eating and drinking, as suggested by the following participants:

'Socialising doesn't really happen. X [partner], struggles with meals, she doesn't drink, there is some social interaction but not to the extent a normal couple would,' **Interview 011**

'We don't travel, he's afraid of flying, being away with foreign food, he will not eat out and these are things I love. He doesn't drink anymore it's about control and the fear of nausea. Socially it's difficult.' **Interview 014**

Participants also limit couple social engagement in order to protect their partner and the couple relationship. Firstly, by limiting social engagement participants believe that their partner is protected from having to experience the distress of socialising, especially if food is involved, as socialising is perceived by the participants to evoke high levels of anxiety in their partner. In addition, many of the participants' experiences are that EDs are not understood by other people and to expose their partner's ED to people in their wider social world is difficult for their partner because of the stigma attached to having a mental 'illness':

'And she would have said to me, 'I can't go, the reason I can't go is if I go and we would be invited for a meal, there is no way that I couldn't not go for a meal. So we didn't go.' **Interview 003**

'People find it [mental illness] is still stigmatising...Eating disorders are hushed too, people don't know or don't say anything about it...I can see people I know who have an eating disorder but they don't talk about it because of the stigma. There is something wrong with you if you have that, a person doesn't want to be found out.' **Interview 017**

Secondly, limiting social engagement is perceived by the participants to be a way of protecting the relationship from being thought of, by others, as a carer/cared for relationship. The participants also want to protect the relationship from judgements other people might make about how they interact as a couple, particularly if their interactions are strained or difficult. Contrary to the high value participants place on their relationship, their perception is that when other people see the relationship in these ways they devalue it, often to the level of advising them to leave:

'I told one friend about it [ED] and he's still, he's a good mate but he has seen her at her worst and we have gone on some sort of couples holidays together and they were pretty bad to be honest, and he says "you don't deserve it", he's like "finish it I don't care if she is sick" but I still love her, do you know but it's hard when he [friend], says that.' **Interview 005**

'My parents were very angry, they maybe are a little more reserved in their criticism but I still think they still don't accept it. They just see it [the relationship], as me having to look after her...of course they don't want their son to have a wife to have a (pause), but I feel hurt, angry, betrayed and let down [by parents]...it's probably for the best that there is distance between us now.' **Interview 010**

Thirdly, limiting social engagement as a couple is a strategy to protect the self. Often when socialising, the participants feel different from other couples or are embarrassed by their partner's ED behaviours or cognitions which they perceive other people do not understand. In addition, in an effort to protect themselves against a perception that others blame them for their partner's ED, the participants limit social engagement as a couple so they are not exposed to this thinking from others. Examples to demonstrate these issues are provided below:

'When she is pushing the food around on the plate, I can see how people at the table are looking at her and then at me as if I should be doing something about her not eating, I'd prefer to avoid those situations.' **Interview 009**

'We couldn't have people over for food because of her eating, I suggest we have everyone up for a meal and divide a head of lettuce between them all, I think it's embarrassing.' **Interview 012**

A further dimension to limiting social engagement as a couple is the participant's need to protect other people from the potential distress of knowing what is happening in the relationship or to prevent them from worrying about what both members of the dyad may be experiencing:

'They [participants parents] have, they have said "I'm concerned about your own mental health at this stage", which is a bit of a shock for someone to say that, because I wouldn't have said anything to them.' **Interview 005**

'Well, I know her family are there but then I can see her family stressing out as well so it [seeing family members' distress] is hard, I don't want them to see what's happening and then get stressed out.' **Interview 006**

As participants encounter disruptions to their partner, the self and the intimate relationship, the need to be able to make sense of and counter the disruptions effectively is the catalyst that moves them on to the next stage in the cycle of 'Reconstructing Livability', namely 'Informed self'.

6.7 Summary

This chapter discussed the first stage in the theory of 'Reconstructing Livability', conceptualised as 'Encountering a disruption' which signifies a recognition of a disruption to various aspects of the participants' lives which they consider to occur as a result of their

partner experiencing an ED. It is usually the partner's ED behaviours and cognitions that are first encountered by the participants where changes to the physical and psychological health of the partner are acknowledged. Over time the participants become increasingly aware of the disruptions to the self, where their own psychological, social and physical functioning becomes impaired as a result of living with a partner who is experiencing repeated ED setbacks. The third aspect of encountered disruption to be acknowledged are the disruptions that come about to relationship functioning, namely to the relationship roles, intimate interacting and social engagement as a couple. Once the participants have an awareness of the encountered disruptions, they seek to understand more about what is going on for their partner and the relationship, thus they transition to the next stage in the cycle which is conceptualised as '*Informed self*', which will be discussed in the following chapter

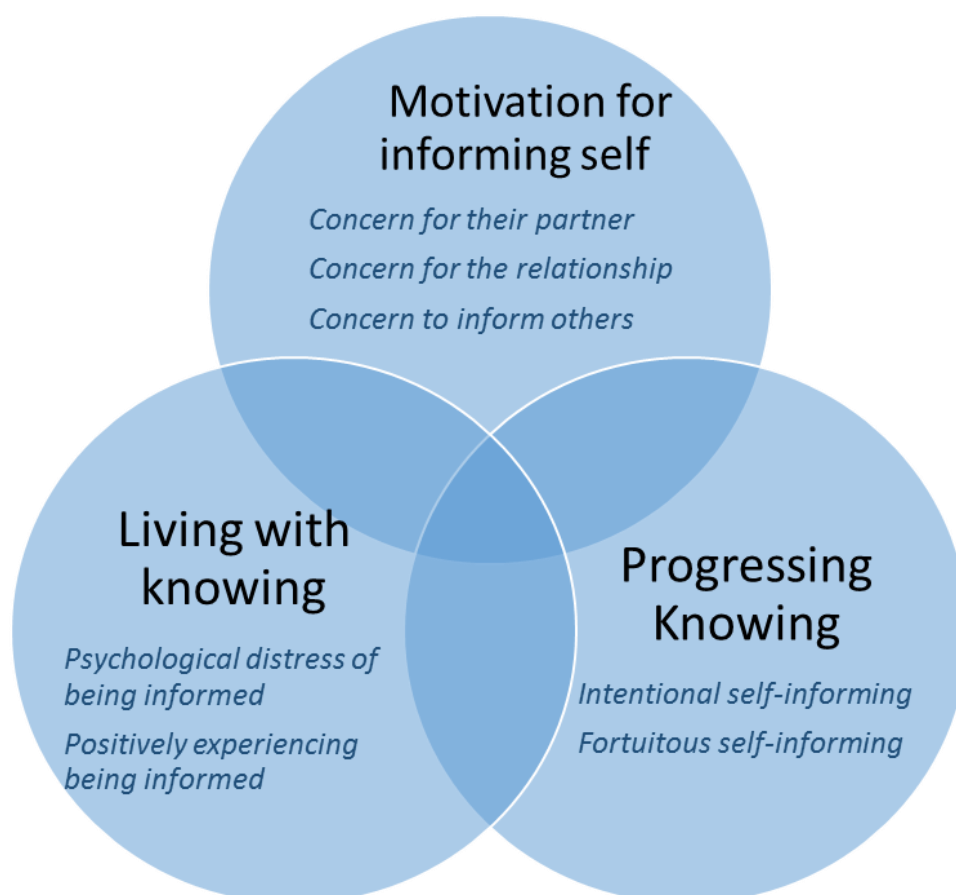
Chapter 7

INFORMED SELF

7.1 Introduction

The second stage of the theory of *'Reconstructing Livability'* is concerned with the participants informing themselves in relation to the encountered disruptions that have come about to their partner, the self and the intimate relationship. The need to understand the eating disorder (ED) so they can make sense of the disruptions and be in a position to support their partner is the catalyst for moving them onto this stage in the cycle, which is conceptualised as *'Informed self'*. This chapter presents the stage of *'Informed self'* which consists of the subcategories *'Motivation for informing'*, *'Progressing knowing'* and *'Living with knowing'*, (Figure 7.1)

Figure 7.1 Informed self



7.2 Motivation for informing self

Encountering ED disruptions to their partner, the self and the intimate relationship presents participants with a situation where they feel poorly informed as to the nature of EDs¹³. Being poorly informed impacts on their ability to make sense of the disruptions and on their ability to support their partner effectively. The lack of information regarding the nature of EDs is a common experience for most of the participants in the current study and is more pronounced in earlier cycles of *'Reconstructing Livability'* when living with the ED in their lives is a newer experience. However, even when the participants live through successive cycles of *'Reconstructing Livability'*, they continue to encounter new issues relating to the ED experienced by their partner that require further self-informing. The nature of information seeking therefore is time and situation specific. Time is related to the information gained in previous cycles of *'Reconstructing Livability'* and situational related to the new ED issues experienced by the participants. An example of a participant having limited knowledge of EDs is evidenced below:

'She fainted one time when we were driving along. I thought she had dropped dead, I just heard her head hit the dashboard, I had to pull in and I didn't know what was wrong. She put it down to "oh I ran too much, low sugars, I might be diabetic, I might be all these things" etc. Me being a business man, I knew nothing about all this health stuff.' **Interview 015**

Not having adequate knowledge of the nature of EDs is compounded by feeling alone in the experience of living with a partner with an ED, where the participants do not have access to other people's similar lived experiences from which they can gain some understanding. All but one of the participants report not knowing any other person who is living with a partner experiencing an ED, and for the one participant who does know another partner in a similar situation, he reports they have never discussed the ED. In addition, very few participants even know another person who has an ED. One participant did report gaining some ED information through the experience of living with a sibling who had an ED as a teenager. As demonstrated below, this participant's experience of living with a sibling was different from that of living with a partner with an ED, which suggests

¹³ The nature of EDs in the current theory refers to the development and maintenance of the ED cognitions and behaviours for the partner experiencing the ED, and the meanings that are attributed to it by both the partner and the participants

the information and support needs for partners are different from the information needs of other family members:

'...because, I suppose me personally I was, my sister had anorexia. I would always be a little bit aware of it or a little bit, I would notice the little signs. But I suppose with my sister I was able to take a backseat a little bit...I had my mam and dad they were very good and very supportive whereas with X [partner], it's very much me.'

Interview 009

Participants are aware however, that others in their wider social world do experience EDs, but their lack of knowing or interacting with these people is, in part, explained by them as a reluctance to talk about the ED. This is in contrast to other mental health issues such as depression which the participants seem to be more familiar with, as evidenced in the following extracts:

'Nobody has told me if they have been or have any experience in it [ED].' **Interview 005**

'I have never met anyone with an ED but I have met those with depression. I know it [ED] is not rare as I have googled it. Interesting, it is common but I haven't come across it before, maybe I am naive about it, I've probably seen it [others with an ED] but not noticed, or maybe it's just not said...' **Interview 012**

'I don't know anyone else in the same position as me, although I have friends with wives and husbands who have depression and one who has bipolar.' **Interview 016**

Regardless of the number of cycles of 'Reconstructing Livability' participants live through, a realisation that they do not have adequate ED knowledge or access to that knowledge through others' experiences motivates them to seek information. The need to become self-informed is primarily driven by concern for their partner, concern for the relationship and concern for others in their lives such as family and friends. These three areas of the participants' concerns are discussed in the next subsections.

7.2.1 Concern for their partner

The initial motivation for the participants to become informed arises in the context of encountering the ED behaviours and cognitions experienced by their partner. This is perceived by the participants to affect their partners' psychological and physical health which, as discussed in the subsection 'Encountering disruptions to the partner' (chapter

6.4), many of the participants fear might result in their partner dying. Not having the necessary information on the nature of EDs or the understanding of what their partner is experiencing reduces participants' self-efficacy in relation to supporting their partner effectively. This evokes feelings of powerlessness and helplessness, as demonstrated by the following participants:

'...she was getting very annoyed with me saying you don't know what I'm going through, and I said actually I don't, I hundred percent agree with you, I don't, I would love to understand what you're going through but I don't...I don't know what else to do...' **Interview 005**

'...I never knew how to help her the next step. It was kind of, what can I do in order to help her? It was probably, bar her giving birth to X [their child], it was probably the most helpless I have ever felt in my life.' **Interview 011**

Participants continue to provide support to their partner despite feeling ill equipped to do so; however, they often perceive their attempts at providing this support to be inadequate or unhelpful. Most of the participants identify times when their attempts at providing support caused further distress to their partner or created conflict within the relationship, which compounded their sense of low self-efficacy and powerlessness. Even when participants live through further cycles of 'Reconstructing Livability', and begin changing what they perceive to be the less helpful supportive interactions, they continue to hold onto these past experiences with a deep sense of regret and shame:

'...you know, threatening, you know, is not the way to do it [support the partner], because to come back from those threats takes a long, long time, you know. And X [partner], would probably currently, she would currently be suffering with comments that I have made and I suppose, particularly around the physical, how she physically looked in terms of sexual relationship whatever, and I know, that I have, years ago, said stuff that I absolutely regret saying because, trying to undo that...' **Interview 003**

In addition to feeling a sense of powerlessness, their lack of knowledge evokes numerous other emotional experiences for participants. The emotions of guilt and self-blame are concerned with the self of participant where, through the lack of knowledge of the ED, the participants feel they failed to recognise an ED setback or feel they did not support their partner well enough to prevent further ED setbacks occurring. Further emotions such as anger, fear, disgust and sadness are experienced by participants in the context of their lack

of understanding of what their partner may be going through, where making sense of why their partner continues to engage in ED behaviours is difficult. Examples of some of these emotional experiences are provided below:

'The last time he got unwell I missed it for a long time, as I said, he is so good at hiding things, but I feel so guilty about not knowing what was happening. I do wonder if I had been more aware, aware of what was happening, if I knew what to look out for would he be in a better place now?' **Interview 013**

'I would love sometimes to just grab her and shake her and tell her to come on get over it. There are times I just can't understand why she keeps at it [ED behaviours] despite all she has in life.' **Interview 011**

The motivation to becoming self-informed out of concern for their partner therefore, is about gaining information so they can support their partner to work towards recovery in a helpful way. Initially, in earlier cycles of *'Reconstructing Livability'*, the information they require is primarily of a practical nature, where they look for ways in which they can help their partner with the difficulties around the ED behaviours, such as not eating, bingeing or purging. As a result of being faced with new challenging ED situations or not having access to adequate practical information from previous cycles, the need for practical information remains a consistent issue throughout the process of *'Reconstructing Livability'*:

'...and the main question I asked was what can I do to help X [partner]....' **Interview 001**

'Not getting on the ground, practical information is a huge piece missing.' **Interview 002**

In addition to the need for practical information, information requirements begin to include the need to understand what their partner is going through in order to be able to support their partner emotionally. This is linked with participants' perceptions that often the practical support they provide is not helpful because they do not understand the psychological aspects of the ED their partner experiences, as suggested by the following participants:

'I think the mind is such a complex thing I think it's very difficult to get it [nature of ED], to get it completely so I'm not sure you ever can get it completely, and then you can end up saying or doing the wrong thing.' **Interview 002**

'She might say I'm sad and I think, what's wrong? One second she was fine, happy and laughing and then she's sad. How can I help with that when I don't know?'

Interview 004

The need to gain an understanding of the psychological aspects of the ED for their partner is also linked with the participant's need to make sense of the disruptions that have come about to the intimate relationship, as discussed in the previous chapter. This is an important aspect of the participants remaining committed to the relationship despite encountering repeated ED setbacks, where the intimate relationship disruptions can be understood in the context of ED cognitions and emotions experienced by their partner. Therefore, concern for the intimate relationship is a further factor motivating the participants to become informed.

7.2.2 Concern for the relationship

As discussed in *'Encountering intimate relationship disruptions'* (chapter 6), participants experience disruptions to various aspects of relationship functioning. These changes can be difficult for the participants to make sense of, particularly in earlier cycles of *'Reconstructing Livability'*, when living with the ED is a new experience:

'It doesn't feel, the relationship isn't like a normal boyfriend girlfriend relationship, partner relationship in any sense of the word. The more I think about it the more I sit down, I more or less said it to X [partner], last week, this is just, it's dysfunctional at some level do you know? But yeah, it's a weird one...' **Interview 005**

As concern for the relationship develops over recurring cycles of *'Reconstructing Livability'* that are lived through, most participants experience a sense of loss for the relationship they had previously enjoyed with their partner. All of the participants repeatedly refer back to a time when the ED did not unduly influence the way in which the relationship functioned, often describing a longing to return to this state of being. Not having adequate knowledge or understanding of the nature of EDs compounds the participants' sense of powerlessness where their efforts at restoring their relationship to a previous level of functioning are ineffectual. This is linked with not knowing how to support their partner through recovery in a helpful way, when their attempts at support are perceived to hinder rather than help intimate interacting as demonstrated by the following extract:

'It all comes down to the food we argue over it. If she refuses to eat, I will be very headstrong with her and try to make her, but it will end up in an argument...not every meal 3-4 times a week easily, the same arguments, it gets tiresome.' **Interview 012**

Ongoing difficulties with relationship functioning evokes concerns around the ability to remain committed to the relationship. All of the participants express this concern which is usually more dominant in earlier cycles of *'Reconstructing Livability'*. However, some of the participants live with this concern even after experiencing multiple cycles of *'Reconstructing Livability'*, where living with repeated ED setbacks continue to be experienced in a distressing way:

'So I am kind of at my wits end, trying to do right by her and not knowing how, but at the same time I'm losing the will to actually keep doing it, do you know that kind of way? Sometimes I think it would be easier to walk away.' **Interview 005**

Despite these concerns however, the desire to remain committed to the intimate relationship is something all of the participants wish to do. This becomes an important motivator for the participants to further their understanding of the ED and the impact it has on their partner and on the intimate relationship. Extending beyond the couple dyad and the intimate relationship, relationships with other people in their wider social world also provide the participants with a motivator to become more informed.

7.2.3 Concern to inform others

As the participants do not live in the vacuum of the intimate relationship but live as part of a wider social world, the motivation to self-inform is also driven by their desire to be able to provide appropriate information to other people in their lives. The involvement of other people, primarily family members and friends, features largely in participants accounts of their experiences. How this involvement is experienced however, varies greatly, ranging from some people being helpful and supportive to others being unhelpful and intrusive. The motivation for participants to be informed in order to inform others is linked with how supportive they perceive the involvement of others to be. Where involvement is perceived to be helpful and supportive, the participants want to be able to provide people with information that is useful and effective. There are several reasons why participants need to be able to do this; firstly, they want others to be able, with minimal distress, to support

their partner. Secondly, they want to allay any fears other people may have about the effect the ED is having on their partner, themselves or their relationship. Thirdly, the participants want to be able to access emotional, informational or practical support for themselves. An example illustrating the motivation to inform others who are perceived to be supportive is presented below:

'... but you're not dealing with your run-of-the-mill type of thing, normal person, so at least having insight into it [ED] lets me be able to explain it a bit to friends, or my sisters, and then they wouldn't say the wrong thing...' **Interview 008**

For those people whom the participants feel are unhelpful or intrusive, the motivation to be informed is around protecting their partner, the self and the relationship from what is perceived as unsupportive interactions. In some cases the participants acknowledge that other people, usually family members, become involved out of concern for their partner but they often experience these inputs as ill-informed and intrusive. Having appropriate information regarding the nature of EDs empowers the participants to be able to deal with these situations effectively and make decisions that often are in conflict with others' suggestions, as demonstrated below:

'...because this is something [being involved in the treatment] now, something I have talked to her sister and talked to her dad about and they've even suggested, "oh I'm coming over from X [name of a country], for this, can I go to that session" or whatever, and the answer has been "no" on that one, that it was time for her, because that is what I found out.' **Interview 002**

'X's [Partner], parents tried to stop me trying to get X into treatment around three and a half years ago. I told them it was none of their business, it was very tough, but they went their own way. Since then X's [partner] mum feels shame about how they did what they did, and treatment was successful.' **Interview 010**

The motivation to become more informed about the ED in terms of concern for their partner, the relationship and the self leads onto the strategy of information seeking, conceptualised as '*Progressing knowing*' and discussed in the following section.

7.3 Progressing knowing

'Progressing knowing' is the conceptualisation of the process participants engage in when accessing ED related information. This process involves a combination of accessing information from social sources, where information and advice is acquired from other people, and non-social sources of information such as learning from experience. These sources of information are accessed both intentionally and unintentionally by the participants, discussed below as *'Intentional self-informing'* and *'Fortuitous self-informing'*.

7.3.1 Intentional self-informing

Intentional self-informing refers to participants' active and deliberate engagement in information seeking in order to increase their knowledge of the ED, the initial purpose of which is concerned with being able to provide help and support to their partner. There are various ways in which intentional self-informing is engaged in namely, reflecting on and learning from experience, becoming informed through the use of technology and engaging with others with a specific purpose to gain ED information.

Self-informing from experience: A rich source of gaining information and an understanding of the ED for participants is through reflecting on and learning from their own experiences of living in previous cycles of *'Reconstructing Livability'*. However, having the opportunity to learn from past experiences usually only happens when participants believe their partner to be experiencing an improvement in the ED behaviours and cognitions, and they have the mental space to reflect on the past. Most of the participants find reflecting and learning from experience does not happen while their partner is experiencing an ED setback, as their attention is focused on the health related risks for their partner. In the times their partner is experiencing an ED setback the activity of information seeking tends to be reactionary to meet their immediate needs rather than purposeful as described by this participant:

'Life has been like that this year, whack a mole game, just putting out whatever fire is breaking out next, not a plan, not proactive, reactive because it has to be.'

Interview 014

By reflecting on previous interactions with their partner, the participants begin to identify those interactions that are not so helpful. However, this does not mean the participants

stop using what they perceive as unhelpful interactions when encountering further ED related disruptions, as often the ED related distress they experience interferes with their ability to change these interactions in the short term. Learning from experience occurs incrementally over the course of living through repeated cycles of *'Reconstructing Livability'*, where building on those strategies considered to be more helpful and relinquishing those they feel are not so helpful is achieved by participants as, evidenced below:

'There were many, many arguments around that which I'm not proud about, but there were, because at that time when you are in that situation you don't know how to react, well I certainly didn't know how to react then.' **Interview 004**

'I ask her to talk to me about her problems, this has worked in the past.' **Interview 012**

Learning from the experience of living with repeated cycles of *'Reconstructing Livability'* does not happen in isolation, rather it is accompanied by various other ways in which the participants actively progress their knowing, including seeking information through technology.

Technological self-informing: Supplementing the knowledge gained with learning from experience is the common practice of seeking information from the internet. In contrast to learning from experience, accessing information through the internet is heightened at times when the partner is experiencing an ED setback as participants feel a pressing need to find ways to help them through their difficulties. According to Childs (2004), internet searches for the most part are user friendly and convenient however, the information seeker needs to access and use the most appropriate information in the context of their own needs. Participants are not always clear about the purpose of the information search, particularly in earlier cycles of *'Reconstructing Livability'*, when not being informed includes a difficulty in identifying what information is needed or where that information can be accessed. In addition, finding information on the internet is not always helpful as some of the information available only serves to increase anxieties around the ED. These difficulties are evidenced in the extracts below:

'I hadn't a clue what I was looking for [on the internet], and some of the stuff I found just frightened me even more, that's what they say isn't it? If you google things you will find all sorts of things it could be...' **Interview 013**

'...I have never been on the [voluntary ED organisation] website. I don't need it now. It would have been helpful if I knew about it then. I might have gone onto it in the early days, before it [ED] was developed, at that time I needed stuff just to survive, to get through another day.' **Interview 017**

Usually the purpose of seeking information through internet searches is to learn about the ED behaviours and cognitions, the possible effects the ED might have on their partner and information on treatment options that might be available to them. As the cycles of *'Reconstructing Livability'* are repeated, participants become more aware of what their information needs are and by entering websites already accessed or by entering key ED words such as 'anorexia', access to online information becomes more finely tuned to meet those needs:

'...because I would have read a lot about it over the last few years, different bits...when you're on the internet now, with all that you know, that's all now that it would be, just a three or four minute flick on the internet.' **Interview 004**

A further way the participants *'Progress knowing'*, is by talking and listening to other people, including their partner, which is conceptualised in the current theory as *'Interactional self-informing'*.

Interactional self-informing is primarily concerned with the information gathered from interactions the participants have with other people. This form of self-informing is derived from three main sources: from their partner experiencing the ED, from significant others in their lives including other family members and close friends and from professionals. As discussed in the subsection *'Encountering intimate relationship disruptions'* (chapter 6), gaining information from their partner often proves problematic particularly where the ED related silence limits both partners' ability to share ED related information. With repeated cycles of *'Reconstructing Livability'* however, familiarising the self with the ED related silences and remaining vigilant alerts the participants to ED difficulties their partner may be having. This provides the participants with an opportunity to encourage their partner to talk about the difficulties they are experiencing or challenge the ED behaviours they are

engaging in, which in turn means the participants begin to listen to what their partner is saying to them:

I now try to listen to what she was saying not merely trying to second-guess the next answer that, you know, which I know I used to do.' **Interview 003.**

'She [partner], said to me last week, because she's nearly telling me herself that she is not able to do it herself.' **Interview 006**

The process of becoming informed is often first initiated by other people, primarily family members, usually a parent, a sibling or a close friend with whom the participant has frequent interactions and with whom they feel comfortable talking to. Being informed by other people often occurs in the context of the participants not seeing that an ED disruption is occurring but the disruption has become evident to others in their wider social world. The disruption seen by other people can be in relation to ED behaviours and cognitions experienced by their partner such as restriction of food or social isolation, but usually it is in the form of a physical deterioration such as weight loss. Below is one example of a family member's concern voiced to a participant:

'Eventually my sister, another sister, she tackled me about it and said you need to do something I'm not standing by any longer watching this, you have a serious crises on your hands.' **Interview 003**

Participants also actively seek out information from family members and close friends. This is particularly notable when their partner is experiencing an ED setback and information needs are heightened in response to the distress and concern relating to their partner's health. The nature of the information sought is primarily around accessing help for their partner or finding answers to difficulties the participants themselves may be experiencing. The information is sought from those whom the participants consider to hold some level of expertise or knowledge about EDs, or where the relationship is close enough to justify the risks of disclosing personal information, as indicated by the following participants:

'I find it stressful sometimes, I don't have the answers, I might call a friend to get answers...It was helpful telling him, he always asks after her.' **Interview 012**

'I went to my sister who is training as a psychotherapist or a psychologist, I don't know. I rang her up and explained what was going on. She said she had noticed and I asked her to help me find someone, she had the contacts.' **Interview 015**

Generally however, seeking information from others is challenging for participants where they feel many people have limited or no knowledge of EDs, as demonstrated below:

'Most people I know haven't even the mildest understanding, even though a high amount of people are suffering from this, yeah? Most people have no idea what it [ED] is.' **Interview 003**

Interactional informing also extends to include the strategy of accessing information from professionals. The nature of the information sought is usually concerned with how they can support their partner, on the nature of EDs, on recovery expectations and on the progress or difficulties their partner may be experiencing. However, seeking information from professionals is usually limited to times when their partner is experiencing an ED setback. In these times the participants are experiencing heightened levels of distress relating to concerns for their partners' health and their attempts to access information from professionals is often imbued with panic and can be frantic in nature. In addition, when experiencing these high levels of distress, participants find it difficult to process information as demonstrated below:

'One day I had come home from work, she rang me and I came home from work and that was the time that she was literally slumped in the shower... I didn't know what was happening, didn't know what to do, all common sense went out the window, I just panicked.' **Interview 008**

'I went mad for weeks looking for info, into people who had any background, doctors, psychology, medicine, physios [physiotherapist] anyone who would have information.' **Interview 013**

Where information from professionals is available it is usually from the professionals their partner is attending as part of their ED related treatment such as the GP, psychiatrist or counsellor. Some of the participants experience being included in one or two joint sessions with their partner which, as demonstrated below, provides them with helpful information:

'I had one, I had two other ones [joint therapy sessions with a professional], with different therapists as well...It was good to see their perception of it [ED], and where they see, like even getting, knowing kind of triggers that make it worse...it was good for me to get their perspective on it.' **Interview 006**

Most of the participants however, face barriers in accessing information from professionals. This is understood by participants to occur because of; i) the lack of ED services available within Ireland; ii) professionals not being ED specialists and lacking information with regard to EDs and; iii) because of the confidentiality requirements of their partner, professionals tend not to include the participants in treatment sessions. Not having access to information from professionals adds to the participants' distress and feelings of powerlessness when they are trying to support their partner with limited information or understanding. One way of overcoming limited access to information from professionals was to become involved in the current study, so that information could be accessed from the researcher (the ethical issues of this are discussed in chapter 5). This is evidenced in the majority of interviews where most of the narratives are interspersed with questions relating to information on EDs. These questions ranged from seeking reassurance, to looking for advice on how to manage the ED disruptions to their lives, as demonstrated below:

'And I'm just wondering is this, the things I'm saying is that common...I actually meant to ask you as well, with people say with anorexia or eating disorders is it any way common, that they wouldn't have many friends and that they would kind of...'
Interview 005

'I'd be open to any suggestions to be honest with you, anything.' **Interview 013**

Intentional self-informing is accompanied by other non-deliberate means of becoming informed which is conceptualised in this theory as *'fortuitous self-informing'* as presented in the next subsection.

7.3.2 Fortuitous self-informing

The concept of *'Fortuitous self-informing'* incorporates any knowledge informing situation that is not actively sought out by the participants but provides them with a chance to progress their knowing. Due of the opportunistic nature of self-informing, it is often undervalued or not acknowledged by the participants. As the participants experience repeated cycles of *'Reconstructing Livability'* however, they become more sensitive to, and appreciate the value of fortuitous information. Examples of fortuitous informing are given in the following extracts from one narrative where the participant had undertaken a first aid course that was not related to EDs and also had a chance meeting with a medical

professional who shared his own story with him. Although not directly related to gaining ED information, this participant could apply it to his own experiences:

'...and her chewing gum. It gives you a false thing that you're eating, but, you are not eating and even, from the course I'm doing now, your man said if you're chewing get off it because he was saying, he is an advanced paramedic, he was saying your stomach, it thinks that are actually eating and it releases the acids and it doesn't go into the food. I actually said that to X [partner], it's only since she came for treatment herself, she wants to do everything to, to get better, to stop eating the chewing gum herself, and stop the Coffee.' **Interview 001**

'And while you're honest, he said, I am actually a recovering alcoholic myself, he said, and take it from me he said, a solo run won't work, you need to get counselling and support groups. And, little did we know, how right he was...' **Interview 001**

Another participant applies his experiences of working as a volunteer with a crisis intervention service. Although his experiences are not related to EDs, it provides him with insights into what might and might not be helpful for his partner in working towards recovery:

'Yes I've dealt with loads of psychiatric patients...I'm used to dealing with people with depression but not used to dealing with people with eating disorders, the eating disorder wrecks my head. But I have learned that personal issues won't be resolved by counselling, counselling isn't any good, no, friends are the most important people to talk to. If you don't have friends you have no hope.' **Interview 012**

Although accessing personal psychotherapy was not a common occurrence among participants, for the one participant who did engage in therapy for his own personal reasons it provided an opportunity for fortuitous informing:

'But I think once I started my road with X [therapist], and, and unravelled a lot of stuff that was going on there, and probably started learning more about communication and learning about how to listen. You know listen to X [partner].' **Interview 003.**

Although the participants employ intentional and fortuitous informing each time they enter the stage of '*Informed self*', the nature of the information sought changes with each cycle of '*Reconstructing Livability*' experienced. This occurs as a result of changes in the participant's information needs at a given time such as needing immediate access to treatment when they perceive their partner to be physically at risk or where the participant

is faced with new situations not previously encountered. The nature of information sought also changes as a result of an accumulation of information gained from living through previous cycles of disruption. For example, over successive cycles and learning from experience, the participants become more attuned to the ED and begin to see patterns to their partner's ED behaviours and cognitions. Unless their partner is presenting with a new behaviour that does not fit with the pattern, the participants no longer seek information on ED 'symptoms':

'Last year again she [partner], got to nine stone, just under nine stone so she began to look very well and everything and then that was it, head off into the big world again. and, then I said "Jesus, she is getting thinner again," I said like that, "yes I think she is." Interview 001

'I think, I think yeah that's when I kind of realised, okay well look, this is a very similar situation going down the same path.' Interview 009

The end goals of '*progressing knowing*' however remain constant, to be informed so that they can support their partner effectively and be informed so that they can make sense of the disruptions to their relationship; however, in progressing their knowing, the participants are confronted with a tension between the positive and negative outcomes of knowing. This issue is discussed in the following subsection on '*Living with knowing*'.

7.4 Living with knowing

The subcategory '*Living with knowing*' refers to the impact being informed about EDs has on the participants. There is a dual outcome in relation to being informed, the negative outcome of exacerbating psychological distress experienced and the positive outcome of facilitating the development of self-efficacy and a sense of empowerment among participants. These two outcomes are discussed in the following two subsections: '*Psychological distress of being informed*' and '*Positively experiencing being informed*'.

7.4.1 Psychological distress of being informed

Although the concept of psychological distress has already been discussed in the subsection '*Encountering disruptions to self*' (chapter 6.5), the concept is extended here to include the psychological distress experienced by the participants as a result of having ED related

information. Participants universally express their distress at gaining information and understanding of the psychological and physical risks associated with an ED such as depression, osteopenia, reduced fertility, muscle wasting or death. This distress is compounded by the physical deterioration demonstrated by their partner when they experience an ED setback, and the participants make the association between what they see and the information they have about the risks:

'The eating disorders was named as a more medical concern in the past couple of years, it's becoming a physical fact, osteopenia, fibromyalgia. He is not robust, which has a lot to do with his diet, it's deplorable basically...I'm worried for him.'

Interview 014

In addition to the distress of being informed of the health risks for their partner, distress also arises from the knowledge that the ED may persist over a protracted period of time. While other people framing the ED in a discourse of chronicity can be difficult for the participants, it is particularly distressing when they encounter professionals who think and speak in those terms as demonstrated by the following participant:

'I nearly died when the doctor said it [ED], could go on for a very long time, where X[partner] could become chronic if he didn't start changing now. I don't know how I will cope with that I don't think I am strong enough to go through this for ever...'

Interview 013

As participants experience repeated cycles of 'Reconstructing Livability' becoming more informed about the impact the ED is having on the intimate relationship is also experienced in a distressing way. The changes that have come about to the relationship are universally experienced with dissatisfaction and in some cases the level of intimacy is reduced to a level where participants experience the relationship as more platonic in nature. Becoming informed in relation to the cyclical nature of the ED and the long term impact this may have on the relationship is experienced with a sense of sadness at what has been lost and a yearning to return to the state of relationship functioning that was previously enjoyed:

'I liked the way things were years ago when we could actually sit on the couch do you know, snuggle up together watching TV sort of things like that, it's just, it's cold, I might as well be sitting with one of the lads...I'd love, to get back to that first year if it was ever possible do you know?' **Interview 005**

'I do remember how good it used to be and I still would like to get even a little bit of that back...I would love to have a normal relationship where arguments were about normal things not about her controlling everything, not even food...' **Interview 016**

As demonstrated in the discussion and examples above, the psychological distress of being informed manifests itself in a variety of ways. Concern for their partner's health and concern for how the relationship is functioning evokes feelings of fear and uncertainty for the future. This is linked with feeling overwhelmed and sometimes hopeless, particularly when the participants consider the ED to be a long term problem for their partner. For many of the participants the distress of being informed impacts on their mood where many of their emotions including fear, loneliness, being overwhelmed and sad, manifest as a low mood:

'So once I knew, it [knowing their partner had an ED] me pretty bad and I got depressed and, but I pulled myself up out of it and whatever like but, I reckon it have to have been to do with that, it have to have been' **Interview 008**

'Knowing she had an ED was overwhelming the more I thought about it the more down I got' **Interview 015**

Despite experiencing psychological distress when being informed about EDs, all of the participants express a need to have information and acknowledge the usefulness and positive impact this information has on their own wellbeing. This is discussed in the following subsection '*Positively experiencing being informed*'.

7.4.2 Positively experiencing being informed

Although being informed can be experienced in a psychologically distressing way, more often it is positively experienced. All of the participants express the need to be informed about the ED and to have this need met, even if only partially, is experienced as helpful. The most pressing information need participants express is information on how they can effectively support their partner. Gaining knowledge through intentional and fortuitous self-informing with each cycle of '*Reconstructing Livability*' they experience, provides them with some tools to support their partner. There is a sense of security in having adequate information, particularly when the participants are afraid that by being poorly informed the support they provide to their partner could be damaging or distressing. Having adequate

information therefore, has a positive impact on the participants' psychological wellbeing where they experience an improved sense of empowerment, confidence and self-efficacy in light of an enhanced ability to support their partner:

'...because I know where it's coming from. Now, I know I understand, it's coming from different places. So at least you can work with that because in the past I wouldn't have a clue and I would be saying all the wrong things.' **Interview 004**

'It was great knowing how I could help her rather than saying or doing the wrong thing. I think she really appreciates that'. **Interview 018**

Following on from the need for information to support their partner, participants also have a need for information on the nature of the ED. The positive impact of having information on the nature of the ED is that it provides participants with some understanding of the difficulties their partners are experiencing and helps them make sense of the disruptions to their relationship. For example, making sense of the difficulties with sexual intimacy is explained by the participants as an ED related loss of interest, as demonstrated below:

'She [partner] has never been overly affectionate but she would have been a little bit at the start but obviously the last two years with the eating disorder going on, she clearly shows even, to get a hug is even like, it doesn't, it's difficult for her.'
Interview 006

Making sense of the disruptions also has a positive impact on the physical wellbeing of the participants. Having information in relation to what is going on for their partner dispels other misconceptions that can cause the participants to feel anxious resulting in poor appetite, increased alcohol intake or insomnia, as demonstrated below:

'Even though putting the name of anorexia on what he [partner] had was a shock, it was a bit of a relief to know what it was. I had been having sleepless nights thinking he had cancer.' **Interview 013**

Being able to make sense of the disruptions in the context of the ED supports the participants to remain committed to their partner and the relationship. Participants can now externalise the ED as an 'illness' that can improve rather than considering it a fundamental part of their partner. This facilitates the participants in remaining hopeful for the relationship where they associate an improvement in their partners' ED behaviours and cognitions with an improvement in relationship functioning, as evidenced below:

'We used to always go for a pint on a Friday evening in, in thing, in the local, it's only about 2 miles away. That didn't happen now for years. I said, that will happen now, even this evening. Now, or shortly she definitely will, she's looking forward to going off for a drink.' **Interview 001**

'Because at the end of it all what was in the back of my head as I said earlier was this isn't her, this isn't the person that I fell in love with, this is the illness and that's kind of what has kept me going.' **Interview 011**

Although becoming an informed self improves participants' understanding of the ED or of what their partner might be experiencing, none of the participants in the current study feel their understanding is complete. For those participants who have lived with a partner who has experienced an ED over a protracted period of time however, they feel their understanding is significantly advanced. Although advancing their knowledge does not provide answers as to what keeps the ED going, it does help to reduce the uncertainty around effectively supporting their partner:

'Well I do, I think I do understand as much as I'm going to understand it like...I don't think I need necessarily to understand more because I do, I get it like, I've read the books. Obviously I'm not an expert in this or anything but, I have a fair knowledge of it like.' **Interview 009**

'Going through it with someone you are married to, someone you are not going to walk out on is scary, really scary, it's frightening. They are doing this themselves I don't know why but there is nothing you can do about it, you can't stop them purging or doing things. If it comes back can I help? Can they help themselves? It's living with that unknowing piece but it got easier. It's about me being there for her.' **Interview 017**

Being informed therefore, provides the basis on which the supportive strategies for their partner are developed and facilitates the construction and guidance of strategies used to counter the disruptions to the self and the relationship. Being informed is the catalyst for moving on to the third stage of the cycle of *'Reconstructing Livability'*, where the participants utilise the information gained to *'Counter the disruptions'* as will be discussed in the next chapter.

7.5 Summary

This chapter discussed the second stage in the process of *'Reconstructing livability'* which is conceptualised as *'Informed self'* and is concerned with gaining ED related information and knowledge. This category has three subcategories the first of which is *'Motivation for informing self'*, where the participants' drive to seek information is motivated by three main concerns. The first is concern for their partner and the need to be able to support them effectively, the second is the need to make sense of the disruptions to the intimate relationship and the third is in relation to their concerns around being able to inform other people. The second subcategory, *'Progressing knowing'* is concerned with manner in which information is sought to include intentional and fortuitous self-informing, and the barriers participants are faced with when seeking information. The third subcategory *'Living with knowing'*, is concerned with the negative and positive impact having information has on the participants. However, despite the negative impact having information can have, all participants demonstrate their desire to improve their knowledge and understanding of EDs.

The stage of *'Informed self'* is not mirrored exactly in each cycle of *'Reconstructing Livability'*, rather becoming informed is modified by experience and knowledge acquired in previous cycles, by the occurrence of new issues not previously encountered and by the participant's needs at a given time. Gaining ED information is the catalyst that moves the participants on to the third stage in the cycle of *'Reconstructing Livability'* where participants use the knowledge they have gained to construct and guide the strategies they employ in *'Countering the disruptions'* to their lived environment.

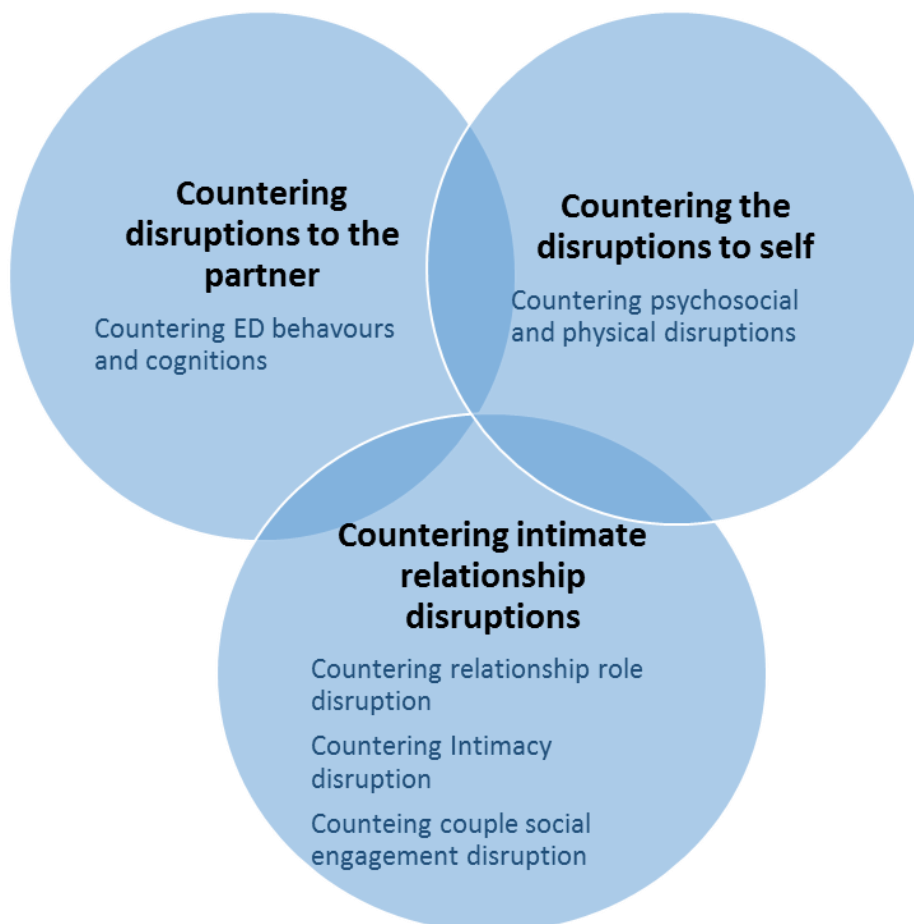
Chapter 8

COUNTERING THE DISRUPTION

8.1 Introduction

This chapter discusses the third stage of the theory conceptualised as ‘*Countering the disruptions*’ and provides an account of the manner in which the participants respond to or counter the disruptions to their lived environment. This stage of the cycle consists of three subcategories, namely ‘*Countering disruptions to the partner*’, ‘*Countering the disruptions to self*’ and ‘*Countering intimate relationship disruptions*’ (see Figure 8.1), representing the strategies engaged by the participants. These subcategories are directly linked with the subcategories contained in the first stage ‘*Encountering a disruption*’ in that they speak to how the disruptions encountered there are addressed.

Figure 8.1 Countering the disruption



8.2 Countering disruptions to the partner

As the eating disorder (ED) behaviours and cognitions (Chapter 6, footnote 7) experienced by their partner are generally the aspects of disruption first encountered, 'Countering disruptions to the partner' is usually the first strategy in the stage of 'Countering the disruptions' that the participants engage in. 'Countering disruptions to the partner' is concerned with the manner in which the participants support their partner in relation to the psychological and physical difficulties associated with the ED. The participants believe that supporting their partner effectively has a dual outcome that of an improvement in their partner's health which they link to the second outcome, an improvement in intimate relationship functioning, as suggested by the following participant:

'When things [ED behaviours and cognitions], are getting better and when X [partner] is starting to enjoy life and we, we both start to connect [emotionally and intimately]. We have had more of that in the last 3 years, it is fantastic, it all seems so worth it, we both feel quite lucky.' **Interview 010**

The strategy of countering the ED behaviours and cognitions experienced by their partner is achieved by providing ED related practical and emotional support for their partner and accessing professional help for them.

ED related support refers to the type of support participants provide to their partner in the context of the ED, which comprises of practical support relating to the ED behaviours and emotional support relating to the ED cognitions their partner is experiencing. Practical ED support is provided when the participants perceive that their partner is not able to tend to their own practical needs adequately which include feeding themselves, maintaining their safety either in the context of the physical risks of the ED or suicidality or, in getting to work or therapy sessions. The participants understand their partner's inability to tend to their own needs has come about as a direct result of the ED behaviours, where a decline in their partner's health impacts their ability to function adequately on a practical level. The manner in which practical support is provided includes shopping and cooking, sitting with their partner at meal times so that they feel supported when eating, providing transport where their partner is no longer driving for themselves, remaining in close proximity to ensure their partner is safe and taking over household duties that are usually shared:

'She had no interest in doing anything so like I'd go home and after work when she would come in, I'd have, I'd make dinner for her, not thinking, just give her a nice portion of dinner...then I would do everything, cleaning, everything in the house because she's not able.' **Interview 004**

ED related emotional support is concerned with providing compassionate support when the participants encounter their partner's distress in the form of low mood, irritability, loss of hope and lack of motivation or anxiety. As they live through successive cycles of 'Reconstructing Livability' and become a more 'Informed self' (Chapter 7), participants link their partner's distress to the ED behaviours and cognitions. Having some understanding of what their partner is experiencing facilitates them in providing support that targets different aspects of the ED related distress. Listening, reassuring, being respectful of their partner, being there for them and verbal expressions of ongoing love and personal validation are ways in which the participants provide this support, as evidenced in the following extracts:

'I assure her I will not let her go back down that hole [depression], again. Her going backwards wouldn't help me in any way. I ask her to talk to me about her problems and positive self-talk [by the participant] helps.' **Interview 012**

'She feels she is not a good enough person anymore. I try to tell her, remind her of all the good things about her like being a great mother, she is smart...' **Interview 016**

'I try and understand it when she is irritable and not be irritable back, sometimes just listening to her seems to help.' **Interview 018**

A further approach to providing emotional support is in the form of instilling hope in their partner, which is particularly evident at times when they perceive their partner to be hopeless about recovery or to have lost the motivation to work towards recovery. Instilling hope is commonly demonstrated by the participants through verbal reassurances that they provide to their partner, where they express their own beliefs around their partner's ability to make improvements, as demonstrated below:

'I keep the positive talk going, especially when she isn't motivated to keep going, we have to keep hoping because without it, it [living with the ED] would just get you down.' **Interview 007**

'It is so easy for her to give up hope after all the years she has struggled...but I keep telling her she has to hold on because there is always hope that things can get better.' **Interview 016**

Learning from experience (Chapter 7.3.1) facilitates the participants to adjust their efforts at providing ED related support. Over time a structured pattern to the way some of the support is provided begins to emerge. As demonstrated in the extracts that follow, there are two main reasons why this occurs. Firstly, having a structured pattern provides participants with an assurance they are not missing opportunities to provide support to their partner in challenging their ED behaviours. Secondly, having a structure of rules in place around food is perceived as providing a sense of safety for their partner both in terms of shielding them from new anxiety provoking experiences or from engaging in distressing ED behaviours:

'We had chicken one day, had turkey the next day and it had to be, the only day I could get steak into her was Saturday. If I missed Saturday, she wouldn't have it on Sunday, disaster...' **Interview 001**

'...but it's rules in the house, I know that sounds very trivial but we can't bring rubbish into the house because it sets her [partner] off, you know like rubbish food basically. She would graze, and then she gets so guilty over that and she starts purging and the whole lot and it's just, you can't have any.' **Interview 008**

The participants acknowledge that often their partner does not respond to the practical and emotional support they provide either because the support is not meeting their needs or due to the ED they are not able to respond to it. *'Positively experiencing being informed'* (Chapter 7.4.2) goes some way towards resolving this issue where the participants learn new ways of providing more effective support, or they gain a better understanding of their partner's difficulties in responding to their support. However, as demonstrated in the data, this does not eliminate the feelings of frustration, anger or helplessness the participants experience throughout the process of *'Reconstructing Livability'*, when faced with a poor response from their partner:

'And in one sense, I was so frustrated with things in my head. At times when I get this feeling of, you try hard to help and it's great for a day but you know you are going to be in the same situation two days, a day down the road.' **Interview 005**

'She would not listen to me, I really tried to encourage her but she would not accept or listen to me. The exercise started up again and she is right back to where she was in the first place...I have to say there are times although I feel sorry for her I am really angry.' **Interview 016**

In addition to providing practical and emotional ED related support to their partner the participants also seek to access support for their partner in the form of professional help. Accessing professional help for their partner is undertaken by all participants at various times in the process of *'Reconstructing Livability'*, but is usually confined to times when their partner is experiencing an ED setback and concern for the ED health risks are heightened. The professional help sought is of a medical and/or psychological nature where participants hope these inputs will assist their partner in working towards their own recovery. As discussed in the subsection *'Progressing knowing'* (Chapter 7.3), accessing information on services that can provide this help is primarily through searching the internet, asking their GP (who also provides professional help) or asking family and friends who have some knowledge of mental health services. How professional help is experienced by the participants ranges from helpful and positive to the not so helpful. In positive experiences the participants not only gain access to therapeutic inputs for their partner but in doing so they often receive some support and information for themselves as demonstrated below:

'So at this stage I said "I need to talk to somebody". So I came up [to ED service], and X [nurse] was very good, I went through the 20 questions [the participant had prepared] and she was very helpful with all the questions and I wasn't as anxious then...' **Interview 001**

'Having X [partner] admitted to a psychiatric hospital was very difficult for me, and her, and I had hoped it would never have come to that, but she had become so unwell at the time I knew there was no other option.' **Interview 016**

The majority of participants however, face challenges in accessing professional help. Similar to the participants' experiences around accessing information from professionals (Chapter 7.3.1), the lack of help is linked with the lack of specialised ED services available in Ireland. Where ED specialised services are available, they are usually from private health services that require funding. Having the money to attend these services can prove challenging, as personal money or health insurance is required or else the participants have to engage in a lengthy and often distressing process to access funding from local health services:

'The problem so far is trying to engage in services, having no money [The health service] in a bad community care area in terms of services and access.' **Interview 014**

'We were told, we were literally led around the garden path as they said we had funding [from the health service to attend a private treatment centre] one week and then it was gone and then it went on for ages, like it was a nightmare.' **Interview 008**

As evidenced in the extracts below, many of the participants also face challenges in accessing professional help because of inexperienced professionals or professionals who have limited knowledge of EDs. Engaging with inexperienced or poorly informed professionals who cannot provide the appropriate help or information further adds to participants' distress as they continue to worry for the health of their partner. In addition, some of the participants perceive professionals to be more knowledgeable in other areas of mental health such as depression and this can influence their approach to care, if the ED is not considered a part of the problem:

'She [doctor], had no idea at all about the issue [ED], or she had no experience in it, she's only a young doctor now...but she wouldn't have any experience in it and didn't really know where to go from there...and the doctor said it had nothing to do with an eating disorder because again the lack of experience down in X [Name of a County], they wouldn't know what it was.' **Interview 001**

*'So like we [Nurses] all love schizophrenia, it's the really big hard-core one and bipolar and depression but that is all we talk about, like never talk about eating disorders...how are we supposed to know how to treat it [EDs]?' **Interview 008***

'She [partner] is not under the care of the psychiatric services, in our area they are a joke. My wife went there with the ED and they said she had depression. She stopped going to the psych because it is a joke.' **Interview 017**

As well as countering the ED related disruptions to their partner, as the participants become more aware of the impact their partner having an ED has on the self, they begin to use strategies to respond to these disruptions.

8.3 Countering the disruptions to self

'Countering disruptions to self' is a strategy the participants engage in order to manage the psychosocial and physical disruptions to the self that have come about as a result of their

partner experiencing an ED (Chapter 6.5). The strategy of '*Countering disruptions to self*' is enacted by accessing professional support for the self, accessing every day support from others in their wider social world and managing disruptions to physical health. The participants engage various methods to counter the psychological disruptions to self, some of which are helpful in their long term recovery from the distress of living with the disruptions in their lives. For example, any participants who accessed individual medical and psychological help in order to assist them in dealing with their distress, report this as being helpful:

'I remember going to counselling with this counsellor and within the, probably 6 minutes from the start of the session I was in a heap. You know, she was trained, fair play to her she could see it [distress] sticking out of me like a big thing of black on my head...I suppose I spent 3 years talking to a local psychotherapist who was brilliant.' **Interview 003**

'About two or three years ago I was getting more and more stressed and I think I just said to X [partner], at some stage I just said 'all we ever seem to do is talk about your illness'....and she got all upset, and I got upset and I just, you know felt an awful weight on me so, I went down to the Doctor and I went on antidepressants, a small amount, I was on them for about a year.' **Interview 007**

Having the opportunity to be included in some of their partner's therapeutic sessions is also experienced as having a positive impact on psychological distress. By gaining information and understanding of the ED and receiving guidance on how to provide effective support to their partner, their sense of empowerment and self-efficacy in countering the ED disruptions to their partner is enhanced:

'I have met with the counsellor [their partner is attending] once and I'm due to meet with her again in a couple of weeks. That was very helpful as it gave me some understanding of what it is we are dealing with. Up to that I was going around in the dark, not sure what to say or do.' **Interview 018**

Although accessing professional support either in the form of individual help for themselves or on a couple basis through their partner's treatment was generally experienced in a positive way, none of the participants in the current study felt accessing professional support in the form of support groups would suit their needs:

'I don't go for the [group] support piece, similar situations doesn't give me much comfort because individuality is a big part.' **Interview 010**

'Peer support would be, meah'. **Interview 014**

'Gosh I don't think going to a support group wouldn't be my thing, it would be like AA or something, no not for me, but as I said I have met with the counsellor and that was helpful.' **Interview 018**

However, although many participants voiced their negative attitude towards support groups, much of this was in the context of never having attended one. Because they had never experienced one or not had adequate information on them, their attitudes were based on their perceptions of what other support groups such as Alcoholics Anonymous might be like, much of which was influenced by how they were portrayed on television. To demonstrate this point, the following extract is from notes that were taken after an interview reflecting a conversation I had with the participant after the recorder was turned off.

He told me he hadn't heard of X [ED voluntary organisation] and then he jotted down the web address.

I asked him if he would think attending a support group would be helpful.

He thought about it first and then said he didn't want to automatically say yes. He wondered would it be like Alcoholics Anonymous where on TV people stood up, introduced themselves and said how long they were sober.

I suggested it is more on the lines of sharing with others their experiences, suggestions, concerns and questions etc.

He said in that case definitely yes. **Interview 002**

Linked with managing disruptions to personal social engagement, managing psychological distress is also achieved by accessing everyday support from other people in their wider social world. The concept of everyday support refers to the emotional, informational and practical supports that arise from daily living. Having access to everyday support not only provides social connectedness with other people but also provides the participants with a mental distance from the distress associated with living with the ED disruptions, as evidenced below;

'But as well it's like I'm so frustrated at home and then you go out and you're actually enjoying yourself with a bunch of people who are in good spirits, nice to be around.' **Interview 005**

'My friends were very supportive but I didn't really like to talk about it [ED]. I used my friends as an escape rather than to talk about it, that was my escape.' **Interview 010**

As discussed in the subsection *'Encountering disruptions to self'* (Chapter 6.5), Some of the strategies participants use to manage their psychological distress such as misuse of alcohol, over eating or not exercising, although helpful in reducing distress in the short term, can negatively impact on their physical health in the long term. Countering these disruptions to their physical wellbeing is achieved by the participants actively changing these unhealthy or maladaptive ways of managing the distress. This usually happens only after living through several cycles of *'Reconstructing Livability'*, when they become aware of the negative effects some of their strategies have on their physical health, and they begin to build on the more helpful ways to manage their distress, as demonstrated below:

'So, I said, I'm not going to be stuck in the pub, and get down, I'll keep doing my own thing, like, joining the gym just to keep myself sane.' **Interview 001**

'I think half of it as well is what we were going through, I was just eating all around me...I looked at a photo and I went Oh my God I need to get some weight off, stop overeating, do something healthy, get out of the house to clear my head instead' **Interview 011**

As *'Countering the disruptions to self'* progresses with each cycle of *'Reconstructing Livability'*, the participants also begin to engage strategies to counter the disruptions to the intimate relationship, which is discussed in the following section.

8.4 Countering intimate relationship disruptions

Having become aware of the disruptions to the intimate relationship (Chapter 6) the participants engage the strategy of countering these disruptions. They engage this strategy in order to be able to experience the relationship in a satisfactory way so they can remain committed to their partner and the intimate relationship. The areas of relationship functioning the participants focus on when countering these disruptions correspond with the areas of relationship functioning that have become disrupted, as presented in chapter 6. These areas include relationship roles, intimate interacting and social engagement as a couple, which although interlinked are presented separately in the following discussion.

8.4.1 Countering relationship role disruption

Countering relationship role disruption is centred on rejecting the identity of carer, as participant's fear they will acquire the identity of carer or be seen by other people as a carer. Although, as discussed in the subsection '*Encountering intimate relationship disruption*' (Chapter 6.6), participants acknowledge the need to take on ED related caring and do so willingly, their reluctance to consider themselves a carer is demonstrated in their narratives, where they strive to maintain the identity of 'partner':

'I definitely would not frame it as a carer. It was always a boyfriend/girlfriend relationship. I never wanted to fall into the role of carer and I worked very hard at that.' **Interview 010**

Countering this disruption to the roles within the intimate relationship therefore, becomes an important aspect of the participant's own recovery where they believe, to experience the relationship in a satisfying way it needs to function as a partnership rather than a carer/cared for dyad. The ways in which they counter this disruption are by 'normalising' the caring they provide, changing their approach to caring, handing over responsibility to their partner and maintaining ED related silences with others. Firstly, the participants frame the ED related caring they take on as part of normal relationship functioning rather than as a separate activity, as suggested by the following participant:

'I feel I have taken on the caring role with X [Partner], but the caring role is part and parcel of a relationship...' **Interview 014**

Secondly, with repeated experiences of cycles of '*Reconstructing Livability*', the participants begin to change the way in which they provide ED related caring. By '*self informing form experience*' (Chapter 7.3), the participants see caring, in the form of taking on a parental role, as unhelpful both to their partner and for the relationship. Although relinquishing the parental role is often difficult since participants worry for the health of the partner, they change their approach in caring to a way they perceive as more helpful to their partner:

'Well I try not to be [the parent] but I would've been of course at some stages, yes there would've been stages...not as much as say that her mother would be to her,

nothing like that you know, nor do I want to get into that state of things anymore you know.' **Interview 007**

'I did the whole hard fast stubborn thing with her when she was going through the illness and it is just kind of I don't want to go down that road again.' **Interview 011**

Thirdly, participants begin to re-establish their identity of partner by encouraging their partner to take responsibility for their own recovery. This only happens with repeated experiences of 'Reconstructing Livability', as they begin to have a better understanding of the nature of EDs (Chapter 7). The participants encourage their partner to take responsibility by stepping back from some of the aspects of caring they have provided such as ensuring their partner attends therapy sessions and handing over responsibility for decision making around their recovery as demonstrated below:

'It was important for me that she was the person who initiated even that [treatment for ED], so rather than it's "we have arranged this appointment for you" or anything else that she, she went and did it and that she admits this and like came to terms with it herself.' **Interview 002**

'I never really want to [take over control], because I don't see how that would help, I mean it might be good for a very short-term, unless she decided herself I don't see how it would improve, she has to decide for herself' **Interview 006**

Finally, as demonstrated below, countering the perception that other people consider them to be a carer is achieved by enacting ED related silence. By not providing other people with information on the ED related difficulties their partner is having, or the associated caring activities they provide for their partner, they perceive others will not be in a position to view the relationship as a carer/cared for dyad. However, although the ED silence is perceived to protect the relationship from being viewed in this way, it also reduces the opportunities for the participants to access social support:

'...I now don't tell them [partners family] much about what is going on for X [partner] because that way they won't see him as sick as he is or won't see me as his personal nurse.' **Interview 013**

Countering disruptions to intimate relationship functioning extends beyond the issues associated with changed relationship roles to include the changes in intimate interacting.

8.4.2 Countering intimacy disruptions

Countering the intimacy disruptions refers to the ways in which the participants counter the disruptions to intimate interacting including communication, trust and sexual intimacy (Chapter 6). The ways in which these disruptions are countered is by encouraging their partner to break some of their ED silence within the relationship, changing how they interact with their partner, developing trust and engaging in a level of physical closeness that their partner is comfortable with. As participants live through successive cycles of *'Reconstructing Livability'* and develop an awareness of the ED related silences engaged by both themselves and their partner (Chapter 6.6.2), they begin to try to break this silence. However, the focus of breaking the silence is usually in relation to their partner while at the same time, in an effort to protect their partner from feeling blame and guilt for the distress experienced by them, they maintain their own ED related silence with their partner. In order to help their partner break the silence, participants begin to encourage them to talk about their difficulties while actively listening to what they are telling them:

I learned about how to listen you know listen to X [partner], to listen to what she was saying.' **Interview 003**

'Then when I was sitting down listening to, when she was speaking, telling the truth, it was very difficult. And I was telling her, when I was sitting there with her I was saying 'X [partner], say whatever, it doesn't bother me'. **Interview 004**

As participants become more informed in relation to the ED behaviours and cognitions they also begin to notice when their partner is having ED difficulties and use what they know to instigate a conversation around what they are seeing, as demonstrated by the following participant:

'The eating disorder gets worse when she is stressed, you can see the difference and so I will ask her about the stress and point out how her eating has changed.' **Interview 012**

Despite efforts at trying to break the ED silences, for the most part, the partner continues to engage silence around the ED difficulties they may be having. In order to begin to manage this in a less distressing way, participants reframe it's meaning by *'explaining away'*

the silence as a consequence of the ED and as a result, something their partner is unable to change:

'I have heard so many times that it [vomiting] has stopped so she's not vomiting anymore and I know, I know well she's at it, you know? She's [partner] trying to hide it all the time hide everything, but she just can't help it, it [ED] is driving her to do it [vomiting and hiding the fact].' **Interview 004**

Whilst trying to break the ED silences, participants also try to continue to communicate with their partner around other everyday events in order to normalise relationship interacting. However, some participants struggle with this aspect of communicating within the relationship particularly at times when their partner is experiencing an ED setback or where conversations around 'normal life' are no longer part of their communications, as evidenced below;

'I don't really know anymore, what is the way to go about basic conversations around normal life, that seems to be gone.' **Interview 002**

'No we don't always talk about food, no never, no I won't say never obviously, we talk about movies and stuff like that and music, we talk about people (participant laughs) yes we do yeah...I try to normalise everything.' **Interview 008**

As the participants experience repeated cycles of 'Reconstructing Livability', they begin to recognise that the high emotionally charged interactions they engage in with their partner around the ED, further disrupts relationship functioning (Chapter 6.6). In order to reduce the tension and arguments within the relationship, participants begin to change how they interact with their partner around the ED by maintaining their own ED silences. For example, conceptualised as 'keeping the peace', some participants avoid confronting their partner about their ED behaviours for fear it will start arguments as demonstrated by the following extracts:

'But for the sake of avoiding a fight I would be like "how are you getting on, what's on TV, what you are watching" you know something, something small like that, not talk about it [ED].' **Interview 005**

'I wouldn't ask her [about the ED behaviours she is engaging], I'd be afraid I'd wake a dragon or set her off, upset her and then a big blow up. I've learned to hold my tongue, if she is going to disclose she will.' **Interview 017**

Although maintaining their own ED related silence usually achieves the end goal of reducing the potential for arguments, participants acknowledge that in many situations this strategy does not result in an improvement in their partner's ED. Whilst the silence results in the relationship being experienced by participants in a less distressing way, it also serves to accommodate their partner's ED behaviours and cognitions as demonstrated below:

'You know sometimes when I ignore it [ED behaviours], he takes a liberty to keep doing what he knows he shouldn't be doing, but at least it does stop the arguments and we can have somewhat of a normal evening.' **Interview 013**

Improving ED related communication with their partner goes some way towards countering the experience of mistrust that arises when their partner conceals their ED behaviours and cognitions. As participants continue to experience some degree of ED related silence from their partner, they focus on what they see as the positive aspects of their partner with an intention to rebalance their perception of them as being a trusting person. In addition, seeing the ED related silence as part of an 'illness' rather than a behaviour of their partner, and drawing on experiences of being able to trust them in the past, facilitates the development of trust:

'I don't know why I just trusted her, maybe a small part in the back of my head somewhere, it's always there, that I know I can trust her.' **Interview 010**

'I don't really trust her around the vomiting or eating but look, she is fundamentally a good person who doesn't usually lie so I have to begin to trust her more.' **Interview 017**

Developing trust in their partner is evidenced in the participant's activities of handing over the responsibility of recovery to their partner and relinquishing their role of vigilant parent, as demonstrated below;

'If you [professionals] get me too involved then the responsibility is taken away from X [partner], and eventually her recovery is her own responsibility I have to trust her with that.' **Interview 007**

The third area of intimate relationship disruption the participants counter is concerned with sexual intimacy and physical closeness. The aim of countering this disruption is to protect the self against feeling rejected by their partner and to improve intimacy in a way

that protects their partner from the distress of engaging in sexual activity and physical closeness. Firstly, participants 'Explain away' the disruption to sexual intimacy as ED driven and related to their partner's negative body image. By explaining it as ED related, the participant's feelings of rejection are reduced as demonstrated by the following participants:

I think our lack of intimacy has a lot of, it's got a lot to do with self-image on her part.'
Interview 006

'I don't even try anymore as it feels sometimes like it [her not wanting to have sexual intercourse], is a rejection even though I know it is the eating disorder.' **Interview 016**

While explaining away reduces some of the participant's feelings of rejection, it does not ameliorate the feelings of loss, as many of the participants admit to missing the sexual closeness that was once part of their relationship. They manage this loss by cognitively reframing sexual intimacy as not important to their relationship function and where possible, engage in a level of physical closeness that is less distressing for their partner, as demonstrated in the following extracts:

'Well I wouldn't, telling you it suits probably is putting it a bit strong. It's, it's it [having a sexual relationship] would be nice, but it's not like the most important thing that might be a better way to put it.' **Interview 003**

'You know we do hold hands when we go out for a walk and we would say have a, I would give her a kiss in the morning before I go to work, before leaving. She wouldn't really be a hugger so to speak.' **Interview 007**

'We still, we still, like we don't have obviously sex morning, noon and night, were gone from that seven years later like. But, intimacy is in like say around the kitchen like we'd hug a lot, we would touch each other an awful lot.' **Interview 008**

In addition to countering the disruptions to relationship functioning, the participants also begin to counter the disruptions to social engagement as a couple. This next section therefore, discusses the manner in which they approach this aspect of countering.

8.4.3 Countering couple social engagement disruption

Countering the disruptions to social engagement as a couple is concerned with managing the ED related changes that have influenced how the participants experience social engagement as a couple. Participants counter this disruption by working around the ED, going alone to events or avoiding social events. Working around the ED is primarily focused on helping their partner to negotiate the ED related difficulties such as eating out, in order to reduce their distress. Planning a social event ahead of time is perceived by the participants to reduce the uncertainty of not knowing for their partner, and thus facilitating them to engage in some social activities, as demonstrated below:

'If we haven't planned somewhere beforehand, she always likes to plan the place you know, beforehand if we are going out we like to plan somewhere beforehand so it would be okay. Otherwise if we were going out on the spur of the moment and it's, and you can see how apprehensive she is.' **Interview 005**

'When we're going out for a meal with friends we'll have looked up the menu [of the restaurant] so she'll know what she can order when we get there. There's a better chance we'll get there if she is not so stressed out.' **Interview 009**

Working around ED difficulties also includes the activity of covering up the ED difficulties their partner may have when out socially. This is primarily aimed at reducing their partner's distress but is also undertaken to avoid the judgements of other people. A common way of covering up around their partner's difficulty with food is to eat the food they are not able to eat, as demonstrated below:

'I would cover for her nearly, almost like, if two plates of food would come out and hers has something on it that she wouldn't like, then I would swap mine. Or just little things that I could do to try and avoid it been seen. Anything like that so I suppose it is probably partly to protect her and partly I don't want it to be a big issue.' **Interview 009**

'Yeah because X's big thing was, they [people with EDs] don't want to be seen eating it, so I just switch plates and then I ended up eating it...' **Interview 011**

As the participants live through successive cycles of 'Reconstructing Livability', they are often faced with the situation where socialising for their partner becomes increasingly difficult, to the extent that their partner does not go out with them. In order to maintain social contacts or out of a sense of duty to friends or family, the participants will go to the

social event on their own. Going alone is difficult for most participants because they feel different from other couples, they find it lonely or they find having to explain their partner's absence embarrassing:

'There would've been weddings I would have gone to, but she [partner] just couldn't, and I'd go [on my own].' **Interview 003**

'The hardest part is when we get invited to a wedding, because a lot of our friends are getting married now, I know he won't be able to go and to be honest having to go on my own and have to make excuses for him is very embarrassing.' **Interview 013**

A further way the participants counter the disruptions to social engagement as a couple is to avoid socialising in situations where they perceive they are expected to attend as part of a couple. As discussed in the subsection *'Encountering disruptions to self'* (Chapter 6.5) this often occurs because of the difficulties they have with socialising on their own. However, a second aspect to avoiding going out is that participants choose to stay with their partner, either out of the need to support them or because they prefer to do so:

'We don't have a massive group of friends, so we spend a lot of time together. There are opportunities for me to go out but I choose to stay with X [partner] it's more enjoyable.' **Interview 010**

Similar to other areas of disruption such as ED silences in communication or disruption to sexual intimacy, remaining connected socially as a couple continues to be an issue for the participants despite their efforts at countering the disruption. However, as the ED behaviours and cognitions begin to abate for their partner or as a result of the countering strategies engaged by participants, the disruptions begin to be experienced in a less problematic way. This marks the end of the third stage in the cycle of *'Reconstructing Livability'* and the beginning of the final stage which is conceptualised as *'Reclaimed livability'*. It is in this stage the participants engage strategies to assist them to adapt to the changes that have come about to their relationship so that, as part of their own recovery, they can remain committed to the relationship.

8.5 Summary

This chapter discussed the third stage in the cycle of *'Reconstructing Livability'* where the participants counter the ED related disruptions that have come about to their lived environment, namely their partner, the self and the intimate relationship. The strategies to counter the ED related disruptions to their partner are concerned with the participants providing practical and emotional support to them. In countering the disruptions to self, the participants look after their psychological health by seeking ED related support from professionals while seeking everyday support from other people and actively taking steps to look after their physical health. Countering the disruptions to intimate interacting involves changing how they communicate with their partner, developing trust and engaging a level of physical closeness that their partner can respond to. These strategies to counter the disruptions develop with each cycle of *'Reconstructing Livability'* the participants live through, as they become more informed of the nature of the ED and more attuned to their partner's needs. As the ED difficulties for their partner reduce and the countering strategies engaged by the participants help limit their distress around the disruptions, they begin to focus on recovering the self, so that they can continue to live in the relationship in a satisfactory way. This is the fourth stage in the theory of *'Reconstructing Livability'* which is conceptualised as *'Reclaimed livability'* and is presented in the following chapter.

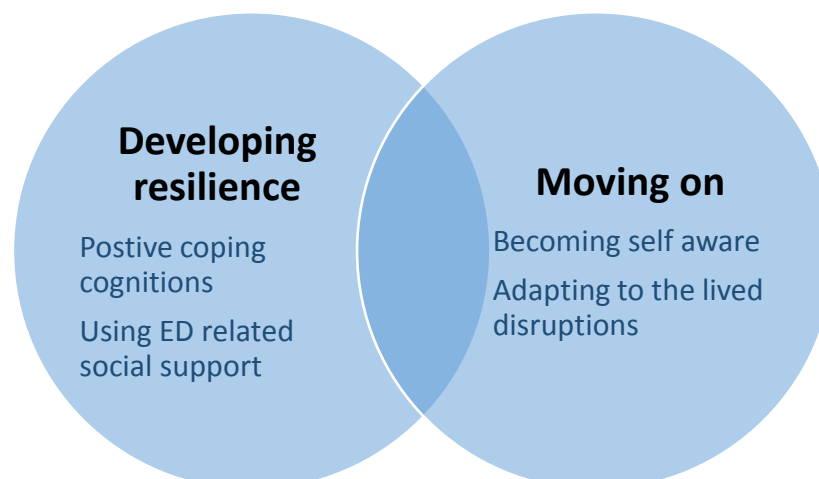
Chapter 9

RECLAIMED LIVABILITY

9.1 Introduction

The previous chapter discussed the strategies participants engaged in order to counter disruptions to the various aspects of their lived environment; however, despite these efforts they continue to encounter disruptions to the intimate relationship. They understand this to come about as a result of the cyclical nature of the eating disorder (ED), where their partner experiences repeated ED setbacks that continue to impact on relationship functioning. In light of this understanding, when their partner's ED behaviours and cognitions begin to lessen and, because of the countering strategies engaged by the participants, the disruptions are experienced in a less distressing way, the participants move onto the fourth stage of the cycle conceptualised as *'Reclaimed livability'*. In this stage participants begin to focus on recovering the self, so that they can remain committed to the relationship and experience it in a satisfactory way. Unlike previous stages in the cycle of *'Reconstructing Livability'*, which often involve a dialogical process with others including their partner, this stage is primarily centred on the self of the participant with a focus on the future. The strategies engaged in this stage of the cycle, although linked with those in *'Countering disruptions to self'* (Chapter 8) are more focused on the participants developing a sense of control over their own lives. The two subcategories in this stage of the process are *'Developing resilience'* and *'Moving on'* (Figure 9.1)

Figure 9.1 Reclaimed livability



9.2 Developing resilience

'Developing resilience' refers to the participant's ability to recover from the ED related disruptions to their psychosocial and physical wellbeing. This extends the concept of 'Countering the disruptions to self' (Chapter 8), as it relates to the recovery of the self within the relationship. Participants link the development of resilience to their ability to remain committed to the relationship, as demonstrated below:

'But there is some resilience in that after all these years...I think there is a resilience otherwise I wouldn't still be there we still wouldn't be together if there wasn't something holding us together.' **Interview 005**

'You become more resilient over the years, you have no choice really because this is what it is, it is what it is.' **Interview 013**

The building blocks to the development of resilience are situated in other stages of the cycle of 'Reconstructing Livability,' where engaging the strategies of becoming an 'Informed self' (Chapter 7) and 'Countering the disruptions' (Chapter 8) facilitate this development. This occurs as the participants are exposed to repeated ED setbacks experienced by their partner and the strategies they engage to manage the resultant disruptions become more finely tuned with each cycle they live through. Developing resilience extends beyond merely surviving each disruption, rather it is concerned with participants adapting to, growing from and coping with the challenges they face, facilitating them to experience life and the intimate relationship in a more satisfying way, as demonstrated below:

'There are some nights I don't sleep from worrying about her and this blasted thing, but I still have to get up for work in the morning and keep going, you get used to it and have to be able to do normal things.' **Interview 016**

Contained within the second and third stages of the cycle of 'Reconstructing Livability' (Chapter 7 & 8) are mechanisms supporting the development of resilience, namely 'Positive coping cognitions' and 'Using ED related social supports'. It is only by living through successive cycles where the strategies to manage the disruptions become more finely tuned and participants gain a better understanding of the ED, that these mechanisms develop to become part of 'Reclaimed livability'. These mechanisms are presented in the discussion below.

9.2.1 Positive coping cognitions

Positive coping cognitions are concerned with the variety of positive thinking approaches used by the participants, which enable them to look beyond the distressing aspects of living with the disruptions and see their partner and relationship in a more positive way. In the earlier cycles of *'Reconstructing Livability'*, positive coping cognitions are more active when their partner is experiencing an improvement in the ED because participants are experiencing less distress around the health concerns for their partner. Although positive coping cognitions continue to be more active in these times, as the participants live through successive cycles of *'Reconstructing Livability,'* these cognitions also begin to be evident in times when their partner is experiencing an ED setback. This happens as the participants are building on their understanding of the ED and their self-efficacy in providing effective support improves. The positive coping cognitions supporting the development of resilience are primarily partner and relationship orientated.

There are several ways in which the participants engage partner orientated positive cognitions. Firstly, when the participant's distress at encountering their partner's repeated ED setbacks is experienced as anger and frustration at their partner's inability to overcome the ED or because of the resultant disruptions (Chapter 6.6.2), positively appraising their partner helps to negate these feelings. Being able to see beyond their partner's ED behaviours and cognitions and reflecting on what they perceive as the positive aspects of them, facilitates the development of resilience as it helps participants to cope in the long term with their partner's repeated ED setbacks. In addition, seeing their partner beyond the ED promotes improved relationship functioning, where participants begin to change their emotionally charged interactions with their partner, thus reducing tension and arguments and supporting an ongoing commitment to the relationship:

'I relate to her as a person not a sickness. I am more aware of how I react around her, I see beyond the illness and that way I can treat her like a person rather than an illness.' **Interview 010**

'...and it came to a stage where it was very touch and go whether I was going to walk away or not because it literally became that intolerable...and the only reason I stayed then was I knew that it wasn't who she was that, everything that had controlled her, that was what was making her like this.' **Interview 011**

Secondly, even in the midst of experiencing anger, frustration and worry at facing repeated disruptions to the relationship, all of the participants reflect on the feelings of love they have for their partner. Being mindful of their love facilitates them in withstanding the ongoing disruptions and thus they remain committed to their partner, as demonstrated below:

'I have asked myself that [what is good about the relationship] recently, and I don't think anything, only I do still love her for whatever reason.... I still love her to bits after all the years and after all the difficult times, I couldn't ever imagine life without her.' **Interview 005**

'I am worried for him, but I love him and it's [ED] not an impediment to being with him.' **Interview 014**

Thirdly, the positive coping cognition of hoping for a better life for their partner also contributes to the development of resilience. By focusing on a positive outcome for their partner, participants are motivated to continue to counter the disruptions and provide support to their partner. The nature of hoping for a better life for their partner however, changes over the course of experiencing repeated cycles of *'Reconstructing Livability'*. This change comes about as participants, engaging strategies to inform themselves (Chapter 7), become more informed of the cyclical nature of the ED and develop a better understanding of what their partner is going through. Initially hope for the partner is focused on their partner not experiencing further ED setbacks but this changes to hoping that their partner can have a better life even if experiencing further ED setbacks. The examples below demonstrate the changing nature of the participants hope for their partner's recovery. The first example is from a participant who has been in the relationship for many years and the second, from a participant whose relationship is of a much shorter duration:

'Yeah, I'm hopeful, yeah. It's [partner's recovery] long, she knows herself it is long, years, she might never be fully cured but if she can just take it [recovery] on, and get on with her life, be happy with her life.' **Interview 004**

'I am very hopeful, yes very. She is a very strong person and if she sets her mind to something then she can beat it...I wouldn't give up hope for her anyway because what would you be without that.' **Interview 018**

Finally, once aware their partner may experience further ED setbacks, the participants continue to hope that professional help will be available to help their partner through recovery. Hope for professional inputs that will make a difference to their partner's life is often based on experiences in previous cycles of *'Reconstructing Livability'*, where links with professionals have begun to be made. However, even for those participants who have not had successful links with professionals, they continue to hope these inputs will become available. Having a belief that professional help will be available supports the development of resilience where participants feel this help will mean a better life for their partner and subsequently a better life for them both as a couple into the future.

'I, I know with any addiction it could come back but I, it's not that I don't care, but there is help, more help now than we had before this.' **Interview 001**

'I hope something will work, something will show up, I'm hopeful something will turn up. Fundamentally I'm very optimistic and pragmatic. I know something will have to go right because so far it hasn't. It can be a chance encounter, a referral, a back door, something changing.' **Interview 014**

Linked with partner orientated hope is hope for the relationship, where participants are of the belief that ED related improvements for their partner will be reflected in improvements to relationship functioning, as demonstrated below:

'We can work on all the small things together and when the eating disorder is in the background we really work well on the small things and they all add up to something good.' **Interview 012**

Positively appraising the relationship even in times when disruptions are experienced in a distressing way also contributes to the participant's ability to withstand the disruptions and remain committed to the relationship. Reflecting on what is fundamentally good about them as a couple and separating this from the ED associated difficulties, allows the participant to appreciate the relationship in a positive light, as demonstrated by the following participant:

'We actually are very close, we, we are like. It's only about the weight issue, it is only ever the thing we argue about, about food or not eating. I can't remember the last time we had an argument, there wasn't anything it was just about the weight issue. I can't remember because we don't argue to be honest, we don't go to bed mad or cross, unless it about the eating disorder.' **Interview 001**

A combination of using partner and relationship orientated positive coping cognitions instils a sense of optimism for reclaiming the livability of the relationship, where participants are hopeful of a positive outcome for the self in the relationship. This positive outcome is concerned with the participant being able to experience the relationship in a satisfying way, regardless of facing repeated disruptions. Having this belief for the self in the relationship further supports the development of resilience, where participants feel that by continuing to counter the disruptions, the livability of the relationship can be reclaimed, as evidenced below:

'When it's bad it can be very bad and it is getting progressively worse but I know we have a good thing together so I will keep fighting to get that back.' **Interview 014**

The development of resilience is further enhanced by participants having access to social supports, discussed below.

9.2.2 Using ED related social supports

In addition to hoping for access to professional support for their partner as discussed above, actually having access to and using ED related social support from professionals also supports the development of resilience. For those few participants who engage in their own psychological therapy when *'Countering the disruptions to self'* (Chapter 8.3), the experience is helpful in dealing with their emotional distress. Having access to ED related information from professionals also supports participants in setting realistic goals around supporting their partner in recovery. This facilitates the development of their self-efficacy in relation to providing more effective support to their partner, as demonstrated below:

'We have a great GP who is supportive, compassionate, progressive, I know I can go to him to get clarity on where we are going with this [partner's recovery process], or what the next step is, to move forward rather than back.' **Interview 014**

'So when she [partner] was admitted I got the chance to talk to one of the nurses there and that was really helpful because I got some tips on how I could help X [partner] and what to expect after she was discharged.' **Interview 016**

Using ED related support from non-professionals, namely family members and friends, also facilitates the development of resilience for participants. This aspect of support extends

the concept of accessing everyday support from others in order to '*Counter the disruptions to self*' (chapter 8.3), as it includes the emotional, informational and practical support needs specifically relating to the ED. Using this support helps to reduce the emotional distress the participants experience when they believe they do not have the informational or practical resources to counter the disruptions. Being able to draw on others' support therefore, is seen by the participants as a further means of supporting their partner towards recovery while providing themselves with a sense of gratification and relief at having these supports available for the self, as demonstrated below;

'My own mother is very supportive, X [partner] and her have a great relationship. Mum helped cement the fact he [partner] needed to do something [about the ED]. We are a peer support group [Mum, partner and participant] it's such a relief to have that.' **Interview 010**

The ED related informational supports from other people that the participants use, as discussed in the subcategory '*Intentional informing*' (Chapter 7.3.1), are usually in relation to accessing help for their partner or seeking advice on how best to manage their own distress. Practical support is usually in the form of others helping them 'care' for their partner when the participants feel they are not in a position to support their partner adequately, or providing the financial support necessary to be able to access treatment for their partner. Accessing and using ED related emotional support for the self is concerned with being able to talk to someone about the distress they themselves are experiencing. Some examples of accessing different types of non-professional supports are provided below:

'My mother, I can tell her a lot more with regard to the more recent treatment, I could tell her how I feel about that.' **Interview 002**

'I spoke to my brother about it as well actually he'd be one of the few people who I would confide in, and that is really helpful because he is able to think about it clearly as an outsider.' **Interview 005**

'I think her [partner's] dad had been looking at different options to see about how the family could kind of take control of it [ED setback].... He [partner's dad] was thinking about bringing her home to do it [supervise the partner's eating] I think her mother could have watched more closely as she has only very short days at work and with my work I might be abroad a lot, it's just I couldn't do it...I knew I couldn't have done it [supervised the partner] myself.' **Interview 006**

Where ED related social support from others is not actually provided but is perceived by participants to be available, it has a similar effect to receiving the actual support, as participants believe they can rely on this support becoming available in the event it is needed, as demonstrated by the following participants:

'I have heaps, of people, you know honestly I can go and talk to, my mom...I tend to not use it [speaking to people] but it is there if I need.' **Interview 003**

'...it's nice to know you can have it (support)... now my mam, she'll say "oh how are you getting on and how is X [partner]," but she doesn't push too hard...so, yeah but like, I always know they [parents] are kind of there.' **Interview 009**

Accessing ED related support from non-professionals however, is challenging for the majority of participants. Two of the reasons why this can be challenging are in relation to other people's lack of understanding or knowledge regarding EDs, or because participants perceive that other people do not want to know or provide ED related support which can be experienced in a distressing way, as seen below:

'I think a lot of people don't understand it and would probably agree they don't understand it.' **Interview 002**

'I don't know how it would be, like if I said to her [partner's mother], " X [partner] has an eating disorder and was admitted for eight weeks", like she was in a place for eight weeks, her mother never even knew because she doesn't want to know, she has no idea, and it frustrates me.' **Interview 004**

In order for the non-professional supports to facilitate developing resilience, they need to fit with the wants and needs of the participant, otherwise these supports can be counterproductive by increasing the level of distress. For example, the perception that other people will judge them, the relationship or their partner negatively is experienced by the participants in a distressing way (Chapter 6.6.3). In addition, as participants live through successive cycles of '*Reconstructing Livability*', their social support needs change in response to becoming more informed (Chapter 7) and from encountering further disruptions (Chapter 6). Therefore as demonstrated below, when accessing social supports from non-professionals, all participants carefully choose who to access support from and what that support will be, while all the time remaining mindful of their own issues around accessing the supports. However, this cautious approach combined with their own

difficulties at accessing social support limits the amount of support participants can actually draw on:

'I suppose you can only get the amount of support you willing to take so like I'm, I'm, I'm not great first, at looking for it or accepting it when it's in front of me like...'
Interview 009

'I choose the people who I want to talk to about it and I chose the people when I talk to them I know can help me and help X [partner] behind the scenes who can help me, they would be supportive.' **Interview 012**

Developing resilience is an important aspect of *'Reclaiming livability'* because the participants are faced with repeated disruptions to their lived environment and in order to remain committed to the relationship, they must be able to withstand the disruptions and continue to counter them. Remaining committed to the relationship however, also requires the participants to be able to experience their own personal life in a satisfying way, which requires them to be able to move forward with their own lives, even if they are living with actual or potential ongoing disruptions. Therefore, the second subcategory to *'Reclaimed livability'*, conceptualised as *'Moving on'*, is concerned with the participants finding a balance between remaining committed to their partner while reclaiming the livability of their personal life.

9.3 Moving on

The concept of *'Moving on'* refers to a process where participants reclaim the livability of their lives by adapting the self, so that they can experience the relationship and their lives in a satisfactory way. *'Moving on'* occurs even though some aspects of the relationship remain disrupted, such as social engagement or sexual intimacy (Chapter 6.6). The concept of *'Moving on'* is interlinked with the *'Developing resilience'*, as participants need to be resilient against experiencing repeated disruptions in order to be able to move on. In turn, the activities participants engage in order to *'Move on'* further facilitate the development of resilience. *'Moving on'* is enacted by *'Becoming self-aware'* and *'Adapting to the lived disruptions'*, which are discussed in the following two subsections.

9.3.1 Becoming self-aware

'Becoming self-aware' is concerned with participants developing an understanding of their personal strengths, limitations and needs in the context of their ability to counter the disruptions and move on with their lives. Similar to that of *'Developing resilience'*, the foundations of *'Becoming self-aware'* are located in the other three stages in the cycle of *'Reconstructing Livability'*. By living through successive cycles, participants gradually increase awareness of self, which guides them in the strategies used to counter the disruptions and subsequently guides them to the strategies required to move on with their lives.

As they progress through the cycles of *'Reconstructing Livability'* and learn through experience (Chapter 7.3.1), participants become conscious of their personal strengths and limitations with regard to countering the ED disruptions to their partner or in preventing further ED setbacks from occurring. For example, they become aware of the limitations their countering strategies have on changing their partner's ED behaviours, such as taking on the role of vigilant parent, or they become aware that their ability to listen to their partner is supportive (Chapter 8). Being aware of these strengths and limitations is experienced in an empowering way as it facilitates participants to change their approach or fine tune the strategies they consider to be helpful, so they are more beneficial to their partner and less distressing for themselves. In this way, participants are continuously *'moving on'* into an improved livability:

'By talking to her you could get a good month out of her [where ED behaviours are less], by not talking it doesn't work. I've learned that from the past, when you don't talk she will wander off [engaging ED behaviours], when you do talk she's able to eat normally and not be thinking she's fat and just get on with things.' **Interview 012**

Becoming self-aware of their strengths and limitations with regard to countering the disruptions to the relationship and their ability to remain committed to the relationship also develops over repeated cycles of *'Reconstructing Livability'*. By gaining an understanding that the relationship disruptions are as a result of the ED rather than due to an incompatibility within the couple dyad (Chapter 8), participants come to believe they can limit the disruptions through informed countering strategies. Although relationship

disruptions continue to occur with each ED setback, the countering strategies engaged by the participants facilitate them to move on to experience the relationship in a more satisfying way. For example, when sexual intimacy is disrupted the participants engage a level of physical closeness that is less distressing for their partner, while going some way towards satisfying their own intimacy needs (Chapter 8.4.2). 'Moving on' is also facilitated by an awareness of their ability to remain true to their values. Even when faced with the distress of the disruptions or faced with the uncertainty of being able to remain in the relationship, drawing on their own belief system supports them in moving beyond the disruptions while remaining committed to the relationship:

'They [living with the ED] are difficult, though not impossible though, but there is also the commitment where you know, you can't just say, you have to, you have to be able to stay with it [relationship] as well.' **Interview 002**

'Well, we're married, I'm not religious not at all fundamentalist, I'm an atheist personally, so it's got nothing to do with God, but that said I do, we did make a commitment to each other and that is very important to me.' **Interview 007**

The ability to move on with their lives is also influenced by the participants becoming aware of their personal needs. This extends the awareness of their emerging needs as a result of 'Encountering disruptions to self' (Chapter 6.5), to include further psychosocial and physical needs participants have in relation to their own long term personal recovery. Becoming aware of their own needs however, usually only occurs in later cycles of 'Reconstructing Livability' as in early cycles the focus of attention is primarily on the needs of their partner. Participants often recognise the need to remain socially connected as a way in which they can 'Move on', as it provides a valuable way in which to manage their psychological distress and 'normalise' the livability of their environment, as demonstrated below:

'I suppose that's the greedy side of her [partner] she doesn't like me being up in X [a different county to where they live] she is very mean with my time. She prefers my time to be all in X [county where they live] and not up with my family whereas I know I have to spend some of my time with my family, where my family is, and I need to be able to visit and be with them, for a bit of normality.' **Interview 008**

'I was losing all my friends, not the close ones because they will always be there, but even just the people I work with. I had stopped going out with them on Friday nights because I needed to be home for X [partner]. But I miss that and I think getting out again would be good for my head.' **Interview 013**

The participants also begin to become aware of their needs in relation to their physical health which is linked with their need to change the maladaptive patterns they may have developed to manage distress such as abusing alcohol or food (Chapter 8.3). Self-awareness for their physical health is extended here to include the needs arising from not taking adequate care of the self because the needs of their partner are prioritised as demonstrated below:

'So I lost track of the running, I don't have time for the exercise at the moment. It's hard, at the moment, I'm on the road [visiting his partner who is in hospital] so I've upped, I've upped my own weight again, it's upped again but I know the walking, I will get it back again, once things settle down a bit.' **Interview 001**

'It's huge pressure on me as a partner trying to be rigid at meal times. I try to manage my food around him, cook what he likes or what he might eat but then I might not be eating properly.' **Interview 014**

Becoming self-aware of their strengths and limitations is linked with developing resilience where the participants begin to engage countering strategies that are consistent with their perceived ability to make a difference to the livability of the relationship. In addition, becoming self-aware of their psychosocial and physical needs provides the basis on which the participants begin to engage strategies to self-care which make a difference to the personal self. As participants encounter ongoing or further disruptions to the lived environment, *'Becoming self-aware'* supports them in adapting the self to the disruptions, so they can continue to live in the relationship in a satisfying way. The second subcategory to *'Moving on'* therefore, is conceptualised as *'Adapting to the lived disruptions'*, which provides an account of self-adaptation to the disruptions as presented in the next subsection.

9.3.2 Adapting to the lived disruptions

'Adapting to the lived disruptions' is concerned with the participants adjusting to the changes that have come about to relationship functioning. Although a series of adaptations in the form of *'Countering the disruptions'* occurs throughout the process of *'Reconstructing Livability'*, adapting as it relates to the subcategory *'Moving on'* is focused on being able to continue to live in the relationship in the future. *'Adapting to the lived*

disruptions' arises in the context of the participants becoming both self-aware and aware of the cyclical nature of the ED, as demonstrated below:

'Now, I suppose I've come to the conclusion myself that she is not, is not going to get better, and better being in inverted commas, as you know. And most people would agree with that you know. So, I suppose you know in a way that releases you a little bit it allows you just get on with it, rather than getting really disappointed when she has to go in somewhere [hospital admission] again.' **007**

In addition to becoming self-aware and aware of the cyclical nature of the ED, *'Adapting to the lived disruptions'* is built around the participants developing an acceptance that their partner will continue to experience ED setbacks and, as a result the relationship will continue to experience disruptions into the future. This is not about giving up hope for reclaiming the livability of the relationship, rather it is about acknowledging a reality that ED setbacks will continue to occur but despite these setbacks the relationship can and will continue to function. As demonstrated below, many of the participants explicitly refer to developing acceptance:

'I think, I mean I think I can accept, like kind of, there are things in my head it will always be there, and it's just, it's how you live with it.' **Interview 002**

'But you know will I cry into my pint over that [not socialising as a couple], not really no, because that's, you know that's how it is... you have to accept it.'
Interview 003

Acceptance develops over the course of experiencing repeated cycles of *'Reconstructing Livability'* when participants gain an understanding of the nature of the ED and their own limitations in preventing further ED setbacks from occurring. For many participants acceptance is about acknowledging to themselves that disruptions are part and parcel of the relationship, and although still distressing, they are no longer an unusual occurrence but something they get used to, as evidenced below:

'And it's [ED] a daily thing, you get used to it you just, you're used to it.' **Interview 002**

'It [ED] has impacted over the years but I have, I have got used to it and it has got better and I suppose habituation or whatever, you get used to it...' **Interview 008**
'We [partner and adult children], have all have got used to the anorexia over the years, it has become part of our lives...' **Interview 016**

Becoming aware of and accepting their own limitation with regard to their partner's recovery is linked with acceptance that their partner needs to take personal responsibility for their own recovery. It is in this way the subcategory of 'Moving on' is interlinked with the subcategory 'Developing resilience', where an acceptance that their partner needs to take responsibility; i) reduces the participant's feelings of failure and powerlessness when their partner experiences further ED related setbacks; ii) allows the participant to modify their countering and supportive strategies to ones that are considered by them to be more realistic and iii) supports the participant in feeling hopeful for the future of their relationship when their partner is seen to take on the responsibility for recovery. Evidence of these findings is provided in the examples below:

'I'd say if I stood on my head upside down for a year it would make no difference, until she decided herself. So, I notice now she is making the effort herself and, that's a great relief for me then, looking back to my side of things, she's sitting down now more relaxed and talking. We used to always go for a pint on a Friday evening in, in thing, in the local, it's only about 2 miles away. That didn't happen now for years. I said, that will happen now, even this evening. Now, or shortly she definitely will.'

Interview 001

'Also I know, at some point he has to decide himself that he wants to do it, there is only so much I can do. I can support him as best I can but really, he has to just go for it himself.' **Interview 013**

Accepting recovery resides with their partner also enables participants to take a step back from the ED related caring they provide for their partner. Stepping back facilitates them moving on with their own lives, where a process of adaptation of the self is achieved by responding to their own psychosocial and physical needs as demonstrated below:

'I know this sounds really weird now but I don't think I'd throw into her as much as I did. I threw myself into her and gave of everything else. The thing is she can look after herself...and I would take a bit more of a step back I think I would now and look after my own side of things.' **Interview 008**

'I felt I needed to move on with things, live my own life, otherwise two lives were lost. I work, socialise and do my own thing. If I didn't I feel I would be in a very bad place.' **Interview 016**

Responding to their own needs is primarily concerned with the participants taking control of their own life so that improvements in their psychological, social and physical functioning allows them to experience life in a more satisfying way. Many of the activities engaged by

the participants in responding to specific needs such as using physical exercise to improve psychological distress, also help to meet other needs such as providing opportunities for connecting with other people. Examples of how engaging specific self-care activities can simultaneously impact on several areas of personal needs are provided below;

'One of the pieces of advice that my, my psychotherapist gave to me was "you have to find something for you, that you do." It's probably the best bit of advice anybody ever gave me, you know, ever....So I discovered hillwalking and trekking, I joined a walking club.' **Interview 003**

'I now make sure I have my own meals even if she is not eating because I find when I don't eat I don't sleep properly and then I'm irritable the next day.' **Interview 011**

In order to reclaim the livability of the relationship however, taking control over their own life involves a balance between participants meeting their own needs and meeting the needs of their partner. As demonstrated below, participants perceive that when both people's needs are met relationship functioning such as communication improves and the relationship is an easier place to live in:

'As she has changed since the therapy, I play golf on a Saturday morning, but straight after golf I am conscious I have to go home, to go home...So, Just that end of things you'd be always conscious of, I suppose even now, we just, you know, you'd get dinner in. If I was home, I would get dinner and just eat it there, be with her.' **Interview 004**

'I'm hugely aggressive by nature. The rugby gets it [the aggression] out of my head, it helps me, it gets it out of me...I only go out on a Wednesday to rugby so she can go to therapy any other night...that way I won't take my aggression out by screaming at her.' **Interview 015**

The level of acceptance and ability to move on varies across the participants' experiences. What is evidenced in the data however, is that acceptance and the ability to move on is linked with the extent to which a participant's partner experiences ED setbacks. For those participants who are living with a partner who has experienced several ED setbacks, their level of acceptance and moving on is more developed. This can be explained by the participants building their understanding of; i) the nature of EDs, ii) the disruptions to their intimate relationship and iii) their limitations and strengths in countering the disruptions, which guide them in making the necessary adaptations to self so they can reclaim the livability of their relationship. Once participants have adapted and moved on from the

disruptions encountered in any given cycle of *'Reconstructing Livability'*, a period of stability in the lived environment is experienced. This period of stability continues until their partner experiences an ED setback and further disruptions are encountered. When this occurs the participants enter a new cycle of *'Reconstructing Livability'*.

9. 4 Summary

This chapter presented the fourth stage in the theory of *'Reconstructing Livability'* which is conceptualised as *'Reclaimed livability'*. This stage of the process is concerned with the participants experiencing the relationship in a satisfactory way despite ongoing disruptions to their partner, the self and the relationship. In order to be able to remain committed to the relationship, participants go through a process of *'Developing resilience'* which facilitates their own recovery from each episode of disruption they experience. Resilience develops over the course of their partner experiencing repeated ED setbacks through the mechanisms of positive coping cognitions and accessing ED related support. Developing resilience supports participants in *'Moving on'* with their lives where the activities they utilise to move on further builds their resilience. *'Moving on'* progresses as the participants become aware of and accept their own strengths and limitations in relation to countering the disruptions, become aware of their own needs, and accept the reality of the cyclical nature of the ED. Participants then begin to work within their strengths, limitations and needs to adapt the self so that life and the relationship can be experienced in a satisfying way. Once the participants have adapted the self, they experience a period of stability in the relationship which continues until a further ED setback is experienced by their partner. This becomes the catalyst for re-entry into the cycle of *'Reconstructing Livability'*.

Chapter 10

DISCUSSION

10.1 Introduction

The preceding four chapters presented the substantive theory of '*Reconstructing Livability*', which provided an account of the way in which participants, who are living with a partner experiencing an eating disorder (ED), address their main concern of '*Encountering and living in a disrupted relationship*'. In the theory this is conceptualised as a personal journey of recovery, where participants recover from the ED related disruptions that have impacted on their lived environment and develop strategies to enable them to live in the intimate relationship in a satisfying way. To my knowledge this is the first theory developed that accounts for how partners of people experiencing an ED cope with and respond to the disruptions to their lived environment that arise as a result of the ED.

This chapter discusses the central concepts contained in the theory and in doing so demonstrates how the theory of '*Reconstructing Livability*' provides a new lens on a previously under researched area. In addition the discussion also demonstrates how the current theory fits with, and expands on what is already known about partners' experiences and, in particular, partners' experience in relation to EDs. The discussion is presented with reference to the following four concepts which emerged from the analysis as central to the theory:

'Reconstructing Livability' and personal recovery.

'Reconstructing Livability' and hope.

'Reconstructing Livability' and identity.

'Reconstructing Livability' and social support.

10.2 '*Reconstructing Livability*' and personal recovery

The theory of '*Reconstructing Livability*' is the conceptualisation of a social process undertaken by participants in response to encountering disruptions to their lived

environment as a result of their partner experiencing an ED. Disruptions to their lived environment are in the form of disruptions to their partner, the self and the intimate relationship. Using a Classic Grounded Theory (CGT) approach facilitated the conceptualisation of this process as a personal recovery journey, where the participants need to recover from the ED related disruptions in order to reclaim the livability of their intimate relationship. This adds a new dimension to the term personal recovery, where the importance of the intimate relationship for personal recovery is acknowledged.

The experience of personal recovery for the participants in the theory of '*Reconstructing Livability*' fits with, and expands on our current understanding of personal recovery as discussed in the review of the literature (Chapter 2). Consistent with the Mental Health Commission's (2005) view on recovery and personal recovery, personal recovery for the participants in my theory is concerned with meaningful life adjustment, which is grounded in the process of personal change and growth. However, my theory expands on what is already known about personal recovery as it views recovery from the unique perspective of the participants, who are partners of people experiencing mental 'illness'/distress, rather than from the perspective of the people who are themselves experiencing the mental 'illness'. This expanded concept of recovery is innovative in that it applies to the participants' experiences based on the belief that every day human experiences of distress or upheaval require people to face the challenge of recovering and moving on from these experiences (Anthony 1993).

Personal recovery is a highly subjective experience, unique to each individual, and therefore the general consensus in the literature is that it is a complex, multivalent concept (Higgins 2008). The current theory further adds to this complexity by including not only the experiences of partners living with a person experiencing an ED, but also has the added dimension of recovery of the self in the intimate relationship. In order to capture all aspects of recovery as they apply to the current theory, the personal recovery of the participants is defined in this study as, '*The subjective experience of personal life adjustment in response to encountering ED related disruptions and associated distress, so that life and the intimate relationship can be experienced in a satisfying way.*'

The participants' recovery journeys, therefore, are framed in the current theory as a recovery from the psychological distress of living with ED related disruptions to the lived environment including that of the intimate relationship. The psychological distress participants experience in relation to their partner is about the ED health concerns, which increase when their partner is experiencing an ED setback. Consistent with reports in the literature on difficulties for people experiencing EDs (Farrell *et al.* 2006, Tchanturia *et al.* 2012, Meng & D'Arcy 2015), participants in my study report poor physical wellbeing, low mood, and loss of interest in social, relationship and personal activities as the ED health related concerns they have for their partner arise. Although not a theme acknowledged in the literature, a major distress for participants in the current theory is the concern their partner could die as a result of the ED. This fear can be understood in the context of the medical risks associated with EDs and where mortality for those experiencing Anorexia Nervosa (AN) over a protracted period of time is reported to be as high as 20% (Birmingham *et al.* 2005, Crisp 2006, Fichter *et al.* 2006).

Psychological distress in relation to the intimate relationship arises from disruptions to relationship functioning. Consistent with findings in studies that examine the experiences of partners of people experiencing an ED (Van den Broucke & Vandereycken 1989, Van den Broucke *et al.* 1994, Alexakos 2004), these disruptions are evidenced in participants' accounts of changes to intimate interacting, relationship roles and social engagement as a couple. Participants' distress is evidenced in their reports of various emotional responses to the disruptions to include low mood, poor concentration, feeling worried, angry or upset. The psychological distress experienced by participants is consistent with accounts of family members' psychological distress discussed in the review of the literature (Chapter 3); however, much of this literature uses the language of the medical model, which pathologises people's experiences. Within the medical model, family members' distress is understood to be as a result of the cumulative effects of living with a person with mental health difficulties and is spoken about using the language of anxiety and depression as symptoms (Drapeau *et al.* 2012). Framing family members' distress in terms of symptoms and diagnosis, however, overlooks the idea that distress can be a normative response to disrupted or stressful social circumstances (Horwitz 2007). Understanding the concept of psychological distress in the current theory is not about framing it in a pathologised way or framing it in what Pearlin *et al.* (1981) name as a stress process. It is instead, about how

participants manage the distress so that they can move on with their own recovery journey. This approach is consistent with the concept of personal recovery (Chapter 2.5) where the focus is not on defining a person by their mental distress, but rather on the person embracing a hopeful and satisfied way of living (Barber 2012).

Understanding participants' experiences as a journey of recovery fits with the suggestion that family members also need to recover from the distress of having a person who experiences a mental 'illness' (Dixon 2000, Deane *et al.* 2015). Generally, however, little attention has been given to family members' perspectives on their own recovery, with only a minority of authors in the last few years specifically exploring this phenomenon (O'Grady & Skinner 2012, Wyder & Bland 2014). While this literature considers family members' experiences as a journey of recovery, family members, that is partners, parents, and siblings, are treated as a homogeneous group. In so doing, the particular voice and perspective of partners as a subgroup of family is lost, as it is by and large merged with others. This is problematic given the fundamental differences in couple relationships where interdependent functioning, symmetry and mutual facilitation are core to couple relationships compared to other family relationships (Kelley *et al.* 1983). The theory of '*Reconstructing Livability*' addresses this critique by giving voice to partners' unique experiences, separate from the family as a homogenous group. It also provides practitioners with a more nuanced understanding of recovery from a partner's perspective, which will have significant implications on how partners of people experiencing an ED are understood and supported. This in turn will impact on practice, policy and approaches to care.

The participants' experiences of encountering recurring ED setbacks are consistent with findings in the literature on the recovery trajectories of those experiencing an ED. This research suggests that recovery for people with EDs is associated with a pattern of setbacks alternating with improvements over the lifetime of the ED (McFarlane *et al.* 2008, Bohon *et al.* 2009). In addition, the recovery trajectory for people experiencing an ED can be prolonged, lasting for a duration of 10 years or more (Noordenbos *et al.* 1998, Strober 2004). Similarly, for the majority of the participants in the current study, living with a person who experiences a pattern of setbacks and improvements over a protracted period of time is paralleled with the course of their own recovery journey. This experience of a

protracted recovery journey for the participants is compatible with the recovery literature, which acknowledges that personal recovery often occurs in the presence of ongoing mental distress or where a person experiences repeated setbacks (Davidson & Roe 2007, Higgins 2008). To date however, the personal recovery journey of partners, as a parallel journey, has not been conceptualised in this way, and therefore the theory of '*Reconstructing Livability*' adds a new dimension to the recovery literature.

As part of the recovery journey for the participants, the salient dimensions of hope, identity and social support that are identified in the theory are mirrored in writings on the process of personal recovery (Leamy *et al.* 2011, Wyder & Bland 2014). What is different in my theory, however, is the way in which hope, identity and social support, in the context of the intimate relationship, facilitate the participants in recovering from the distress of living with the disruptions. This provides a new contextual orientation to personal recovery, that of the couple dyad and the importance of intimate relationship functioning for the participant's recovery. The three dimensions of hope, identity and social support are explored in more detail in the remainder of this chapter, where each dimension includes the perspective of the intimate relationship. The first dimension to be discussed is that of hope.

10.3 '*Reconstructing Livability*' and hope

The concept of hope, as applied to the theory of '*Reconstructing Livability*', expands on what is already suggested in the recovery literature on hope, emphasising the importance of the person who is experiencing the mental 'illness' to have hope for the possibility of recovery (Higgins 2008). It also expands the concept of hope as applied to family members' experiences of recovery when living with a person experiencing a mental 'illness', which is concerned with personal dreams and aspirations (Wyder & Bland 2014). In the current theory, the concept of hope is extended to include the participant's hope that they can live in the intimate relationship in a satisfying way, despite encountering ongoing disruptions. However, the participant's hope for self in the relationship only grows in the presence of hope for the recovery of their partner where, as evidenced in the category '*Countering the disruptions*' (Chapter 8), ED improvements in the ED behaviours and cognitions experienced by their partner are linked with improvements in relationship functioning.

Hence, hope in the current theory is an interlinking three dimensional concept that applies to the partner, the self and the relationship.

Hope in the context of living in the intimate relationship in a satisfying way is influenced by the participant's ability to alter their perception of the meaning of recovery for their partner. In doing so, more realistic and achievable end goals for their partner's recovery are envisioned and new ways to help their partner achieve these goals are considered. This is consistent with what Snyder *et al.* (2000) and Snyder (2002) describe as positive goal outcome type, which is concerned with the cognitive process of hoping and comprises goal thoughts (goal setting), pathway thinking (ways of achieving goals) and agency thoughts (believing one can achieve the goal). What this means for participants is that by altering their perception of end goals for their partner's recovery, they remain hopeful they can find ways in which these goals can be achieved.

As described in the category '*Reclaimed livability*' (Chapter 9), the meaning of recovery for their partner is not a fixed construct for participants, as their expectations change over time in response to their partner encountering repeated ED setbacks. Similar to what Young (1999) refers to as gaining insight for a person recovering from 'psychiatric disability', altering the perception of recovery for their partner requires gaining insight into the relationship between the cyclical nature of EDs and recovery from them. '*Reclaimed livability*' (Chapter 9) highlights the fact that gaining insight assists participants in looking at their partner's recovery in a different way. For example, hope that their partner will not encounter further ED setbacks in earlier cycles of '*Reconstructing Livability*' changes to what is considered a more achievable end goal of hoping their partner can live a satisfactory life despite experiencing repeated ED disruptions. Gaining insight, however, requires participants to have access to information so that the links between the cyclical nature of the ED and recovery for the partner can be more readily achieved. In the absence of appropriate information participants are often required to live through the distress of multiple cycles of '*Reconstructing Livability*' before '*self informing from experience*' (Chapter 7.3.1) enables them to make the links that facilitate changing to more realistic end goals of recovery for their partner.

The current theory expands beyond the cognitive factors of goal thoughts, pathway thinking and agency thoughts (Snyder *et al.* 2000) to explain the behavioural aspects of achieving the end goals which in turn, when successful, reinforce hope for the partner's recovery. As participants arrive at this new meaning of recovery for their partner, they begin to modify the strategies they use for countering the ED disruptions experienced by their partner. For example, in light of understanding that disruptions to sexual intimacy will be ongoing, participants support their partner by engaging in a level of physical closeness that is acceptable to both their partner and themselves. The modified strategies used, such as hugging or cuddling, rather than engaging in sexual intercourse, are utilised to reduce their partner's distress and subsequently reduce relationship distress. Being able to support their partner in a more effective way goes some way towards instilling hope for the self, as self-efficacy and a sense of empowerment are improved.

Self-efficacy is concerned with a belief that one can effectively manage situations (Bandura 1995) and for the participants in the current study, the overarching situation that requires management is captured in their main concern of '*Encountering and living within a disrupted relationship*'. The development of self-efficacy for participants is therefore demonstrated in their progression towards reclaiming the livability of their relationship, as they build on their ability to effectively resolve their main concern. Consistent with the theory on self-efficacy (Bandura 1977, 1982), a belief in the self develops primarily from mastering experiences where participants learn from past experiences (chapter 7) and, in line with their personal strengths and limitations, adjust the strategies they use to resolve their main concern. Similar to the link between self-efficacy and hope made by Magaletta and Oliver (1999), where both are related to expectations for the future, in the current theory self-efficacy supports the participants in hoping they can live in the relationship in a satisfying way in the future.

Development of self-efficacy in managing the disruptions does not progress in a linear fashion however, as often when participants are faced with new ED related situations that they have not previously mastered they lose confidence in their ability to manage the disruptions effectively. In addition and in keeping with the position outlined by Stillar *et al.* (2016), that fear can impact on carer self-efficacy; when participants experience distressing emotions such as fear, they find it difficult to access their ED related knowledge and skills

in order to manage the disruption. For example, when faced with the fear their partner may die, participants tend to revert to more unhelpful ways of managing the situation by, for example, adopting the role of vigilant parent even though it is recognised by them to be not conducive to satisfactory relationship functioning.

'Becoming self-aware' (Chapter 9.3.1) in relation to their own needs also supports the development of hope, which is linked in the current theory to the concept of self-empowerment. Self-empowerment as it relates to the process of personal recovery is concerned with having control over one's life (Leamy *et al.* 2011, Wyder & Bland 2014). It is linked with hope here, where having control over their life means the participants hope to live in the relationship in a more satisfying way. In a synthesis of the literature on empowerment, Hur (2006) provides a framework by which the process of empowerment in the current theory can be explained. This process involves the introduction of a disturbance, becoming cognitively aware of the disturbance, becoming aware of the limitations and strengths in terms of changing the disturbance and transforming the lived environment by acting on the disturbance. As evidenced in the subcategory *'Moving on'*, (Chapter 9.3), the participants engage this process in relation to their own personal needs. By responding to these needs they experience improvements in their own psychosocial and physical wellbeing, which in turn facilitate them to experience life in a more satisfactory way. Remaining hopeful for their partner by reframing the meaning of their recovery and remaining hopeful for the self to be able to experience life in a more satisfying way leads to the hope for the self in the relationship.

Similar to hope for their partner, hope in the context of the relationship is not a fixed construct, as the meaning of hope changes over the course of repeated cycles of *'Reconstructing Livability'* experienced. Initially hope for recovery of the relationship is about returning to a level of relationship functioning that had been enjoyed by the couple prior to encountering the ED disruptions. By gaining insight into the cyclical nature of the ED, and the impact the ED is having on relationship functioning, participants begin to reframe the meaning of recovery in terms of the relationship. The participant's hope for recovery of the relationship to previous states of livability therefore becomes hope that the relationship can recover from the disruptions to the extent that they can continue to live in it in a satisfying way. The new meaning of recovery of the relationship, however,

requires participants to be able to adjust to the changes that have come about to the relationship. It is in this way hope is linked back with hoping for the recovery of the self within the relationship, where the development of self-efficacy and self-empowerment facilitates long term hoping that they can experience the relationship in a satisfying way.

Whilst hope is central to the participants' own recovery, it can easily become disrupted. As evidenced in the category '*Informed self*' (Chapter 7), sometimes it is through the very process of gaining understanding of the nature of EDs that participants can become overwhelmed and hopeless. For example, understanding the impact the ED can have on their partner's health each time they experience an ED setback is felt in a distressing way. This is consistent with findings from Stillar *et al.* (2016), who suggest carer's awareness and concern regarding ED related disruptions to their relative reduces carer self-efficacy and increases hopelessness. Whilst that is true for the participants in my study, hopelessness also stems from other sources, such as not having access to professional support, or as demonstrated in the subcategory '*Living with knowing*' (Chapter 7.4), when the ED is spoken about by people, and in particular professionals, using the language of chronicity. In addition, hope also becomes disrupted at times when their partner experiences an ED setback. Similar to findings from Stillar *et al.* (2016), during these times participants experience intense levels of emotions, their concerns and fears for the health of their partner escalate, their problem solving ability is reduced and they engage in highly emotionally charged interactions with their partner. All of these responses impact on their ability to support their partner effectively, which in turn fosters a loss of hope for the recovery of their partner and ultimately the livability of the relationship.

Hope for participants in the theory of '*Reconstructing Livability*' therefore can be seen to exist on a continuum, ranging from loss of hope to hopefulness, where progression along the continuum is in part dependent on the strategy of reframing the meaning of recovery for the partner and the relationship. Similar findings of fluctuating hope are reported in studies of partners who are living with someone with a long standing 'illness' such as HIV or dementia (Kylmä 2005, Bandeira *et al.* 2007, O'Dwyer *et al.* 2013). However, hope has not previously been conceptualised in this way in relation to partners' experiences of living with someone experiencing an ED.

In addition to maintaining hope, part of being able to live in the relationship in a satisfying way includes the need for participants to maintain their identity of partner in the intimate relationship, which is discussed in the following section.

10.4 ‘Reconstructing Livability’ and Identity

The concept of identity as it applies to the theory of ‘*Reconstructing Livability*’ is primarily concerned with the participant’s need to safeguard the self, their partner and the relationship from acquiring an ED defined identity. There are differences in what an ED defined identity means in relation to self, partner and relationship where to the self it means carer, to the partner it means ‘illness’ and to the relationship it means a carer/cared for dyad as opposed to an intimate partnership. Acquiring an ED defined identity in all three of these domains combined is perceived by participants as irreconcilable with their end goal of experiencing the intimate relationship in a satisfying way. This is because having an ED defined identity is perceived by participants to disrupt intimate interacting and change other people’s perceptions of them as a couple. Therefore, the motivation to safeguard against acquiring an ED defined identity has a dual aspect. The first is the desire to maintain the identity of partner so the relationship can be experienced as an intimate partnership and second to ensure the relationship is accepted as a couple relationship in their wider social world.

The concept of identity and self as it relates to the personal journey of recovery for the participants in this study is consistent with the limited literature exploring the issue of identity for family members’ own experiences of recovery (O’Grady & Skinner 2012, Wyder & Bland 2014). In this literature, identity is primarily concerned with the family member relinquishing the role of carer, re-defining their relationship with their relative and re-establishing their own identity. Similarly, the concept of identity of self in the current theory is related to the role of carer; however, my theory provides new perspectives to identity and personal recovery in two of ways. Firstly, the current theory considers the impact acquiring a carer identity has on intimate relationship functioning. Secondly, the current theory considers how participants experience societal attitudes towards their partner, self and the relationship when they are considered to be a ‘carer’ to their partner.

A carer is defined as ‘Someone who is providing an ongoing significant level of care to a person who is in need of that care in the home due to illness or disability or frailty’ (Government of Ireland 2012, p. 8). This definition is consistent with many of the participants’ experiences in the current study as they provide ED related care to their partner. As highlighted in the subsection ‘*Countering disruptions to the partner*’ (Chapter 8.2) and consistent with findings in the literature, ED related caring includes the provision of psychological, physical and social support plus practical assistance to the person experiencing the ED (Berk *et al.* 2011, Goldberg & Rickler 2011). It is in the context of providing this care to their partner over a protracted period of time, as they experience repeated ED setbacks, that participants perceive they acquire an ED defined identity, namely a carer identity.

The literature recognises that people live with a variety of contemporaneous identities aligned to the multiple roles they take on (Stryker & Burke 2000), including that of a caring role. Some of these identities are more central to how a person views the self and loss or damage to these more central identities is reported to result in psychological distress (Thoits 1995). In the current theory, dyadic identity, described by Eifert *et al.* (2015) as a shared identity based on the couple relationship, is considered to be central to relationship functioning, personal wellbeing and personal recovery for the participants. Loss of dyadic identity, where the identity of carer begins to take over the identity of partner as participants increasingly provide care to their partner, causes them to experience distress. When the shared identity of intimate partner, previously established in the relationship, becomes disrupted, relationship and personal wellbeing are effected.

As demonstrated in the subcategory ‘*Encountering intimate relationship disruption*’ (Chapter 6.6), taking on a carer role often results in participants communicating with their partner like it was a parent/child dyad, rather than an intimate partnership dyad. In addition, by taking on a carer role participants perceive that their partner is becoming increasingly dependent on them, to the point where they fear their partner could not survive without them. As interdependent functioning within the relationship becomes more disrupted over time, it also impacts on the participant’s psychosocial and physical wellbeing, particularly where their partner’s needs are prioritised over their own. Although this is often considered to be warranted, particularly when a partner’s health is at risk,

participants often ignore their own needs, further adding to their distress. The combination of disruptions to relationship functioning and personal wellbeing as a result of taking on a carer role therefore means living in the relationship is experienced in a less satisfactory way.

None of the participants in the current study wanted to take on the identity of carer in the relationship, preferring instead to maintain the dyadic identity of an intimate partnership. This is similar to findings in the literature on partners living with someone with a long standing 'illness' other than EDs such as manic depression or multiple sclerosis (Henderson 2001, Hughes *et al.* 2013), where many partners consider themselves first and foremost as a partner rather than a carer. Safeguarding against acquiring a carer identity is centred round identity management, where participants acknowledge the need to take on caring activities but strive to ensure this does not become central to how the relationship functions or is viewed. Over time, similar to the carer/caregiver dyadic model of interacting described by Coeling *et al.* (2003), participants engage the identity management strategy of renegotiating the dyadic rules so that the dyadic identity of intimate partnership is re-established whilst ED related caring is still provided. This only occurs as participants become a more '*Informed-self*' (Chapter 7), which enables them to build their capabilities to change and adapt the strategies they engage to counter the disruptions.

As identified in the category '*Reclaimed livability*' (Chapter 9), renegotiating dyadic rules is achieved by participants stepping back from the caring role and allowing their partner to take more responsibility for their own recovery. By stepping back, participants are provided with opportunities to respond to their own needs and in doing so can re-establish a sense of self, both within the relationship and in their wider social world. Furthermore, as participants progress through the cycles of '*Reconstructing Livability*', they begin to modify their ED related caring interactions to match their partner's ED related needs at a given time. However, none of the participants fully relinquished the ED related caring activities, such as remaining vigilant for signs of a setback. Instead they reframe them as an extension of normal couple caring.

Despite participants' efforts not to construct themselves as a carer, as demonstrated in the category '*Encountering a disruption*' (Chapter 6), they often perceive that others in their

social world, mainly health professionals and other family members, view them as carers. This perception of being a carer is in keeping with how family members living with someone with a long term illness are often constructed (Henderson 2001, Eifert *et al.* 2015). It is also consistent with O'Connor's (2007) findings that the awareness of self as a caregiver often arises because of other people's assumptions that they are caregivers. Being constructed as a carer by other people is problematic for the personal recovery of the participants in my study for several reasons. Firstly, the expectations of them being a carer entail taking responsibility for their partner and include providing their partner with effective support. In the absence of adequate information and support for themselves, they often feel unprepared and poorly equipped to do this. When their partner experiences an ED setback, their self-efficacy is reduced as they harbour self-doubts regarding their own ability to support their partner effectively. In addition, the participants perceive that others in their social world also judge them by questioning the effectiveness of their support when their partner continues to experience ED setbacks.

Secondly, with regard to the partner experiencing the ED, having the identity of carer supposes a binary approach of 'carer' and 'being cared for', thus conferring an 'illness' identity on the partner. This can be experienced by participants as stigmatising and thus unhelpful to their partner's recovery. They can also regard this as stigmatising towards the relationship (The issue of stigma will be discussed in the following section). Thirdly, as a consequence of the self being viewed as a carer, and their partner being viewed as being cared for, the participants feel this influences how others regard their intimate relationship. As referred to in the category '*Encountering a disruption*' (Chapter 6), participants perceive others as viewing the relationship in a negative way and often these other people, particularly family members and friends, advise them to leave the relationship. Although the participants again suggest that other people's negative attitudes are the result of their lack of understanding of EDs, their advice to leave the relationship is experienced as distressing, as remaining in the relationship is something the participants want to continue to do .

The identity management strategies the participants engage to deal with their perception of how other people view them, their partner and their relationship in the context of the identity as carer reflect what Goffman (1969) refers to as impression management. In his

theory on dramaturgical self presentation he suggests that people present a carefully staged self to others so that these people will formulate a desired impression of them. As evidenced in the category '*Encountering a disruption*' (Chapter 6) and consistent with Goffman's (1969) theory, the participants influence other people's perceptions of them as a carer in several different ways. Firstly, they carefully choose who they share ED related information with, limiting these interactions to people they trust not to be judgemental. Secondly, they help their partner to negotiate the ED difficulties they have when socialising, such as eating their partner's food, so that the ED behaviours are less noticeable to others. Thirdly, they often avoid social occasions as a couple or avoid social situations where they may have to explain their partner's absence as ED related.

Acquiring the identity of carer therefore is viewed by participants as not only impacting on intimate relationship functioning but also impacts on how they interact in their wider social world which in turn can interfere with the way they satisfy their need to remain connected with others or their ability to access social support. This is problematic for the participants given that social connectedness and support facilitate their ability to cope with the distress of living with a long term 'illness', and are considered to be an integral part of a person's recovery journey (Leamy *et al.* 2011, Wyder & Bland 2014). Therefore the issue of social support as it applies to the theory of '*Reconstructing Livability*' will be discussed in greater detail in the following section.

10.5 '*Reconstructing Livability*' and social support

The concept of social support, in the theory of '*Reconstructing Livability*' is concerned with participants' access to various dimensions of support as they progress through their journey of recovery. Consistent with the meaning of social support in the recovery literature (Machin & Repper 2013, Higgins & McGowan 2014), social support in the theory of '*Reconstructing Livability*' relates to the participant's need to be valued, understood and respected by others, and not to be defined in terms of the ED. The meaning of social support is extended in the current theory to include the participant's need for respect and understanding for both their partner and for the relationship. The concept of social support as it applies to the current theory has two dimensions; that of every day emotional, informational and practical support and also ED specific emotional, informational and

practical support. As evidenced in the category '*Countering the disruption*' (Chapter 8), in light of the participants understanding that people in their wider social world do not have the appropriate knowledge of EDs, accessing ED related social support can be more challenging than accessing every day social support.

The social world of the participants consists of a variety of social groups (including family, friends and work colleagues), all of which can potentially provide opportunities for support. Hogg and Reid (2006) suggest that social groupings establish relative norms which, if conformed to, provide a basis for acceptance and validation of the self. In the context of the current theory, this suggests that if the participants have access to other couples in a similar situation they could be provided with an opportunity for acceptance and validation. Living with a partner experiencing an ED, however, is not experienced as a social norm for the participants as all but one of them report not knowing any other couple living with an ED. Consequently, and consistent with Faulkner's (2010) suggestion, the participants live outside the established social norms and this evokes feelings of being different, of being embarrassed or of concern regarding the potential disapproval and judgement from other people. To manage the distress associated with these feelings, the participants often remove themselves from social groups that can potentially provide support; however, as time goes on and with each cycle of '*Reconstructing Livability*' the participants begin to identify which dimension of support (ED or everyday support) can be accessed from which social group (family, friends or professionals). They subsequently tailor their support seeking strategies in accordance with what they perceive to be acceptable within a particular social group and most beneficial to their goals. These strategies, such as accessing emotional support by talking to people they perceive to be non-judgemental, are consistent with Topors (2006) suggestion that social support can be accessed from a wide range of relationships. These strategies are also consistent with Gottlieb and Bergan's (2010) suggestion that the type of support available depends on the personal and environmental factors at a given time.

As identified by Cutrona (1990), social support is conceptualised in many different ways in the literature. However, accessing social support in the current theory is conceptualised as a two faceted process. The first facet is in relation to the social groups from whom the participants can access support including non-professional and professional social

supports. The second facet is in relation to the types of social support accessed including emotional, informational and practical assistance (Thoits 2010). These dimensions apply to both the everyday life support needs and ED specific support needs of the participants. The remainder of the discussion will focus on these two dimensions of support and will be discussed in relation to the social groups that can provide them.

10.5.1 Accessibility of non-professional support

Non-professional social support in the theory of '*Reconstructing Livability*' includes the social groups of family members comprising of their partners, parents and siblings, and the wider community groups comprising of friends and colleagues. There are a wide range of people who can potentially provide participants with different dimensions of support. As pointed out by many researchers and as applicable to the theory of '*Reconstructing Livability*', in order for social support to be of benefit it needs to be appropriately matched to the needs of the person who requires it (Cutrona *et al.* 2007, Sarason & Sarason 2009). In addition to a needs fit, being able to access beneficial social support is also influenced by an 'interpersonal' fit. An 'interpersonal' fit refers to the participants accessing social support from those who are socially similar, and with whom they have positive non-judgemental relationship. Dehle *et al.* (2001) suggest that because partners are likely to be socially similar and share experiences, it places them in a prime position to provide appropriate and effective social support to each other. Other authors support this thinking where the primary source of social support for those living in a close intimate relationship is considered to be provided by one's partner, and the nature of this support can be both emotionally and practically based (Verhofstadt *et al.* 2013). Given the theory of '*Reconstructing Livability*' is situated within the intimate relationship, partner social support as it applies to the current theory will be discussed first.

Accessibility of Partner support: Partner support is concerned with the dimensions of support the participants can access from their partner who is experiencing the ED. There is a very clear distinction between the accessibility of everyday life support needs and ED specific support needs in relation to partner support. In particular, all three dimensions of support from their partner are considered by the participants to be available for the general life disruptions they encounter such as stress at work or conflict they experience within

their extended family, reflecting reciprocity within the relationship. Although the participants can access some ED related practical support such as financing therapy from their partner, accessing the ED related emotional and informational dimensions of support from them is more challenging.

One approach to explain why the participants face challenges in accessing the ED related support from their partner is to consider it in the context of the dyadic communication disruptions that are experienced by the participants. In the limited research exploring the communication style in couples where one member is experiencing an ED (Van den Broucke *et al.* 1995, Newton *et al.* 2005, Dick *et al.* 2013), secrecy surrounding the ED is identified as a dominant issue. Similar findings in the current study are reported in the sub-category '*Encountering intimate relationship disruptions*' (Chapter 6.6), where conversations regarding the ED are silenced, including ED related conversations that could potentially be experienced by the participants as supportive and helpful in increasing their understanding of ED behaviours and cognitions.

The motivation for secrecy in relation to EDs has primarily been examined from the perspective of the person experiencing the ED (Vandereycken 2006, Vandereycken & Van Humbeeck 2008, Dick *et al.* 2013). This literature suggests people experiencing EDs conceal the ED from others because of a lack of self-awareness regarding the ED, as an avoidance of feared consequences such as having to engage in treatment or having to experience the stigmatising attitudes of others, or in order to avoid expressing emotion. The theory of '*Reconstructing Livability*', however, adds a new dimension to understanding the concept of secrecy as here it applies to couples where one member has an ED. It does so by providing an insight into the motivation for secrecy from the perspective of the participants. As demonstrated in the subcategory '*Encountering intimate relationship disruptions*' (Chapter 6.6), within the couple dyad the participants limit the conversations about the ED or limit self-disclosure with regard to the distress they are experiencing. The strategy of limiting the sharing of information is a way to protect their partner from being burdened and feeling blame for the distress they, as participant, are experiencing due to the ED, and to protect the relationship from possible conflict. Finkenauer and Hazam (2000) suggest that a strategy of limiting information sharing in couples is warranted where

protection of a partner is prioritised. However, engaging this strategy comes at a cost to the participants as it impedes them in accessing ED related support from their partner.

In the non-eating disorder literature, lack of support from a partner is widely reported to induce relationship dissatisfaction and relationship dissolution (Sarason *et al.* 1994, Bradbury *et al.* 2000, Lawrence *et al.* 2008). Although relationship dissatisfaction for couples where one member is experiencing an ED has been examined in the literature (Van den Broucke & Vandereycken 1989, Dick *et al.* 2013), this has not been looked at in the context of reciprocal partner support. The current theory provides preliminary insights into reciprocal partner support from the perspective of the participants where, despite having limited support from their partner, remaining committed to the intimate relationship continues to be a central aspect of their personal recovery journey.

Encountering ED related silences within the couple dyad (Chapter 6.6.2) can explain a lack of support from the partner, where the participants do not speak of their ED related distress in order to protect their partner from feeling guilt or to blame for this distress. In addition, the cognitive strategy conceptualised as '*Explaining away*' goes some way towards understanding the participant's ability to cope with the lack of ED related support from their partner. As evidenced in the subcategory '*Countering intimate relationship disruptions*' (Chapter 8.4), by explaining away their partner's ED related silence as a consequence of the ED and therefore something they cannot change, participants have a valid and understandable reason for this lack of support. Consistent with Wilson and Gilbert's (2008) suggestion that explaining away supports affective adaptation, by explaining the partner's lack of ED related support as a consequence of the ED, participants adapt their expectations of the ED related supports their partner can provide to more achievable expectations. In the absence or limited availability of support from their partner, however, there are other non-professional sources of social support which the participants can access.

Accessibility of other non-professional supports: The other non-professional supports, in the theory of '*Reconstructing Livability*', are mainly derived from family members, friends and colleagues. Accessing everyday emotional, informational and practical support from others in the social world is not voiced as an issue of concern for the participants. In

contrast however, accessing ED related emotional, informational or practical support from other non-professional people is more challenging. The primary impediment for the participants in accessing ED related social support from others in their wider social world is concerned with other people not having an adequate understanding or knowledge regarding EDs. This is problematic in the context of the participants' need to protect their partner, the self and the relationship from the opinions and judgements of other people, which is reflected in their attempts to safeguard against acquiring the identity of carer as discussed in the section above in '*Reconstructing Livability and identity*'.

Many of the participants refer to their fear of experiencing other people's opinions and judgements as stigmatising. This experience of stigma is consistent with the recovery literature, where stigma for people experiencing mental 'illness' is considered one of the fundamental issues that needs to be addressed in order to support personal recovery (Leamy *et al.* 2011, Higgins & McGowan 2014). The concept of stigma as it relates to the participant's experiences, however, provides an alternative perspective on stigma and personal recovery, that of stigma by association. Stigma by association or courtesy stigma (Angermeyer *et al.* 2003), refers to how relatives of people experiencing mental 'illness' also experience the stigmatising opinions of others (Goffman 1963, Werner *et al.* 2010). Although stigma by association has been examined for family members in a variety of contexts such as living with a relative experiencing substance abuse or schizophrenia (Angermeyer *et al.* 2003, Corrigan *et al.* 2006), stigma by association has not been conceptualised in this way for partners of people experiencing an ED. Therefore the theory of '*Reconstructing Livability*' adds to the discourse on stigma in mental health and that literature relating to stigma by association in particular.

Consistent with suggestions from Larson and Corrigan (2008), and Corrigan and Miller (2006), stigma by association is evidenced in the participant's perception that other people blame them for their partners ED, which is demonstrated in the category '*Encountering a disruption*' (Chapter 6). In order to limit exposing the ED related behaviours engaged by their partner, the participants use the protective strategies of avoiding or limiting social interactions as a couple. In addition, as evidenced in the category '*Countering the disruptions*' (Chapter 8), the participants minimise exposure of their lived experience to others by not engaging with some people or by limiting the ED related information they

share with others. These protective strategies however often result in the participants feeling alone and isolated, particularly when their partner is experiencing an ED setback and participants do not have anyone to share their distress with.

Two further issues in relation to stigma by association are noted in the data. Firstly, in contrast to Corrigan's (2004) suggestion that people with mental 'illness' often accept and take on the stigmatising opinions of others, the participants in the current theory do not do this. As evidenced in the data the participants' perceptions are that they are not, nor are their partners, personally to blame for the ED. Secondly, the experience of stigma by association appears to be a subjective interpretation that is not completely supported by the data in relation to the participants' direct experiences. This finding is consistent with other research where stigma by association, although reported to exist in the general public, is less than that perceived by the family members (Wahl & Harman 1989, Corrigan *et al.* 2006). The experience of not directly encountering stigma by association could be explained by the strategies engaged by participants to limit their exposure to other people.

In addition to protecting the self, partner and relationship, the strategy of limiting interactions with other people is also related to protecting others in the wider social world. As evidenced in the category '*Countering the disruption*', the participants do not want other people to become worried or concerned for their welfare, the welfare of their partner or the welfare of the relationship. Although the participants are aware of other people's concerns, they perceive that in sharing ED related concerns with others it will raise their anxieties. This is similar to findings from Albert and Simpson (2015), who suggest that carers find it difficult to seek social support from others in times of crises because of fears of traumatising others.

A further way of understanding the challenges facing the participants in accessing ED related social support is to consider the problem in the context of gender-role conflict (GRC). As the theory of '*Reconstructing Livability*' is located within the experiences of partners of people experiencing an ED, the fact that the participants are primarily male gendered is not surprising for two primary reasons. A distorted gender distribution of those experiencing EDs is well documented, where only 5-11% of people experiencing an ED are male (Bramon-Bosch *et al.* 2000, Kjelsås *et al.* 2004, Button *et al.* 2008). In addition,

Feldman and Meyer (2007) suggest a disproportionate number of males experiencing EDs are gay or bisexual. It stands therefore that the majority of partners of people with EDs are male. The participants' reluctance to seek social support in the current theory may be considered as gender role driven, where aspects of gender role socialisation impede them from utilising social support (Blazina & Marks 2001, Hill & Donatelle 2005).

One of the domains of GRC, that of restrictive verbal expressions of emotion, can go some way to account for the participants limited utilisation of social support (Wester *et al.* 2007). This is not to frame it as normative male alexithymia which, according to Levant *et al.* (2006), is the lack of awareness of one's emotions or difficulty finding words to describe distressing emotions. The participants in this study are able to identify their emotions which they readily discuss with the researcher. However, the way in which the participants carefully manage expression of concerns or emotions within the wider social world can be explained as a way of conforming to masculine ideals or as a reflection of what Spandler *et al.* (2014) consider to be the prevailing rules governing gender communication. This is evidenced in the participants' accounts of not admitting to others when they are distressed or saying they are okay even when they are not.

Although seeking ED related support from others is challenging, the participants do engage strategies to facilitate them in accessing this support. By compartmentalising the dimensions of support to include everyday support and ED related emotional, information and practical support, the participants identify those in their social world who they perceive to be in a position to provide the support in a non-judgemental way. For example as recounted in the category '*Countering the disruptions*' (Chapter 8), the everyday support need to remain emotionally connected with others is achieved by the participants continuing to socialise with friends in the absence of ED related conversations. As an example of accessing ED related practical support, participants access financial support for their partner's therapy only from family members, or ED informational support is accessed from relatives and professionals the participants perceive will have the appropriate information.

A primary way of realising the benefits of social support for the participants in the current theory is the perception that the support is available to them, even if they do not access it.

Perceived social support, which is the belief that support is available from others, is reported to act as a buffer against the effects of stress (Callaghan & Morrissey 1993, Lakey & Cohen 2000, Haber *et al.* 2007). As identified in the subcategory '*Using ED related social support*' (chapter 9.2.2), a belief that support is available from others, primarily family members, is sufficient to meet some of the participants support needs; however, some ED related emotional, informational and practical support needs require specific supportive interventions which participants believe are best provided by professionals.

10.5.2 Accessibility of professional support

Professional support in the theory of '*Reconstructing Livability*' is concerned with ED related emotional, informational and practical support that can be accessed from professionals who work within a medical and/or mental health system. The need to seek professional support is heightened at times when partners are experiencing an ED setback, and participants' ED related distress is elevated. As previously suggested, ED related distress is linked to the ED related psychological and medical risks for their partner which the participants feel ill equipped to manage effectively. Seeking professional support is perceived by the participants as a resource to manage the risks for the person experiencing the ED, which indirectly supports the self by helping to reduce their distress.

Encountering competent and knowledgeable professionals is experienced in a helpful and supportive way, where the participants receive ED related emotional, informational and practical support. However, as highlighted in the categories '*Informed self*' (Chapter 7) and '*Countering the disruptions*' (Chapter 8), for the best part efforts at accessing and receiving the necessary support from professionals are impeded. Consistent with reports in the literature of family members living with an adult with an ED, lack of professional support can be explained by the confidentiality and legal constraints that apply to professional practice (Winn *et al.* 2004, Treasure *et al.* 2005). In addition however, the participants are also of the view that the problem arises in the context of limited specialised ED services, a lack of professional skill and knowledge in relation to EDs and the fact that they are excluded from professional discussions regarding their partner's wellbeing. The participants' experiences are in keeping with reports that mental health professionals are often reluctant to work collaboratively with family members (Gamble & Brennan 2006,

McDaid & Higgins 2014) and specific to the field of EDs, where training and supervision for professionals is reported to be very limited (Mahr *et al.* 2015). Consistent with reports that a lack of professional support can add to a family members distress (Van der Voort *et al.* 2009), as demonstrated in the subcategory '*Countering the disruptions*' (Chapter 8.), the participants in my study experience ongoing frustration when encountering a lack of access to professional support further adding to their reported distress levels.

The importance of professional support for family members living with a person experiencing an ED is acknowledged in the literature (Graap *et al.* 2008b, Treasure *et al.* 2012). Research has been conducted in an effort to inform the development of professional services to respond to family support needs. The principle aim of family supportive interventions, however, is about how family members can support the recovery of the person experiencing the ED, rather than addressing the family members own recovery. One aspect of developing professional services for family members living with someone with an ED has resulted in the development of family support groups (Treasure *et al.* 2007, Gísladóttir & Svavarsdóttir 2011); however, there are several limitations to the usefulness of these support groups for certain people, such as the participants in the current theory. Firstly, although these support groups provide education regarding EDs and on aspects of self-care, their main focus is on recovery for the person experiencing the ED. Secondly, they do not consider the unique perspective and the needs relating to partners or intimate relationship functioning. Thirdly, as seen in the subcategory '*Countering the disruptions to self*' (Chapter 8.3), the majority of participants are reluctant to access professional support in the form of groups. This reluctance is consistent with findings from a study exploring male college students' attitudes to accessing psychological treatments where the participants viewed support groups negatively (Blazina & Marks 2001). Similar to the current theory, the authors suggest this could be as a consequence of GRC.

Evidenced in the current theory is the lack of knowledge participants have regarding what attending a support group would entail. Their perceptions are based on support groups such as AA and how these are generally portrayed in the media. Therefore, the participants may be more willing to attend these groups if they had adequate information and a better understanding of what support groups for partners of people with EDs entail. Another possible reason for participants' reluctance in my study to access support groups is that the

majority of support groups are framed as groups for carers. As previously discussed, the participants actively engage strategies to safeguard against being viewed as a carer, which might explain why they do not want to engage in carer groups. In addition, similar to findings from the EOLAS project (Higgins *et al.* 2012), where some of the spouses and partners involved in an information programme on recovery felt that by talking about relationship issues they were in some way betraying their spouse or partner, the bonds of the intimate relationship may also have inhibited participants in my study from speaking openly in a support group.

Despite not wanting to access support groups, the participants do acknowledge their need for ED related emotional, informational and practical support from professionals. Consistent with findings from other studies involving family members living with a person experiencing an ED (De La Rie *et al.* 2005, Graap *et al.* 2008a, Coomber & King 2012), these support needs include practical advice on how to support their partner, education on the nature of EDs and for some, the need to be included in their partner's treatment. However, as indicated in the subsection '*Countering the disruptions to self*' (Chapter 8.3), this support is generally preferred by participants to be in the form of individual or couple based interventions from professionals as opposed to group based interventions. This finding, therefore, has implications for the development of services to provide support for partners of people experiencing an ED

10.6 Summary

This chapter discussed the theory of '*Reconstructing Livability*', where the primary social process undertaken by participants is considered to be a personal journey of recovery from the ED related disruptions that have come about to their lives. Although the participants' journeys are similar to other journeys of personal recovery described in the recovery literature, the current theory reconceptualises personal recovery by providing a new perspective, that being from the viewpoint of the participant in the context of the couple dyad. The key issues of hope, identity and social support discussed in this chapter are consistent with the issues identified in the wider body of knowledge in relation to the recovery literature. However, what is unique in the current study is how these issues relate

to the intimate relationship, which is considered to be a significant component of participants' recovery.

The discussion illustrates that the recovery journey for the participant is paralleled and interlinked with the recovery journey of the person experiencing the ED. This implies therefore that, consistent with the recovery trajectory associated with a person experiencing an ED, the recovery journey for the participant involves a process of improvements interspersed with setbacks, often occurring over a protracted period of time. This illustrates the dynamic and unfolding nature of living with a partner who is experiencing an ED. Recovery for participants, which is signified by their ability to reclaim the livability of their relationship, therefore develops over time; with each cycle of '*Reconstructing Livability*' that is experienced the underlying behaviours and strategies to reclaim their lives are built on. The elements of hope, identity and social support emerge from the data as significant issues that impact on the strategies engaged by participants as they work towards resolving their main concern of '*Encountering and living in a disrupted relationship.*'

The element of hope as it applies to the theory of '*Reconstructing Livability*' is considered to be fundamental to the participants remaining committed to their relationship. A new conceptualisation of hope as experienced by the participants is presented in the current theory. Here, hope is considered to exist on a continuum ranging from a loss of hope to hopefulness. Three interlinking elements of hope are identified in the current theory to include hope for the recovery of their partner, hope for recovery of the relationship and hope for recovery of the self within the relationship. Remaining hopeful for all three elements requires the participants to reconstruct the meaning of recovery for their partner, which in turn enables them to modify the strategies they engage to support their partner to ones that are considered more realistic. Reconstructing the meaning of recovery sometimes occurs with access to information but more often occurs as a result of learning from experiencing repeated cycles of '*Reconstructing Livability*'. Loss of hope in contrast, is experienced by the participants at various times throughout their own journey of recovery. Loss of hope, is particularly evident at times when their partner is experiencing an ED setback and the participants feel they lack the knowledge or understanding to be able to support their partner effectively. In addition, loss of hope also occurs in the context of other

people not understanding the nature of EDs or when other people consider the ED to be a long term 'illness'. The discussion illustrates, however, that by reframing the meaning of recovery and engaging positive coping cognitions, the participants can maintain a hope that they can continue to experience the relationship in a satisfying way.

The second area of discussion focuses on the element of identity where the ED defined identity, namely the identity of carer, is a dominant issue of concern for the participants. The current theory provides a new perspective on identity and personal recovery, as it considers the identity of carer in the context of the intimate relationship and in relation to societal attitudes towards participants as carers. The main concern for the participants in acquiring the identity of carer is that it will replace their identity of partner, which is perceived by them to disrupt relationship functioning. Although the participants are reluctant to consider themselves a carer and indeed frame their caring activities as an extension of normal couple caring, their experience is that others in their wider social world continue to view them as a carer. The discussion illustrates how the experience of being framed as a carer is perceived by the participants to impact on how other people view not only them, but also their partner and the relationship. The interpretation of other people's attitudes towards them is experienced in a stigmatising way, as their partner is considered an 'ill' person and the relationship is devalued, especially when they are advised by others to leave the relationship. This is problematic where commitment to the relationship is an integral part of the participants' own recovery journey. The impact of others framing them as a carer also influences their ability to connect socially, as the need to protect themselves, their partner and the relationship from being viewed through a caring lens limits their opportunities to share their ED related distress. Again this is problematic for the participant's journey of recovery as social support and the opportunities to remain socially connected are reduced.

The recovery literature identifies social support and connectedness as a significant element of a person's recovery journey; however, the findings in the current study suggest that accessing this support for the participants is complex and challenging. The social support needs comprise the emotional, informational and practical needs, arising for the participants and are categorised as either everyday support needs or ED related support needs. Meeting everyday support needs do not appear as problematic for participants as

meeting ED related support needs. Challenges facing the participants in accessing ED related support from their partner are discussed in the context of communication within the dyad. The current theory provides a new angle on communication within couples where one member has an ED as it looks at ED related silence from the perspective of the participant as a partner. The reason participants maintain ED related silence is to protect their partner from feeling worry or blame for the participant's own distress. What this means, however, is that it limits ED related support they in turn can receive from their partner. The difficulties in accessing social support from other non-professional people in the participants lives is discussed in relation to stigma by association, where participants are faced with a perception that others will judge them negatively because of the inability to support their partner effectively or because they remain in a disrupted relationship. As a consequence the participants engage strategies that limit their social engagement or limit their ability to call on other people for support. In addition, as the majority of participants in the current study are male, the difficulties in accessing social support in the context of GRC are also presented. Despite the challenges in accessing social support, however, there are people in their lives that the participants believe to be supportive and they carefully choose to access this support from those they feel will not be judgemental. In addition the perception that support from other people is available, even if not accessed, is experienced by participants as helpful.

Accessing social support from professionals when available, for the best part is experienced in a positive way; however, gaining access to this support is usually challenging. In particular the participants identify a lack of existing specialised professional services from which they or their partner can access ED specific supports. This serves to add to their levels of distress, when the badly needed information or support for their partner or themselves is not available. Continuing with the issue of social support from professionals, the discussion concludes with reference to the professional support services that have been developed for family members, including partners, who are living with someone with an ED. As demonstrated in the literature review (Chapter 3.7.1,) these services are mainly concerned with recovery for the person with the ED rather than recovery for the partner. In addition, and in conflict with the participants' preference for professional support in the form of individual or couple work, many of the services focus on providing support in the form of traditional support groups. The implication of providing group interventions as the primary

source of support for partners of people with an ED therefore means that because they prefer not to avail of them, they have limited access to professional social supports.

The current theory adds to the existing literature in several areas. Firstly, it adds a new perspective on what is already known on family members' experiences of living with someone with an ED by considering the unique position of partners. Secondly, it provides insights into relationship functioning for couples where one member has an ED by considering it from the perspective of the participant as a partner to a person living with an ED. Thirdly, it adds to the knowledge in the field of personal recovery by including the personal recovery for a partner who is living with a person with an ED, and identifies the importance of the intimate relationship for their recovery. Finally, it challenges the suitability of some of the current professional support interventions provided for partners, thus stimulating thought on how best to support partners of people with EDs in moving on in their recovery journey. The following chapter therefore, while reflecting on the limitations and quality considerations as they applied to the conduct of the research, will discuss the implications and recommendations arising from the findings of this study.

Chapter 11

LIMITATIONS, TRUSTWORTHINESS AND RECOMMENDATIONS OF THE STUDY

11.1 Introduction

This thesis so far has presented the theory of *'Reconstructing Livability'* which explicated the process the participants, who were partners of individuals with an Eating Disorder (ED), enacted in order to resolve their main concern of *'Encountering and living in a disrupted relationship'*. However, some remaining issues need to be considered in this final chapter before concluding. These include identifying the contextual limitations and quality considerations that apply to the conduct of this study. The final section of this chapter then presents the implications and recommendations that have emerged for future consideration.

11.2 Contextual limitations

The theory of *'Reconstructing Livability'* is grounded in the social world of both the participants and the researcher, therefore the process and findings are subject to various contextual factors which are;

1. The potential impact of researcher influence on the participant needs to be considered, particularly in relation to the concept of identity management where participants may have been concerned with the opinions and judgements of other people. Although the participants' narratives do not overly suggest this, it is possible they presented their narratives in the context of a positive self presentation bias.
2. As the participants' behaviours were not directly observed and the study presents a retrospective view of their experiences, there is no assurance that the participants accounts are an accurate description of reality, or indeed that their accounts are not influenced by memory recall biases.

3. Given the gender distribution relating to EDs where the majority of people experiencing an ED are female, the majority of participants in the current study are male. Although examination of the data suggests the experiences for the males are similar to those of the female participants interviewed, the possibility that the unequal gender distribution of participants influenced the theory, must be considered.
4. This study was confined to participants who were still living with the person with an ED. The experiences of those who have disengaged from the intimate relationship were not considered. Including the experiences of partners who do not remain committed to the relationship might have identified alternative ways of resolving the main concern of *'Encountering and living in a disrupted relationship'*, or perhaps this may not have been the main concern for such persons.
5. The majority of participants were living with a person experiencing Anorexia Nervosa (AN) or Other Specified Feeding and Eating Disorders (OSFED). In the current study the exploration of living with a partner with BN was limited and no participant reported living with a person with BED. Broadening the exploration to include partners who are living with a person with BN or BED may have provided further categories for consideration in the analysis.
6. Given that achieving theoretical saturation of the data is determined by the subjective interpretation of the researcher, it is possible that if further interviews had been conducted in the current study, additional information could have emerged to provide alternative explanations for participants' behaviour. However, after 16 interviews were completed no new data emerged to augment the categories further and despite the researcher conducting 2 further interviews this continued to be the case.
7. In keeping with the delimiting nature of selective coding and theoretical sampling, which are employed once the core category has been identified (Chapter 4.6.2), data not consistent with existing categories are not included in the analysis.

Therefore, some data such as that relating to the participants' children or to their wider social networks has not been included.

8. This study was conducted by a researcher who has worked in the field of eating disorders for many years; hence, the researcher came to the field with prior knowledge and suppositions relating to the substantive area under study. The impact of researcher bias on data collection and analysis and how this was managed therefore, is an issue for consideration. This issue will be discussed in more detail in the discussion relating to the trustworthiness of the study.

11.3 Quality and trustworthiness

Criteria and standards for measuring quality in qualitative research have long been debated in the literature (Sandelowski 1986, Whitemore *et al.* 2001, Elliott & Lazenbatt 2005, Licqurish & Seibold 2011). This debate arises not only in the context of the uncertainty and probability in understanding phenomena in the non-positivist traditions, but also and more specifically in relation to qualitative approaches, it arises in relation to the uncertainty associated with the representation of social reality. Morse *et al.* (2002) identify that approaches to measuring quality in qualitative research have shifted from using the quantitative language of validity and reliability to reconceptualised criteria that measure the relevance, significance and utility of qualitative research. Hope and Waterman (2003) outline the three primary approaches for measuring quality in qualitative studies as; i) using criteria that are aligned with quantitative research; ii) based on the thinking that reality cannot be directly accessed, there is no criteria on which quality can be measured other than from the consensus of individuals and; iii) a reconceptualisation of quality criteria that fits with qualitative approaches.

Although there are similarities in the quality considerations across the various methodological approaches to qualitative research, generally there is no standardisation of criteria for measuring the quality or trustworthiness of a study (Creswell & Miller 2000, Tobin & Begley 2004). In view of the methodological diversity across qualitative approaches, Rolfe (2006) posits that using quality frameworks or predetermining quality criteria for qualitative research is pointless. He suggests quality issues should not be

dependent on epistemology rather the quality will reveal itself to the reader in the write up, but the written report should be accompanied by a detailed audit trail reflecting the researcher's stance and decision trail. This thinking is in contrast to other writers who advocate for a paradigmatic framework and philosophical basis for measuring quality so that the adherence to the rules governing quality within the framework chosen can be demonstrated (Creswell & Miller 2000, Mantzoukas 2004, Guba & Lincoln 2005). Choosing the most appropriate quality criteria for a Classic Grounded Theory (CGT) study based on the philosophical assumptions underlying the methodology is problematic given the various research paradigms within which CGT is situated¹⁴; however, Glaser and Strauss (1967) suggest the quality of a CGT will be dependent on the method of generation and the most likely theory will be better if developed inductively from data. The authors propose the criteria of fit, work, modifiability and relevance as appropriate for determining the quality of a CGT study, and it is in the context of these criteria that the quality of the current study is discussed.

11.3.1 Fit

The criterion of fit, an important process for ensuring the validity of a study (Morse & Singleton 2001), is met when the categories and their properties in a study express what is happening in the data (Glaser 1978), and reflect the social reality being studied (Lomborg & Kirkevold 2003). Central to theory development and data analysis, Morse and Singleton (2001) suggest fit is achieved by examining two elements of data for similarities and commonalities so that each piece of the data can be linked to another. By grouping data together based on similarity, the properties and dimensions of the grouped data are developed. The authors' further state that in the development of a theory, concepts are then fit with other concepts, merging at the point of shared components. These merged concepts generate the categories found in CGT. Several ways in which to ensure a study meets the quality criteria of 'fit' are debated in the literature and include member checking, reflexivity, triangulation and peer debriefing (Creswell & Miller 2000, Tobin & Begley 2004, Jootun *et al.* 2009); however Glaser (1998) points out that if the CGT analysis is systematically conducted then fit will automatically be achieved. Therefore, the rigorous application of core CGT analytical strategies namely the simultaneous collection and

¹⁴ See chapter 4, Methodology for a detailed discussion on the philosophical basis of CGT

analysis of the data, using the constant comparative method (CCM), theoretical sampling and the recording and integration of memos, was a key method to ensure the criteria of 'fit' was achieved in the current theory.

As analysis in the current theory commenced on completion of the first interview, codes reflecting what was happening in the data were developed from the very outset of the research process. As further interviews were conducted, not only were the codes added to but using the CCM, categories began to emerge as existing codes were examined and compared with each other and with new incoming data. The categories were developed based on grouping codes together at a conceptual level and with ongoing comparison of the data, the theoretical properties of the categories were developed. The theoretical properties accounted for all dimensions within a category. For example the dimensions of the category 'hoping' ranged from loss of hope to hopefulness, the properties of which included hope for the partner, the relationship and the self of participant in the relationship (Chapter 10.3). Through the process of constantly comparing existing categories both with each other and with incoming data the categories were continuously refined, while remaining grounded in the data.

The process of using the CCM also ensured my own pre-conceived ideas or ideas from existing theory, unless supported by the data, were not introduced into the theory. Glaser (1998) refers to this phenomenon as forcing the data which, although he considers a normative behaviour, he advises the grounded theorist to take precautions against. He advises that the researcher 'suspends what he knows, keep studying the data, conceptualises and constantly compares' (Glaser 1998, p. 81). If indeed my own preconceived ideas or ideas from existing theory were included, they needed to pass the rigorous test of being constantly compared to the existing categories and only if relevant would they be included. For example, the concept of '*Encountering silence*' (Chapter 6.6.2) that emerged is reflected in literature on ED related silence within couples where one person experiences an ED. Through the use of CCM this was not only seen to be relevant to the current study but further properties to this concept were developed where ED related silence extended beyond that which is already known, to include silences from the perspective of the partner not experiencing the ED. Therefore, although the concept

already existed in the literature, it was seen to fit with and reflect the social reality of the participants in the current study.

In relation to my own biases and pre-conceived ideas, it was difficult to suspend what I knew just because this was the advice given in the literature on rigour in qualitative research. However, similar to the practice of reflexivity where the researcher reflects on their own values and biases throughout the research process (Jootun *et al.* 2009), the use of memoing in a CGT study can provide a means to record and track the development of conceptual ideas (Elliott & Lazenbatt 2005). According to Charmaz (2006, p. 72), 'Memos catch your thoughts, capture the comparisons and connections you make and crystallise questions and directions for you to pursue'. The use of memos from the outset of the development of the current theory facilitated me in examining the ideas and biases I may have brought to the study or how my beliefs influenced the analytical assumptions I made throughout the process. The memos were treated as data and the concepts emerging as a result of analysis of the memos had to earn their way into the theory. If the ideas in the memos did not 'fit' with what was happening in the data, this quickly became very evident. For example, reflecting what is known in the literature and based on my experience of working with family members of people with an ED, in my memos I had constructed the participants as carers. This construction was challenged by the data emphasising the importance participants placed on constructing the self as a partner. Although my own constructions did not fit with the social reality of the participants, having them documented in the memos stimulated further scrutiny of the data which helped clarify how the carer issue did fit with the participants' lived experience.

A further way in which the criterion of 'fit' was facilitated in the current study included using the strategy of peer debriefing. Peer debriefing, also referred to as analytic triangulation, is concerned with utilising other people, not invested in the study, as a means to explore the researcher's thinking in all aspects of the research (Given 2008). Peer debriefing was available both in the form of the supervision process and from colleagues experienced in working with people with EDs. Supervision meetings were a regular part of the research process from the outset of the study. The supervisors who were experienced grounded theorists but had little experience in the substantive area under study, constantly encouraged me to explore the links between the concepts I was generating with the

evidence in the data. When they were not clear on how the data might fit with the concepts, rather than provide me with alternatives, they encouraged me to modify the concepts or conceptualise alternate ways of explaining what was happening in the data. Two colleagues also provided me with the opportunity for peer debriefing. The first was a nurse who had recently completed her psychotherapy training and was familiar with conceptualisation and abstract thinking. The second was an occupational therapist who was more pragmatic in her thinking. Meeting with these colleagues provided me with the opportunity to critically explore how and what knowledge the research was generating and how that might fit with what was emerging in the data.

Morse (2015) questions the usefulness of peer debriefing for the purpose of validity as difficulties may arise if other people try to impose their own beliefs onto the study; however she suggests that ultimately the responsibility for the findings and implications of a study rests with the researcher. My own experience in the supervision sessions was the supervisors were mindful of not trying to imposing their beliefs onto me rather, they encouraged me to think for myself. My colleagues however did put forward some of their own thoughts around what they thought might fit with the participants experiences. Both the conversations and thoughts arising from the meetings with supervisors and colleagues were documented in memos and, as discussed above, using the self-corrective method of constantly comparing across interviews and across memos, only those concepts that fit with what was going on in the data earned their way into the theory.

Although member checking is advocated by some authors as a method to ensure 'fit' in qualitative research (Sandelowski 1986, Krefting 1991), this was not a strategy adopted in the current study. This was because, in keeping with Morse *et al.* (2002), my understanding was based on the premise that raising the data to conceptual level could mean participants may not identify their individual experiences in the write up of the theory. I was also mindful participants were at various stages in the process of '*Reconstructing Livability*', therefore they might not be able to identify with some aspects of theory. In addition, I believed those participants who were in the relationship a shorter period of time might find the prospect of living through further cycles of '*Reconstructing Livability*' a difficult reality to contemplate and this could further add to their distress; however, omitting these participants from the process of member checking, in my view, would have been unethical.

As such, member checking of the participants was not felt to be a suitable way in which to ensure the criteria of fit was met in the current study.

Although Glaser and Strauss (1967) identify four criteria appropriate for considering the quality of a CGT study, Lomborg and Kirkevold (2003) suggest 'fit' forms the basis on which the other three criteria are centred. Some issues therefore overlap, as is evidenced in the following subsections discussing the criteria of work, modifiability and relevance.

11.3.2 Work

The criterion of work refers to the manner in which the theoretical concepts are related and subsumed into the theory, interpreting and accounting for how the participants continuously resolve their main concern. According to Glaser (1978), in order for a study to meet the criteria of work it needs to fulfil the properties of explanation, interpretation and prediction in the substantive area under study. The systematic procedures, conducted throughout data collection and analysis, support the workability of the theory of '*Reconstructing Livability*'. The concepts and categories that explain and interpret the participants' behaviours were directly derived from the data provided by them, beginning with line by line coding of the interviews. For example, in order to support the concepts to stay as close as possible to the data, in vivo coding was used, where data was labelled by words taken directly from the transcripts, such as '*treading on egg shells*'. Through the CGT analysis process, the code '*treading on eggshells*' became part of the concept '*Keeping the peace*' which subsequently was labelled a property of the category '*Countering intimacy disruptions*' (Chapter 8.4.2).

As the theory is grounded in the lived experiences of the participants, it provides new information on the predictable ways they respond to certain events in their lives, which can be projected onto future similar events (Andrews & Nathaniel 2015). However, that is not to claim generalisability to all partners living with a person with an ED, such as those who are in a relationship with a person experiencing Binge Eating Disorder (BED) as they were not interviewed in the current study. Nor does it claim certainty and stability of the findings, as new data can modify the properties of explanation and interpretation found in the current study.

11.3.3 Modifiability

The criterion of modifiability in CGT methodology works on the premise that the theory generated can be modified in light of new data. Glaser (1978) points out that this is not to dismiss what has previously been discovered; rather, in keeping with the ever changing social world that we live in, variations to basic social processes can be accounted for by modifying what has already been discovered. When new incidents in the substantive area emerge the theory is modified through the constant comparative method (Glaser 1998), ensuring the theory has ongoing relevance and fit. The methodological procedures operated in the current theory, as discussed in chapter 4, meant the theory of '*Reconstructing Livability*', was constantly being modified with new data until saturation of the categories was achieved. Even on completion of the theory, with the nature of an ever changing social world or by including other partners' experiences such as those who do not remain committed to the relationship, the theory can be modified. It is through the application of the CGT analytic strategies to new incoming data that ongoing modification of the current theory can be achieved facilitating the criterion of relevance of the theory.

11.3.4 Relevance

The criterion of relevance means the emergent theory is relevant to the area under study and provides insight into the substantive area in a way that is useful to the participants and readers. Relevance is only achieved when the participants' main concern and patterns of behaviour are allowed to emerge from the data rather than imposed on the theory from preconceived ideas or prior theoretical conjecture (Glaser 1978). Although Glaser and Strauss (1967) acknowledge that the CGT researcher does not enter the field without some prior knowledge in the substantive area, they stress that insight, prior knowledge and concepts must earn their way into the theory in order for them to be relevant. As discussed in section 11.3.1 above, this was achieved by applying the corrective approach of the CCM.

Having worked with people with eating disorders for many years, I was far from entering the substantive field with no prior knowledge. As discussed in chapter 4 and section 11.3.1 above in relation to researcher bias, I was mindful of my own preconceptions and mindful of insights provided in the literature on family members' experiences of living with a person with an ED. For example, I had a preconceived idea that the issue of control, relating to

their partners need for control over such things as food and eating, was going to be a major issue of concern. However, as data was collected and analysed, it became apparent the issue of control was not relevant to the study and subsequently did not earn its way into the theory. However, with ongoing analysis, supervision and memo writing, other concepts such as 'identity' began to emerge as relevant to the study and became a part of explaining the behaviours participants engaged when resolving the main concern of *'Encountering and living within a disrupted relationship'*.

Throughout the conduct of the study, the supervisory process available to me was invaluable in challenging the relevance of the study. Firstly, when I was grappling with identifying and naming the main concern my supervisors encouraged me to keep going back to the data and, by using memos, identify the data that supported or refuted the ideas that were coming to mind. Even when I had potentially identified the main concern, they encouraged me to refine it further so that it could account for what was happening in the data and be named in a way that was relevant to the participants. As the study progressed, the supervisors continued to keep me focused by asking me to challenge my conceptualisations, constantly repeating the advice to remain mindful of what the participants' main concern was and how they were continuously trying to resolve it. In this way the concepts that were developing were at all times relevant to the experiences of the participants in the study.

As the theory developed I also discussed what emerged as the main concern and the underlying behaviours employed by the participants to resolve this concern, with colleagues who also worked with people who were experiencing EDs and their family members. Although they had not previously considered the experience of the partner not experiencing the ED as a journey of personal recovery, colleagues could see how the findings from the current study were relevant to their own practice when working in the couple context. The colleagues I spoke with felt the current theory would provide them with an alternative perspective they could use in their therapy sessions with couples. In particular, they felt approaching the concept of recovery from the dual perspective of both partners would improve the personal and relational wellbeing for each person as well as the relationship itself.

For me, becoming an informed self with regard to partners' experiences impacted on my practice in terms of working with couples where one member had an ED. Inadvertently, bringing what I had learned from the study to sessions with couples, served to reinforce the relevance of the study. This happened where the partners not experiencing the ED could relate to issues such as the need to maintain the identity of partner or the need to remain committed to the relationship despite experiencing ongoing disruptions. Many have voiced their surprise at how I can identify and name some of their concerns, particularly where they themselves have difficulty identifying or naming them. Many of the couples I have worked with since commencing this study have expressed a sense of relief at being understood better. Although not considered member checking in the traditional sense, bringing what I learned to other partners in a similar situation of living with a person with an ED, could be considered a form of member checking. The criterion of relevance for the current study therefore, was supported by the usefulness of the theory when I applied it to my practice of working with other partners of people experiencing an ED.

11.4 Implications and Recommendations

The theory of '*Reconstructing Livability*' provides new information on partners' experiences of living with a person with an ED. In the current theory, this experience has been conceptualised as a personal journey of recovery for the person not experiencing the ED, where being able to live in the intimate relationship in a satisfactory way is a significant component of their recovery. It is in the context of personal recovery and encountering repeated ED related disruptions to the intimate relationship that the emotional, informational and practical needs of the partner not experiencing the ED have been identified. The findings from the current study therefore, have implications for clinical practice, education for professionals, research and policy. The recommendations to address these issues are provided below.

11.4.1 Implications and recommendations for clinical practice

Although the majority of research in the area of couples, where one member has an ED, is focused on how partners can effectively support that person, the current theory also highlights the need for partners of people experiencing an ED to be supported through their own recovery. Provision of emotional, informational and practical support from

professionals is highlighted in the theory as a primary area for consideration. However, the current theory highlights the contextual issues that impact on the nature of supports required and the means by which to provide them. As evidenced in the theory, the nature of professional supports required is not constant rather, it changes at various stages in the process of *'Reconstructing Livability'*. These changes are paralleled with the ED setbacks experienced by the partner as it impacts on the participants' level of distress. Changes to the professional supports required also occur as participants become a more *'Informed self'* with each cycle of *'Reconstructing Livability'* they live through. When given voice, the partners of people experiencing an ED are clear on what the support should be and how it should be provided, so they feel comfortable in accessing and utilising it. The support they are looking for in relation to information is on the nature of EDs and how best they can support their partner, emotional support is in relation to helping them manage their own distress and practical support is around having access to professional inputs for their partner. Their preference is to access this support on an individual or couple basis rather than in a group format.

In providing appropriate professional supports however, the importance of the participant wanting to protect the self, partner and the relationship from the judgements of others or from being considered a carer, needs to be considered in the context of the participants' ability to engage with professionals. In addition, the ED related silences participants maintain in order to reduce their partner's distress or relationship conflict also need to be considered when providing these supports, as they may hinder the ability of the participant to engage fully when accessing support in the couple context. In light of these contextual issues, the recommendations for clinical practice are as follows;

1. That the theory of *'Reconstructing livability'* is utilised as a framework for developing appropriate and timely interventions which reflect where partners not experiencing the ED are positioned in the process of *'Reconstructing livability'* and reflect their developing expertise as they live with repeated ED disruptions.

2. That partners as experts are involved in the development and delivery of interventions and that the format of delivery include individual, couple and group interventions which is needs based.
3. That supportive interventions are developed to meet the specific and individual needs of the partner not experiencing the ED, and not assume needs are homogenous across family members who are living with a person with an ED.
4. That professionals extend the principles of recovery to include the experiences of the partner not experiencing the ED, as in the current theory their experiences are considered to be a journey of recovery from the distress of living with ED related disruptions to their lives.
5. That professionals work on improving life balance and self-care with the partner not experiencing the ED, so they are supported in reclaiming the livability of their lives, even if they continue to live with ED related disruptions.
6. That specific education on how best to support the person in their recovery from the ED occurs in the context of the couple, where negotiation and an understanding is reached between the couple on how and when that support can be provided.
7. That the interventions provided must address intimate relationship functioning. In the situation where the partner not experiencing the ED has difficulty with breaking their own ED related silence (Chapter 8.4.2), this may need to be provided on an individual basis for this partner.
8. That interventions are rolled out nationally and in a manner that is accessible to all partners who are living with a person with an ED.
9. That professional interventions focus on promoting hope for the partner not experiencing the ED for example, where using the language of recovery rather than the medicalised language of 'chronic and enduring' gives hope for a

recovery of the partner experiencing the ED. As demonstrated in the theory of *'Reconstructing Livability'* maintaining hope for recovery of their partner supports hope for the intimate relationship and hope for the self of participant in reclaiming the livability of their relationship.

10. That professionals consider the partner who is not experiencing the ED beyond the identity of carer and see them in the context of the intimate relationship, where the identity of partner is given precedence and ED related caring is seen as an extension of normal couple caring.
11. Keeping in mind the legal and ethical constraints guiding others involvement in the treatment of an adult person experiencing the ED, partners of people experiencing an ED should be included as far as is possible in the assessment and ongoing care planning for their partner.
12. Professionals should be able to direct the partners not experiencing the ED to ED related educational information such as books and appropriate online information, and to support services such as voluntary organisations and community educational mental health programmes. In particular, as highlighted in the current theory, professionals need to provide detailed information on what support groups for partners of people experiencing an ED entail (Chapter 8.3).

11.4.2 Implications and recommendations regarding education for professionals

Consistent with reports in the literature suggesting ED related training and supervision for professionals is limited (Mahr *et al.* 2015), with the exception of those who have particular expertise in the area of EDs, the theory of *'Reconstructing Livability'* also highlights a deficiency in professionals' knowledge of EDs. As the issue of EDs comes under the umbrella of mental health and knowledge in relation to mental health issues is reported to be limited for professionals working in the general field of medicine (McDaid 2013), it is not surprising that professionals working outside the area of mental health lack knowledge and information regarding EDs. However, more worryingly are the findings in the current theory that point to the lack of knowledge or understanding of EDs among professionals working

in the area of mental health. In addition, a scarcity of services offering care and treatment for people experiencing EDs and their family members is also highlighted by participants. This is problematic for partners who are challenged not only by trying to access to treatment for their partner who is experiencing the ED, but also when they are trying to access support and information for themselves. The recommendations for the education of professionals in the area of EDs therefore are;

1. That professionals working with people experiencing an ED and their partners work within evidenced based, best practice guidelines such as the National Institute for Health and Clinical Excellence (2004) or The American Psychiatric Association (2006) which, although are relevant now, may change in the future.
2. That various levels of educational programmes are developed to meet the needs of the range of medical, nursing and allied health professionals¹⁵ working in the area of EDs. Each professional programme should provide the knowledge and skills appropriate to that discipline's scope of practice in relation to ED.
3. That education modules specific to EDs are integrated into undergraduate and postgraduate training programmes for medical, nursing and allied health professionals who are not specifically working in the area of EDs.
4. That educational programmes utilise active or participatory teaching and learning approaches that enable students to explore their personal assumptions and attitudes towards partners' experiences of living with a person with an ED.
5. In line with reports suggesting the involvement of service users and their family members in health care programmes is beneficial to all (Morgan & Jones 2009, McKeown *et al.* 2012), it is recommended that ED educational programme design and content include the involvement of not just service users and but also their partners who have experiences of EDs.

¹⁵ Allied health professionals refer to those health professionals other than doctors and nurses to include psychologists, social workers, occupational therapists, psychotherapists, counsellors and dieticians.

6. Providing training on the principles of recovery has been found to have a positive impact on professionals skills, knowledge and attitudes (Higgins *et al.* 2012). It is recommended therefore that training programmes on recovery principles are provided to all professional disciplines working in the field of EDs.
7. That health services embrace a model of collaborative caring with those who are recovering from the distress of living with mental 'illness', including partners who are recovering the distress of living with ED related disruptions in their lives.

11.4.3 Implications and Recommendations for research

It has been acknowledged in the current study that research and theory in the area of partners' experiences of living with a person with an ED is seriously lacking. What knowledge is available regarding partners' experiences is generally merged with other family members' experiences. Although the existing research provides some insights regarding partners, it is difficult to separate out the needs that are unique for partners living in the intimate relationship. Therefore, as highlighted in the theory of '*Reconstructing Livability*', the current interventions based on what is already known in the context of family members who are living with a person with an ED are in some instances insufficient and in others inappropriate for practice when professionals are specifically working in the context of the couple.

Although this study goes some way to understanding the experiences of partners living with a person with an ED, it also highlights areas of research that need addressing in order to improve knowledge and practice in the substantive area. If services are to effectively meet the needs of the partner not experiencing the ED as they embark on their own recovery journey, then further research into this phenomenon is required. The recommendations for research therefore, are as follows;

1. That in future researchers disaggregate participants in their studies according to relationship type and move away from viewing family members as a homogeneous group.

2. Although the theory of '*Reconstructing Livability*', provides some explanation for partners' lack of utilisation of support services, further exploration of this phenomenon is recommended.
3. In addition to the carer assessment tools that measure various aspects relating to the caring role, there is a need to develop an integrated assessment tool that include aspects of caring, the intimate relationship and personal recovery for partners who are living with a person experiencing an ED.
4. That further research into the area of partners' experience of living with a person with an ED is conducted with a view to exploring the influence gender may have on these experiences. This may identify gender differences in needs for partners, which will impact on the models of care that are recommended and utilised in practice.
5. In order to gain further insights into the associations between the intimate relationship and personal recovery, it is recommended that research is extended to include the personal recovery experiences of partners who do not remain in the intimate relationship, for those living with a person with BED and for those who have children, that experiences relating to children are included.
6. That research relating to personal recovery for family members and in particular for partners as a family member is expanded so that further insights and knowledge into their experiences can be acquired.
7. In keeping with the understanding that with new data a CGT can be modified, further exploration in the area of partners' experiences of living with a person with an ED could expand the concepts contained in the current theory.
8. For the purpose of generating a formal theory that has a more generalised relevance and applicability, the exploration of partners' experiences as a recovery journey could be expanded to other substantive areas, such as living with a person with depression, schizophrenia, rheumatoid arthritis or multiple sclerosis.

11.4.4 Implications and recommendations for policy

The findings in the current study highlight policy issues that need to be addressed if the vision of health and wellbeing for all is to be achieved (Department of Health and Children 2013). Although several Irish policy documents go some way towards addressing the needs of partners who are living with a person with an ED (Government of Ireland 2006, 2012), again these needs are often merged with the needs of other family carers and, in the context of personal recovery, with the needs of other service users. In addition, many of the recommendations put forward in these policy documents have not been fully implemented. These issues are problematic for partners who have limited access to care and treatment for their partner experiencing the ED, and limited access to support and education for themselves which have been identified as necessary requirements for their own journey of recovery. The recommendations for policy therefore are as follows;

1. That the unique perspective of partners should be valued and included in policy development and in particular in the development of strategies for people who take on a caring role.
2. The current National Carer Strategy (Government of Ireland 2012) aims to encourage carer self-identification for the purposes of accessing support. Similar to a report from Care Alliance Ireland (2015), the theory of *'Reconstructing Livability'* challenges this thinking by acknowledging that not everyone engaging in a caring role wants to be identified as a carer but they still have informational, emotional and practical needs relating to living with a person with an ED. In addition to the caring narrative, it is recommended that alternative ways of identifying and framing the caring activities people engage in when living with a partner experiencing an ED are considered.
3. Although there have been recent improvements in the provision of services for people experiencing an ED (Health Service Executive 2012), many of the recommendations made in the document *'A Vision for Change'* (Government of Ireland 2006) have not been realised (Mental Health Reform 2015). Therefore, accessing care and treatment remains an ongoing challenge for people with EDs and their partners. It is recommended that the focus continues on developing the

services and that policy be expanded to specifically address issues pertinent to the experiences partners have when living with a person with an ED. This will require the provision of adequate resources.

4. Recent policy and national strategy documents relating to mental health promote a recovery culture (Government of Ireland 2006, Mental Health Commission 2008). The findings in the current theory suggest these strategies need to be extended to include the recovery journey of partners and other family members who are living with a person experiencing mental health difficulties including EDs.
5. That national policy aimed at reducing stigma (Government of Ireland 2006) and stigma reducing programmes, for example 'See Change' (The National Mental Health Stigma Reduction Partnership 2010) are extended to include stigma by association, so partners and family members who experience stigma when living with a person with a mental 'illness', including EDs, are also supported.

11.5 Summary and conclusion

This final chapter of the thesis, considered the theory of '*Reconstructing Livability*' in the context of the limitations, trustworthiness, implications and recommendations arising from the study. As the theory is underpinned by social constructionist epistemology, the limitations regarding the construction of knowledge and the social context within which the research was conducted were presented. The issue of trustworthiness was discussed in relation to the debates around quality in qualitative research and the criteria as proposed by Glaser and Strauss (1967) were used to demonstrate how the current theory emerged from the data as opposed to being forced from pre-conceived ideas or theoretical conjecture.

The theory of '*Reconstructing Livability*' provides a unique conceptualisation of the research phenomenon where the experience of partners who are living with a person with an ED is considered a personal journey of recovery from disruptions to their intimate relationship. It is in the context of encountering ongoing disruptions to the relationship that the partner not experiencing the ED is faced with challenges and impact on their own

recovery journey. The theory of '*Reconstructing Livability*' provides new information on how these challenges are experienced and the emotional, informational and support needs required in order to overcome them. The theory developed provides the basis on which the recommendations, which are focused on providing partners of people experiencing an ED with appropriate, effective and timely supports, are made. The recommendations are primarily directed to clinical practice, education for professionals, research and policy. It is hoped that the theory of '*Reconstructing Livability*', while stimulating discussion around the experiences of partners who are living with a person with an ED, is given due consideration in terms of the recommendations so that the partners can be supported in their own personal recovery journey.

REFERENCES

- Ackard D.M., Fulkerson J.A. & Neumark-Sztainer D. (2007) Prevalence and utility of DSM-IV eating disorder diagnostic criteria among youth. *International Journal of Eating Disorders* **40**(5), 409-417.
- Ackard D.M., Kearney-Cooke A. & Peterson C.B. (2000) Effect of body image and self-image on women's sexual behaviors. *International Journal of Eating Disorders* **28**(4), 422-429.
- Ackard D.M., Richter S., Egan A. & Cronemeyer C. (2014) Poor outcome and death among youth, young adults, and midlife adults with eating disorders: an investigation of risk factors by age at assessment. *International Journal of Eating Disorders* **47**(7), 825-835.
- Ackard D.M., Richter S., Frisch M.J., Mangham D. & Cronemeyer C.L. (2013) Eating disorder treatment among women forty and older: increases in prevalence over time and comparisons to young adult patients. *Journal of Psychosomatic Research* **74**(2), 175-178.
- Agras W.S., Brandt H.A., Bulik C.M., Dolan-Sewell R., Fairburn C.G., Halmi K.A., Herzog D.B., Jimerson D.C., Kaplan A.S., Kaye W.H., Grange D.L., Lock J., Mitchell J.E., Rudorfer M.V., Street L.L., Striegel-Moore R., Vitousek K.M., Walsh B.T. & Wilfley D.E. (2004) Report of the National Institutes of Health workshop on overcoming barriers to treatment research in anorexia nervosa. *International Journal of Eating Disorders* **35**(4), 509-521.
- Agras W.S., Crow S.J., Halmi K.A., Mitchell J.E. & et al. (2000) Outcome predictors for the cognitive behavior treatment of bulimia nervosa: data from a multisite study. *The American Journal of Psychiatry* **157**(8), 1302-1308.
- Al-Amoudi I. & Willmott H. (2011) Where constructionism and critical realism converge: interrogating the domain of epistemological relativism. *Organization Studies* **32**(1), 27-46.
- Albert R. & Simpson A. (2015) Double deprivation: a phenomenological study into the experience of being a carer during a mental health crisis. *Journal of Advanced Nursing* **71**(12), 2753-2762.
- Aldiabat K. & Le Navenec C. (2011) Philosophical roots of classical grounded theory: its foundations in symbolic interactionism. *The Qualitative Report* **16**(4), 1063-1080.
- Alexakos S.L. (2004) Male partners of women with eating disorders: a qualitative exploration of the man's experience. *Dissertation Abstracts International* **6**, 1069.
- Altabe M. & Thompson J.K. (1996) Body image: a cognitive self-schema construct. *Cognitive Therapy & Research* **20**(2), 171-193.
- American Psychiatric Association (2006) *Practice guideline for the treatment of patients with eating disorders*. 3rd edn. Washington DC: American Psychiatric Association.
- American Psychiatric Association (2013) *Diagnostic and statistical manual of mental disorders*. 5th edn. Washington DC: American Psychiatric Association.

Andrews T. & Nathaniel A. (2015) Awareness of dying remains relevant after fifty years. *Grounded Theory Review* **14**(2), 3-10.

Angen M.J. (2000) Evaluating interpretive inquiry: reviewing the validity debate and opening the dialogue. *Qualitative Health Research* **10**(3), 378-395.

Angermeyer M.C., Schulze B. & Dietrich S. (2003) Courtesy stigma. *Social Psychiatry & Psychiatric Epidemiology* **38**(10), 593.

Anells M. (1996) Grounded theory method: philosophical perspectives. Paradigm of inquiry, and postmodernism. *Qualitative Health Research* (6), 379-393.

Anells M. (1997) Grounded theory method, part 11: options for users of the method. *Nursing Inquiry* (4), 176-180.

Anthony W. (1993) Recovery from mental illness: the guiding vision of the mental health system in the 1990's. *Innovations and research* **2**, 17-24.

Appleton J.V. & King L. (2002) Journeying from the philosophical contemplation of constructivism to the methodological pragmatics of health services research. *Journal of Advanced Nursing* **40**(6), 641-648.

Arcelus J., Yates A. & Whiteley R. (2012) Romantic relationships, clinical and sub-clinical eating disorders: a review of the literature. *Sexual and Relationship Therapy* **27**(2), 147-161.

Armstrong J.C. & Roth D.M. (1989) Attachment and separation difficulties in eating disorders: a preliminary investigation. *International Journal of Eating Disorders* **8**(2), 141-155.

Armstrong L.L. (2006) Barriers to intimate sexuality: concerns and meaning-based therapy approaches. *The Humanistic Psychologist* **34**(3), 281-298.

Backman K. & Kyngas H., A. (1999) Challenges of the grounded theory approach to a novice researcher. *Nursing and health sciences* **1**, 147-153.

Baez B. (2002) Confidentiality in qualitative research: reflections on secrets, power and agency. *Qualitative Research* **2**(1), 35-58.

Bandeira D.R., Pawlowski J., Gonçalves T.R., Hilgert J.B., Bozzetti M.C. & Hugo F.N. (2007) Psychological distress in Brazilian caregivers of relatives with dementia. *Aging & Mental Health* **11**(1), 14-19.

Bandura A. (1977) Self-efficacy: toward a unifying theory of behavioural change. *Psychological Review* **84**(2), 192-215.

Bandura A. (1982) Self-efficacy mechanism in human agency. *American Psychologist* **37**(2), 122-147.

- Bandura A. (1995) Exercise of personal and collective efficacy in changing societies. In *Self-efficacy in changing societies* (Bandura A., ed), New York: Cambridge University Press, pp. 1-45.
- Barber M.E. (2012) Recovery as the new medical model for psychiatry. *Psychiatric Services* **63**(3), 277-279.
- Barkin J.S. (2003) Realist constructivism. *International Studies Review* **5**(3), 325-342.
- Baronet A.-M. (1999) Factors associated with caregiver burden in mental illness: a critical review of the research literature. *Clinical Psychology Review* **19**(7), 819-841.
- Basile B. (2004) Self-disclosure in eating disorders. *Eating and Weight Disorders - Studies on Anorexia, Bulimia and Obesity* **9**, 217-223.
- Beales D.L. & Dolton R. (2000) Eating disordered patients: personality, alexithymia, and implications for primary care. *British Journal of General Practice* **50**, 21-26.
- Beauchamp T. & Childress J. (2001) *Principles of biomedical ethics*. 5th edn. New York: Oxford University Press.
- Belangee S.E. (2007) Couples and eating disorders: an individual psychology approach. *Journal of Individual Psychology* **63**(3), 294-305.
- Bell L. (2003) What can we learn from consumer studies and qualitative research in the treatment of eating disorders? *Eating and Weight Disorders - Studies on Anorexia, Bulimia and Obesity* **8**(3), 181-187.
- Ben-Zeev D., Young M.A. & Corrigan P.W. (2010) DSM-V and the stigma of mental illness. *Journal of Mental Health* **19**(4), 318-327.
- Benas J. & Gibb B. (2011) Cognitive biases in depression and eating disorders. *Cognitive Therapy & Research* **35**(1), 68-78.
- Berg C.A. & Upchurch R. (2007) A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychological Bulletin* **133**(6), 920-954.
- Berger P.L. & Luckman T. (1967) *The social construction of reality*. London: Allen Lane the Penguin Press.
- Berk L., Jorm A.F., Kelly C.M., Dodd S. & Berk M. (2011) Development of guidelines for caregivers of people with bipolar disorder: a Delphi expert consensus study. *Bipolar disorders* **13**(5-6), 556-570.
- 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**(4), 293-309.

Berscheid E. (2006) Searching for the meanings of "love". In *The new psychology of love* (Sternberg R.J. & Weis K., eds), New Haven, CT: Yale University Press.

Berscheid E. (2010) Love in the fourth dimension. *Annual Review of Psychology* **61**(1), 1-25.

Berscheid E. & Meyers S. (1996) A social categorical approach to a question about love. *Personal Relationships* (3), 19-43.

Beumont P., Beumont R., Beaumont D., Birmingham L., Derham H., Hay P., Jordan A., Kohn M., McDermott B., Marks P., Mitchell J., Paxton S., Surgenor L., Thornton C., Wakefield A. & Weigall S., eds. (2004) *Australian and New Zealand clinical practice guidelines for the treatment of anorexia nervosa*. Australia: Royal Australian and New Zealand College of Psychiatrists.

Birks M., Chapman Y. & Francis K. (2006) Moving grounded theory into the 21st century: part 1- An evolutionary tale. *Singapore nursing journal* **33**(4-10).

Birks M. & Mills J. (2011) *Grounded theory a practical guide*. London, California. New Delhi, Singapore: Sage Publications Ltd.

Birmingham C.L., Su J., Hlynsky J.A., Goldner E.M. & Gao M. (2005) The mortality rate from anorexia nervosa. *International Journal of Eating Disorders* **38**(2), 143-146.

Birnie-Porter C. & Lydon J.E. (2013) A prototype approach to understanding sexual intimacy through its relationship to intimacy. *Personal Relationships* **20**(2), 236-258.

Blazina C. & Marks L.I. (2001) College men's affective reactions to individual therapy, psychoeducational workshops, and men's support group brochures: the influence of gender-role conflict and power dynamics upon help-seeking attitudes. *Psychotherapy: Theory, Research, Practice, Training* **38**(3), 297-305.

Bohon C., Stice E. & Burton E. (2009) Maintenance factors for persistence of bulimic pathology: a prospective natural history study. *International Journal of Eating Disorders* **42**(2), 173-178.

Bonfils K.A., Firmin R.L., Salyers M.P. & Wright E.R. (2015) Sexuality and intimacy among people living with serious mental illnesses: factors contributing to sexual activity. *Psychiatric Rehabilitation Journal*.

Bowen G.A. (2008) Naturalistic inquiry and the saturation concept: a research note. *Qualitative Research* **8**(1), 137-152.

Boychuk Duchscher J. & Morgan D. (2004) Grounded theory: reflections on the emergence vs. forcing debate. *Journal of Advanced Nursing* **48**(6), 605-612.

Bradbury T.N., Fincham F.D. & Beach S.R.H. (2000) Research on the nature and determinants of marital satisfaction: a decade in review. *Journal of Marriage and Family* **62**(4), 964-980.

- Bramon-Bosch E., Troop N.A. & Treasure J. (2000) Eating disorders in males: a comparison with female patients. *European Eating Disorders Review* **8**(4), 321-328.
- Braun D.L. & Sunday S.R. (1999) More males seek treatment for eating disorders. *International Journal of Eating Disorders* **25**(4), 415-424.
- Brody J.L., Cluck J.P. & Aragon A.S. (1997) Participants' understanding of the process of psychological research: informed consent. *Ethics & Behavior* **7**(4), 285-298.
- Brown G.W., Carstairs G. & Topping G.G. (1958) The post-hospital adjustment of chronic mental patients. *Lancet* **2**, 685-689.
- 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.
- Bruch H. (1973) *Eating disorders*. Basic Books, New York.
- Bruch H. (1974) *Eating disorders obesity, anorexia nervosa and the person within*. London: Routledge & Kegan Paul.
- Brumberg J.J. (1998) *Fasting girls: the emergence of anorexia nervosa as a modern disease*. Cambridge Massachusetts, London England: Harvard university Press.
- Bryant A. & Charmaz K. (2010) Grounded theory in historical perspective: an epistemological account. *The sage handbook of grounded theory*. London: Sage publications Ltd.
- Bucchianeri M., Serrano J., Pastula A. & Corning A. (2014) Drive for muscularity is heightened in body dissatisfied men who socially compare. *Eating disorders: The journal of treatment and prevention* **22**(3), 221-232.
- Bulik C.M. (2005) Exploring the gene-environment nexus in eating disorders. *Journal of Psychiatry & Neuroscience* **30**(5), 335-339.
- Bulik C.M., Baucom D.H. & Kirby J.S. (2012) Treating anorexia nervosa in the couple context. *Journal of Cognitive Psychotherapy* **26**(1), 19-33.
- Bulik C.M., Baucom D.H., Kirby J.S. & Pisetsky E. (2011) Uniting couples (in the treatment of) anorexia nervosa (UCAN). *International Journal of Eating Disorders* **44**(1), 19-28.
- Bulik C.M., Reba L., Siega-Riz A. & Reichborn-Kjennerud T. (2005) Anorexia nervosa: definition, epidemiology, and cycle of risk. *International Journal of Eating Disorders* **37**, 2-9.
- Burr V. (2003) *Social constructionism*. 2nd edn. East Essex: Routledge.
- Bussolotti D., Fernández-Aranda F., Solano R., Jiménez-Murcia S., Turón V. & Vallejo J. (2002) Marital status and eating disorders: an analysis of its relevance. *Journal of Psychosomatic Research* **53**(6), 1139-1145.

Button E., Aldridge S. & Palmer R. (2008) Males assessed by a specialized adult eating disorders service: patterns over time and comparisons with females. *International Journal of Eating Disorders* **41**(8), 758-761.

Caglar-Nazali H.P., Corfield F., Cardi V., Ambwani S., Leppanen J., Olabintan O., Deriziotis S., Hadjimichalis A., Scognamiglio P., Eshkevari E., Micali N. & Treasure J. (2014) A systematic review and meta-analysis of 'Systems for Social Processes' in eating disorders. *Neuroscience & Biobehavioral Reviews* **42**(0), 55-92.

Callaghan P. & Morrissey J. (1993) Social support and health: a review. *Journal of Advanced Nursing* **18**(2), 203-210.

Caparrotta L. & Ghaffari K. (2006) A historical overview of the psychodynamic contributions to the understanding of eating disorders. *Psychoanalytic Psychotherapy* **20**(3), 175-196.

Care Alliance (2015) Defining carers. Care Alliance, Ireland.

Carr-Nangle R.E., Johnson W.G., Bergeron K.C. & Nangle D.W. (1994) Body image changes over the menstrual cycle in normal women. *International Journal of Eating Disorders* **16**(3), 267-273.

Cash T.F. & Fleming E.C. (2002) The impact of body image experiences: development of the body image quality of life inventory. *International Journal of Eating Disorders* **31**(4), 455-460.

Castellini G., Lelli L., Lo Sauro C., Fioravanti G., Vignozzi L., Maggi M., Faravelli C. & Ricca V. (2012) Anorectic and bulimic patients suffer from relevant sexual dysfunctions. *The Journal of Sexual Medicine* **9**(10), 2590-2599.

Charmaz K. (2000) Grounded theory: objectivist and constructivist methods. In *Handbook of qualitative research* (Denzin K. & Lincoln Y., eds), Thousand Oaks: Sage Publications, pp. 509-535.

Charmaz K. (2006) *Constructing grounded theory. A practical guide through qualitative analysis*. London, California, New Delhi, Singapore: Sage Publications.

Charmaz K. (2008) Constructionism and the grounded theory method. In *Handbook of constructionist research* (Holstein J.A. & Gubrium J.F., eds), New York: The Guilford Press, pp. 397-412.

Chenitz W., C. & Swanson J., M (1986) *From practice to grounded theory: qualitative research in nursing*. Menlo Park, CA: Addison-Wesley.

Cheung J. & Hocking P. (2004) Caring as worrying: the experience of spousal carers. *Journal of Advanced Nursing* **47**(5), 475-482.

Childs S. (2004) Editorial - When to use Google for health queries? *He@lth Information on the Internet* (42), 1-2.

- Chisholm K.E., McCabe M.P., Wootten A.C. & Abbott J.-A.M. (2012) Review: psychosocial interventions addressing sexual or relationship functioning in men with prostate cancer. *The Journal of Sexual Medicine* **9**(5), 1246-1260.
- Christians C. (2003) Ethics and politics in qualitative research. In *The landscape of qualitative research: Theories and issues* (Denzin N. & Lincoln Y., eds), Thousand Oaks, London, New Delhi: Sage Publications, pp. 208-243.
- Clark A. (1998) The qualitative-quantitative debate: moving from positivism and confrontation to post-positivism and reconciliation. *Journal of Advanced Nursing* **27**(6), 1242-1249.
- Clark A. (2006) Qualitative interviewing: encountering ethical issues and challenges. *Nurse Researcher* **13**(4), 19-29.
- Clark M.S. & Monin J.K. (2006) Giving and receiving communal responsiveness as love In *The new psychology of love* (Sternberg R.J. & Veis K., eds), Yale University Press.
- Clark M.S. & Reis H.T. (1988) Interpersonal processes in close relationships. *Annual Review of Psychology* **39**(1), 609.
- Clay D., Vignoles V.L. & Dittmar H. (2005) Body image and self-esteem among adolescent girls: testing the influence of sociocultural factors. *Journal of Research on Adolescence (Blackwell Publishing Limited)* **15**(4), 451-477.
- Coeling H.V., Biordi D.L. & Theis S.L. (2003) Negotiating dyadic identity between caregivers and care receivers. *Journal of Nursing Scholarship* **35**(1), 21.
- Collier E. (2010) Confusion of recovery: one solution. *International Journal of Mental Health Nursing* **19**(1), 16-21.
- Collins N.L., Kane H.S., Metz M.A., Cleveland C., Khan C., Winczewski L., Bowen J. & Prok T. (2014) Psychological, physiological, and behavioral responses to a partner in need: the role of compassionate love. *Journal of social and personal relationships* **31**(5), 601-629.
- Conrad P. (2007) *The medicalization of society: on the transformation of human conditions into treatable disorders*. Baltimore, Maryland: The John Hopkins University Press.
- Cook W.L. & Kenny D.A. (2005) The actor-partner interdependence model: a model of bidirectional effects in developmental studies. *International Journal of Behavioral Development* **29**(2), 101-109.
- Coomber K. & King R. (2012) Coping strategies and social support as predictors and mediators of eating disorder carer burden and psychological distress. *Social Psychiatry & Psychiatric Epidemiology* **47**, 789-796.

Coomber K. & King R. (2013) A longitudinal examination of burden and psychological distress in carers of people with an eating disorder. *Social Psychiatry & Psychiatric Epidemiology* **48**, 163-171.

Cooper Z. (1995) The development and maintenance of eating disorders. In *Eating disorders and obesity. A comprehensive Handbook* (Brownell K.D. & Fairburn C.G., eds), New York, London: The Guilford Press, pp. 199-206.

Corbin J. & Morse J.M. (2003) The unstructured interactive interview: issues of reciprocity and risks when dealing with sensitive topics. *Qualitative Inquiry* **9**(3), 335-354.

Corbin J. & Strauss A. (2008) *Basics of qualitative research: techniques and procedures for developing grounded theory*. 3rd edn. Los Angeles, London, New Delhi, Singapore: Sage Publications.

Corrigan P. (2004) How stigma interferes with mental health care. *American Psychologist* **59**(7), 614-625.

Corrigan P.W., Watson A.C. & Miller F.E. (2006) Blame, shame, and contamination: the impact of mental illness and drug dependence stigma on family members. *Journal of Family Psychology* **20**(2), 239-246.

Cort J.E. (2002) Singing the glory of asceticism: devotion of asceticism in Jainism. *Journal of the American Academy of Religion* **70**(4), 719.

Coyne I.T. (1997) Sampling in qualitative research: Purposeful and theoretical sampling; merging or clear boundaries? *Journal of Advanced Nursing* **26**(3), 623-630.

Creswell J.W. (2007) *Qualitative inquiry and research design*. 2nd edn. London, New delhi, Thousand oaks: Sage Publications.

Creswell J.W. & Miller D.L. (2000) Determining validity in qualitative inquiry. *Theory Into Practice* **39**(3), 124.

Crisafulli M.A., Von Holle A. & Bulik C.M. (2008) Attitudes towards anorexia nervosa: the impact of framing on blame and stigma. *International Journal of Eating Disorders* **41**(4), 333-339.

Crisp A. (2006) Death, survival and recovery in anorexia nervosa: a thirty five year study. *European Eating Disorders Review* **14**(3), 168-175.

Crooks D.L. (2001) The importance of symbolic interaction in grounded theory research on women's health. *Health Care for Women International* **22**(1-2), 11-27.

Crotty M. (1998) *The foundations of social research: meaning and perspective in the research process*. Thousand Oaks, New Delhi: Sage Publications.

Crow S.J., Frisch M.J., Peterson C.B., Croll J., Raatz S.K. & Nyman J.A. (2009) Monetary costs associated with bulimia. *International Journal of Eating Disorders* **42**(1), 81-83.

- Culbert K.M., Racine S.E. & Klump K.L. (2015) Research review: what we have learned about the causes of eating disorders- a synthesis of sociocultural, psychological and biological research. *Journal of child psychology and psychiatry* **56**(11), 1141-1164.
- Cutcliffe J.R. (2000) Methodological issues in grounded theory. *Journal of Advanced Nursing* **31**(6), 1476-1484.
- Cutcliffe J.R. (2005) Adapt or adopt: developing and transgressing the methodological boundaries of grounded theory. *Journal of Advanced Nursing* **51**(4), 421-428.
- Cutrona C.E. & Russell D.W. (1990) Type of social support and specific stress: toward a theory of optimal matching. In *Social support: An interactional view* (Sarason B.R., Sarason I.G. & Pierce G.R., eds), Chichester England: Wiley, pp. 319-366.
- Cutrona C.E., Shaffer P.A., Wesner K.A. & Gardner K.A. (2007) Optimally matching support and perceived spousal sensitivity. *Journal of Family Psychology* **21**(4), 754-758.
- Dalzell H.J. (2000) Whispers: the role of family secrets in eating disorders. *Eating disorders* **8**(1), 43.
- Dare C., Eisler I., Russell G., Treasure J. & Dodge L. (2001) Psychological therapies for adults with anorexia nervosa: randomised controlled trial of out-patient treatments. *The British Journal of Psychiatry* **178**(3), 216-221.
- Davidson L., O'Connell M., Tondora J., Styron T. & Kangas K. (2006) The top ten concerns about recovery encountered in mental health system transformation. *Psychiatric Services* **57**(5), 640-645.
- Davidson L., O'Connell M.J., Tondora J., Lawless M. & Evans A.C. (2005) Recovery in serious mental illness: a new wine or just a new bottle? *Professional Psychology: Research and Practice* **36**(5), 480-487.
- Davidson L. & Roe D. (2007) Recovery from versus recovery in serious mental illness: one strategy for lessening confusion plaguing recovery. *Journal of Mental Health* **16**(4), 459-470.
- Davison T.E. & McCabe M.P. (2005) Relationship between men's and women's body image and their psychological, social, and sexual functioning *Sex Roles* **52**(7/8), 463-475.
- 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. (2007) The patient's view on quality of life and eating disorders. *International Journal of Eating Disorders* **40**(1), 13-20.
- De La Rie S., Van furth E., De Koning A., Noordenbos G. & Donker M. (2005) The quality of life of family caregivers of eating disorder patients. *Eating disorders* **13**(4), 345-351.

De Silva P. (1995) Cognitive-behavioural models of eating disorders. In *Handbook of eating disorders: theory, treatment and research* (Szmukler T., Dare C. & Treasure J., eds), John Wiley & Sons Ltd, pp. 141-153.

Deane F.P., Marshall S., Crowe T., White A. & Kavanagh D. (2015) A randomized controlled trial of a correspondence-based intervention for carers of relatives with psychosis. *Clinical Psychology & Psychotherapy* **22**(2), 142-152.

Dehle C., Larsen D. & Landers J.E. (2001) Social support in marriage. *The American Journal of Family Therapy* **29**(4), 307-324.

Della Porta D. & Keating M. (2008) How many approaches in the social sciences? An epistemological introduction. In *Approaches and methodologies in the social sciences. A pluralist perspective* (Della Porta D. & Keating M., eds), Cambridge: Cambridge University Press.

Department of Health and Ageing (2009) Fourth national mental health plan: an agenda for collaborative government action in mental health 2009-2014. Canberra, Australia: Commonwealth of Australia.

Department of Health and Children (2013) Healthy Ireland: a framework for improved health and wellbeing 2013-2025. Department of Health, Dublin.

Dick C.H., Renes S.L., Morotti A. & Strange A.T. (2013) Understanding and assisting couples affected by an eating disorder. *American Journal of Family Therapy* **41**(3), 232-244.

Dimitropoulos G., Farquhar J.C., Freeman V.E., Colton P.A. & Olmsted M.P. (2015) Pilot study comparing multi-family therapy to single family therapy for adults with anorexia nervosa in an intensive eating disorder program. *European Eating Disorders Review* **23**(4), 294-303.

Dimitropoulos G., Lackstrom J. & Woodside B. (2007) Couples with eating disorders: a review of the literature. In *Annual review of eating disorders* (Wonderlich S., Mitchell J., de Zwaan M. & Steiger H., eds), Oxford, New York: Raddiffe Publishing, pp. 15-22.

Dixon L. (2000) Reflections on recovery. *Community mental health journal* **36**(4), 443-447.

Downs K.J. & Blow A.J. (2013) A substantive and methodological review of family-based treatment for eating disorders: the last 25 years of research. *Journal of Family Therapy* **35**, 3-28.

Drapeau A., Marchand A. & Beaulieu-Prévost D. (2012) Epidemiology of psychological distress. In *Mental illnesses - Understanding, prediction and control* (L'Abate L., ed), Rijeka, Croatia: InTech, pp. 105-134.

Duffy K., Ferguson C. & Watson H. (2004) Data collecting in grounded theory - some practical issues. *Nurse Researcher* **11**(4), 67-78.

- Eifert E.K., Adams R., Dudley W. & Perko M. (2015) Family caregiver identity: a literature review. *American Journal of Health Education* **46**(6), 357-367.
- Eisler I. (2005) The empirical and theoretical base of family therapy and multiple family day therapy for adolescent anorexia nervosa. *Journal of Family Therapy* **27**(2), 104-131.
- Eisner E. (1992) Introduction to special section on objectivity, subjectivity, and relativism. *Curriculum Inquiry* **22**(1), 5-7.
- Elliott N. & Lazenbatt A. (2005) How to recognise a 'quality' grounded theory research study. *Australian Journal of Advanced Nursing* **22**(3), 48-52.
- Eriksson M. & Svedlund M. (2006) 'The intruder': spouses' narratives about life with a chronically ill partner. *Journal of Clinical Nursing* **15**(3), 324-333.
- Evans L. & Wertheim E.H. (2005) Attachment styles in adult intimate relationships: comparing women with bulimia nervosa symptoms, women with depression and women with no clinical symptoms. *European Eating Disorders Review* **13**(4), 285-293.
- Fadden G., Bebbington P. & Kuipers L. (1987) Caring and its burdens. a study of the spouses of depressed patients. *The British Journal of Psychiatry* **151**(5), 660-667.
- Fairburn C.G. & Cooper P.J. (1982) Self-induced vomiting and bulimia nervosa: an undetected problem. *British Medical Journal (Clinical Research Edition)* **284**(6323), 1153-1155.
- Fairburn C.G., Cooper P.J. & Shafran R. (2008) Enhanced cognitive behavior therapy for eating disorders ("CBT-E"): an overview. In *Cognitive behavior therapy and eating disorders* (Fairburn C.G., ed), New York: Guilford Press.
- Fairburn C.G., Cooper Z., Doll H.A., O'Connor M.E., Palmer R.L. & Dalle Grave R. (2013) Enhanced cognitive behaviour therapy for adults with anorexia nervosa: a UK-Italy study. *Behaviour Research and Therapy* **51**(1), R2-R8.
- Fairburn C.G., Cooper Z. & Shafran R. (2003) Cognitive behaviour therapy for eating disorders: a "transdiagnostic" theory and treatment. *Behaviour Research and Therapy* **41**(5), 509-528.
- Fairburn C.G. & Harrison P.J. (2003) Eating disorders. *The Lancet* **361**(9355), 407-416.
- Farrell C., Shafran R. & Lee M. (2006) Empirically evaluated treatments for body image disturbance: a review. *European Eating Disorders Review* **14**(5), 289-300.
- Fassinger R.E. (2005) Paradigms, praxis, problems, and promise: grounded theory in counseling psychology research. *Journal of Counseling Psychology* **52**(2), 156-166.
- Faulkner P. (2010) Norms of trust. In *Social epistemology* (Haddock A., Millar A. & Pritchard D., eds), New York: Oxford University Press Inc.

Fay B. (1996) *Contemporary philosophy of social science*. Oxford, Mass: Blackwell publishing Ltd.

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), 1-10.

Fehr B., Harasymchuk C. & Sprecher S. (2014) Compassionate love in romantic relationships: a review and some new findings. *Journal of social and personal relationships* **31**(5), 575-600.

Feldman M.B. & Meyer I.H. (2007) Eating disorders in diverse lesbian, gay, and bisexual populations. *International Journal of Eating Disorders* **40**(3), 218-226.

Fichter M.M., Quadflieg N. & Hedlund S. (2006) Twelve-year course and outcome predictors of anorexia nervosa. *International Journal of Eating Disorders* **39**(2), 87-100.

Fichter M.M., Quadflieg N. & Hedlund S. (2008) Long-term course of binge eating disorder and bulimia nervosa: relevance for nosology and diagnostic criteria. *International Journal of Eating Disorders* **41**(7), 577-586.

Fincham F.D. & Bradbury T.N. (1987) Cognitive processes and conflict in close relationships: an attribution-efficacy model. *Journal of Personality and Social Psychology* **53**(6), 1106-1118.

Fincham F.D. & Bradbury T.N. (1992) Assessing attributions in marriage: the relationship attribution measure. *Journal of Personality and Social Psychology* **62**(3), 457-468.

Finkenauer C. & Hazam H. (2000) Disclosure and secrecy in marriage: do both contribute to marital satisfaction? *Journal of social and personal relationships* **17**(2), 245-263.

Finkenauer C., Kerkhof P., Righetti F. & Branje S. (2009) Living together apart: perceived concealment as a signal of exclusion in marital relationships. *Personality and Social Psychology Bulletin* **35**(10), 1410-1422.

Fischer M.S., Baucom D.H., Kirby J.S. & Bulik C.M. (2015) Partner distress in the context of adult anorexia nervosa: the role of patients' perceived negative consequences of AN and partner behaviors. *International Journal of Eating Disorders* **48**(1), 67-71.

Fisher C.A., Hetrick S.E. & Rushford N. (2010) Family therapy for anorexia (review). In *Cochrane database of systematic reviews*, John Wiley & Sons, Ltd.

Fishler P.H., Sperling M.B. & Carr A.C. (1990) Assessment of adult relatedness: a review of empirical findings from object relations and attachment theories. *Journal of Personality Assessment* **55**(3/4), 499-520.

Flanagan L.M. (2011) Object relations theory. In *Inside out and outside in*, 3rd edn. (Berzoff J., Flanagan L.M. & Hertz P., eds), Rowman & Littlefield Publishers, Inc., pp. 118-157.

- Forgas J.P. (2011) Affective influences on self-disclosure: mood effects on the intimacy and reciprocity of disclosing personal information. *Journal of Personality and Social Psychology* **100**(3), 449-461.
- Gamble C. & Brennan G. (2006) Working with families and informal carers. In *Working with serious mental illness: A manual for clinical practice*, 2nd edn. (Gamble C. & Brennan G., eds), Edinburgh: Elsevier.
- Garner D.M. (1993) Pathogenesis of anorexia nervosa. *The Lancet* **341**(8861), 1631-1635.
- Geist R., Heinmaa M., Katzman D. & Stephens D. (1999) A comparison of male and female adolescents referred to an eating disorder program. *Canadian Journal of Psychiatry* **44**(4), 374-378.
- Geller J., Cockell S.J., Hewitt P.L., Goldner E.M. & Flett G.L. (2000) Inhibited expression of negative emotions and interpersonal orientation in anorexia nervosa. *International Journal of Eating Disorders* **28**(1), 8-19.
- Geller J., Williams K.D. & Srikameswaran S. (2001) Clinician stance in the treatment of chronic eating disorders. *European Eating Disorders Review* (9), 365-373.
- Gergen K.J. (1985) The social constructionist movement in modern psychology. *American Psychologist* **40**(3), 266-275.
- Ghezeljeh T.N. & Emami A. (2009) Grounded theory: methodology and philosophical perspective. *Nurse Researcher* **17**(1), 15-23.
- Ghizzani A. & Montomoli M. (2000) Anorexia nervosa and sexuality in women: a review. *Journal of Sex Education & Therapy* **25**(1), 80.
- Gísladóttir M. & Svavarsdóttir E.K. (2011) Educational and support intervention to help families assist in the recovery of relatives with eating disorders. *Journal of Psychiatric and Mental Health Nursing* **18**(2), 122-130.
- Gitlin M. (2003) Sexual dysfunction with psychotropic drugs. *Expert Opinion on Pharmacotherapy* **4**(12), 2259-2269.
- Given L., ed (2008) *The sage encyclopedia of qualitative research methods*. Vol. 1& 2. Los Angeles, London, New Delhi, Singapore: Sage Publications Ltd.
- Glaser B. (1978) *Theoretical sensitivity: advances in the methodology of grounded theory*. Mill Valley, CA: Sociology Press.
- Glaser B. (1992a) *Basics of ground theory analysis*. Mill valley, CA: Sociology Press.
- Glaser B. (1992b) *Emergence vs forcing: basics of grounded theory analysis*. Mill valley, CA: Sociology Press.

- Glaser B. (1998) *Doing grounded theory: issues and discussions*. Mill Valley, CA: Sociology Press.
- Glaser B. (2001) *The grounded theory perspective: conceptualization contrasted with description*. Mill Valley, CA: Sociology Press.
- Glaser B. (2002) Constructivist grounded theory? *Forum: Qualitative Social Research* **3**(3) Art 12.
- Glaser B. (2005a) *The grounded theory perspective 111: theoretical coding*. Mill Valley, CA: Sociology Press.
- Glaser B. (2005b) The impact of symbolic interaction on grounded theory. *Grounded Theory Review* **4**(2), 1-22.
- Glaser B. (2013) Free style memoing. *The Grounded Theory Review* **12**(2).
- Glaser B. & Holton J. (2004) Remodelling grounded theory. *Qualitative Social Research* **5**(2), 1-17.
- Glaser B. & Strauss A. (1965) Discovery of substantive theory: a basic strategy underlying qualitative research. *American Behavioral Scientist* **8**(6), 5-12.
- Glaser B. & Strauss A. (1967) *The discovery of grounded theory: strategies for qualitative research*. New Brunswick, London: AldineTransaction.
- Glaserfeld E.v. (2007) Aspects of constructivism. Vico, Berkeley, Piaget. In *Key works in radical constructivism*, Rotterdam: Sense, pp. 91-99.
- Glauert R., Rhodes G., Byrne S., Fink B. & Grammer K. (2009) Body dissatisfaction and the effects of perceptual exposure on body norms and ideals. *International Journal of Eating Disorders* **42**(5), 443-452.
- Goffman E. (1963) *Stigma*. London: Penguin
- Goffman E. (1969) *The presentation of self in everyday life*. London: Penguin books Ltd.
- Goldberg A. & Rickler K.S. (2011) The role of family caregivers for people with chronic illness. *Medicine & Health Rhode Island* **94**(2), 41-42.
- Golden N.H. & Meyer W. (2004) Nutritional rehabilitation of anorexia nervosa: goals and dangers. *International Journal of Adolescent Medicine and Health* **16**(2), 131-144.
- Goldstein T.R., Miklowitz D.J. & Richards J.A. (2002) Expressed emotion attitudes and individual psychopathology among the relatives of bipolar patients. *Family Process* **41**(4), 645-657.

González N., Padierna A., Martín J., Aguirre U. & Quintana J.M. (2012) Predictors of change in perceived burden among caregivers of patients with eating disorders. *Journal of Affective Disorders* **139**(3), 273-282.

Gorin A.A., Le Grange D. & Stone A.A. (2003) Effectiveness of spouse involvement in cognitive behavioral therapy for binge eating disorder. *International Journal of Eating Disorders* **33**(4), 421-433.

Gottlieb B.H. & Bergen A.E. (2010) Social support concepts and measures. *Journal of Psychosomatic Research* **69**(5), 511-520.

Government of Ireland (2006) Vision for change: report of the expert group on mental health policy. Dublin: Stationary Office.

Government of Ireland (1988, 2003) Data Protection Act. Dublin: Stationary Office.

Government of Ireland (2006) A vision for change, report on the expert group of mental health policy. The Stationary Office, Dublin.

Government of Ireland (2012) The national carers strategy: recognised, supported empowered. Brunswick Press Ltd.

Government of Ireland (2014) Eating disorders.
<http://www.welfare.ie/en/downloads.protocol9.pdf>

Goyal S., Pal Singh Balhara Y. & Khandelwal S.K. (2012) Revisiting classification of eating disorders-toward diagnostic and statistical manual of mental disorders-5 and international statistical classification of diseases and related health problems-11. *Indian Journal of Psychological Medicine* **34**(3), 290-296.

Graap H., Bleich S., Herbst F., Scherzinger C., Trostmann Y., Wancata J. & Zwaan M. (2008a) The needs of carers: a comparison between eating disorders and schizophrenia. *Social Psychiatry and Psychiatric Epidemiology* **43**(10), 800-807.

Graap H., Bleich S., Herbst F., Trostmann Y., Wancata J. & de Zwaan M. (2008b) The needs of carers of patients with anorexia and bulimia nervosa. *European Eating Disorders Review* **16**(1), 21-29.

Graham J.M. (2011) Measuring love in romantic relationships: a meta-analysis. *Journal of social and personal relationships* **28**(6), 748-771.

Griffiths S., Mond J., Murray S., Thornton C. & Touyz S. (2015) Stigma resistance in eating disorders. *Social Psychiatry and Psychiatric Epidemiology* **50**(2), 279-287.

Grix J. (2004) *The foundations of research*. Hamshire, New York: Palgrave Macmillan.

Groff S.E. (2015) Is enhanced cognitive behavioral therapy an effective intervention in eating disorders? A review. *Journal of Evidence-Informed Social Work* **12**(3), 272-288.

Grover S., Chakrabarti S., Sharma A. & Tyagi S. (2014) Attitudes toward psychotropic medications among patients with chronic psychiatric disorders and their family caregivers. *Journal of Neurosciences in Rural Practice* **5**(4), 374-383.

Guba E. (1990) The alternative paradigm dialog. In *The paradigm dialog* (Guba E., ed), Newbury Park, CA: Sage, pp. 17-30.

Guba E. & Lincoln Y. (1994) Competing paradigms in qualitative research. In *Handbook of qualitative research* (Denzin N. & Lincoln Y., eds), Thousand Oaks: Sage

Guba E. & Lincoln Y. (2005) Paradigmatic controversies, contradictions and emerging confluences. In *The sage handbook of qualitative research*, 3rd edn. (Denzin K. & Lincoln Y., eds), Thousand Oaks, London, New Delhi: Sage Publications, pp. 191-215.

Guerrero L.K., Andersen P.A. & Afifi W.A. (2014) *Close encounters: communication in relationships*. 4th edn. Los Angeles, London, New Delhi, Singapore, Washington DC: Sage

Gull W.W. (1874) *Anorexia nervosa (apepesia hysterica, anorexia hysterica)*. Transactions of the Clinical Society of London **vii**, 22.

Haber M.G., Cohen J.L., Lucas T. & Baltes B.B. (2007) The relationship between self-reported received and perceived social support: a meta-analytic review. *American Journal of Community Psychology* **39**(1-2), 133-144.

Haigh R. & Treasure J. (2003) Investigating the needs of carers in the area of eating disorders: development of the Carers' Needs Assessment Measure (CaNAM). *European Eating Disorders Review* **11**(2), 125-141.

Hall H., Griffiths D. & McKenna L. (2013) From Darwin to constructivism: the evolution of grounded theory. *Nurse Researcher* **20**(3), 17-21.

Hall W.A. & Callery P. (2001) Enhancing the rigor of grounded theory: incorporating reflexivity and relationality. *Qualitative Health Research* **11**(2), 257-272.

Halmi K. (1983) Classification of eating disorders. *International Journal of Eating Disorders* **2**(4), 21-26.

Halmi K., Agras S., Crow S., Mitchell J.E., Wilson G., Bryson S. & Kraemer H. (2005) Predictors of treatment acceptance and completion in anorexia nervosa. *Archives of general psychiatry* **62**(7), 776-781.

Halvorsen I., Rø Ø. & Heyerdahl S. (2013) Nine-Year follow-up of girls with anorexia nervosa and their siblings: retrospective perceptions of parental bonding and the Influence of Illness on their everyday life. *European Eating Disorders Review* **21**(1), 20-27.

Hamer S. & Haddad P. (2007) Adverse effects of antipsychotics as outcome measures. *British Journal of Psychiatry* **191**(50), s64-s70.

- Hammersley M. & Atkinson P. (1995) *Ethnography: principles in practice*. London: Routledge.
- Hammersley M. & Traianou A. (2014) Foucault and research ethics: on the autonomy of the researcher. *Qualitative Inquiry* **20**(3), 227-238.
- Harper D. & Speed E. (2012) Uncovering recovery: The resistible rise of recovery and resilience. *Studies in Social Justice* **6**(1), 9-25
- Hartmann A., Zeeck A. & Barrett M.S. (2010) Interpersonal problems in eating disorders. *International Journal of Eating Disorders* **43**(7), 619-627.
- Hatfield E. & Walster W.G. (1978) *A new look at love: a revealing report on the most elusive of all emotions*. Boston, London: University Press of America Inc.
- Haverkamp B.E. (2005) Ethical perspectives on qualitative research in applied psychology. *Journal of Counseling Psychology* **52**(2), 146-155.
- Heap J. (1995) Constructionism in the rhetoric and practice of fourth generation evaluation. *Evaluation and programme planning* **18**(1), 51-61.
- Heath H. & Cowley S. (2004) Developing a grounded theory approach: a comparison of Glaser and Strauss. *International Journal of Nursing Studies* **41**(2), 141-150.
- Hegi K.E. & Bergner R.M. (2010) What is love? An empirically-based essentialist account. *Journal of social and personal relationships* **27**(5), 620-636.
- Health Service Executive (2012) National clinical programme for mental health. Dublin: Health Services Executive.
- Henderson J. (2001) 'He's not my carer—he's my husband': personal and policy constructions of care in mental health. *Journal of Social Work Practice* **15**(2), 149-159.
- Hernandez C.A. (2009) Theoretical coding in grounded theory methodology. *Grounded Theory Review* **8**(3), 51-60.
- Heru A.M. (2000) Family functioning, burden, and reward in the caregiving for chronic mental illness. *Families, Systems, & Health* **18**(1), 91-103.
- Hesse-Biber S., Leavy P., Quinn C.E. & Zoino J. (2006) The mass marketing of disordered eating and eating disorders: the social psychology of women, thinness and culture. *Women's Studies International Forum* **29**(2), 208-224.
- Higgins A. (2008) *A recovery approach within the Irish Mental Health services: a framework for development*. Dublin: Mental Health Commission.
- Higgins A., Barker P. & Begley C.M. (2008) 'Veiling sexualities': a grounded theory of mental health nurses responses to issues of sexuality. *Journal of Advanced Nursing* **62**(3), 307-317.

Higgins A., Breen M., Boyd F., Hevey D., Sharek D. & McBennett P. (2012a) *Eolas Project: the design, delivery and evaluation of a peer and clinician led information programme on recovery and mental health difficulties for users of services and family members*. Trinity College Dublin

Higgins A., Callaghan P., deVries J., Keogh B., Morrissey J., Nash M., Ryan D., Gijbels H. & Carter T. (2012b) Evaluation of mental health recovery and Wellness Recovery Action Planning education in Ireland: a mixed methods pre–postevaluation. *Journal of Advanced Nursing* **68**(11), 2418-2428.

Higgins A. & McGowan P. (2014) Recovery and the recovery ethos: challenges and possibilities. In *Mental health in Ireland; Policy practice and law* (Higgins A. & McDaid S., eds), Dublin: Gill & Mcmillan, pp. 61-78.

Hight N., Thompson M. & King R. (2005) The experience of living with a person with an eating disorder: the impact on the carers. *Eating disorders* **13**(4), 327-344.

Hill W.G. & Donatelle R.J. (2005) The impact of gender role conflict on multidimensional social support in older men. *International Journal of Men's Health* **4**(3), 267.

Hillege S., Beale B. & McMaster R. (2006) Impact of eating disorders on family life: individual parents' stories. *Journal of Clinical Nursing* **15**(8), 1016-1022.

Hinchliff S. & Gott M. (2004) Intimacy, commitment, and adaptation: sexual relationships within long-term marriages. *Journal of social and personal relationships* **21**(5), 595-609.

Hogg M.A. & Reid S.A. (2006) Social identity, self-categorization, and the communication of group norms. *Communication Theory* **16**(1), 7-30.

Holloway I. & Wheeler S. (2010) *Qualitative research in nursing and healthcare*. 2nd edn. UK: John Wiley & Sons Ltd.

Holmqvist K. & Frisé A. (2010) Body dissatisfaction across cultures: findings and research problems. *European Eating Disorders Review* **18**(2), 133-146.

Holt A. & Lyness K.P. (2007) Body image and sexual satisfaction: implications for couple therapy. *Journal of Couple & Relationship Therapy* **6**(3), 45-68.

Holton J. (2007) The coding process and its challenges. In *The Sage handbook of Grounded Theory* (Bryant A. & Charmaz K., eds), Los Angeles, London, New Delhi, Singapore: Sage Publications, pp. 265-290.

Holton J. (2008) Grounded theory as a general research methodology. *The Grounded Theory Review* **7**(2), 67-93.

Holton J. (2009) Qualitative tussles in undertaking a grounded theory study. *Grounded Theory Review* **8**(3), 37-49.

- Hope K.W. & Waterman H.A. (2003) Praiseworthy pragmatism? Validity and action research. *Journal of Advanced Nursing* **44**(2), 120-127.
- Horwitz A.V. (2007) Distinguishing distress from disorder as psychological outcomes of stressful social arrangements. *Health:* **11**(3), 273-289.
- Hoste R.R. & le Grange D. (2008) Expressed emotion among white and ethnic minority families of adolescents with bulimia nervosa. *European Eating Disorders Review* **16**(5), 395-400.
- Houghton C.E., Casey D., Shaw D. & Murphy K. (2010) Ethical challenges in qualitative research: examples from practice. *Nurse Researcher* **18**(1), 15-25.
- Hsu L.K.G., Crisp A.H. & Callender J.S. (1992) Recovery in anorexia nervosa-The patient's perspective. *International Journal of Eating Disorders* **11**(4), 341-350.
- Hua Liu C. & Matthews R. (2005) Vygotsky's philosophy: constructivism and its criticisms examined. *International education journal* **6**(3), 386-399.
- Hudson J.I., Hiripi E., Pope Jr H.G. & Kessler R.C. (2007) The prevalence and correlates of eating disorders in the national comorbidity survey replication. *Biological Psychiatry* **61**(3), 348-358.
- Hughes N., Locock L. & Ziebland S. (2013) Personal identity and the role of 'carer' among relatives and friends of people with multiple sclerosis. *Social Science & Medicine* **96**, 78-85.
- Huke K. & Slade P. (2006) An exploratory investigation of the experiences of partners living with people who have bulimia nervosa. *European Eating Disorders Review* **14**(6), 436-447.
- Hur M.H. (2006) Empowerment in terms of theoretical perspectives: exploring a typology of the process and components across disciplines. *Journal of Community Psychology* **34**(5), 523-540.
- Imber-Black E. (2014) Will talking about it make it worse? Facilitating family conversations in the context of chronic and life-shortening illness. *Journal of Family Nursing* **20**(2), 151-163.
- Jarman M. & Walsh S. (1999) Evaluating recovery from anorexia nervosa and bulimia nervosa: integrating lessons learned from research and clinical practice. *Clinical Psychology Review* **19**(7), 773-788.
- Jeon Y.-H. (2004) The application of grounded theory and symbolic interactionism. *Scandinavian Journal of Caring Sciences* **18**(3), 249-256.
- Jones S. (1985) Depth interviewing. In *Applied qualitative research* (Walker R., ed), England, USA: Gower Publishing Company Ltd.
- Jootun D., McGhee G. & Marland G.R. (2009) Reflexivity: promoting rigour in qualitative research. *Nursing Standard* **23**(23), 42-46.

Jungbauer J., Wittmund B., Dietrich S. & Angermeyer M.C. (2004) The disregarded caregivers: subjective burden in spouses of schizophrenia patients. *Schizophrenia Bulletin* **30**(3), 665-675.

Kadish Y.A. (2012) The role of culture in eating disorders. *British Journal of Psychotherapy* **28**(4), 435-453.

Kaplan A. (1964) *The conduct of inquiry: methodology for behavioural science*. San Francisco: Chandler Publications Co.

Kaplan A.S. & Strasburg K. (2009) Chronic eating disorders. *Psychiatric Times* **26**(8), 31-34.

Karraker A. & DeLamater J. (2013) Past-year sexual inactivity among older married persons and their partners. *Journal of Marriage and Family* **75**(1), 142-163.

Katzman M.A. & Lee S. (1997) Beyond body image: the integration of feminist and transcultural theories in the understanding of self starvation. *The International Journal Of Eating Disorders* **22**(4), 385-394.

Kautz D.D. (2007) Hope for love: practical advice for intimacy and sex after stroke. *Rehabilitation Nursing* **32**(3), 95-103.

Kaye W.H., Frank G.K., Bailer U.F. & Henry S.E. (2005) Neurobiology of anorexia nervosa: clinical implications of alterations of the function of serotonin and other neuronal systems. *International Journal of Eating Disorders* **37**, 15-19.

Kaye W.H., Klump K.L., Frank G.K.W. & Strober M. (2000) Anorexia and bulimia nervosa. *Annual Review of Medicine* **51**(1), 299.

Keel P.K. & Brown T.A. (2010) Update on course and outcome in eating disorders. *International Journal of Eating Disorders* **43**(3), 195-204.

Kelley H. (1983) Love and commitment. In *Close relationships* (Kelley H., Berscheid E., Christensen A., Harvey J., Huston T., Levinger G., McClintock E., Peplau L. & Peterson D., eds), New York: W.H. Freeman and Company, pp. 265-314.

Kelley H., Berscheid E., Christensen A., Harvey J., Huston T., Levinger G., McClintock E., Peplau L. & Peterson D. (1983) Analysing close relationships. In *Close relationships*, New York: W.H. Freeman and Company.

Kelley H. & Thibaut J. (1978) *Interpersonal relations: a theory of interdependence*. New York, Chichester, Brisbane, Toronto: John Wiley & Sons.

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**(S1), S80-S86.

Kjelsås E., Bjørnstrøm C. & Gøttestam K.G. (2004) Prevalence of eating disorders in female and male adolescents (14–15 years). *Eating Behaviors* **5**(1), 13-25.

- Klump K.L., Bulik C.M., Kaye W.H., Treasure J. & Tyson E. (2009) Academy for eating disorders position paper: eating disorders are serious mental illnesses. *International Journal of Eating Disorders* **42**(2), 97-103.
- Knobloch L.K. & Solomon D.H. (2002) Intimacy and the magnitude and experience of episodic relational uncertainty within romantic relationships. *Personal Relationships* **9**(4), 457-478.
- Knobloch L.K. & Solomon D.H. (2004) Interference and facilitation from partners in the development of interdependence within romantic relationships. *Personal Relationships* **11**(1), 115-130.
- Krefting (1991) Rigor in qualitative research: the assessment of trustworthiness. *The Journal of American Occupational Therapy* **45**(3), 241-222.
- Kvale S. & Brinkmann S. (2009) *Interviews: learning the craft of qualitative research interviewing*. 2nd edn. London, New Delhi, Singapore, Thousand Oaks: Sage Publications.
- Kylmä J. (2005) Hope despair and hopelessness in significant others of adult persons living with HIV. *Journal of Theory Construction and Testing* **9**(2), 49-54.
- Kyriacou O., Treasure J. & Schmidt U. (2008a) Expressed emotion in eating disorders assessed via self-report: an examination of factors associated with expressed emotion in carers of people with anorexia nervosa in comparison to control families. *International Journal of Eating Disorders* **41**(1), 37-46.
- Kyriacou O., Treasure J. & Schmidt U. (2008b) Understanding how parents cope with living with someone with anorexia nervosa: modelling the factors that are associated with carer distress. *International Journal of Eating Disorders* **41**(3), 233-242.
- Lahey B. & Cohen S. (2000) Social support theory and measurement. In *Social support measurement and intervention: A guide for health and social scientists* (Cohen S., Underwood L. & Gottlieb B., eds), Oxford, New York: Oxford University Press pp. 29-52.
- Laliberte-Rudman D. & Moll S. (2001) In-depth interviewing. In *Qualitative research in occupational therapy: Strategies and experiences* (Cook J., V., ed), Australia, Albany NY: Delmar Thomson Learning.
- Larson J.E. & Corrigan P.W. (2008) The stigma of families with mental illness *Academic Psychiatry* **32**, 87-91.
- Laurenceau J.-P., Barrett L.F. & Pietromonaco P.R. (1998) Intimacy as an interpersonal process: the importance of self-disclosure, partner disclosure, and perceived partner responsiveness in interpersonal exchanges. *Journal of Personality and Social Psychology* **74**(5), 1238-1251.

Lawrence E., Bunde M., Barry R.A., Brock R.L., Sullivan K.T., Pasch L.A., White G.A., Dowd C.E. & Adams E.E. (2008) Partner support and marital satisfaction: support amount, adequacy, provision, and solicitation. *Personal Relationships* **15**(4), 445-463.

Leamy M., Bird V., Le Boutillier C., Williams J. & Slade M. (2011) Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *The British Journal of Psychiatry* **199**(6), 445-452.

Leichner P.P., Harper D.W. & Johnston D.M. (1985) Adjunctive group support for spouses of women with anorexia nervosa and/or bulimia. *International Journal of Eating Disorders* **4**(2), 227-235.

Lektorskii V.A. (2010) Realism, antirealism, constructivism, and constructive realism in contemporary epistemology and science. *Journal of Russian & East European Psychology* **48**(6), 5-44.

Lelwica M.M. (1999) *Starving for salvation*. London: Oxford University Press.

Lemay E.P., Jr. & Melville M.C. (2014) Diminishing self-disclosure to maintain security in partners' care. *Journal of Personality and Social Psychology* **106**(1), 37-57.

Lempert L. (2007) Asking questions of the data: memo writing in the grounded theory tradition. In *The sage handbook of grounded theory* (Bryant A. & Charmaz K., eds), Sage, Los Angeles, London, New Delhi, Singapore pp. 245-264.

Levant R.F., Good G.E., Cook S.W., O'Neil J.M., Smalley K.B., Owen K. & Richmond K. (2006) The normative male alexithymia scale: measurement of a gender-linked syndrome. *Psychology of Men & Masculinity* **7**(4), 212-224.

Levers M.-J. (2013) Philosophical paradigms, grounded theory, and perspectives on emergence. *Sage Open* **3**(4), 1-6.

Levine M.P. & Piran N. (2004) The role of body image in the prevention of eating disorders. *Body Image* **1**(1), 57-70.

Levkovitz V., Fennig S., Horesh N., Barak V. & Treves I. (2000) Perception of ill spouse and dyadic relationship in couples with affective disorder and those without. *Journal of Affective Disorders* **58**(3), 237-240.

Licqurish S. & Seibold C. (2011) Applying a contemporary grounded theory methodology. *Nurse Researcher* **18**(4), 11-16.

Lilenfeld L.R., Kaye W.H., Greeno C.G., Merikangas K.R., Plotnicov K.H., Pollice C., Rao R., Strober M., Bulik C.M. & Nagy L. (1998) A controlled family study of anorexia nervosa and bulimia nervosa: psychiatric disorders in first-degree relatives and effects of proband comorbidity *Archives of general psychiatry* **55**, 603-610.

Lincoln Y. & Guba E. (2003) Ethics: the failure of positivist science. In *Turning points in qualitative research: tying knots in a handkerchief* (Lincoln Y. & Denzin K., eds), CA: Alta Mira Press, pp. 219-238.

Linville D., Cobb E., Shen F. & Stadelman S. (2016) Reciprocal influence of couple dynamics and eating disorders. *Journal of Marital and Family Therapy* **42**(2) 326-340.

Linville D. & Oleksak N. (2013) Integrated eating disorder treatment for couples. *Journal of Couple & Relationship Therapy* **12**(3), 255-269.

Lock J., Le Grange D., Agras S. & Dare C. (2005) *Treatment manual for anorexia nervosa: a family based approach*. New York: Guildford Publications Inc.

Lock J., Reisel B. & Steiner H. (2001) Associated health risks of adolescents with disordered eating: how different are they from their peers? Results from a high school survey. *Child Psychiatry & Human Development* **31**(3), 249-265.

Lomborg K. & Kirkevold M. (2003) Truth and validity in grounded theory – a reconsidered realist interpretation of the criteria: fit, work, relevance and modifiability. *Nursing Philosophy* **4**(3), 189-200.

Lundgren J.D., Danoff-Burg S. & Anderson D.A. (2004) Cognitive-behavioral therapy for bulimia nervosa: an empirical analysis of clinical significance. *International Journal of Eating Disorders* **35**(3), 262-274.

Machado P.P.P., Gonçalves S. & Hoek H.W. (2012) DSM-5 reduces the proportion of ednos cases: evidence from community samples. *International Journal of Eating Disorders* **46**(1), 60-65

Machin K. & Repper J. (2013) *Recovery: a carer's perspective*. Implementing Recovery through Organisational Change (ImROC). www.imroc.org › Resources

Madill A. (2008) Realism. In *The Sage encyclopedia of qualitative research methods*, Vol. 1&2 (Given L., ed), California, London, Delhi, Singapore: Sage Publications Inc.

Madill A., Jordan A. & Shirley C. (2000) Objectivity and reliability in qualitative analysis: realist, contextualist and radical. *British Journal of Psychology* **91**(1), 1.

Magaletta P.R. & Oliver J.M. (1999) The hope construct, will, and ways: their relations with self-efficacy, optimism, and general well-being. *Journal of Clinical Psychology* **55**(5), 539-551.

Mahr F., Farahmand P., Bixler E.O., Domen R.E., Moser E.M., Nadeem T., Levine R.L. & Halmi K.A. (2015) A national survey of eating disorder training. *International Journal of Eating Disorders* **48**(4), 443-445.

Manderson L. & Smith-Morris L. (2010) Introduction: chronicity and the experience of illness. In *Chronic conditions, fluid states: Chronicity and the anthropology of illness*

(Manderson L. & Smith-Morris C., eds), New Brunswick, New Jersey, London: Rutgers University Press.

Mantzoukas S. (2004) Issues of representation within qualitative inquiry. *Qualitative Health Research* **14**(7), 994-1007.

Markey C.N., Markey P., M & Birch L.L. (2004) Understanding women's body satisfaction: the role of husbands. *Sex Roles* **51**(3/4), 209-216.

Martín J., Padierna A., Aguirre U., Quintana J.M., Hayas C.L. & Muñoz P. (2011) Quality of life among caregivers of patients with eating disorders. *Quality of Life Research* **20**(9), 1359-1369.

Maurin J.T. & Boyd C.B. (1990) Burden of mental illness on the family: a critical review. *Archives of Psychiatric Nursing* **4**(2), 99-107.

Maxwell M., Thornton L.M., Root T.L., Pinheiro A.P., Strober M., Brandt H., Crawford S., Crow S., Fichter M.M., Halmi K.A., Johnson C., Kaplan A.S., Keel P., Klump K.L., LaVia M., Mitchell J.E., Plotnicov K., Rotondo A., Woodside D.B. & Berrettini W.H. (2011) Life beyond the eating disorder: education, relationships, and reproduction. *International Journal of Eating Disorders* **44**(3), 225-232.

Mayes C. (2014) Medicalization of eating and feeding. In *Encyclopedia of food and agricultural ethics* (Thompson P.B. & Kaplan D.M., eds), Netherlands; Springer, pp. 1371-1378.

McCallin A.M. (2003) Designing a grounded theory study: some practicalities. *Nursing in Critical Care* **8**(5), 203-208.

McDaid S. (2013a) Mental health in primary care in Ireland: a briefing paper. Mental Health Reform, Dublin.

McDaid S. (2013b) Recovery: what you should expect from a good quality mental health service. Mental Health Reform, Dublin.

McDaid S. & Higgins A. (2014) The paradoxical role of families in mental health. Mental health in Ireland: Policy, practice and law. Gill & Macmillan, Dublin.

McFarlane T., Olmsted M.P. & Trottier K. (2008) Timing and prediction of relapse in a transdiagnostic eating disorder sample. *International Journal of Eating Disorders* **41**(7), 587-593.

McKeown M., Malihi-Shoja L., Hogarth R., Jones F., Holt K., Sullivan P., Lunt J., Vella J., Hough G., Rawcliffe L. & Mather M. (2012) The value of involvement from the perspective of service users and carers engaged in practitioner education: not just a cash nexus. *Nurse Education Today* **32**(2), 178-184.

Mehler P.S., Crews C. & Weiner K. (2004) Bulimia: medical complications. *Journal of Women's Health (15409996)* **13**(6), 668-675.

- Mehler P.S. & Krantz M. (2003) Anorexia nervosa medical issues. *Journal of Women's Health (15409996)* **12**(4), 331.
- Meng X. & D'Arcy C. (2015) Comorbidity between lifetime eating problems and mood and anxiety disorders: results from the Canadian community health survey of mental health and well-being. *European Eating Disorders Review* **23**(2), 156-162.
- Mental Health Commission (2005) A vision for a recovery model in Irish Mental Health Services: Discussion paper. Dublin: Mental Health Commission.
- Mental Health Commission (2008) A recovery approach within the Irish mental health services: a framework for development. Dublin: Mental Health Commission.
- Mental Health Reform (2015) A vision for change: nine years on. A coalition analysis of progress.
- Meyer C., Leung N., Barry L. & De Feo D. (2010) Emotion and eating psychopathology: links with attitudes toward emotional expression among young women. *International Journal of Eating Disorders* **43**(2), 187-189.
- Mikulincer M. & Nachshon O. (1991) Attachment styles and patterns of self-disclosure. *Journal of Personality and Social Psychology* **61**(2), 321-331.
- Milhausen R.R., Buchholz A.C., Opperman E.A. & Benson L.E. (2015) Relationship between body image, body composition, sexual functioning and sexual satisfaction among heterosexual young adults. *Archives of sexual behaviour* **44**(6), 1621-1633.
- Miller M.N. & Pumariega A.J. (2001) Culture and eating disorders. *Psychiatry* **64**, 93-110.
- Miller P. (2008) Objectivity. In *The sage encyclopedia of qualitative research methods*, Vol. 1&2 (Given L., ed), California, London, New Delhi, Singapore: Sage Publications, Inc.
- Miller R.S. (2012) *Intimate relationships*. 6th edn. New York: McGraw-Hill.
- Milliken P.J. & Schreiber R. (2012) Examining the nexus between grounded theory and symbolic interactionism. *International Journal of Qualitative Methods* **11**(5), 684-696.
- Mills J., Chapman Y., Bonner A. & Francis K. (2007) Grounded theory: a methodological spiral from positivism to postmodernism. *Journal of Advanced Nursing* **58**(1), 72-79.
- Mills J., Clark M.S., Ford T.E. & Johnson M. (2004) Measurement of communal strength. *Personal Relationships* **11**(2), 213-230.
- Minuchin S., Rosman B., L. & Baker L. (1978) *Psychosomatic families: anorexia nervosa in context*. Cambridge, Massachusetts, London: Harvard University Press
- Mitchell J.E., Roerig J. & Steffen K. (2013) Biological therapies for eating disorders. *International Journal of Eating Disorders* **46**(5), 470-477.

- Moncrieff J., Cohen D. & Porter S. (2013) The psychoactive effects of psychiatric medication: the elephant in the room. *Journal of psychoactive drugs* **45**(5), 409-415.
- Monin J.K., Clark M.S. & Lemay E.P. (2008) Communal responsiveness in relationships with female versus male family members. *Sex Roles* **59**(3/4), 176-188.
- Montagnese C., Scalfi L., Signorini A., De Filippo E., Pasanisi F. & Contaldo F. (2007) Cholinesterase and other serum liver enzymes in underweight outpatients with eating disorders. *International Journal of Eating Disorders* **40**(8), 746-750.
- Montgomery P. & Bailey P.H. (2007) Field notes and theoretical memos in grounded theory. *Western Journal of Nursing Research* **29**(1), 65-79.
- Moor J. (1990) The ethics of privacy protection. *Library Trends* **39**(1&2).
- Morais M.B.L. (2002) Eating disorders: a bond between medicine, culture and psychoanalysis. *International Forum of Psychoanalysis* **11**(2), 135-140.
- Morgan A. & Jones D. (2009) Perceptions of service user and carer involvement in healthcare education and impact on students' knowledge and practice: a literature review. *Medical Teacher* **31**(2), 82-95.
- Morrow S.L. (2007) Qualitative research in counselling psychology: conceptual foundations. *The Counseling Psychologist* **35**(2), 209-235.
- Morse J. (2001) Going in blind. *Qualitative Health Research* **4**(1), 3-5.
- Morse J.M. (2015) Critical analysis of strategies for determining rigor in qualitative inquiry. *Qualitative Health Research* **25**(9), 1212-1222.
- 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), 1-19.
- Morse J.M. & Singleton J. (2001) Exploring the technical aspects of "fit" in qualitative research. *Qualitative Health Research* **11**(6), 841-847.
- Morton R. (1720) *Phthisiologia: or, a treatise of consumptions*. London: W. and J. Innys.
- Murphy N. (1990) Scientific realism and postmodern philosophy. *The British Journal for the Philosophy of Science* **41**(3), 291-303.
- Nakazato M., Tchanturia K., Schmidt U., Campbell L., Treasure J., Collier D., Hashimoto K. & Iyo M. (2009) Brain-derived neurotrophic factor (BDNF) and set-shifting in currently ill and recovered anorexia nervosa (AN) patients. *Psychological Medicine* **39**, 1029-1035.

- National Institute for Health and Clinical Excellence (2004) Eating Disorders: core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders. CG9. London: National Institute for Health and Clinical Excellence.
- Newton M., Boblin S., Brown B. & Ciliska D. (2005) 'An engagement–distancing flux': bringing a voice to experiences with romantic relationships for women with anorexia nervosa. *European Eating Disorders Review* **13**(5), 317-329.
- Newton M., Boblin S., Brown B. & Ciliska D. (2006) Understanding intimacy for women with anorexia nervosa: a phenomenological approach. *European Eating Disorders Review* **14**(1), 43-53.
- Noordenbos G., Jacobs M. & Hertzberger E. (1998) Chronic eating disorders: the patients' view of their treatment history. *Eating disorders* **6**, 217-223.
- Noordenbos G., Oldenhave A., Muschter J. & Terpstra N. (2002) Characteristics and treatment of patients with chronic eating disorders. *Eating disorders* **10**(1), 15-29.
- Noordenbos G. & Seubring A. (2006) Criteria for recovery from eating disorders according to patients and therapists. *Eating disorders* **14**(1), 41-54.
- Nordbø R.H.S., Espeset E.M.S., Gulliksen K.S., Skårderud F. & Holte A. (2006) The meaning of self-starvation: qualitative study of patients' perception of anorexia nervosa. *International Journal of Eating Disorders* **39**(7), 556-564.
- Norton L. (1999) The philosophical bases of grounded theory and their implications for research practice. *Nurse Researcher* **7**(1), 31-31.
- Nursing and Midwifery Board of Ireland (2015) Ethical conduct in research: professional guidance Dublin: Nursing and midwifery Board of Ireland.
- O'Connor D.L. (2007) Self-identifying as a caregiver: exploring the positioning process. *Journal of Aging Studies* **21**(2), 165-174.
- O'Dwyer S., Moyle W. & van Wyk S. (2013) Suicidal ideation and resilience in family carers of people with dementia: a pilot qualitative study. *Aging & Mental Health* **17**(6), 753-760.
- O'Grady C.P. & Skinner W.J.W. (2012) Journey as destination: a recovery model for families affected by concurrent disorders. *Qualitative Health Research* **22**(8), 1047-1062.
- O'Reilly M. & Parker N. (2013) 'Unsatisfactory saturation': a critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative Research* **13**(2), 190-197.
- Oberlin V.K. (2013) Eating disorder recovery: understanding the change process from the stories told by those who experienced it. Department of psychology, Vol. PhD. Trinity College, Dublin.

Oliver P. (2010) *The student's guide to research ethics*. 2nd edn. England: Open University Press.

Oluyori T. (2013) A systematic review of qualitative studies on shame, guilt and eating disorders. *Counselling Psychology Review* **28**(4), 47-59.

Oman D. (2011) Compassionate love: accomplishments and challenges in an emerging scientific/spiritual research field. *Mental Health, Religion & Culture* **14**(9), 945-981.

Omarzu J. (2000) A disclosure decision model: determining how and when individuals will self-disclose. *Personality & Social Psychology Review* **4**(2), 174-185.

Orbach S. (1993) *Hunger strike*. 2nd edn. Penguin books, New York, London.

Overall N.C., Fletcher G.J.O., Simpson J.A. & Sibley C.G. (2009) Regulating partners in intimate relationships: the costs and benefits of different communication strategies. *Journal of Personality and Social Psychology* **96**(3), 620-639.

Oyamot C.M., Fuglestad P.T. & Snyder M. (2010) Balance of power and influence in relationships: the role of self-monitoring. *Journal of social and personal relationships* **27**(1), 23-46.

Padierna A., Martin J., Aguirre U., Gonzalez N., Munoz P. & Quintana J. (2013) Burden of caregiving amongst family caregivers of patients with eating disorders. *Social Psychiatry & Psychiatric Epidemiology* **48**, 151-161.

Parry-Jones B. & Parry-Jones W.L. (1991) Bulimia: an archival review of its history in psychosomatic medicine. *International Journal of Eating Disorders* **10**(2), 129-143.

Parton N. (2003) Rethinking professional practice: the contributions of social constructionism and the feminist 'ethics of care'. *British Journal of Social Work* **33**(1), 1-16.

Pearlin L.I., Menaghan E.G., Lieberman M.A. & Mullan J.T. (1981) The stress process. *Journal of Health and Social Behavior* **22**(4), 337-356.

Perkins S., Winn S., Murray J., Murphy R. & Schmidt U. (2004) A qualitative study of the experience of caring for a person with bulimia nervosa. Part 1: the emotional impact of caring. *International Journal of Eating Disorders* **36**(3), 256-268.

Peterson C.B., Crow S.J., Swanson S.A., Crosby R.D., Wonderlich S.A., Mitchell J.E., Agras W.S. & Halmi K.A. (2011) Examining the stability of DSM-IV and empirically derived eating disorder classification: implications for DSM-5. *Journal of Consulting and Clinical Psychology* **79**(6), 777-783.

Pettersen G. & Rosenvinge J.H. (2002) Improvement and recovery from eating disorders: a patient perspective. *Eating disorders: The journal of treatment and prevention* **10**(1), 61-71.

- Pettersen G., Thune-Larsen K.-B. & Rosenvinge J.H. (2012) Recovery from eating disorders: psychometric properties of a patient-related measure. *Patient Related Outcome Measures* **3**, 85-93.
- Phillips D.C. (1995) The good, the bad and the ugly: the many faces of constructivism. *Educational Researcher* **24**(7), 5-12.
- Piaget J. (1971) The theory of stages in cognitive development. In *Measurement and Piaget* (Green D.R., Ford M.P. & Flamer G.B., eds), New York: McGraw-Hill.
- Pimenta A.M., Sánchez-Villegas A., Bes-Rastrollo M., López C.N. & Martínez-González M.Á. (2009) Relationship between body image disturbance and incidence of depression: the SUN prospective cohort. *BMC Public Health* **9**, 1-9.
- Pinheiro A.P., Raney T.J., Thornton L.M., Fichter M.M., Berrettini W.H., Goldman D., Halmi K.A., Kaplan A.S., Strober M., Treasure J., Woodside D.B., Kaye W.H. & Bulik C.M. (2010) Sexual functioning in women with eating disorders. *International Journal of Eating Disorders* **43**, 123-129.
- Pole M., Crowther J.H. & Schell J. (2004) Body dissatisfaction in married women: the role of spousal influence and marital communication patterns. *Body Image* **1**(3), 267-278.
- Polivy J. & Herman C.P. (2002) Causes of eating disorders. *Annual Review of Psychology* **53**, 187-213.
- Popper K.R. (1959) *The logic of scientific discovery*. New York: Basic Books.
- Posavac S.S. & Posavac H.D. (2002) Predictors of women's concern with body weight: the roles of perceived self-media ideal discrepancies and self-esteem. *Eating disorders* **10**(2), 153-160.
- Prager K.J. (1995) *The psychology of intimacy*. New York: Guilford Press.
- Prager K.J. (2014) *The dilemmas of intimacy: conceptualisation, assessment and treatment*. New York, London: Routledge.
- Presnell K., Bearman S.K. & Stice E. (2004) Risk factors for body dissatisfaction in adolescent boys and girls: a prospective study. *International Journal of Eating Disorders* **36**(4), 389-401.
- Pressler C. & Dasilva F. (1996) *Sociology and interpretation: from Webber to Habermas*. Albany: State University of New York Press.
- Pruitt J.A., Kappius R.E. & Gorman P.W. (1992) Bulimia and fear of intimacy. *Journal of Clinical Psychology* **48**(4), 472-476.
- Pujols Y., Meston C.M. & Seal B.N. (2010) The association between sexual satisfaction and body image in women. *Journal of Sexual Medicine* **7**(2), 905-916.

QSR International Pty Ltd (2012) *NVivo 10*. Doncaster, Victoria: International Pty Ltd.

Raenker S., Hibbs R., Goddard E., Naumann U., Arcelus J., Ayton A., Bamford B., Boughton N., Connan F., Goss K., Lazlo B., Morgan J., Moore K., Robertson D., Schreiber-Kounine C., Sharma S., Whitehead L., Beecham J., Schmidt U. & Treasure J. (2012) Caregiving and coping in carers of people with anorexia nervosa admitted for intensive hospital care. *International Journal of Eating Disorders* **46**(4) 346-354

Räsänen U. & Hunt K. (2014) The role of gendered constructions of eating disorders in delayed help-seeking in men: a qualitative interview study. *BMJ Open* **4**(4). doi:10.1136/bmjopen-2013-004342

Ramon S., Healy B. & Renouf N. (2007) Recovery from mental illness as an emergent concept and practice in Australia and the UK. *International Journal of Social Psychiatry* **53**(2), 108-122.

Raphael F.J. & Lacey J.H. (1994) The aetiology of eating disorders: a hypothesis of the interplay between social, cultural and biological factors. *European Eating Disorders Review* **2**(3), 143-154.

Raskin J.D. (2001) On relativism in constructivist psychology. *Journal of Constructivist Psychology* **14**(4), 285-313.

Raskin J.D. (2008) The evolution of constructivism. *Journal of Constructivist Psychology* **21**(1), 1-24.

Ratner C. (2008) Objectivism. In *The sage encyclopedia of qualitative research methods*, Vol. 1&2 (Given L., ed), California, London, New Delhi, Singapore: Sage Publications Inc.

Rauer A.J., Sabey A. & Jensen J.F. (2014) Growing old together: compassionate love and health in older adulthood. *Journal of social and personal relationships* **31**(5), 677-696.

Recovery In The Bin (2014). Retrieved from <http://recoveryinthebin.org>

Regan P.C. (2006) Love. In *Sex and sexuality. Vol 2 Sexual function and dysfunction* (McAnulty R.d. & Burnette M., eds), Westport, CT; Praeger, pp. 87-113.

Reis H.T., Maniaci M.R. & Rogge R.D. (2014) The expression of compassionate love in everyday compassionate acts. *Journal of social and personal relationships* **31**(5), 651-676.

Reupert A., Maybery D., Cox M. & Scott Stokes E. (2015) Place of family in recovery models for those with a mental illness. *International Journal of Mental Health Nursing* **24**(6), 495-506.

Ribeiro O., Paúl C. & Nogueira C. (2007) Real men, real husbands: caregiving and masculinities in later life. *Journal of Aging Studies* **21**(4), 302-313.

Røijen S. (2000) Eating disorders and family therapy: why, how and when? *Eating and Weight Disorders - Studies on Anorexia, Bulimia and Obesity* **5**(1), 16-23.

- Rolfe G. (2006a) Judgements without rules: towards a postmodern ironist concept of research validity. *Nursing Inquiry* **13**(1), 7-15.
- Rolfe G. (2006b) Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Journal of Advanced Nursing* **53**(3), 304-310.
- Rolland J.S. (1994) In sickness and in health: the impact of illness on couples' relationships. *part of a special section on: Illness, health and family therapy* **20**, 327-347.
- Rose D. (2014) The mainstreaming of recovery. *Journal of Mental Health* **23**(5), 217-218
- Rosenblatt P.C. & Wieling E. (2013) *Knowing and not knowing in intimate relationships*. United Kingdom: Cambridge University Press.
- Rössler W. (2013) What is normal? The impact of psychiatric classification on mental health practice and research. *Frontiers in Public Health* **1**.
- Rubin H. & Rubin I. (2005) *Qualitative interviewing: the art of hearing data*. 2nd edn. London, New Delhi, Thousand Oaks: Sage Publications.
- Russell G. (1979) Bulimia nervosa: an ominous variant of anorexia nervosa. *Psychol Med* **9**(3), 429-448.
- Ryan M.R., Patrick H., Deci E.L. & Williams G.C. (2008) Facilitating health behaviour change and its maintenance: interventions based on self-determination theory. *The European Health Psychologist* **10**, 2-5.
- Saito H., Nomura K., Hotta M. & Takano K. (2007) Malnutrition induces dissociated changes in lymphocyte count and subset proportion in patients with anorexia nervosa. *International Journal of Eating Disorders* **40**(6), 575-579.
- Sandelowski M.R.N.P. (1986) The problem of rigor in qualitative research. *Advances in Nursing Science* **8**(3), 27-37.
- Sands R. (2000) Reconceptualization of body image and drive for thinness. *International Journal of Eating Disorders* **28**(4), 397-407.
- Sankey H. & Ginev D. (2011) The scope and multidimensionality of the scientific realism debate. *Journal for General Philosophy of Science* **42**(2), 263-283.
- Santonastaso P., Saccon D. & Favaro A. (1997) Burden and psychiatric symptoms on key relatives of patients with eating disorders: a preliminary study. *Eating and Weight Disorders - Studies on Anorexia, Bulimia and Obesity* **2**(1), 44-48.
- Sarason I.G. & Sarason B.R. (2009) Social support: mapping the construct. *Journal of social and personal relationships* **26**(1), 113-120.

Sarason I.G., Sarason B.R. & Pierce G.R. (1994) Social Support: global and relationship-based levels of analysis. *Journal of social and personal relationships* **11**(2), 295-312.

Sayer A. (2000) *Realism and social science*. London, CA, New Delhi: Sage Publications Ltd.

Scazufca M. & Kuipers E. (1996) *Links between expressed emotion and burden of care in relatives of patients with schizophrenia*. *British Journal of Psychiatry* **168**(5), 580-587.

Schumacher K.L.M.S.D.C. & Gortner S.R.P.P. (1992) (Mis)conceptions and reconceptions about traditional science. *Advances in Nursing Science Critique and Replication* **14**(4), 1-11.

Schwandt T.A. (1994) Constructivist, interpretivist approaches to human inquiry. In *Handbook of qualitative research* (Denzin K. & Lincoln Y., eds), Thousand Oaks: Sage Publications, pp. 118-137.

Schwandt T.A. (2000) Three epistemological stances for qualitative inquiry. In *Handbook of qualitative research: Theories and issues*, 2nd edn. (Denzin N. & Lincoln Y., eds), Thousand Oaks, London, New Delhi: Sage Publications, pp. 292-331.

Scott H. (2009) Data analysis: getting conceptual. *The Grounded Theory Review* **8**(2), 89-111.

Seidman I. (2013) *Interviewing as qualitative research: a guide for researchers in education and the social sciences*. 4th edn. New York: Teachers College Press

Sepulveda A.R., Todd G., Whitaker W., Grover M., Stahl D. & Treasure J. (2010) Expressed emotion in relatives of patients with eating disorders following skills training program. *International Journal of Eating Disorders* **43**(7), 603-610.

Shah A.J., Wadoo O. & Latoo J. (2010) Psychological distress in carers of people with mental disorders. *British Journal of Medical Practitioners* **3**(3), 18-25.

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.

Sharabi L.L., Delaney A.L. & Knobloch L.K. (2016) In their own words: how clinical depression affects romantic relationships. *Journal of social and personal relationships* **33**(4), 421-448.

Sheets V.L. (2014) Passion for life: self-expansion and passionate love across the life span. *Journal of social and personal relationships* **31**(7), 958-974.

Shera W. & Ramon S. (2013) Challenges in the implementation of recovery-oriented mental health policies and services. *International Journal of Mental Health* **42**(2/3), 17-42.

Silverman D. (2011) *Interpreting qualitative data*. 4th edn. London, California, New Delhi, Singapore: Sage Publications Ltd.

- Silverman J. (1997) Sir William Gull (1819–1890): limner of anorexia nervosa and myxoedema. *Eating and Weight Disorders - Studies on Anorexia, Bulimia and Obesity* **2**(3), 111-116.
- Sim L.A., Homme J.H., Lteif A.N., Vande Voort J.L., Schak K.M. & Ellingson J. (2009) Family functioning and maternal distress in adolescent girls with anorexia nervosa. *International Journal of Eating Disorders* **42**(6), 531-539.
- Smith L. (1990) Ethics. In *The paradigm dialog* (Guba E., ed), Newbury Park, London, New Delhi: Sage Publications pp. 139-157.
- Smith L. (1992) Ethical issues in interviewing. *Journal of Advanced Nursing* **17**(1), 98-103.
- Snyder C.R. (2002) Hope theory: rainbows in the mind. *Psychological Inquiry* **13**(4), 249-275.
- Snyder C.R., Feldman D.B., Taylor J.D., Schroeder L.L. & Adams Iii V.H. (2000) The roles of hopeful thinking in preventing problems and enhancing strengths. *Applied and Preventive Psychology* **9**(4), 249-269.
- Soh N.L., Touyz S.W. & Surgenor L.J. (2006) Eating and body image disturbances across cultures: a review. *European Eating Disorders Review* **14**(1), 54-65.
- Spandler H., Roy A. & McKeown M. (2014) Playing by the Rules? Gender Relations in a Football and Mental Health Project. *Journal of Men's Studies* **22**(2), 140-154.
- Sprecher S. & Cate R. (2004) Sexual satisfaction and sexual expression as predictors of relationship satisfaction and stability. In *The handbook of sexuality in close relationships* (Harvey J., Wenzel A. & Sprecher S., eds), Lawrence Erlbaum Associates Publishers, Mahwah, New Jersey, pp. 235-256.
- Sprecher S. & Fehr B. (2005) Compassionate love for close others and humanity. *Journal of social and personal relationships* **22**(5), 629-651.
- Stanford J.N. & McCabe M.P. (2002) Body image ideal among males and females: sociocultural influences and focus on different body parts. *Journal of Health Psychology* **7**(6), 675-684.
- Steiger H., Goldstein C., Mongrain M. & van der Feen J. (1990) Description of eating-disordered, psychiatric, and normal women along cognitive and psychodynamic dimensions. *International Journal of Eating Disorders* **9**(2), 129-140.
- Stern P.N. (1980) Grounded theory methodology: its uses and processes. *Image* **12**(1), 20-23.
- Sternberg K. (2014) *Psychology of love 101*. New York: Springer Publishing Company
- Stewart M.-C., Keel P.K. & Schiavo R.S. (2006) Stigmatization of anorexia nervosa. *International Journal of Eating Disorders* **39**(4), 320-325.

Stillar A., Strahan E., Nash P., Files N., Scarborough J., Mayman S., Henderson K., Gusella J., Connors L., Orr E.S., Marchand P., Dolhanty J. & Lafrance Robinson A. (2016) The influence of carer fear and self-blame when supporting a loved one with an eating disorder. *Eating disorders* **24**(2), 173-185.

Stimmel G.L. & Gutierrez M.A. (2006) Sexual dysfunction and psychotropic medications. *CNS Spectrums* **11**(SupplementS9), 24-30.

Stormer S.M. & Thompson J.K. (1996) Explanations of body image disturbance: a test of maturational status, negative verbal commentary, social comparison, and sociocultural hypotheses. *International Journal of Eating Disorders* **19**(2), 193-202.

Strauss A. (1987) *Qualitative analysis for social scientists*. Cambridge, New York: Cambridge University Press.

Strauss A. & Corbin J. (1994a) Grounded theory methodology: an overview. In *Handbook of qualitative research*, 2nd edn. (Denzin K. & Lincoln Y., eds), Thousand Oaks: Sage Publications, pp. 273-285.

Strauss A. & Corbin J. (1994b) Grounded theory methodology: An overview. In *Handbook of qualitative research* (Denzin K. & Lincoln Y., eds), Thousand Oaks: Sage Publications, pp. 273-285.

Strauss A. & Corbin J. (1998) *Basics of qualitative research: techniques and procedures for developing grounded theory*. 2nd edn. London: Sage.

Strauss A. & Corbin J. (2008) *Basics of qualitative research: techniques and procedures for developing grounded theory*. 3rd edn. Thousand Oaks, CA: Sage Publications

Strober M. (1995) Family-genetic perspectives on anorexia nervosa and bulimia nervosa. In *Eating disorders and obesity A comprehensive handbook* (Brownell K.D. & Fairburn C.G., eds), New York: The Guilford Press, pp. 212-218.

Strober M. (2004) Managing the chronic, treatment-resistant patient with anorexia nervosa. *International Journal of Eating Disorders* **36**(3), 245-255.

Strober M., Freeman R., Lampert Jane D. & Kaye W. (2000) Controlled family study of anorexia nervosa and bulimia nervosa: evidence of shared liability and transmission of partial syndromes. *The American Journal of Psychiatry* **157**(3), 393-401.

Stryker S. & Burke P., J (2000) The past, present and future of an identity theory. *Social Psychology* **63**(4), 284-297.

Stunkard A. (1959) Eating patterns and obesity. *Psychiatric quarterly* **33**(2), 284-295.

Subrin M. (2010) Stumbling towards termination. *The International Journal of Psychoanalysis* **91**(2), 251-261.

Szmukler G.I., Eisler I., Russell G.F. & Dare C. (1985) Anorexia nervosa, parental 'expressed emotion' and dropping out of treatment. *The British Journal of Psychiatry* **147**(3), 265-271.

Tasca G.A. & Balfour L. (2014) Attachment and eating disorders: a review of current research. *International Journal of Eating Disorders* **47**(7), 710-717.

Tchanturia K., Davies H., Harrison A., Fox J.R.E., Treasure J. & Schmidt U. (2012) Altered social hedonic processing in eating disorders. *International Journal of Eating Disorders* **45**(8), 962-969.

The National Mental Health Stigma Reduction Partnership (2010) *See Change* Retrieved from <http://www.seechange.ie/>.

The Royal College of Nursing (2003) The Royal College of Nursing Research Society: nurses and research ethics. *Nurse Researcher* **11**(1), 7-21.

Thibaut J. & Kelley H. (1956) *The social psychology of groups* New York: John Wiley & Sons Inc.

Thoits P. (2010) Stress and health: major findings and policy implications. *Journal of Health and Social Behavior* **51** (SI), S41-S53.

Thoits P.A. (1995) Identity-relevant events and psychological symptoms: a cautionary tale. *Journal of Health and Social Behavior* **36**(1), 72-82.

Thompson B. (1994) *A hunger so wide and so deep*. New York: William Morrow.

Tierney S. & Fox J.R.E. (2009) Chronic anorexia nervosa: a Delphi study to explore practitioners' views. *International Journal of Eating Disorders* **42**(1), 62-67.

Tilley L. & Woodthorpe K. (2011) Is it the end for anonymity as we know it? A critical examination of the ethical principle of anonymity in the context of 21st century demands on the qualitative researcher. *Qualitative Research* **11**(2), 197-212.

Tobin G.A. & Begley C.M. (2004) Methodological rigour within a qualitative framework. *Journal of Advanced Nursing* **48**(4), 388-396.

Tolhurst E. (2012) Grounded theory method: sociology's quest for exclusive items of inquiry. *Forum Qualitative Social Research* **13**(3, Art. 26).

Topor A., Borg M., Mezzina R., Sells D., Marin I. & Davidson L. (2006) Others: the role of family, friends, and professionals in the recovery process. *American Journal of Psychiatric Rehabilitation* **9**(1), 17-37.

Tozzi F., Sullivan P.F., Fear J.L., McKenzie J. & Bulik C.M. (2003) Causes and recovery in anorexia nervosa: the patient's perspective. *International Journal of Eating Disorders* **33**(2), 143-154.

Treasure J., Claudino A.M. & Zucker N. (2010) Eating disorders. *The Lancet* **375**(9714), 583-593.

Treasure J., Corfield F. & Cardi V. (2012a) A three-phase model of the social emotional functioning in eating disorders. *European Eating Disorders Review* **20**(6), 431-438.

Treasure J., Gavan K., Todd G. & Schmidt U. (2003) Changing the environment in eating disorders: working with carers/families to improve motivation and facilitate change. *European Eating Disorders Review* **11**(1), 25-37.

Treasure J., Murphy T., Szmukler T., Todd G., Gavan K. & Joyce J. (2001) The experience of caregiving for severe mental illness: a comparison between anorexia nervosa and psychosis. *Social Psychiatry & Psychiatric Epidemiology* **36**(7), 343.

Treasure J., Sepulveda A.R., Whitaker W., Todd G., Lopez C. & Whitney J. (2007a) Collaborative care between professionals and non-professionals in the management of eating disorders: a description of workshops focussed on interpersonal maintaining factors. *European Eating Disorders Review* **15**(1), 24-34.

Treasure J., Smith G.R. & Crane A. (2007b) *Skills-based learning for caring for a loved one with an eating disorder: the new Maudsley method*. New York; Routledge

Treasure J., Whitaker W., Todd G. & Whitney J. (2012b) A description of multiple family workshops for carers of people with anorexia nervosa. *European Eating Disorders Review* **20**(1), e17-e22.

Treasure J., Whitaker W., Whitney J. & Schmidt U. (2005) Working with families of adults with anorexia nervosa. *Journal of Family Therapy* **27**(2), 158-170.

Turner H., Marshall E., Stopa L. & Waller G. (2015) Cognitive-behavioural therapy for outpatients with eating disorders: effectiveness for a transdiagnostic group in a routine clinical setting. *Behaviour Research and Therapy* **68**, 70-75.

U.S. Department of Health and Human Services (2006) Consensus statement on mental health recovery. Substance abuse and mental health services administration.

Underwood L.G. (2009) Compassionate love: a framework for research. In *The science of compassionate love: Theory, research and applications* (Fehr B., Sprecher S. & Underwood M., eds), West Sussex UK: Wiley-Blackwell, pp. 3-25.

Urquhart C. (2001) An encounter with grounded theory: tackling the practical and philosophical issues. In *Qualitative Research in IS: Issues and trends* (Trauth E., M, ed), London, Melbourne, Singapore: Idea Group Publishing pp. 104-140.

Van Buren D.J. & Williamson D.A. (1988) Marital relationships and conflict resolution skills of bulimics. *International Journal of Eating Disorders* **7**(6), 735-741.

Van den Broucke S. & Vandereycken W. (1989) The marital relationship of patients with an eating disorder: a questionnaire study. *International Journal of Eating Disorders* **8**(5), 541-556.

- Van den Broucke S., Vandereycken W. & Norré J. (1997) *Eating disorders and marital relationships*. London, New York: Routledge.
- Van den Broucke S., Vandereycken W. & Vertommen H. (1994) Psychological distress in husbands of eating disorder patients. *American Journal of Orthopsychiatry* **64**(2), 270-279.
- Van den Broucke S., Vandereycken W. & Vertommen H. (1995a) Marital communication in eating disorder patients: a controlled observational study. *The International Journal Of Eating Disorders* **17**(1), 1-21.
- Van den Broucke S., Vandereycken W. & Vertommen H. (1995b) Marital intimacy in patients with an eating disorder: a controlled self-report study. *British Journal of Clinical Psychology* **34**(1), 67-78.
- Van den Broucke S., Vandereycken W. & Vertommen H. (1995c) Marital intimacy: conceptualization and assessment. *Clinical Psychology Review* **15**(3), 217-233.
- Van der Ham T., Meulman J.J., Van Strien D.C. & Van Engeland H. (1997) Empirically based subgrouping of eating disorders in adolescents: a longitudinal perspective. *British Journal of Psychiatry* **70**(4), 363-368
- Van der Voort T.Y.G., Goossens P.J.J. & Van der Bijl J.J. (2009) Alone together: a grounded theory study of experienced burden, coping, and support needs of spouses of persons with a bipolar disorder. *International Journal of Mental Health Nursing* **18**(6), 434-443.
- Vandereycken W. (2006) Denial of illness in anorexia nervosa—a conceptual review: part 2 different forms and meanings. *European Eating Disorders Review* **14**(5), 352-368.
- Vandereycken W. & Van Humbeeck I. (2008) Denial and concealment of eating disorders: a retrospective survey. *European Eating Disorders Review* **16**(2), 109-114.
- Vandereycken W. & Vansteenkiste M. (2009) Let eating disorder patients decide: providing choice may reduce early drop-out from inpatient treatment. *European Eating Disorders Review* **17**(3), 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**(5), 357-365.
- Vasilachis de Gialdino I. (2009) Ontological and epistemological foundations of qualitative research. *Forum Qualitative Social Research* **10**(2), ART, 30.
- Vaughn C.E. & Leff J.P. (1981) Patterns of emotional response in relatives of schizophrenic patients. *Schizophrenia Bulletin* **7**(1), 43-44.
- Verhofstadt L.L.L., Lemmens G.M.D. & Buysse A. (2013) Support-seeking, support-provision and support-perception in distressed married couples: a multi-method analysis. *Journal of Family Therapy* **35**(3), 320-339.

von Soest T. & Wichstrøm L. (2006) Cohabitation reduces bulimic symptoms in young women. *International Journal of Eating Disorders* **39**(6), 484-491.

Vrabel K.R., Rosenvinge J.H., Hoffart A., Martinsen E.W. & Rø Ø. (2008) The course of illness following inpatient treatment of adults with longstanding eating disorders: a 5-year follow-up. *International Journal of Eating Disorders* **41**(3), 224-232.

Wahl O.F. & Harman C.R. (1989) Family views of stigma. *Schizophrenia Bulletin* **15**(1), 131-139.

Walford G. (2005) Research ethical guidelines and anonymity. *International Journal of Research & Method in Education* **28**(1), 83-93.

Walker-Bynum C. (1987) *Holy feast and holy fast: the religious significance of food to medieval women*. CA: University of California Press

Walker D. & Myrick F. (2006) Grounded theory: an exploration of process and procedure. *Qualitative Health Research* **16**(4), 547-559.

Waller G., Corstorphine E., Cordery H., Hinrichsen H., Lawson R., Mountford V. & Russell K. (2007) *Cognitive behavioural therapy for eating disorders: a comprehensive treatment guide*. Cambridge: Cambridge University Press

Waller G., Gray E., Hinrichsen H., Mountford V., Lawson R. & Patient E. (2014) Cognitive-behavioral therapy for bulimia nervosa and atypical bulimic nervosa: effectiveness in clinical settings. *International Journal of Eating Disorders* **47**(1), 13-17.

Ward A., Ramsay R., Turnbull S., Benedettini M. & Treasure J. (2000) Attachment patterns in eating disorders: past in the present. *International Journal of Eating Disorders* **28**(4), 370-376.

Waring E.M. & Reddon J.R. (1983) The measurement of intimacy in marriage: the Waring Intimacy Questionnaire. *Journal of Clinical Psychology* **39**(1), 53-57.

Wasserman J.A., Clair J.M. & Wilson K.L. (2009) Problematics of grounded theory: innovations for developing an increasingly rigorous qualitative method. *Qualitative Research* **9**(3), 355-381.

Watson H.J., Allen K., Fursland A., Byrne S.M. & Nathan P.R. (2012) Does enhanced cognitive behaviour therapy for eating disorders improve quality of life? *European Eating Disorders Review* **20**(5), 393-399.

Wechselblatt T., Gurnick G. & Simon R. (2000) Autonomy and relatedness in the development of anorexia nervosa: a clinical case series using. *Bulletin of the Menninger Clinic* **64**(1), 91.

- Werner P., Goldstein D. & Buchbinder E. (2010) Subjective experience of family stigma as reported by children of Alzheimer's disease patients. *Qualitative Health Research* **20**(2), 159-169.
- Wester S.R., Christianson H.F., Vogel D.L. & Wei M. (2007) Gender role conflict and psychological distress: the role of social support. *Psychology of Men & Masculinity* **8**(4), 215-224.
- Whitney J. & Eisler I. (2005) Theoretical and empirical models around caring for someone with an eating disorder: the reorganization of family life and inter-personal maintenance factors. *Journal of Mental Health* **14**(6), 575-585.
- Whitney J., Haigh R., Weinman J. & Treasure J. (2007) Caring for people with eating disorders: factors associated with psychological distress and negative caregiving appraisals in carers of people with eating disorders. *British Journal of Clinical Psychology* **46**(4), 413-428.
- Whitney J., Murray J., Gavan K., Todd G., Whitaker W. & Treasure J. (2005) Experience of caring for someone with anorexia nervosa: qualitative study. *British Journal of Psychiatry* **187**, 444-449.
- Whittemore R., Chase S.K. & Mandle C.L. (2001) Validity in qualitative research. *Qualitative Health Research* **11**(4), 522-537.
- Whitton S., Stanley S. & Markman H. (2002) Sacrifice in romantic relationships: an exploration of relevant research and theory. In *Stability and change in relationships* (Vangelisti A., Reis H. & Fitzpatrick M., eds), Cambridge: Cambridge University Press, pp. 156-181.
- Wiederman M.W. (2012) Body image and sexual functioning In *Encyclopedia of body image and human appearance*, Vol. 1 (Cash T.F., ed), San Diego: Academic Press, pp. 148-152.
- Wilcox J.A. (1990) Fluoxetine and bulimia. *Journal of psychoactive drugs* **22**(1), 81-82.
- Wildes J.E. & Marcus M.D. (2013) Incorporating dimensions into the classification of eating disorders: three models and their implications for research and clinical practice. *International Journal of Eating Disorders* **46**(5), 396-403.
- Williams-Baucom K.J., Atkins D.C., Sevier M.I.A., Eldridge K.A. & Christensen A. (2010) "You" and "I" need to talk about "us": linguistic patterns in marital interactions. *Personal Relationships* **17**(1), 41-56.
- Williams S.E., Watts T.K.O. & Wade T.D. (2012) A review of the definitions of outcome used in the treatment of bulimia nervosa. *Clinical Psychology Review* **32**(4), 292-300.
- Williamson D.A., White M.A., York-Crowe E. & Stewart T.M. (2004) Cognitive-behavioral theories of eating disorders. *Behavior Modification* **28**(6), 711-738.

Wilson T.D. & Gilbert D.T. (2008) Explaining away: a model of affective adaptation. *Perspectives on Psychological Science (Wiley-Blackwell)* **3**(5), 370-386.

Winn S., Perkins S., Murray J., Murphy R. & Schmidt U. (2004) A qualitative study of the experience of caring for a person with bulimia nervosa. Part 2: carers' needs and experiences of services and other support. *International Journal of Eating Disorders* **36**(3), 269-279.

Winn S., Perkins S., Walwyn R., Schmidt U., Eisler I., Treasure J., Berelowitz M., Dodge L., Frost S., Jenkins M., Johnson-Sabine E., Keville S., Murphy R., Robinson P. & Yi I. (2007) Predictors of mental health problems and negative caregiving experiences in carers of adolescents with bulimia nervosa. *International Journal of Eating Disorders* **40**(2), 171-178.

Wonderlich S., Mitchell J.E., Crosby R.D., Myers T.C., Kadlec K., LaHaise K., Swan-Kremeier L., Dokken J., Lange M., Dinkel J., Jorgensen M. & Schander L. (2012) Minimizing and treating chronicity in the eating disorders: a clinical overview. *International Journal of Eating Disorders* **45**(4), 467-475.

Wonderlich S.A., Joiner T.E., Jr., Keel P.K., Williamson D.A. & Crosby R.D. (2007) Eating disorder diagnoses: empirical approaches to classification. *American Psychologist* **62**(3), 167-180.

Woodside D.B., Lackstrom J.B. & Shekter-Wolfson L. (2000) Marriage in eating disorders: comparisons between patients and spouses and changes over the course of treatment. *Journal of Psychosomatic Research* **49**(3), 165-168.

Woodside D.B., Shekter-Wolfson L., Brandes J.A. & Lackstrom J.B. (1993) *Eating disorders and marriage: the couple in focus*. New York: Brunner/Mazel

World Health Organisation (1992) *The ICD-10 classification of mental and behavioural disorders: clinical descriptions and diagnostic guidelines*. Geneva: World Health Organisation

Wright M. & Leahey M. (2009) The Calgary Family Intervention Model. In *Nurses and families: A guide to family assessment and interventions*, 5th edn. (Wright M. & Leahey M., eds), Philadelphia: F.A. Davis Company, , pp. 153-179.

Wyder M. & Bland R. (2014) The recovery framework as a way of understanding families' responses to mental illness: balancing different needs and recovery journeys. *Australian Social Work* **67**(2), 179-196.

Yeh H.-C., Lorenz F.O., Wickrama K.A.S., Conger R.D. & Elder G.H., Jr. (2006) Relationships among sexual satisfaction, marital quality, and marital instability at midlife. *Journal of Family Psychology* **20**(2), 339-343.

Young S.L. & Ensing D.S. (1999) Exploring recovery from the perspective of people with psychiatric disabilities. *Psychiatric Rehabilitation Journal* **22**(3), 219.

Zachrisson H.D. & Skårderud F. (2010) Feelings of insecurity: review of attachment and eating disorders. *European Eating Disorders Review* **18**(2), 97-106.

Zerbe K. (2010) Psychodynamic therapy for eating disorders. In *The treatment of eating disorders: A clinical handbook* (Grilo C.M. & Mitchell J.E., eds), The Guilford Press, New York, London.

APPENDICES

Appendix 1: Classification system for Feeding and Eating disorders: DSM-5 (American Psychiatric Association 2013)

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 if:

In partial remission: After full criteria for anorexia nervosa were previously met, Criterion A has not been met for a sustained period, but either Criterion B or C is still met.

In full remission: After full criteria for anorexia nervosa were previously met, none of the criteria have been met for a sustained period of time.

Specify current severity:

The minimum level of severity is based, for adults, on current body mass index (BMI) (see below) or for children and adolescents, on BMI percentile. The ranges below are derived from World Health Organization categories for thinness in adults; for children and adolescents, corresponding BMI percentiles should be used. The level of severity may be increased to reflect clinical symptoms, the degree of functional disability, and the need for supervision.

Mild: BMI > 17 kg/m²

Moderate: BMI 16-16.99 kg/m²

Severe: BMI 15-15.99 kg/m²

Extreme: BMI < 15 kg/m²

Bulimia Nervosa:

A. Recurrent episodes of binge eating. An episode of binge eating is characterized by BOTH of the following:

1. Eating in a discrete amount of time (ex: within a 2 hour period) an amount of food that is definitely larger than what most individuals would eat in a similar period of time under similar circumstances.
2. Sense of lack of control over eating during an episode.

- 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 three months.
- D. Self-evaluation is unduly influenced by body shape and weight.
- E. The disturbance does not occur exclusively during episodes of anorexia nervosa.

Specify if:

In partial remission: After full criteria for bulimia nervosa were previously met, some, but not all of the criteria have been met for a sustained period of time.

In full remission: After full criteria for bulimia nervosa were previously met, none of the criteria have been met for a sustained period of time.

Specify current severity:

The minimum level of severity is based on the frequency of inappropriate compensatory behaviours (see below). The level of severity may be increased to reflect other symptoms and the degree of functional disability.

Mild: An average of 1-3 episodes of inappropriate compensatory behaviours per week

Moderate: An average of 4-7 episodes of inappropriate compensatory behaviours per week

Severe: An average of 8-13 episodes of inappropriate compensatory behaviours per week

Extreme: An average of 14 or more episodes of inappropriate compensatory behaviours per week

Binge Eating Disorder:

- A. Recurrent episodes of binge eating. An episode of binge eating is characterized 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 what 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 afterward.
- C. Marked distress regarding binge eating is present.
- D. The binge eating occurs, on average, at least once a week for 3 months.
- E. The binge eating is not associated with the recurrent use of inappropriate compensatory behaviour as in bulimia nervosa and does not occur exclusively during the course of bulimia nervosa or anorexia nervosa.

Specify if:

In partial remission: After full criteria for binge-eating disorder were previously met, binge eating occurs at an average frequency of less than one episode per week for a sustained period of time.

In full remission: After full criteria for binge-eating disorder were previously met, none of the criteria have been met for a sustained period of time.

Specify current severity:

The minimum level of severity is based on the frequency of episodes of binge eating (see below). The level of severity may be increased to reflect other symptoms and the degree of functional disability.

Mild: 1-3 binge-eating episodes per week

Moderate: 4-7 binge-eating episodes per week

Severe: 8-13 binge-eating episodes per week

Extreme: 14 or more binge-eating episodes per week

Other Specified Feeding or Eating Disorder:

This category applies to presentation in which symptoms characteristic of a feeding and eating disorder that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning predominate but do not meet the full criteria for any of the disorders in the feeding and eating disorders diagnostic class. The other specified feeding or eating disorder category is used in situations in which the clinician chooses to communicate the specific reason that the presentation does not meet the criteria for any specific feeding and eating disorder. This is done by recording "other specified feeding or eating disorder" followed by the specific reason (e.g., bulimia nervosa of low frequency).

Examples of presentations that can be specified using the "other specified" designation include the following:

1. 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.
2. Bulimia nervosa (of low frequency and/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 3 months.
3. Binge-eating disorder (of low frequency and/or limited duration): All of the criteria for binge-eating disorder are met, except the binge eating occurs, on average, less than once a week and/or for less than 3 months.
4. Purging Disorder: Recurrent purging behaviour to influence weight or shape (e.g., self-induced vomiting, misuse of laxatives, diuretics, or other medications) in the absence of binge eating.
5. Night eating syndrome: Recurrent episodes of night eating, as manifested by eating after awakening from sleep or by excessive food consumption after the evening meal. There is awareness and recall of the eating. The night eating is not better explained by external influences such as changes in the individual's sleep-wake cycle or by local social norms. The night eating causes significant distress and/or impairment in functioning. The disordered pattern of eating is not better explained by binge-eating disorder or another mental disorder, including substance use, and is not attributable to another medical disorder or to an effect of medication.

Unspecified Feeding or Eating Disorders:

This category applies to presentation in which symptoms characteristic of a feeding and eating disorder that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning predominate but do not meet the full criteria for any of the disorders in the feeding and eating disorders diagnostic class. The unspecified feeding and eating disorder category is used in situations in which the clinician chooses not to specify the reason that the criteria are not met for a specific feeding and eating disorder, and includes presentations in which there are insufficient information to make a more specific diagnosis (e.g., in emergency room settings)

Appendix 2: Ethical approval



COLÁISTE NA TRÍONÓIDE, BAILE ÁTHA CLIATH TRINITY COLLEGE DUBLIN
Ollscoil Átha Cliath The University of Dublin

Dámh na nEolaíochtaí Sláinte,
An Chéad Urlar, Foirgneamh na Ceimice (an sineadh)
Colaiste na Tríonóide,
Baile Átha Cliath 2, Éire.

Faculty of Health Sciences,
1st Floor, Chemistry Building
Extension,
Trinity College,
Dublin 2, Ireland.
T:- +353 (0)1 8964255

Patricia O'Connor
19 Landscape Crescent,
Churchtown
Dublin 14

29 February 2012

Study: An exploration of the experience of living with and supporting a person with an eating Disorder: A partners perspective.

Dear Applicant(s),

Further to a meeting of the Faculty of Health Sciences Ethics Committee held in March 2011, we are pleased to inform you that the above project has been approved without further audit.

Yours sincerely,

Prof. Orla Sheils
Chairperson
Faculty Research Ethics Committee

Supervisor:

Prof. Agnes Higgins

Eating Disorders Research Study



An exploration of the experience of living with and supporting a person with an eating disorder: A partner's perspective

- Are you in a relationship where your partner has an eating disorder?
- Are you with your partner for more than 6 months and are currently living with them?
- Are you over the age of 18 years?
- Do you speak English?

If you can answer yes to these questions, I would like to hear your story.

If you are considering taking part and would like more information please contact

Appendix 4: Letter of invitation

Dear Sir/Madam

My name is Patricia O'Connor. I am a PhD student at the School of Nursing and Midwifery, Trinity College, Dublin and am currently undertaking a research study. The study aims to build on the small amount of knowledge that currently exists on partners' experience of living with someone with an eating disorder by exploring your own experiences and understanding in this regard. I am interested in interviewing men and women over the age of 18 years who have been in a relationship for six or more months with someone who has an eating disorder and are currently living with them.

I would be very grateful if you would consider taking part in this study. Your involvement is entirely voluntary. Attached is an information sheet, which explains the study in more detail. After reading the information sheet, if you decide to participate in the study, please complete the attached page and return it to me in the envelope provided. I will then contact you to discuss the study. After this discussion, if you are happy to participate I will arrange a time and place that suits you, to conduct the interview.

If you need any further information about this research or if anything in this letter is unclear, please contact me at the following telephone number 087 6952304 or at the following email address: oconn11@tcd.ie and I will be happy to discuss any of this information with you.

If you decide to participate in this research study, I look forward to hearing from you.

I have enclosed an information sheet and consent form.

Thanking you for taking the time to read this and I do hope you will consider becoming involved in this important research study.

Yours sincerely,

Patricia O'Connor

Appendix 5: Information leaflet for participants

Information Sheet for Interview Participants

The aim of this leaflet is to provide you with information about the study before you consent to participate in it.

Title of the study– An exploration of the experience of living with and supporting a person with an eating Disorder: A partner’s perspective

Introduction My name is Patricia O’Connor and I am a PhD student at the School of Nursing and Midwifery, Trinity College, Dublin. The study is being supervised by Professor Agnes Higgins at the School of Nursing and Midwifery, Trinity College, Dublin

Background to the study: There are approximately 200,000 people in Ireland suffering from some form of an eating disorder and about 10% of those presenting are male, a figure that is reported to be on the rise. Although there are many studies that look at the experience of living with someone with an eating disorder very little is known about the experiences from a partners’ point of view. This research is attempting to fill this gap.

The aims of the study are to explore the partner’s view of the relationship, to gain an understanding of how the illness has affected their lives, to identify the ways in which they cope and to identify their specific needs as a partner.

Procedures: I am inviting both men and women, over the age of 18 years who have been living, for at least six months, with a partner who has an eating disorder, to participate in the study.

If you agree to take part in the study, you will be asked to sign a consent form, giving me permission to interview you and tape record the interview. I will interview you at a place and time that is suitable and accessible for you. The interview will last no longer than one and a half hours. I will ask you to talk about your experiences of living with someone with an eating disorder,

The interview will be recorded, so I can listen to afterwards, to ensure that I represent your views and opinions as completely as possible. A transcript of your interview will be made available to you if you so wish. At the end of the interview you will be asked to sign a second part of the consent form, allowing the information you have given me to be used in the study

You may be asked to participate in more than one interview, but you have a choice as to whether or not to be interviewed more than once

Benefits of the study: If you participate in this research study, there may be no specific benefits to you directly. It is hoped, however, that the findings from the study will have a direct impact on improving the quality of supportive services for partners of people with eating disorders and subsequently be of benefit to the person with the eating disorder.

Risks: There are no foreseeable risks to you being involved in this study. However, I am aware that you may become upset when talking about your experiences. Should this happen when discussing your experiences, the interview will be stopped and I will provide some time for you to talk about your distress. I am an experienced mental health nurse and counsellor. The interview will only continue if you or I consider that it is not going to cause you any further upset. You may stop the interview at any time.

I will provide you with a list of local counselling /support services if you so wish.

Exclusion from participation: You cannot participate in this study if any of the following are true

- You are under 18 years of age
- You are not fluent in the spoken English
- You are in the relationship for less than six months
- You are not living with the person with the eating disorder

Confidentiality: Your identity will remain confidential. Your name will not be published and will not be disclosed to anyone outside the study group. Data will be stored on a password protected computer and only accessible to me, the researcher.

Will everything I say be treated in confidence?

During the interview I will treat everything you say in the strictest confidence. There are however, some circumstances where strict confidentiality cannot apply, and I am morally and/or legally obliged to involve appropriate others. For instance, if you revealed that you were contemplating harming yourself, I would have to insist that you or I contact a family member, your GP or your local community mental health team or if your story revealed information where there is current risk to a child under 18 years of age, I would need to inform the duty social worker in the local area.

Compensation: This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails your rights.

Voluntary Participation: If you decide to volunteer to participate in this study, you may withdraw at any time. If you decide not to participate, or if you withdraw, you will not be penalised and will not give up any benefits that you had before entering the study.

Stopping the study: You understand that the investigators may withdraw your participation in the study at any time without your consent.

Permission: This study has Research Ethics Committee approval from: The Faculty of Health Sciences Ethics Committee Trinity College Dublin..

Further information: You can get more information or answers to your questions about the study, your participation in the study, and your rights, from Patricia O'Connor who can be telephoned at 087 6952304. If the study team learns of important new information that might affect your desire to remain in the study, you will be informed at once.

Thank you for taking the time to read this information sheet in the study

Appendix 6: Inclusion criteria

Inclusion criteria:

- Male and female partners of a person with an eating disorder
- Participants will be over the age of 18 years of age
- Those partners who consent to participate in the study
- The relationship must be a minimum of six months duration and the participant is to be cohabiting with the person with the eating disorder at the time of the study
- Participants are fluent in spoken English

Exclusion criteria:

- Partners who do not consent to being involved in the study
- Partners under 18 years of age
- Partners who are not fluent in the spoken English
- Partners in the relationship for less than six months and/or not cohabiting with the person with the eating disorder

Appendix 7: Consent form

CONSENT FORM

TITLE OF THE RESEARCH STUDY:

An exploration of the experience of living with and supporting a person with an eating Disorder: A partners' perspective

RESEARCHER'S CONTACT DETAILS:

Patricia O'Connor

Telephone number: 087 6952304 E-mail: oconnp11@tcd.ie

BACKGROUND AND PROCEDURES :

There are over 200,000 people in Ireland who have some form of an eating disorder. Although the area of care and family needs has been looked at in the research, there is very little known about a partner's experience and understanding in this respect. This research is attempting to fill this gap in knowledge, by exploring your own experiences of living with someone with an eating disorder. The aims of the study are to explore the relationship from your viewpoint, to look at how the illness has affected your life, to identify how you manage any difficulties that might arise and to look at what your needs are and how best they can be addressed.

Your participation will involve an interview with me at a time and place convenient for you. The interview will take no longer than one and a half hours. The objective is to hear and record your experiences. The interview will be tape recorded so I can listen to it afterward, to ensure that I record your experiences as completely as possible. You can have a typed copy of the interview if you so wish.

The information obtained from you will only be used for the specific purposes of this study. Your identity will remain confidential. Your name will not be published and will not be disclosed to anyone outside the study group.

DECLARATION (Please read and sign if you agree):

I have read the study information sheet and this consent form.

I have had the opportunity to ask questions and all my questions have been answered to my satisfaction.

I understand that all information collected in this study will be treated as confidential and that my identity will remain confidential.

I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights.

I have received a copy of this agreement

I understand that the results of this research may be published.
I understand I may withdraw from the study at any time.

PARTICIPANT'S NAME:

CONTACT NUMBER:

PARTICIPANT'S SIGNATURE:

Date:.....

Statement of investigators responsibility: I have explained the nature and purpose of this study to the persons named above, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and have fully answered such questions. I believe that the person named above understood my explanation and has freely given informed consent.

Investigator's Signature

.....

Date:.....

TO BE COMPLETED AT THE END OF THE INTERVIEW

I consent for the information, provided by me in this interview, to be used in the study.

PARTICIPANT'S NAME :

PARTICIPANT'S SIGNATURE:

Date:.....

Investigator's Signature

.....

Date:.....

Appendix 8(a) Examples of open codes

Accommodating/colluding with ED	Changing the approach
Getting used to it	Being criticised
Explaining away	Living with negativity
Keeping the peace	Not being able to ask for help
Being blamed	Not being noticed
Being depended on	Feeling disappointed
Finding it difficult	Being unhappy
Having no time	Feeling indebted
Not being oneself	Regretting
Feeling different	Asking for help
Experiencing frustration	Depending on oneself
Seeing the good in the partner	Not believing/denying
Making decisions	Protecting oneself
Needing to spend time with others	Protecting the partner
Concern for how others see	Taking care of oneself
Being aware	Acknowledging the seriousness
Encouraging the partner to talk	Talking about depression
Not seeing	noticing
Seeing the cycle of ED	Encountering inexperience
Being told	Encountering professionalism
Telling others	Looking for information
Attending sessions	Knowing what is helpful
Becoming informed	Making sense of things
Managing partners distress	Fears around dying
Being the only support	Getting it wrong
Encountering resistance	Hiding it
Involving others	overeating
Living with self harm	Being alone
readjusting	Being realistic
hoping	Being prepared
Arguing	bargaining
Not being available	avoiding
Living with deceit	Taking over the care
Being positive	Staying in the relationship
Distancing from others	Making excuses
Fitting in with plans	Living by rules
Making sacrifices	Looking for information

Appendix 8(b): Open codes grouped together based on similarity

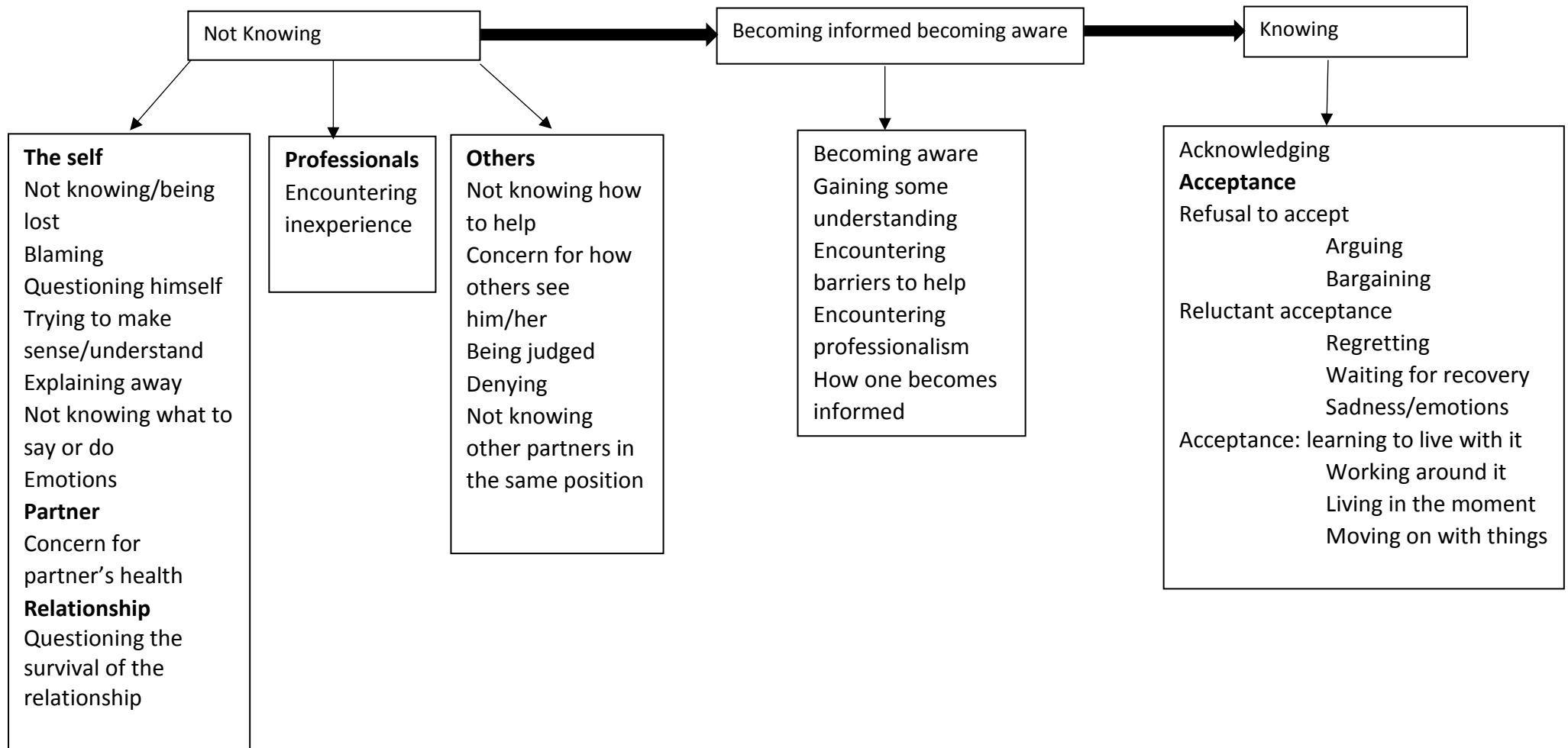
The screenshot displays the NVivo software interface. At the top is a menu bar with options: File, Home, Create, External Data, Analyze, Query, Explore, Layout, View. Below the menu is a ribbon with various tool icons grouped into Workspace, Item, Clipboard, Format, Paragraph, Styles, Editing, and Proofing.

The main workspace is divided into several panes:

- Nodes:** A tree view on the left lists various nodes such as 'acknowledging ones own psychological or physical difficultie', 'becoming informed', 'concern for the partner', 'concern for body image', 'concern for safety', 'concern for the future', 'concern for the health of the partner', 'empathy with partner', 'fears around dying', 'managing partners distress', 'motivating', 'not adhering to treatment', 'pleasing the partner', 'protecting her keeping secrets', 'providing partner with friends', 'recounting the partners past', 'upsetting the partner', 'wanting the partner to be happy', 'wanting the partner to be independant', 'seeing the cycle of illness', and 'identifying ones needs'.
- Sources:** A pane on the left showing a list of sources.
- Search Results:** The central pane shows search results for the query 'concern for the future'. It lists two results:
 - <Internal\Interview 006> - § 3 references coded [0.86% Coverage]**
 - Reference 1 - 0.12% Coverage**: How she will get better and how she can see her way forward
 - Reference 2 - 0.33% Coverage**: between the eating disorder and thoughts of going back to work as well I think it's just even to think about what to do going forward, it's just the future really
 - Reference 3 - 0.41% Coverage**: because looking at that I can see how in the long-term, I mean again that could be like coming into the daycare, coming into hospital for a few weeks, eat away up, and how do go forward after that you know
 - <Internal\Interview 007> - § 2 references coded [0.73% Coverage]**
 - Reference 1 - 0.17% Coverage**: But and I don't know what's going to happen and in six months time or in one year or two years.
- Summary, References, Text:** A vertical pane on the right side of the search results.

At the bottom of the interface, there is a taskbar showing system icons, a clock displaying 21:57 on 20/09/2016, and the language set to UK.

Appendix 9(a): Diagrammatic memo representing the process of not knowing to knowing
2/4/2014



Appendix 9(b): Memos on the concept of '*Being the carer*'

Memo 1. 2/12/12 Caring for the partner

Having completed and coded 2 interviews, the issue of having to provide a significant level of caring to their partner, particularly when they are really physically and psychologically unwell because of the ED. I would think this is normal when a partner is unwell but it just feels different to that. Having to provide this care, how does that impact on them? I won't simplify this issue by just thinking about the impact in terms of the participant's physical, psychological and social health although I expect these to be issues, but it just seems deeper than that.

Memo 2. 20/1/13 Interview 003

The participant can clearly see that the way they interact with their partner around the ED is not OK. '*not something that is no way to talk to another to your partner*'. If he is not treating her or talking to her like a partner than like what? To date all of the participants describe behaviours of vigilance (being vigilant) as a part of providing ED care, where they feel the need to watch their partner like a hawk, its nearly like watching a bold child. Some aspects of the care they give is like a parent would give to a child

Memo 3. 26/8/13 Interview 007

The code 'Being vigilant' applies to all interviews so far, and for some it is actually referred to as being the parent such as in this interview 'Well I try not to be (the parent) but I would've been of course at some stages' Vigilance is heightened when their partner is experiencing an ED setback, but there is an element of it even when their partner is well. Is this about mistrusting the partner? It changes how they interact as a couple. So the concept of being the carer I can link with the memo on the concept of '*Changing the essence of the relationship*'

Some of the caring they give is no longer what is expected as normal couple caring even if one partner is unwell. Going back to the first memo, and the feel that it goes deeper what I think might be happening is caring can end up like that of a parent/child, and this changes how the couple interact with each other, therefore the essence of the relationship is moving away from what they are used to, what was good about the relationship?

Memo 4. 19/10/13 Interview 008

Partners do not want to think of themselves as a carer or don't want other people to see them as a carer. I can see this is as a thread in all the previous interviews maybe because of the way some of the caring they provide is not OK and it effects the essence of the relationship so the associations of being a carer are negative. I can link this with the concept of '*handing over responsibility*' which comes back to not being the carer = not being in a parent/child relationship = improvement to the essence of the relationship.

Memo 5. 28/10/14

Family members, (and I am extending this to partners) are conceptualised in the literature as carers, but this is not how the partners want to see themselves or others see them. Even if they don't see themselves as carers they enact caring behaviour. Is there a mixed picture where some see themselves as carers others do not and others again see it as a fluctuating position (process). Maybe it depends on certain criteria i.e. where their partner is in the context of the cycle of illness, severity of symptomatology, support systems (others willing to take on the role or allowing others to take on the role). I will make a note to myself to follow this query in the rest of the interviews until I can get a full picture of what is happening around providing care (saturate the concept).

Memo 16. 14/3/15

Providing care is something participants are willing to do because they consider it to be part and parcel of a relationship. It becomes problematic when it goes beyond normal caring resulting in a shift in the relationship where they feel they are more like a parent. When they are 'the parent', interactions between them as a couple tend to be highly emotionally charged which adds to their distress, the distress of their partner and relationship distress. However, when they perceive their partner is not in a position to care for themselves they have to take over the caring and it becomes a balancing act between providing higher levels of care and the need for their partner to maintain their independence. The other thing about taking on the carer role is it means someone is 'sick' (partner) they don't want others in their lives to consider their partner as being sick so not taking on the identity of carer is not just about protecting the essence of the relationship but also about protecting their partner from others seeing them as sick, and others seeing them as a carer and feeling sorry for them or even advising them to leave the relationship as in interview 005, (others devaluing the relationship).