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UNDERSTANDING ANOREXIA NERVOSA:
AN ONLINE PHENOMENOLOGICAL
APPROACH

SARAH WILLIAMS

A thesis submitted in partial fulfilment of the
requirements for the degree of
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Abstract

Anorexia has often been theorised as a way of obtaining a sense of control and a sense of identity. Previous research has identified the positive functions anorexia plays for those who experience it. Healthcare professionals perceive anorexia as something to be treated whilst those experiencing it are often ambivalent and see it as something to maintain. Those who feel misunderstood in their offline environment can turn to the physically anonymous environment of the internet to discuss their experiences and opinions.

The aims of the research were (1) to determine the understandings of anorexia, recovery and treatment through participants' lived experiences, and (2) to identify how participants' understandings affected pathways to and through treatment.

An online phenomenological approach was used to explore the experiences of those recruited through online resources for anorexia. Data was collected using online focus groups and e-mail interviews and was analysed using Interpretative Phenomenological Analysis.

Results indicated a strong theme of maintenance of anorexia due to its egosyntonic and functional role. Anorexia was initially perceived as a solution to problems or crises but over time it became problematic. Nonetheless, strong psychosocial mechanisms such as feelings of ambivalence, an 'anorexic voice' and a sense of feeling addicted to anorexia affected its maintenance.

Recovery required the acceptance of anorexia as a problem. Recovery was interpreted as a sense of living rather than existing and required four main factors: self-acceptance, acceptance of and from others, the development of alternative, healthy behaviours and the ability to manage residual anorexic cognitions. Implications for treatment are discussed.

Online communication is considered a safe environment due to its physical anonymity, allowing people to feel more comfortable disclosing views and experiences that may be stigmatised or uncomfortable to discuss in an offline situation. Future research should utilise the internet in conducting studies with people with body image issues.

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Preface

This thesis is concerned with understanding anorexia nervosa from the perspectives of those who have a lived experience of it. It begins with three literature reviews. Chapter 1 introduces the thesis and addresses the issues of importance to sufferers of anorexia through reviewing the existing literature detailing qualitative research. Chapter 2 places the issues highlighted in previous qualitative research in a theoretical context by exploring the etiological and treatment issues relating to anorexia. Chapter 3 explores the uses of the internet by those with anorexia and develops a rationale for taking the current research online. The advantages and disadvantages of the online medium in these areas will be extensively reviewed.

Chapter 4 outlines the online phenomenological approach used in the research. This chapter begins by developing a rationale for the phenomenological approach before considering the utilisation of online focus groups as a research method. Chapter 4 ends by presenting the method for the current research.

Chapters 5, 6 and 7 present the empirical work of the thesis - three online phenomenological studies with three participant groups. Study 1 (chapter 5) explores the experiences and meanings of those who wish to maintain anorexia. Study 2 (chapter 6) explores those who wish to recover from their anorexia and study 3 (chapter 7) presents the experiences of those who have recovered from their disorder.

The final chapters discuss the implications of the present research. First, chapter 8 discusses the implications of the research on current theoretical understandings and the ways in which the findings can inform treatment practice. Then, chapter 9 reflexively discusses the methodological implications of the online phenomenological approach. Both, chapters 8 and 9 will also consider recommendations for future research.

Chapter 1: The Experience of Anorexia: A Review of Qualitative Findings

1.1. Introduction

Where there are thousands of anorectics and recovered anorectics, there are thousands of different stories, thousands of stories of pleasure, of rejection, and of acceptance. [...]

We have to begin
To listen,
To talk,
And to write,
But, how?

(Mukai, 1989, pp635-636)

This quote is by Takayo Mukai, a recovered anorexic, whose article detailing her experience of anorexia ends with this call for other anorexics to share their experiences and for them to be given the platform to do so. Mukai's account emphasises how her own experience was often dissimilar to the ideas and accounts on offer from the professional community. A number of researchers in the eating disorder field have highlighted the much-needed importance of focusing on sufferers' perspectives in order to obtain a better understanding of both the disorder and how to treat it (e.g., Bell, 2003; Colton & Pistrang, 2004; Jarman & Walsh, 1999; Matoff & Matoff, 2001; Williams & Reid, 2007). For example, Jarman and Walsh express how:

Qualitative research, examining recovery from the client's perspective, can provide important insights for clinicians seeking information about the recovery process.

(Jarman & Walsh, 1999, p781)

Similarly, Dias (2003, p.39) recognises how the "*the patient's own words*" are often absent from eating disorder studies, despite the fact that "*[c]linical studies of anorexia and recovery which have trusted patients' ideas and given them voice have provided far richer understandings.*"

Anorexia has been described as "a puzzling disease, full of contradictions and paradoxes" (Bruch, 1978, p.3). It is "puzzling" in that it may be seen by the anorexic

as a “solution” (Bruch, 1978; Orbach, 1993) but is considered problematic by healthcare professionals. A person may ‘want’ their anorexic behaviours (Williams & Reid, 2007), but what may be seen as non-problematic and even a solution for the person would be medically and psychologically defined as a problem (Gremillion, 2003; Vitousek, Watson & Wilson, 1998). Research that focuses on the meanings of anorexia from those who have experienced it should help inform current academic and clinical understandings of the disorder and the provision of effective treatment.

Further research into understanding anorexia is essential. It is suggested that the incidence of anorexia is increasing (American Psychiatric Association [APA], 2000; Brumberg, 2000; van Hoeken, Seidell & Hoek, 2005). Anorexia, which was once considered an eating disorder that only concerned white, young women in westernised societies and higher social classes (APA, 2000; Hoek & van Hoeken, 2003), is now apparent in other populations. There is evidence to suggest increased prevalence in men (Bordo, 1999; Soban, 2006), children (Rosen, 2003), people of lower social classes (McClelland & Crisp, 2001) and people from other ethnic and racial backgrounds (Simpson, 2002). There is also increased interest in body image dissatisfaction and eating disorders in older women (Kally & Cumella, 2008). Further research into understanding anorexia may determine why ever more people are developing this disorder.

Anorexia can have severe consequences on the physical health of those who experience it, some of which can be irreversible and even life threatening (Katzman, 2005). Mortality rates for eating disorders are higher compared to other mental health disorders such as depression, schizophrenia and alcoholism (Harris & Barraclough, 1998) with anorexia often described as having the highest mortality rate than any psychiatric disorder (Herzog, Nussbaum, & Marmor, 1996; Palmer, 2003). The American Psychiatric Association (APA, 2000) reports a long-term mortality rate of 10% with starvation, suicide and electrolyte imbalance as the most common causes. Recent reviews of studies on mortality suggest standardised rates ranging between 9.6 and 10.5 (Birmingham, Su, Hlynsky, Goldner, & Gao, 2005; Van Hoeken et al.,

2005). It is therefore crucial that effective treatment is provided for those with anorexia and this can only come from understanding sufferers' treatment needs.

1.2. The Anorexic Perspective

The aim of this chapter is to present the current literature regarding sufferers' understandings of anorexia, recovery and treatment. Through this, the issues of importance for sufferers will be explored. Qualitative work is the focus of this chapter as this approach draws on participants' own experiences and perspectives through their own words.

Bell (2003) reviewed the existing qualitative and questionnaire studies on service users' perspectives of treatment for anorexia and found four common themes: (1) The importance of control; (2) the importance of supportive relationships; (3) the importance of addressing psychological issues; and (4) the importance of experiences outside the treatment setting. These themes will be explored here with reference to other qualitative research and further themes not found by Bell will also be examined. For the purpose of this review, work already reviewed by Bell (2003) will not be looked at again here. Since Bell (2003), further research has been conducted on the perspectives of anorexia, recovery and treatment although much of this research has focused on the experience of recovery.

One of the best places to obtain true emotions and experiences of something is through people's own words; therefore, this chapter will also include the views expressed by those who have experienced anorexia by drawing on published autobiographical accounts.

1.3. The Importance of Control

I felt that if I lost my control over a trivial matter such as eating, then I would lose my control over myself and I would, therefore, no longer be myself

(Wilkinson, 1984, p.53)

Control is an important factor for many people with eating disorders (Hepworth, 1999, Malson, 1998). Psychological theories of anorexia posit a need for control in the person's life as a key precipitating and maintaining factor (e.g. Fairburn, Cooper & Shafran, 2003). These theories will be discussed in detail in chapter 2, however to summarise, the onset of anorexia is thought to occur when uncontrollable life events cause the person to want to retain a feeling of control (Bruch, 1978; Selvini-Palazzoli, 1974). Furthermore, and as the quote from Wilkinson (1984) above illustrates, the need for control is often intrinsically linked to a person's sense of self (Duker & Slade, 2004; Slade, 1982). A need for control was an important concept throughout the qualitative studies. Participants in a number of studies described how anorexia provided a sense of control that they felt could not be obtained in other aspects of their life (Dignon, Beardsmore, Spain, & Kuan, 2006; Lamoureux & Bottorff, 2005; Malson, 1998; Reid, Burr, Williams & Hammersley, 2008).

An interview study by Malson (1998) found that for participants the thin body symbolised self-control because by controlling weight and food the person with anorexia feels in control of their life. Many of the women interviewed mentioned how their anorexia made them feel more in control. Malson (1998) put forward a dualist discourse of anorexia, where for the anorexic the body and mind are separated; the body wants the food but the mind forbids it and therefore exercises control over the body not to have it. Here we can see that the concept of control is intrinsically linked to body shape.

Dignon et al. (2006) explored sufferers' perspectives of the causes of anorexia using a grounded theory approach. Participants in their study described how negative experiences during their lives had caused feelings of loss and unhappiness and led to subsequent body dissatisfaction. Consequently, they wanted to control their food intake as a way of remedying these distressing feelings. The participants believed they had control over food even when they did not have control over anything else. The following extract from Krasnow also emphasises a strong need to feel in control:

I'm 99 percent sure that it's my way of feeling in control of myself. I also know that my greatest fear of ever gaining weight, even just a couple of

pounds, is that I will lose all my willpower and self-control and not be able to stop.

(Krasnow, 1996, p.82)

Participants in the study by Dignon et al. (2006) described a feeling of gratification or a 'buzz' from the control and these positive feelings motivated them to maintain their restrictive behaviours. However, these positive feelings soon led to a 'spiral' situation where individuals felt the need to lose ever more weight and employ stricter behaviours to maintain a sense of achievement. The reinforcement of restriction, due to positive emotions, ended up going too far for many of the participants and this led to feelings of obsession and ritualistic behaviours around food. These ritualistic behaviours were interpreted by Dignon et al. (2006) as part of the participants' perfectionist personality and as a way of "fine tuning" control.

Dignon et al's (2006) study suggests that although anorexia may begin as a way of feeling in control it can go too far. Similarly, participants in a study by Colton and Pistrang (2004) expressed how anorexia had taken away their feelings of control. Additionally, Weaver, Wuest, and Ciliska (2005) report how anorexia, for their participants, took "*control of their minds*" (ibid, p.194), anorexia became a habit, a way of life and their identity. This theme is further explored by Reid et al. (2008) whose participants expressed a feeling of ambivalence towards the level of control that they had. As found in previous studies, participants felt a need to control their food and weight as other elements of their life were deemed out of control. However as their behaviours became more entrenched, participants began to feel that they had lost control of their restriction and instead were being controlled by their eating disorder. The following extracts from autobiographical accounts further illustrate the experience of not being in control of their eating disorder:

Like an alcoholic, the anorexic begins in control but ends up not knowing when to stop.

(Chisholm, 2002, P.26)

Ironically, this time however, I wasn't worried about the calories. As much as I wanted to, I really couldn't physically swallow this liquid.

(Paterson, 2000, p.134)

For the participants in Reid et al's (2008) study, these feelings of lost control caused them to seek treatment. However, they were fearful that during treatment, control may be completely taken away from them and thus it was important for them that treatment allowed them to retain a degree of control. This need for an element of control in the treatment process is iterated in many of the studies reviewed in Bell (2003). Similarly, participants in Colton and Pistrang's (2004) study described a conflict of wanting some responsibility in treatment but worrying about how they would use this freedom. Thus, it is suggested that treatment needs to strike a balance between a collaborative yet directive approach (Colton & Pistrang, 2004; Reid et al, 2008).

The importance of having an element of control during treatment can also be seen in a study conducted by Eivors, Button, Warner & Turner (2003) who found that individuals dropped out of their treatment as a way of re-exerting the control they felt that they had lost. Participants in this study described how the treatment process had left them feeling out of control as a result of focussing too strongly on the symptoms of anorexia rather than the underlying reasons. Whilst the individuals placed a 'functional' meaning onto their anorexia, one of exerting control and coping, others (family, friends and healthcare professionals) saw the eating disorder as problematic and sought to change their behaviours and increase their weight. As a result, treatment focuses on controlling the food that the person eats, taking the control away from them and causing them to re-exert this control by non-compliant behaviours and dropping out of the treatment program.

Eivors et al. (2003) propose an 'Interactional Model of Control' to exemplify the meanings of control. This model illustrates the cyclical nature of needing control when interactions with others threaten to take it from them. They suggest that as the treatment environment decreases the individual's sense of control, help could be given through "*alternative contexts*". This reflects other research that suggests that experiences outside the treatment setting are considered positive factors in recovering from eating disorders (Bell, 2003; Matoff & Matoff, 2001; Tozzi, Sullivan, Fear, McKenzie & Bulik, 2003).

1.4. The Importance of Supportive Relationships

He was always there for me; he always believed in me and never gave up on me. His love and support were what I needed to find the strength in me to beat this disorder.

(Roe, 2006, p.196)

Supportive and understanding relationships both during treatment (with healthcare professionals) and outside the therapeutic setting (with family and friends) were reported as an important factor in aiding recovery in a number of qualitative studies (Bell, 2003; Cockell, Zaitsoff & Geller, 2004; De la Rie, Noordenbos, Donker, & Van Furth, 2006; le Grange & Gelman, 1998; Matoff & Matoff, 2001; Protinsky & Marek, 1997; Tozzi et al., 2003; Weaver et al., 2005). Participants in a study by Protinsky and Marek (1997) reported needing to improve their relationships with family and friends in order to aid recovery as doing so helped them to reduce their behaviours. These participants also found it helpful to be able to talk openly about their thoughts and feelings without being judged. This was also reiterated by participants in a study conducted by Cockell et al. (2004) who used social interaction and talking openly with others as a coping mechanism in place of their previously used eating disordered behaviours.

Relationships were also thought to be important for recovery in other ways too. Spending time with others can become an alternative to the isolation felt whilst experiencing anorexia and can act as a coping strategy or distraction (Cockell et al., 2004; Matoff & Matoff, 2001; Weaver et al., 2005). Social interaction with others could also help the person feel validated and offset the social isolation experienced when anorexic (Weaver et al., 2005). It can also be a way of learning how others eat (Cockell et al., 2004) and allows people to see the different life that they could be leading if they did not have their eating disorder (Nilsson & Haggloff, 2006). Weaver et al. (2005, p.198) describe how participants recognised the need to “let others in” to aid the recovery process. Participants in their study used three types of support: friends, family and other patients. They found talking to other sufferers particularly

beneficial as it allowed them to “feel safe and accepted” and helped them to express their feelings about their disorder.

Tozzi et al. (2003) explored the most common themes associated with recovery and found that having a supportive partner was the highest rated factor that influenced recovery in their participants. The second highest factor was ‘maturation’, which relates to the theme presented in 1.7 (the role of the self in recovery). Therapy/counselling were the third rated factor. However, this study does not go into any detail about their findings, instead presenting the facts in a quantitative fashion by presenting the percentage of participants who mentioned the factors.

1.5. The Importance of Understanding and Addressing Psychological Issues

I feel that not until the psychological side is cleared will the physical symptoms disappear, because while the pressure is still there the cycle is triggered off.

(Wilkinson, 1984, pp148-149)

Many of the studies reviewed by Bell (2003) reported that participants felt there was too much emphasis on weight gain in their treatment. Participants valued psychotherapies but felt that medical interventions were unhelpful. Both le Grange and Gelman (1998) and Cockell et al. (2004) report how participants found the cognitive skills learnt during treatment beneficial. Respondents in le Grange and Gelman’s (1998) study mentioned the usefulness of specific cognitive-behavioural techniques such as diary keeping and distraction techniques. Cockell et al. (2004) found that six months after discharge, many of their participants were applying the skills learned in treatment to manage both cognitions and emotions as a way of maintaining the changes they achieved during treatment. Around half of the participants in le Grange and Gelman’s (1998) study found behavioural strategies helpful; however, some aspects such as food monitoring were not favoured. Many of the participants also felt that the causes of the disorder were not adequately addressed and some felt that the treatment focused too heavily on issues around eating and not on the psychological issues underlying these dysfunctional behaviours. This aspect of

treatment focusing too heavily on weight and not on psychological issues was also iterated in a number of other studies (Colton & Pistrang, 2004; de la Rie et al., 2006; Rich, 2006). This is important to consider given the propensity for recovery to be measured on physical outcomes (American Psychiatric Association, 2006; Jarman & Walsh, 1999). In chapter 2 the problems with defining recovery are considered in more detail.

Garrett (1998) conducted a phenomenological study of the experiences of recovering and recovered anorexics. Her results highlighted six elements that participants considered essential to the recovery process. Interestingly, these elements do not include physical factors such as weight restoration or return of menstruation; rather, all six elements are concerned with cognitive, behavioural and social factors. These include:

- (a) abandoning obsession with food and weight
- (b) strongly believing that they would never go back to starving, binging or purging
- (c) developing a critique of social pressures to be thin
- (d) having a sense that their lives were meaningful – existentially or spiritually
- (e) believing they were worthwhile people and that the different aspects of themselves were part of a whole person
- (f) no longer feeling cut off from social interaction

(Garrett, 1998, p.67)

Through her accounts of suffering with anorexia and experiences of seeking and receiving treatment, Elkins (2000) offers suggestions for treatment improvement. Amongst these she describes how only concentrating on issues associated with food and weight can cause the patient to resent those trying to make them gain weight and may also have the opposite effect. Elkins (2000) describes how she became determined not to put on any weight as she felt this was all the professionals were interested in, rather than focusing on her psychological problems. She also describes how after her first encounter with a private counsellor, who instead of concentrating on food or weight asked her about her feelings about anorexia, she “*came further along the road to recovery in one hour than I had in six months*” (Ibid, p.47). Elkins (2000) also believes that sufferers should be taught what constitutes healthy well-

balanced meals and should not be put on very high-calorie diets that will cause them to gain weight quickly and resent the professionals for trying to do this.

It is essential for healthcare professionals to have an adequate understanding of eating disorders (de la Rie et al., 2006; Rich, 2006; Rother & Buckroyd, 2005), however, as these extracts from autobiographical accounts illustrate, sufferers often feel misunderstood:

It seems to me that within the medical profession there is a considerable confusion and often difficulty, not only in deciding on the cause and therefore what treatment to administer, but also in diagnosing the disease in its early stages.

(Wilkinson, 1984, p.147)

What is shocking is that the illness has been around for centuries and yet even now so little appears to be understood about how to treat it.

(Chisholm, 2002, p.73-74)

Participants in a number of studies have identified feeling misunderstood by others around them (family, friends, healthcare professionals) who only see anorexia as problematic, or who may only focus on the physical effects of the eating disorder (Eivors et al., 2004; Gremillion, 2003; Malson, Finn, Treasure, Clarke & Anderson, 2004; Rich, 2006). In particular, participants in an ethnographic study by Rich (2006) disliked their eating disorder being medicalised in such a way that only the physical issues of food, weight and the thin body were focused upon and how their psychological, emotional and social difficulties were never addressed. This left them feeling they had no one to turn to and they therefore sought support and comfort from the only other people they felt could understand, other sufferers. Participants in the study felt both a connection and a disconnection to other sufferers through sharing tips and experiences whilst also competing with one another. For participants in Rich's (2006) study, the lack of understanding and stigmatisation from others reinforced the anorexic behaviours and subsequently their anorexic identity. Rich (2006) discusses how these findings have implications for the use of the internet for anorexics (and those with other stigmatised disorders) as the online environment allow sufferers to connect with each other and discuss their eating disorder with

those that understand what they are going through. These ideas will be considered further in chapter 3.

Similarly, a discourse analytic study conducted by Malson et al. (2004) identified how participants felt healthcare professionals concentrated only on the eating disorder and not on the person experiencing it. Participants described occasions where professionals dismissed what they were saying as being the disorder talking. This impersonal approach to treatment was not perceived well by the participants who consequently felt powerless. However, this construction of being only the disorder was also at times ascribed by the participants to themselves. According to Malson et al. (2004) both views are problematic as if a patient feels healthcare professionals only see them as the eating disorder and they feel depersonalised this may lead to resistance in treatment, whilst if they ascribe this construction to themselves they may feel that recovery is not possible.

Elkins (2000), who describes herself as a ‘recovering anorexic’, describes four reasons why anorexics find it difficult to seek help for their eating disorder. First, the secretive nature of the disorder renders it difficult for the person to talk about their behaviours. Second, anorexia is a stigmatised disorder which also makes it difficult for a person to talk to a healthcare professional. Although not explicitly stated as reasons for not seeking help, Elkins (2000) also implicitly describes two other factors. The first is a person’s ambivalence about their eating disorder where they are caught between wanting to receive help but yet feeling they cannot cope without it. The second relates to the idea of ‘not being ill enough’ and feeling too fat to be “worthy” of needing help, she describes this as feeling like “*the original fat fraud*” (p.42). The concept of ambivalence will be discussed later in this chapter.

Rother and Buckroyd (2004) discuss how it was not until participants attended a service ran by someone with a previous history of eating disorders that they felt understood, supported and able to recover. Participants expressed that healthcare professionals needed a better understanding of anorexia through “specific education” and that this education needs to be based on real knowledge of what participants are

experiencing. One of the aims of the current research is to obtain a better understanding of the ways in which anorexia and recovery are experienced by those with first-hand experience with the aim of disseminating the findings to those involved in their care.

To summarise, it is clear that to be beneficial, treatment needs to focus on the psychological effects of having an eating disorder. These studies also have implications for the therapeutic relationship, which should be empathic, non-judgemental and must focus on the person rather than diagnosis.

1.6. The Importance of Experiences outside the Treatment Settings

A number of the studies reviewed by Bell (2003) reported that factors that helped recovery often came from outside the treatment setting, a finding that has been iterated in further studies (Cockell et al., 2004; D'Abundo & Chally, 2004; Matoff & Matoff, 2001; Nilsson & Hagglof, 2006; Tozzi et al., 2003; Weaver, et al., 2005).

Using a grounded theory approach, D'Abundo and Chally (2004) explored the patient's perspective of recovery. All participants had either recovered from an eating disorder or were in the process of recovery. Results identified an "eating disorder curve" where the rise in the curve indicates increasing severity of the disorder, whilst decreasing severity is illustrated by the drop in the curve. At the peak of the curve is the "circle of acceptance" which consists of three areas (acceptance of the disease, acceptance of spirituality, and acceptance of others); all three areas work together to create a feeling of self-worth for the individual, and aided their recovery (see, D'Abundo & Chally, 2004, for a diagram). Participants described how irrational thinking, a struggle for control and social withdrawal led to increased severity of the disorder. The eating disorder continued to increase in severity until it reached a "pinnacle", a person may remain at this pinnacle, however, a 'turning point' may occur to begin the process of recovery. Accepting the disease was typically prompted by an event that caused the person to acknowledge the severity of their problem. This may have been hospitalisation, a life-threatening situation, or the negative health consequences of the eating disorder. Accepting spirituality consisted of the person

realising that they wanted a life beyond their eating disorder through feeling hope, valuing life or trusting in God. The third part of the circle involved accepting others through building or re-establishing a supportive relationship with someone, for most this was a family member or friend but for some this relationship was with a healthcare professional. For those who had a complete circle their eating disorder decreased in severity as they were able to think more rationally, feel more in control and become more sociable.

Many of the studies report 'turning points' for deciding to recover, these can be defined as "*events or people that acted as catalysts to recovery*" (D'Abundo & Chally, 2004, p.1109) or "*an unpredictable or unusual experience like a specific moment of emotional meeting or significant event*" (Nilsson & Haggloff, 2006, p.306). For example, a feminist case study described by Matoff and Matoff (2001) identifies four turning points that helped in their participant's recovery process. The first was a realisation that her thinness was jeopardizing her marriage and career; the second occurred when she realised that she did not want to continue in a cycle of recurrent hospitalisation; third was a trusting and accepting relationship with a psychiatrist; whilst the fourth was the acknowledgement of her husband's imperfections.

A number of common turning points have been described. These include changes in life such as moving home or changing school, travelling, becoming pregnant, or taking up a new activity (Cockell et al., 2004; Nilsson & Haggloff, 2006; Tozzi et al., 2003). This is interesting to note, as these same situations have been considered as contributing to the onset of anorexia (Bruch, 1978). Turning points could also centre on life or death where fears about the health consequences of anorexia, particularly death, and a feeling of being sick of being sick can promote motivation for recovery (Nilsson & Haggloff, 2006).

Conversely, Cockell et al. (2004) report how aspects outside of the treatment environment can also cause difficulties in recovery. For example, dealing with real life and its daily stresses could cause lapses in the recovery process. The strong focus

on dieting in real life through the media and in everyday conversation was also thought to be triggering. Participants also found the reduced professional support, loss of structure and a feeling of misunderstanding from those around them as challenging to them maintaining change. The authors conclude that a combination of social support, effective coping and a person's higher values can aid recovery.

The importance of factors outside the treatment environment suggests that treatment should preferably occur through an outpatient setting. Elkins (2000) advocates outpatient care over inpatient care as it allows the sufferer to continue functioning in their everyday environment. A suggestion that is also supported by current treatment guidelines for anorexia (National Institute for Clinical Excellence, NICE, 2004). Furthermore, it is suggested that outpatient treatment is likely to be more acceptable to the patient than inpatient treatment as it allows patients to work on factors affecting the disorder in their social setting, and allows them to have some responsibility over their treatment (Channon & Wardle, 1991).

1.7. The role of the self in recovery

Participants in a number of studies described a need to change aspects of their self in order to facilitate the recovery process. For example, participants in the study by Nilsson and Haggloff (2006) attributed changes in their own thoughts and their own willpower to their recovery process. Cockell et al. (2004) describe how 'personal development' was important for individuals this included pursuing educational, occupational, volunteer or spiritual interests. Participants in some studies (Matoff & Matoff, 2001; Protinsky & Marek, 1997; Weaver et al., 2005) also described needing to differentiate themselves from their families by becoming more individual and autonomous which therefore meant that they were able to define their own identity. This was done by accepting themselves and their needs, taking care of themselves and being more self-aware. Additionally, Weaver et al. (2005) and Lamoureux and Bottorff (2005) also describe how it was important for their participants to dissociate themselves from the anorexic identity and to recognise it as a problem and not a solution.

Weaver et al. (2005) proposes a self-development model to illustrate participants' journey of recovery from anorexia. For these participants, anorexia developed because of "not knowing myself". Anorexia was perceived as "perilous self-soothing" or the use of unhealthy behaviours to try and feel better about the self. However, participants soon took on an anorexic identity that took over their own minds. Recovery was seen as a process of finding their self. This involved "informed self-care" which included taking care of the self in healthier ways, developing a positive view of the self and finally, celebrating the self. This study highlights the important role of identity in both the onset and recovery of anorexia.

Similarly, for participants in a grounded theory study by Lamoureux and Bottorff (2005), recovery required a process of self-exploration and discovery, though seeing themselves as having value. Whilst anorexic they felt that they did not have a sense of self but during recovery they experienced an increasing sense of identity. These studies highlight the need for treatment to focus on re-building sufferer's sense of self.

1.8. The Egosyntonic and Functional Nature of Anorexia

Eating disorders are sadistic: a patient will be taking great pleasure from the pain and that must be understood when offering them a hand out of that pit.

(Elkins, 2000, p.38)

A number of authors have recognised the egosyntonic role that anorexia plays for the individual (Garner & Bemis, 1982; Vitousek et al., 1998). Anorexia is perceived as egosyntonic because the results of the restraint, the thin body and sense of control, agrees with the goals of the self (Garner & Bemis, 1982; Vitousek et al., 1998). Garner and Bemis (1982) describe how anorexia is different from other mental health problems in that anorexia is seen in a positive way by those who experience it: "*what makes the treatment of anorexia nervosa so difficult is that the system provides its own potent reinforcement.*"(Garner & Bemis, 1982, p.128) They describe how

treating anorexic patients can be difficult as they are often reluctant to give up the positive aspects they get. The following quote from Krasnow illustrates this:

Perhaps I'm scared to get better or don't even want to. I've been this way for so long, I don't know of any other way to live. It's as though for some reason. I'm holding on to the anorexia and don't want to let go. The anorexia is my shield, protecting me from something.

(Krasnow, 1996, p.82)

For participants in Weaver et al's (2005) study, anorexia was of central importance; it gave them feelings of comfort, security, and was considered both their "best friend" and their identity. As a result, participants denied any problems with eating and hid their behaviours and weight loss from others. They were also obscuring the problems from themselves which meant that they did not see any negative health consequences. As will be seen in chapter 3, this egosyntonic nature can cause many to want to maintain their anorexia and may encourage them to visit pro-anorexia websites.

Nordbo, Espeset, Gulliksen, Skaderud and Holte (2006) examined sufferers' meanings of anorexia and found eight common psychological meanings of anorexia all of which highlight anorexia as playing a functional role that brings about desired effects. These included (1) security - the person's strict anorexic rules allowed them to have a sense of structure and predictability to their day. This can be linked to the need for a sense of control described earlier. (2) Avoidance - where anorexia allowed them to avoid negative emotions and experiences. By spending their time thinking about their body, weight and food participants were able to avoid thinking of their problems. This avoidance role has been described by a number of theorists (Cockell, Geller & Linden, 2002; Fairburn et al. 2003; Schmidt & Treasure, 2006) and will be discussed in more detail in chapter 2. (3) Mental strength - this was felt when participants achieved a sense of control or power over food. (4) Self-confidence - weight loss caused participants to feel better about themselves. (5) Identity - anorexia allowed the participants to change their sense of self. (6) Care - some participants described the ability to receive care or attention from others. (7) Communication - anorexia was a way of communicating difficulties to other people.

(8) Death – two of the participants expressed how they used their anorexia as a way of disappearing or starving themselves to death. The authors suggest that these eight motives may act as potential reinforcers or maintaining factors for anorexic behaviours.

Although anorexia may be perceived as egosyntonic and functional by those experiencing it, others (family, friends and healthcare professionals) may only see it as egodystonic, dysfunctional and in need of treatment (Eivors et al., 2004; Gremillion, 2003; Mukai, 1989; Vitousek et al., 1998). This can have a negative effect on the therapeutic relationship and may cause treatment resistance. Mukai (1989) speaks of how anorexia is seen only in a negative light by those in the field of psychology and psychiatry. She believes that healthcare professionals should be looking at the positive side of the disorder that is attributed to it by the anorexic:

*The anorectic doesn't think that there is anything wrong with her.
The anorectic wants to stay where she is now.
The anorectic wants to keep what she has now.
The anorectic likes what she has. That is ...a body as a source for
pleasure.*

(Mukai, 1989)

Healthcare professionals are therefore making a “*fundamental error*” when they do not acknowledge the “*egosyntonic nature of thinness and self-control*” (Vitousek et al., 1998, p.398).

1.9. The Concept of Ambivalence

It is possible to hold two contradictory thoughts in your head at the same time: this is the paradox of anorexia.

(Chisholm, 2002, p.20)

Although anorexia has many egosyntonic characteristics, it also has many features that can be regarded as egodystonic, or unbeneficial. Serpell et al. (1999) explored participant's attitudes towards anorexia by asking them to write two letters to their disorder: one as if it was a friend and the other referring to it as an enemy. Participants were already taking part in a treatment programme that included this task. Using a grounded theory analysis, the researchers found ten common pro-codes

and ten anti-codes. The most commonly expressed pro-theme (indicated by almost all of the 18 patients) was that the disorder acted as a guardian where participants felt that their anorexia looked after them, protected them and made them safe. The second most commonly expressed benefit of anorexia was control where participants felt that anorexia provided control and structure to the person's life. The two most common con themes included: 'food' which related to the constant preoccupations and anxieties surrounding food; and 'take over', where the individual felt out of control and taken over by the disorder, this theme also relates to the individual disliking the way that their identity has become anorexia. The full list of pros and cons are presented in table 1.

These findings also illustrate the strong functional role of anorexia: it protects, provides a sense of control, self-confidence and achievement and allows people to communicate emotions. However, at the same time anorexia was seen as having devastating effects on the individual's physical health, psychological well-being, social interaction and negative effects on others around them. One limitation of the study could be with the nature of the task where by writing to anorexia as a friend and an enemy, participants are already being asked to highlight the positive and negative aspects (Nordbo et al., 2006; Serpell et al., 1999). Future research questions could be designed to illicit these emotions naturally through participants talking about their experiences of living with anorexia.

Table 1: The Pros and Cons of Anorexia from Serpell et al. (1999)

Code	Description
Pro codes	
Guardian	Relates to feeling looked after and protected. Anorexia is always there and can be depended upon.
Control	Anorexia provides a sense of control and/or structure.
Attractiveness	When a participant described looking slim or more attractive.
Confidence	Anorexia provides increased confidence.
Avoidance	Where the individual feels the disorder helps them to cope with or avoid difficult emotions.
Difference	Relates to feeling different, special or superior
Fitness	Feeling an increased fitness as a result of anorexia
Skill	Anorexia is seen as something to be good at or something that others are not as good at.
Communicate	Where anorexia was described as a way of showing distress to others
Periods	Where lack of menses as a result of anorexia is seen as a benefit
Con codes	
Food	Relates to negative feelings regarding constantly thinking about or being controlled by food.
Take Over	Relates to feeling taken over, controlled by anorexia, or feeling that they are not a person separate from the disorder
Social	The negative effects anorexia has on relationships with friends and family
Health	The health consequences of anorexia
Hate	Negative emotions towards anorexia
Waste	Where anorexia was considered a waste of time or had stopped them being able to do things
Others	The effects that having anorexia has on others
Psychological	Negative psychological effects of anorexia such as depression
Pretend	Feeling tricked by anorexia or feeling that anorexia does not work
Emotions	Where anorexia prohibited the expression of true emotions.

Serpell et al. (1999) believe it is worth looking at the pros that individuals attribute to their anorexia in order to get a better understanding of the importance of it and why many patients resist treatment. The fact that the participants in Serpell et al.'s (1999) study experienced a feeling of control from their anorexia yet also felt that their anorexia was taking them over, further illustrates the ambivalent nature of control described by Reid et al. (2008).

Freedman, Leichner, Manley, Sandhu & Wang (2006) replicated the research of Serpell et al. (1999) but with a focus on adolescent sufferers. They aimed to find similarities or differences between the two samples. Similar to the adult sample, participants in Freedman et al.'s (2006) study greatly valued the guardian aspect of anorexia. Although a pro- code in the adult sample, none of the adolescents mentioned loss of menses as a positive aspect. The adolescent sample also had an extra pro-theme as they, unlike the adult sample, saw the "social reinforcement of getting attention from others" as a positive thing. Freedman et al. (2006) found no difference between the two samples in regards to the con themes.

As a result of ambivalent attitudes towards their eating disorder, those with anorexia will invariably feel ambivalence about wanting to recover or receive treatment (Colton & Pistrang, 2004; Elkins, 2000; Malson et al., 2004; Rother & Buckroyd, 2004). For example, Paterson (2000, p.225) describes how:

My mind was split into two parts. One was Anna, who wanted to stay out of hospital, and knew to do so, I had to eat. The other was the self-destructive girl that wanted to starve herself to death.

In a study by Malson et al. (2004) ambivalent or contradictory feelings were also expressed about how participants saw themselves. For example, one participant tells how there is "nothing wrong" with her and then lists all of the medical and psychological problems that she had been experiencing. She also explained a "catch 22" situation where she didn't want to gain any weight but recognised how by doing so she was "feeling better." Malson et al. (2004, p.480) discusses how this participant "*figures in her account as someone occupying and torn between a multiplicity of conflicting subjectivities and desires*". As this account illustrates sufferers'

ambivalence about themselves and whether there is anything wrong links in with ambivalence about whether treatment is needed and wanted.

Participants in a study conducted by Colton and Pistrang (2004) also expressed conflict regarding both their anorexia and treatment including whether they were ready or wanted to get better. Participants in this study also described how at times their anorexia was seen as a friend whilst at other times it was considered an enemy. There was also conflicting feelings about whether being around other anorexics was a good thing. They liked the support of being with others but felt conflict with wanting to compete to be thinner and learning new habits. Participants in the study by Colton and Pistrang (2004) believed that being motivated was a key factor in them benefiting from treatment. Thus, the authors suggest this “*lends support to the utility of applying Prochaska and DiClemente’s (1983) transtheoretical model of stages of change to the field of anorexia*” as their study indicates that treatment is more efficacious for those who were more ready to recover. The Transtheoretical model will be further considered in chapter 2.

Similarly, Keski-Rahkonen and Tozzi (2006) looked at the participants’ stages of change in relation to their perspectives on recovery. They looked at the stages of change using a qualitative approach by using participants’ own words and found that those contemplating change expressed ambivalence about wanting to recover, whilst those in the action and maintenance stages described recovery as difficult and discussed the positive and negative aspects of change and counted the days since their last behaviour. Participants in the study felt that the effectiveness of professional help was dependent on their own willingness to change and the authors point out the importance of treatment goals relating to the patient’s stage of change.

Keski-Rahkonen and Tozzi (2005) also looked briefly at the participants’ meaning of relapse, an aspect of the stages of change model that has not been widely discussed in previous studies. Only nine percent of their participants discussed relapsing, which the authors put down to reluctance of acknowledging failure in a public discussion forum. Those who did describe their relapse discussed this in terms of previous

attempts being only a “pseudorecovery” and that relapse occurred after feeling disappointed with the recovery process.

Ambivalence can also be seen in the way that the anorexic body is signified. Earlier in the chapter a study by Malson (1998) was described whereby participants’ bodies were seen as a symbol of control. This control gave the sufferers a feeling of power and strength. However, Malson (1998) also found that the thin body signified femininity and beauty, inferiority and sickness, and was also seen as boyish. This suggests two sets of contradiction: one in which the anorexic body symbolises control and power (which is socially attributed to males) yet is also seen as child-like, frail and sick (attributes related to the inferior position of the female). The thin body embraces femininity and all connotations thereof yet also connotes a discourse of masculinity through a body that can be described as “boyish” and “amenorrhea-ic”. Thus:

The thin female body signifies a multiplicity of femininities and a rejection of femininity. It signifies a conformity to patriarchal femininity but it also indicates a differing from, and a deferring of prescribed gender positions

(Malson, 1998, p.113)

Similarly Orbach (1993, p.165) describes how “*Anorexia reflects an ambivalence about femininity, a rebellion against femininization that in its particular form expresses both a rejection and an exaggeration of the image.*” The following extract from Hornbacher further illustrates the ambivalence felt by those experiencing anorexia:

It is, at the most basic level, a bundle of deadly contradictions: a desire for power that strips you of all power. A gesture of strength that divests you of all strength. A wish to prove that you need nothing, that you have no human hungers, which turns on itself and becomes a searing need for the hunger itself. It is an attempt to find an identity, but ultimately it strips you of any sense of yourself, save the sorry identity of “sick”...It is the thing you believe in keeping safe, alive, contained – and in the end, of course, you find it’s doing quite the opposite.

(Hornbacher, 1999, p.6)

1.10. The Concept of Addiction

I can recall the beginning of my addiction to not eating. The feeling of lightness – of happiness – and a fuzzy, airy kind of energy which seemed to be irreplaceable. This is the high – every addiction has one – something that makes you feel good, something that is worth the low, or so it seems. Initially, my addiction brought me power and pleasure. [...] I ended up feeding only from my addiction. I was surging off the highs that my super-control gave to me.

(Bowman, 2006, p.27)

The concepts of anorexia as egosyntonic, functional and the subsequent feelings of ambivalence felt by anorexics are synonymous to the feelings expressed by those addicted to alcohol or drugs. Earlier in this chapter, an extract from Chisholm (2002) was used to show how the feelings of lost control could be attributed to the feelings of alcoholism.

Garrett (1998) explains how some of her participants found it useful to position their anorexia as an addiction. One described how she switched from one addiction to another, using anorexia and alcohol to feel “high”. Similarly, participants in a virtual ethnographic study of pro-anorexia websites (Williams & Reid, 2007) naturally expressed feeling addicted to their behaviours because of the positive effects that they had, which affected any motivation to change and served to maintain behaviours.

In the following extract, Paterson (2000, p.118) describes how she felt addicted because she too was no longer in control, this had now been taken by the anorexia, a voice that was now in charge of her actions:

I was addicted to starving myself and to break this addiction, I would have to face the thought of sitting down to regular meals, like everyone else. There was no way I could contemplate this absurd idea. The anorexia had taken over and the voice was in charge.

1.11. Chapter Summary

This literature review has identified eight key themes relating to anorexics' experiences of anorexia, recovery and treatment. To summarise, these themes were: (1) The importance of control; (2) The importance of supportive relationships; (3) The importance of feeling understood and of addressing psychological issues; (4) The importance of experiences outside the treatment setting, (5) The role of the self in recovery; (6) The egosyntonic and functional nature of anorexia; (7) The concept of ambivalence; and (8) The concept of addiction. It is suggested here that all of these themes need to be acknowledged in order to understand and effectively treat those experiencing anorexia.

Supportive relationships are important for the recovery process both in the treatment setting and with family and friends, however, sufferers in the reviewed studies expressed that this often did not occur due to a lack of understanding and a stigma about anorexia. In particular, the strong positive and egosyntonic aspects associated with anorexia cause many to want maintain their behaviours rather than seek treatment. This is often misunderstood by others (who do not have an eating disorder) and therefore people looked for supportive relationships from others in their same situation either in treatment settings or through pro-ana websites (e.g. Rich, 2006). Pro-anorexia websites exist for those who wish to maintain their disorder and websites have also been set up for those needing support and understanding in the recovery process. These sites are further explored in chapter 3. As Rich (2006) argues, the lack of understanding from others reinforces the person's behaviours and anorexic identity both by maintaining and learning new behaviours and through sharing tips with others.

It is important that psychological issues be addressed during treatment as this is thought to be important to those with anorexia. Anorexia plays a functional and egosyntonic role for the anorexic as it helps them to manage underlying psychological problems, especially regarding issues of control and self-esteem. It is therefore essential that these aspects be addressed during the recovery process. In

particular, sufferers expressed a need for recovery to focus on issues of the self and to foster self-acceptance. By engaging with others and encountering experiences in their everyday life, yet also receiving professional help there is more of a possibility for patients to work on these psychological issues and use the techniques they learn during treatment (Elkins, 2000; Nilsson & Hagglof, 2006).

At present, there is limited research on the concept of anorexia as an addiction, however, the autobiographical accounts expressed by recovered anorexics, the egosyntonic and functional nature and strong feelings of ambivalence about anorexia, control and recovery suggest that this is an important theme to follow. Research linking anorexia to addiction theory is reviewed in chapter 2.

The concept of ambivalence in eating disorders has recently been considered in treatment guidelines. For example, the National Institute for Clinical Excellence (NICE, 2004) state, "*Healthcare professionals should acknowledge that many people with eating disorders are ambivalent about treatment.*" Consequently, they believe that professionals need to take into account the difficulties that ambivalent attitudes cause. Participants in the studies reviewed here felt strong ambivalence about many aspects of their anorexia including whether it was positive or negative, whether they wanted to recover or not, whether they were in control or whether their anorexia had taken over, whether relationships with other sufferers were beneficial or harmful and about what the anorexic body signifies.

In acknowledgement of the ambivalent attitudes held by those with anorexia, motivational interviewing techniques in treatment have been recommended (see chapter 2). These motivational techniques allow the therapist and client to collaboratively work together to identify areas where change can occur, this therefore relies on a supportive empathic relationship identified as being central to the recovery process (Bell, 2003; Cockell et al., 2004; le Grange & Gelman, 1998; Matoff & Matoff, 2001; Protinsky & Marek, 1997; Tozzi et al., 2003). This also allows the patient to have an element of control in their treatment which has also

been highlighted as important for successful treatment (Bell, 2003; Colton & Pistrang, 2004; Reid et al., 2008).

The present research aims to obtain a better understanding of the perspectives those who are experiencing or have experienced anorexia have towards their disorder. This research uses a phenomenological approach and is therefore concerned with individuals' lived experiences and the meanings that they attribute to these experiences. Vitousek et al. (1998) identify that one of the ways to validate and understand the client's experience is through "*careful (and atheoretical) listening to the phenomenology reported by current and former patients*" (ibid, p.398). This recommendation can also be applied to this research as the findings can then be disseminated for those involved in providing treatment.

Much of the current research into sufferers' perspectives of anorexia has focused on recovery and treatment factors and as such there is a relative dearth in the research pertaining to their meanings of the experience of anorexia. Therefore the current research aims to explore the ways in which anorexia (as well as recovery and treatment) are understood by participants.

The themes found in this chapter will now be further explored in chapter 2 where the theoretical concepts underlying these themes will be reviewed.

Chapter 2: Current Theoretical and Clinical Understandings of Anorexia

2.1. Introduction

This chapter aims to explore current theoretical and clinical understandings of anorexia and to relate these to the understandings of sufferers presented in chapter 1. This chapter therefore places the themes identified in previous qualitative research in a theoretical context, allowing the areas in which these understandings differ and agree to be identified. This chapter will therefore draw on the eight themes identified in chapter 1 and explores these in relation to the key aetiological and treatment literature.

To summarise, the chapter will explore the current definitions of anorexia and recovery utilised by those involved in research and treatment of those with anorexia. It will then look at the aetiological explanations of anorexia. It is a common acknowledgement that the aetiology of anorexia is multi-factorial and made up of biological, psychological and social elements. It is also recognised that the onset of each case of anorexia will be precipitated by different life experiences. According to the review in chapter 1, control and issues surrounding the person's sense of self were implicated as the most important factors in the onset and recovery of anorexia and the psychological and social theories surrounding these concepts are reviewed here. Biological and feminist theories are not reviewed in detail, as these were not highlighted as issues of importance for sufferers. Chapter 1 also highlighted the perceived functional and egosyntonic roles of anorexia and the feelings of ambivalence experienced by sufferers and these concepts, alongside their implications for motivation for recovery, will also be reviewed here. Chapter 1 suggested a role for addiction theories in understanding the experience of anorexia and these theories are explored. The last two sections of the chapter examine the current psychological treatments for anorexia and the role of helping relationships in the recovery process.

2.2. Defining Anorexia and Recovery

Chapter 1 highlighted the need to feel understood and for treatment to not focus heavily on issues of weight and food. This section considers the ways in which anorexia and recovery are defined (and thus understood) by those in the field of anorexia and considers how well this relates to the needs of sufferers.

Diagnosing Anorexia

Anorexia nervosa has been described as “*a refusal to maintain a minimally normal body weight*” (APA, 2000) and “*a relentless pursuit of excessive thinness*” (Bruch, 1978, p.xxi). Presently, two classification systems are used in the diagnosis of anorexia; the tenth edition of the International Statistical Classification of Diseases (ICD-10; World Health Organisation, 1992) and the Diagnostic and Statistical Manual for Mental Disorders (DSM-IV-R, APA, 2000). However, the DSM-IV “*is arguably superior for the eating disorders*” (Palmer, 2000, p.5) and it is probably for this reason that it is the most often used measure for diagnosis and it is this system that will be reviewed here. Using the DSM-IV-R criteria the following four criteria must be met for a diagnosis of anorexia:

- A. Refusal to maintain body weight at or above a minimally normal weight for age and height (e.g., weight loss leading to maintenance of body weight less than 85% of that expected; or failure to make expected weight gain during period of growth, leading to body weight less than 85% of that expected).
- B. Intense fear of gaining weight or becoming fat, even though underweight.
- C. Disturbance in the way in which one’s body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the current low body weight.
- D. In postmenarcheal females, amenorrhea, i.e., the absence of at least consecutive menstrual cycles. (A woman is considered to have amenorrhea if her periods occur only following hormone, e.g., estrogen, administration.)

(APA, 2000, pp544-545)

Furthermore, anorexia is split into two subtypes: restricting type, where weight is lost through restricting food intake or exercise but not with the use of bingeing or purging

behaviours; and binge-eating/purging type, where the individual may also display bingeing and/or purging behaviours such as self-induced vomiting, laxatives, diuretics or enemas (APA, 2000).

As seen in chapter 1, sufferers of anorexia perceive underlying psychological factors as more important than physical aspects. However, the DSM criteria are heavily focused on aspects of weight. A number of authors suggest that these criteria are not adequate in identifying all cases (Anderson, 1990; Garfinkel et al., 1996; Hebebrand, Casper, Treasure, & Schweiger, 2004; Simpson, 2002). Mitchell, Cook-Myers and Wonderlich (2005) have queried the 85% cut-off point for weight, arguing that it was not determined scientifically. Hebebrand et al. (2004) also discuss the need to revise diagnostic criteria. They argue that the term “*refusal*” in criterion A entails an active decision to maintain a low weight. This may be true for some anorexics when they begin to restrict their behaviours but, as seen in chapter 1, as the disorder progresses to the point of needing treatment the person with anorexia may no longer feel they are in control of their disorder (Dignon et al., 2006; Reid et al., 2008). Mitchell et al. (2005) also dispute the use of the term “*refusal*” and suggest that terms such as “*inability*” or “*unwillingness*” may be better suited.

Fear of fatness and body image disturbance criteria (Criteria B and C) can also be considered problematic especially when the diagnostic criteria are applied to those in non-westernised cultures (Mitchell et al., 2005; Simpson, 2002). Simpson (2002) reviewed previous studies to look at the cultural reasons for food restriction. Some previously non-westernised cultures are becoming more westernised and as a result, many are becoming more body image conscious. However, it is also important to consider other individual cultural meanings that do not relate to body image in both western and non-western societies. In regards diagnostic criteria, Simpson (2002, p.70) recommends: “*Instead of trying to place patients within these criteria, health care professionals should recognize the individual cultural reasons for self-starvation and treat the person accordingly.*”

Additionally, feminist theorists question the pathology of eating disorders explaining how most women in westernised societies exhibit fears of fatness and measure self-worth based on their body weight (Bordo, 2003; Orbach, 1993). It is “normal” for women to be significantly concerned with body shape and these attitudes have been termed “normative discontent” (Rodin, Silberstein & Striegel-Moore, 1985). Bordo (2003) therefore believes there is a “blurry” line between pathology and normality when thinking about issues surrounding eating and body image.

Criterion D is problematic for two reasons. First, it can be considered gender biased (Anderson, 1990; Crosscope-Happel, Hutchins, Getz, & Hayes, 2000; Soban, 2006) as it does not take into account endocrine problems such as lower levels of testosterone and subsequent reduced libido that occur in males with anorexia or the fact that men do not menstruate. Anorexia in males is increasing (Hughes, 2008). It also has a high mortality rate and therefore definitions that can rule out half the population or 10% of its sufferers (APA, 2000; Hoek & van Hoeken, 2005) are dangerous. Eating disorders are socially conceived as feminine problems and some doctors may be less inclined to diagnose eating disorders in males. Similarly, men who do have eating disorders may not admit to it or may not recognise or understand that this is the case (Anderson, 1990; Crosscope-Happel et al., 2000; Soban, 2006).

Second, many women meet all criteria, have an extremely low weight but never lose their period (Bulik, Reba, Siega-Riz, & Reichborn-Kjennerud, 2005; Garfinkel et al., 1996; Mitchell et al., 2005). For example, Garfinkel et al. (1996) compared a group that met all criteria for anorexia with a group that met criteria but still menstruated and found no differences in weight history, comorbid factors, family history, developmental experiences or psychosocial functioning. This criterion therefore fails to account for many who have all other physical and psychological symptoms leading Mitchell et al. (2005) to suggest that criterion D for anorexia should be deleted.

Prevalence rates for anorexia are low due to the strict diagnostic criteria. As a result, many people with disordered eating fit into the category of Eating Disorder Not

Otherwise Specified (EDNOS), this may include: those with all anorexic symptoms but with regular menses (category 1), or those with all anorexic symptoms except the person is in a normal weight range (category 2, APA, 2000). These diagnoses suggest that amenorrhea can occur in those who are still normal weight and may not occur in underweight individuals. EDNOS is far more common than anorexia or bulimia, affecting two-thirds (Fairburn & Bohn, 2005) to three-quarters of all eating disorder cases (Machado, Machado, Gonçalves & Hoek, 2007). Although those with EDNOS often suffer as much distress as those with anorexia or bulimia (Fairburn & Bohn, 2005) this may not be recognised by clinicians and insurance providers who may perceive these clients as less severely ill (Mitchell et al., 2005). Indeed, it may also be true that sufferers diagnosed with EDNOS will consider their behaviours as less problematic and may not seek further treatment.

Fairburn and Bohn (2005) have suggested three possible solutions to the problems associated with the EDNOS label. First, the criteria for anorexia and bulimia could be relaxed. They suggest that for anorexia this relaxation could include abandoning the amenorrhea criteria and redefining the core psychopathology to include overemphasis on controlling eating whilst reducing the emphasis on weight and shape concern. Second, and linked to the first, EDNOS could be reclassified so that those considered “subthreshold” cases of anorexia and bulimia could fit within these diagnoses. Furthermore, EDNOS could be renamed “mixed eating disorder” for those cases that are mixed in nature. Third, a “transdiagnostic” solution is suggested. The authors argue that “*far more unites the various forms of eating disorder than separates them*” (Fairburn & Bohn, 2005, p.697) and sufferers often move between diagnoses, therefore a single diagnostic category “eating disorder” could be considered a possibility. Fairburn and Bohn (2005) advocate the take-up of the second suggestion as a short-term solution but believe that the third solution may be more effective in the long-term.

Although the diagnostic criteria may be considered useful in some respects for the recognition of eating disorders, it is clear that they do not account for every case and this review suggests that a revision of these criteria is required. For the current

research, a person who identifies with anorexia but does not necessarily meet the strict diagnostic criteria for anorexia will still be eligible for participation (see chapter 4).

The Problem of Recovery

At present there is no clear-cut understanding of the causes of anorexia and this makes it difficult to define what is meant by recovery (Jarman & Walsh, 1999). Garrett (1998) believes that experiencing anorexia is only part of the story and that the recovery process must also be taken into account in order to aid understanding of the full experience. Despite this, research into anorexia has focused predominantly on aetiology rather than recovery.

A number of researchers have questioned when recovery is reached. Is it when weight is restored? When diagnostic criteria are no longer met? When physical, psychological and social issues are resolved? Or is recovery only reached when risk of relapse is no longer a problem? At present, there is no “global consensus” as to how recovery is defined for eating disorders (Bachner-Melman, Zohar & Ebstein, 2006; Jarman & Walsh, 1999; Kordy et al., 2002). Reported recovery rates therefore vary depending on what criteria are used and this has major implications for treatment and service evaluation.

Participants in qualitative studies tended to define recovery based on personal aspects relating to self-worth (Weaver et al., 2005; Lamourex & Bottorff, 2005) or on the resolution of underlying psychological issues. Garrett’s (1998) phenomenological study identified how sufferers defined recovery based on cognitive, behavioural and social factors. The review of qualitative studies presented in chapter 1 did not highlight any importance to physical factors. Despite this outcome measures for the treatment of anorexia often focus on weight gain or return of menses (APA, 2006). Defining recovery based on such physical factors allows for measurable and quantifiable outcomes (Jarman & Walsh, 1999) but does not account for the important psychological factors associated with the experience of anorexia.

As seen above, amenorrhea is not a practical criterion for diagnosing cases of anorexia (Garfinkel et al., 1996) thus it is argued that menstruation should not be a criterion for determining recovery. Furthermore, weight-recovered anorexics who have not also worked on psychological issues often return for treatment a couple of months later with a reduced weight (Gremillion, 2003). Couturier and Lock (2006) measured participants' recovery based on various weight criteria using the Eating Disorder Examination (EDE), which measures eating disorder psychopathology across four subscales: restraint, eating concern, shape concern and weight concern. They found that recovery rates ranged from 57.1% when EDE subscales scores were within one standard deviation to 94.4% when measuring recovery as having 85% of ideal body weight. These results show a gross disparity in prognosis between the definitions of recovery highlighting the inefficacy of only using weight criteria.

Windauer, Lennerts, Talbot, Touyz, and Beumont (1993) examined the general psychopathology, eating disorder psychopathology, diet and social functioning of 16 weight recovered (Body Mass Index above 18.5) anorexics. Participants still showed some signs of eating disorder psychopathology with half exhibiting preoccupations with food and weight, five experiencing binge/purge behaviours and 12 eating less than 90% of their recommended energy intake. This study can be criticised for its small sample size, however, the authors conclude that weight alone is not an adequate determinant of recovery.

It is clear that definitions of recovery depend on the person's understanding of anorexia. Thus, a healthcare professional who perceives anorexia as a problem of weight and food will only focus upon this in the recovery process. Bachner-Melman et al. (2006) conducted a study to see how far 'cognitive recovery' affects the "*symptomatic and personality profiles*" of previous anorexics. They compared those who they defined as behaviourally recovered only and those who were defined as both behaviourally and cognitive recovered against women with no history of an eating disorder. They defined cognitive recovery as a lack of fear over weight gain and the absence of body image distortion. They found that those who were both

cognitively and behaviourally recovered were closer to controls than those who had only recovered behaviourally. Although the questionnaires did elicit information about such cognitions as perfectionism, self-esteem and obsessiveness, their definition of cognitive recovery seems limited and does not go beyond those used in the diagnostic criteria. Other cognitive factors in the presence of anorexia such as ‘functional avoidance’, beliefs about anorexia and other factors related to negative self-schemata were not considered – these concepts will be discussed later in this chapter.

To operationalise the way in which recovery from anorexia is measured, Kordy et al. (2002) used a framework from depression research. According to Kordy et al. (2002), full remission from anorexia would be considered if a person has no eating disorder symptoms (according to DSM criteria) for at least two months, then, once a person has been in this state for twelve months they could be considered recovered as they are no longer at risk of relapse. These temporal measurements were based on ‘a reasonable guess’ made by specialists from 19 European countries, and seem simplistic without taking into account individual differences in recovery rates. The authors found that “*the data indicate that duration is not a strong predictor of stability of the stages of full remission and recovery*” (Kordy et al., 2002, p.842).

The lack of a concrete and accepted definition of recovery has resulted in inconsistency across the research literature with respect to recovery rates. However, much of the work in the field has used clinician-based criteria leading to calls for client-based criteria to be developed (Bachner-Melman et al., 2006; Garret, 1998; Jarman & Walsh, 1999). As these authors have noted client perspectives are remarkably absent yet might “*provide important insights for clinicians seeking information about the recovery process*” (Jarman & Walsh, 1999, p781). Garrett (1998, p.64) criticises the clinical literature that focuses on quantifiable measurements of recovery built on pre-determined factors based on the views of clinicians, as they do not take into account the “*factors that patients themselves regard as important*”. In contrast, Garrett (1998) extols the virtues of approaches such as taken by Bruch who based her therapeutic approach on phenomenological

accounts provided by patients. Furthermore, as Garrett (1998, p.65) explains: “[r]ecovery is a process, not an isolated, measurable event and because anorexia itself results from complex causes, recovery is also necessarily complex.” In recognition of this ‘process’ the current research will include participants at various stages of their anorexia journey and will ask them about their experiences of recovery.

2.3. Control and the Sense of Self in Anorexia

The review presented in chapter 1 highlighted the importance of control (which related to distressing emotions and low self-esteem) in the onset of anorexia, where feeling no control in other areas of their life meant that participants used dietary restriction for this purpose. Furthermore, the finding that the recovery process required a level of self-acceptance also suggests issues with the self as a precipitating factor. Psychological and sociocultural theories of anorexia also highlight the precipitating and maintaining roles of the need for control and the need to change the self in various different ways and these will be considered here. As will be seen the need to change the self and the need for control cannot be separated. As Duker and Slade (2003, p.20) describe, a sufferer’s “*entire idea of ‘self’ changes according to whether or not control, as they alone judge it, is being achieved*”.

The Need for Control

The need for control in those with eating disorders was measured by Lugli-Riveo and Vivas (2001). Results indicated that those with subclinical eating disorders had lower levels of subjective (perceived control on emotional events) and objective control (perceived control over the environment), than comparison groups of those considered at risk of an eating disorders and a control group. This group also believed that others had control over events (external locus of control) and the authors suggest that these perceptions of control could explain the development of an eating disorder.

Anorexia typically occurs during adolescence with a mean age of onset of 17 (APA, 2000) and 40% of all cases of anorexia occurring in those aged between 15 and 19 years old (Hoek & van Hoeken, 2003). Adolescence is often a time of significant social and biological change for a person that can cause a person to feel the need to regain some control in their life. Anorexia can be preceded by a change in life events, such as moving away to university, which can cause the adolescent to feel unable to cope and in need of feeling in control (Bruch, 1978). Similarly, the onset of puberty and the accompanying bodily changes can be frightening. The female body, in particular, becomes more rounded and maternal and the adolescent begins to feel that they have no control over it (Bruch, 1978; Selvini-Palazzoli, 1974). These social and bodily changes may be interpreted by the young woman as a sign that she must become independent which, as will be seen may prove difficult and anxiety provoking for the anorexic-to-be (Bruch, 1978; Caparotta & Ghaffari, 2006; Crisp, 1995).

Bruch (1978) believes the development of anorexia is a conscious attempt by the anorexic to achieve individuality, autonomy and a sense of control. According to Bruch (1978), anorexia occurs as result of not being able to express a true identity, express true emotions or do what they want during childhood as a result of living their life as a way of trying to please their parents, live up to their expectations and never saying anything that may upset or anger them. The parents are often unaware of the control and pressure that they put on their child and their child's overcompliance is interpreted as acting like the perfect, well-behaved child. The child's strong desire to please, to be over-compliant and act as the perfect child results in them having no sense of autonomy; they do not know what their own needs are, what their own identity is or how to express any feelings that may show them as imperfect. Thus, controlling food intake and body shape is seen as a way of doing something different and living a life of their own. Bruch (1978, p.59) explains how the body may be "*the arena for their only exercise of control*" but fails to consider the wider social context that may explain why the body is used as the site for achieving identity and control.

The Mother-Daughter Relationship

According to psychoanalytic theories, the anorexic's issues with their sense of self can be attributed to the mother-daughter relationship. Early psychoanalytic theories are permeated with the idea that anorexia results from feelings of ambivalence regarding the mother (Caparrotta & Ghaffari, 2006) affecting their sense of self. Personality develops through the identification of personal needs during childhood and for this to occur the person must be able to recognise their own needs. Therefore, misinterpretations or inadequate facilitation of these needs by the mother during childhood can hinder the development of a personal identity (Bruch, 1978; Orbach, 1993; Selvini-Palazzoli, 1974).

The child's unmet needs both during early experiences of feeding (Orbach, 1993; Selvini-Palazzoli, 1974) and through the child living their life in a way to please their parents (Bruch, 1978) leads to the child feeling a level of ambivalence towards their parents, or more specifically the mother. This ambivalence causes the child to want to separate their identity from their mother's, known in psychoanalytic terms as separation-individuation. Selvini-Palazzoli (1974) employs an object-relation theory to explain anorexia, whereby the mother is perceived as a 'bad object'. When the child's body becomes rounded because of puberty, it begins to resemble the body of the mother and takes on the associated meanings that the anorexic wishes to separate herself from.

Korb (1994, p.69) describes anorexia as "a woman's rejection of her mother's life". Participants with anorexia and non-symptomatic controls were asked to write a paragraph about their feelings and opinions about their mother's life and how they wanted their life to be different or similar. Results found that those with anorexia had a more negative impression of their mother's lives than those without. Those without symptoms admired their mothers and perceived them to be living a successful and fulfilling life.

Psychoanalytic theories of anorexia have been criticised as 'mother-blaming' (Hepworth, 1999, Malson, 1998, Woodman, 1982) and more contemporary theories

recognise others' roles in the sufferer's development of identity including critical fathers and boyfriends and experiences of sexual abuse (Bordo, 2003). Furthermore, these theories focus only on the relationship between female children and their mothers and therefore do not account for the development of eating disorders in males.

Restraint and Self-Control

Brumberg (2000) discusses how social changes regarding both food choice and gender roles cause modern adolescent females to need to maintain control over an aspect of their lives. Since the Second World War food has been in abundance in westernised societies, people can enjoy a range of multi-cultural, convenient foods at any time or place that suits them. However, because of a societal obsession with a thin beauty ideal and a fear of fatness, self-control over the consumption of these foods must be exercised. Furthermore, gender roles are also changing where today young women wish to have equality and power through a professional career but at the same time wish to retain the traditional ideas of marriage and a family. Achieving these ambitions also requires the woman to exercise self-control in order that her goals are met, as she lives in a society that still prescribes to the traditional roles for women.

The positive meanings of the thin body held in westernised culture lay in stark contrast to the negative meanings of fatness. This duality is evidence in such meaning as good/bad, success/failure and control/lack of control (Bordo, 2003; Malson, 1998). Negative connotations about fatness have been found in children as young as eight years old (Grogan, 2008), thus, it is unsurprising that those with anorexia perceive their disorder as positive (see chapter 1). The cultural message of thinness as control is consistently presented to people (particularly females) through the diet, fashion and beauty industries (Bordo, 2003; Brumberg, 2000; Lupton, 1996). This connection between thinness and control has also led Duker and Slade (2004) to refer to eating disorders as "food/body control".

It is important to recognise that these meanings have a historical context. Western religious attitudes have promoted this same message. Ascetic practice, such as that associated with Judeo-Christian religion, is seen as the ultimate self-discipline or self-control through controlling food to a minimum amount and with minimal pleasure (Lupton, 1996). The term asceticism “*is often understood as a discipline of self-denial, rejection of physical and emotional needs for the sake of a “higher goal” of salvation*” (Moore, 1994, p.37). Historical accounts of self-starvation have detailed the early controlling practices of medieval saints and “holy anorexics” (Brumberg, 2000; Hepworth, 1999; Lupton, 1996) and although the cultural meaning of anorexia has changed, from “sainthood to patienthood” (Brumberg, 2000), the meaning of thinness has always signified control.

Fairburn, Shafran & Cooper (1999) provide a cognitive-behavioural theory of maintenance centring on the need to control eating. They explain how low self-esteem and perfectionism provoke an initial need for control that is then sought through food restriction. They propose that maintenance is based on three mechanisms; the sense of being in control, the state of starvation and concerns about shape and weight. First, the increased feeling of a sense of control improves self-esteem and reinforces the restrictive behaviours. Second, feelings of hunger and fullness after eating are perceived as threats to control that need to be remedied through further restriction. Third, in western societies, weight-loss and thin body shape increase self-worth and feelings of control and practices that monitor weight and shape such as weighing and mirror checking support fears of weight gain and reinforce behaviours. Although this theory successfully incorporates the strong roles of control and weight concern that were missing in previous cognitive-behavioural theories (Garner & Bemis, 1982; Slade, 1982) it may be questionable as to how much this theory can be applied to sufferers in non-westernised cultures.

The maintaining nature of the need for control is also described by Duker and Slade (2003) who describe a “whirlpool” situation where weight loss causes an increased need for control through further weight loss. With increased weight loss the person

becomes ever more preoccupied by strict rules about food intake, furthering the need to restrict.

Negative Self-Schemata

The main premise of cognitive-behavioural theory for anorexia is that the anorexic person has a core set of dysfunctional beliefs about the self (or self-schemata) based around issues of low self-esteem, low self-worth and low self-efficacy (Fairburn et al., 1999; 2003; Slade, 1982; Wolff & Serpell, 1998; Vitousek & Hollon, 1990). These self-schemata coupled with highly valued schemata about weight, where personal and social meanings of weight and body shape (especially in westernised society) are directly related to self-esteem has been posited in the development of the disorder:

Given characteristic self-schemata (about personal worth, asceticism, perfectionism, maturity, etc), and given characteristic weight-related schemata (about the private and public implications of thinness and fatness), linkage between these elements becomes a logical if not inevitable development for the future anorexic or bulimic.

(Vitousek & Hollon, 1990, p197)

A “core low self-esteem” is considered a maintenance factor in anorexia (Fairburn et al., 2003; Schmidt & Treasure, 2006). Duker and Slade (2003) describe this as “a deep sense of personal worthlessness”. Even if the sufferer receives a positive comment or achieves something to be proud of they will not believe it. This sense of worthlessness further motivates the need for control:

Where it seems that everything else is going wrong, food control is the one thing that can be got right, the one area in which it is possible to feel effective and relatively confident.

(Duker & Slade, 2003, p.112)

Cooper, Todd and Wells (1998) explored the self-beliefs held by those with anorexia, bulimia and a control group through semi-structured interviews asking about experiences of feeling negative about eating. Beliefs about the self in those with anorexia and bulimia were always negative and unconditional relating to “beliefs about being worthless, useless, inferior, a failure, abandoned and alone” (p.218). Some even reported images of what they would look like if they gained weight.

Beliefs about weight, shape and eating were linked to their beliefs about their self. Most of the patients identified how their negative beliefs about the self derived from early negative experiences such as abuse or times when they had felt abandoned or misunderstood. All of them described how dieting helped with their self-beliefs as it helped them to feel less of a failure and more in control.

Slade's (1982) functional analysis theory proposes that the general setting conditions "dissatisfaction with life and self (low self-esteem)" and "perfectionist tendencies" are at the forefront of the onset of anorexia. He describes how adolescent conflicts regarding dependence/independence, interpersonal problems and stressful situations or failures all contribute to make the person feel dissatisfied with their life and their self, resulting in low self-esteem. Perfectionist tendencies and the subsequent need for perfection combined with low self-esteem causes the individual to need to obtain control over or be completely successful at some part of her life. The individual therefore chooses the regulation of her own body as the object of this control or success as this is an area of her life that is not dependent on the input of other people. The individual also possesses the 'non-specific setting condition' 'weight sensitivity' and so following a triggering event such as another person's comment about their weight they will begin restricting food as a form of control.

According to Slade (1982), the dieting behaviour is both positively and negatively reinforced by the effects of the restricting behaviour. The resulting weight loss will cause "feelings of success and control" presumably increasing levels of self-esteem, positively reinforcing the individual to carry on the behaviours, whilst the fear of the potential weight gain that may occur through stopping the dieting behaviours acts as a negative reinforcer. The positive feelings that arise as a result of the food restriction gives the behaviour a highly valued importance causing a disturbance in the perception of body size and a fear in gaining weight and leading to a preoccupation with food, weight and body shape. This preoccupation, is thought to be the result of another negative reinforcer that of avoiding the original problems that had started the "behaviours in the first place" as by continually focusing on food, dieting and changing the body shape there is no room to think of the underlying problems.

Perfectionism

The self-schemata of the person may consist of the need for perfection and this has been posed as another strong developmental and maintenance factor in anorexia (Fairburn et al., 2003; Schmidt & Treasure, 2006; Shafran, Cooper & Fairburn, 2002; Slade, 1982). Perfection is characterised by dichotomous or ‘all-or-nothing’ thinking such that a person will only perceive things in terms of one extreme or another (Shafran et al., 2002; Wolff & Serpell, 1998). Thus, dichotomous thinking means that the weight-related self-schemata is characterised by thoughts such as ‘If I’m fat, I’m bad, If I’m thin, I’m good’ or ideas that eating one biscuit will result in heavy weight gain (Wolff & Serpell, 1998). Thus, this dichotomous thinking can be seen to be a maintenance factor in anorexia.

People with perfectionist attitudes not only have a fear of failure (Fairburn et al., 2003; Shafran et al., 2002; Wolff & Serpell, 1998) but they also tend to only focus attention on this failure rather than on any success. If the person’s exceptionally high standards are achieved, they do not interpret this as a success (or only fleetingly so) rather they interpret this as the need to increase their standards, believing the goal was too easy to begin with. This further increases negative self-evaluation as setting higher standards can only lead to further feelings of failure (Shafran et al., 2002; Wolff & Serpell, 1998). As Fairburn et al. State:

The resulting secondary negative self-evaluation in turn encourages even more determined striving to meet valued goals-including, in this case, striving to meet goals in the domain of controlling eating, shape and weight-thereby serving to maintain the eating disorder.

(Fairburn et al., 2003, p.516)

Studies have found conflicting evidence as to whether perfectionism is a particular characteristic of the restricting or binge/purge subtypes of anorexia (Forbush, Heatherton & Keel, 2007). Forbush et al. (2007) explored the associations between perfectionism and specific eating disorder behaviours. They used the Eating Disorders Inventory-Perfection scale and a questionnaire looking at eating disorder behaviours on 1,200 college students (400 were men). They found no differences

between men and women on measures of perfectionism although men had lower levels of disordered eating behaviours. Those women who reported a history of fasting, bingeing, purging or laxative/diuretic use had higher levels of perfectionism than those who did not, with higher associations for fasting and purging behaviours. Only a history of fasting was significantly associated with perfectionism in males. This study therefore suggests that perfectionism is associated with fasting and purging behaviours but not bingeing behaviours.

Castro-Fornieles et al. (2007) compared perfectionism in patients with an eating disorder, people from the general population and patients with depressive or anxiety disorders using the Child and Adolescent Perfectionism Scale (CAPS), the Eating Attitudes Test (EAT) and the Eating Disorder Inventory-2 (EDI-2). They found higher scores on self-oriented perfectionism in those with an eating disorder than in the patients with depressive or anxiety disorders and the general population but no significant difference in socially prescribed perfection, suggesting the importance of self-prescribed perfection over socially prescribed. They found no difference in perfection between anorexic and bulimic patients, confounding the findings of Forbush et al. (2007). The high levels of self-oriented perfectionism as opposed to socially prescribed perfection could also have implications for the theories that place perfectionist beliefs within the person's self-schemata.

Anorexia is commonly linked to Obsessive-Compulsive Personality Disorder (OCPD), which includes perfectionism as part of the diagnostic criteria (Lilenfield et al., 2006). Obsessive Compulsive Disorder is a common comorbid symptom in those with anorexia and is considered to play a role in both the aetiology and maintenance of the disorder (O'Brien & Vincent, 2003). A systematic review of Randomised Control Trials (RCTs) and naturalist studies investigating the effects of obsessive-compulsive/perfectionism traits in people with anorexia suggest that such traits are associated with negative outcome and may interfere with treatment (Crane, Roberts & Treasure, 2007).

Shafran et al. (2002, p.178) provide a cognitive-behavioural definition of clinical perfection as “*the overdependence of self-evaluation on the determined pursuit of personally demanding, self-imposed, standards in at least one highly salient domain, despite adverse consequences*”. This definition is compatible with the role of the negative self-schema in the psychopathology of anorexia in that people with clinical perfectionism and anorexia evaluate their self based on the attainment of goals. Similarly, Shafran et al. (2002) interpret eating disorders as “*expressions of perfectionism*”. Using terminology used in the psychopathology of eating disorders, they describe the core psychopathology of clinical perfectionism as “*a morbid fear of failure and the relentless pursuit of success*” (Ibid, p.779). This quote illustrates how perfection fits neatly into the psychopathology of eating disorders whereby, considering the person’s weight-related schema, a “relentless pursuit for thinness”, is unequivocally synonymous with a “pursuit for success” and “intense fear of gaining weight” is tantamount to a “morbid fear of failing”.

Trauma and the Sense of Self

The majority of eating disorder sufferers experience traumatic or difficult events before the onset of their disorder. Those with eating disorders have been found to be less able to cope than those without, with one study identifying greater levels of avoidance or rumination (Troop, Holbrey & Treasure, 1998).

Childhood traumas such as physical, emotional or sexual abuse, abandonment, and neglect have profound effects on the person’s sense of self and their relationships (Etherington, 2003). Etherington (2003, p.29) discusses how trauma that is experienced in childhood may not be able to be expressed either because they do not have the vocabulary or understanding to describe it or because they are not allowed/able to tell their story. The “*child’s mind becomes overwhelmed*” and the trauma may become communicated through the body, “*perhaps through illness, pain, compulsion or addiction*”.

Childhood Sexual Abuse (CSA) has been considered as a risk factor in the onset of eating disorders. Vanderlinden & Vandereycken's (1996) review suggests a range of 40% - 70% accounts of co-morbid CSA and eating disorders although this may be more true for bulimic behaviours. People who have been sexually abused have higher levels of body dissatisfaction and self-consciousness than matched controls (Kearney-Cooke & Ackard, 2000). A person who has been sexually abused may use their body as a way of avoiding further incidences by shaping a prepubertal body through thinness or by moving away from their original body shape through obesity (Goodwin & Attias, 1994). Similarly, Rorty and Yager (1996) suggest that if dieting behaviours help control unwanted negative emotions as a result of Childhood Sexual Abuse (CSA) then it is likely that these behaviours will develop into an eating disorder.

Body Image and the Media

In today's society, dieting amongst women is the norm (Orbach, 1993) and women's self-esteem is generally correlated with their weight or body shape (Etcoff, Orbach, Scott, & D'Agostino, 2006; Furnham, Badmin & Sneade, 2002). For example, in a 2005 global survey as part of the Dove campaign for real beauty presented by Etcoff et al. (2006) two-thirds of the women revealed that when unhappy with the way that she looked she avoided activities such as work, socialising with friends, dating, exercising or keeping doctor's appointments. This study included 3,300 women aged between 15 and 64 from ten countries: UK, USA, Canada, Mexico, Brazil, Italy, Germany, Saudi Arabia, Japan and China. Results indicated that nine out of ten respondents wanted to change an aspect of their appearance with body weight and shape ranked as the areas of most dissatisfaction. Most respondents agreed that society's beauty ideal is too heavily defined by physical factors and 76% of the young girls in the UK believed that it is difficult to feel beautiful when they are confronted with society's beauty ideals; this was the highest than in any of the other countries surveyed.

Grogan (2008) presents a review of research (including her own) on body image and illustrates that women of all ages experience body image dissatisfaction, with girls as young as eight worrying about getting fat and middle-aged women showing the same concerns as their twenty-something counterparts. Her review also indicates that white women are more dissatisfied with their body than Asian British, African American and Afro-Caribbean and this is because the meanings of body shape differ across cultures, for instance in African American culture a fuller-figured body can denote sexuality and power. Despite this, increased levels of body dissatisfaction are being seen in Hispanic and Asian American women, which Grogan (2008) attributes to the lack of positive body images in the media. Grogan's (2008) review covered studies conducted in the United States, Australia and Britain exploring body image in opportunity samples of women with 'normal' relationships with food. The studies indicated that, regardless of actual body size, most women wanted to be slimmer. The review of silhouette studies (whereby participants are presented with drawn figures ranging in body shape) found that women's ideal body shape was much thinner than their perceived body shape and most believed that men found a thinner figure attractive.

Some researchers believe that the media has a role to play in the unhappiness women feel about their body image and consequently the aetiology of eating disorders (Brumberg, 2002; Etcoff et al., 2006; Orbach, 1993; Sypeck, Gray, & Ahrens, 2004). In 1998, the Bread for Life Campaign found that 61% of 18-24 year olds feel inadequate compared to the media's image of beautiful women and 89% wanted more average sized models used in magazines (Flour Advisory Bureau, 1998). Indeed, over the last four decades, magazine sales have increased; fashion models have become increasingly thinner; magazine covers have increasingly displayed full-body images of women as opposed to images centring only on the face; and recently models have been wearing more revealing clothes and exposing their thin bodies even further (Sypeck et al., 2004). However, this argument does not support why only a small proportion of women go on to develop eating disorders and the fashion and media industries should only be seen as a contributing factor rather than a cause. Moreover, it is essential to consider that "*fashion and media itself does not*

cause anorexia but can be triggering and maintaining for those with vulnerabilities” (Ringwood, 2007).

It is clear that body dissatisfaction and overestimation of body size is apparent in women with and without eating disorders (Bordo, 2003; Grogan, 2008; Orbach, 1993; Rodin et al., 1985) leading Bordo (2003) to question the pathologisation of eating disorders. However, it is evident that those with eating disorders show a significantly problematic relationship with food and therefore it is clear that other factors (such as core self-schemata and a need for control presented in other theories), alongside body dissatisfaction, are critical in the onset of anorexia.

It is also important to consider that males also experience body dissatisfaction and eating disorders. Men prefer a more muscular body image and may be more likely to use excessive exercise behaviours to achieve this (Weltzin et al., 2005). The male body is increasingly becoming a focus of society's obsession with beauty (Crosscope-Happel et al., 2000; Soban, 2006) which means that men are also under pressure to maintain a particular body shape (Crosscope-Happel et al., 2000) increasing the risk of them developing eating disorders (Soban, 2006). Indeed, Hughes (2008) reports a growing number of eating disorders in teenage boys. It has also been suggested that with changing gender role expectations for men (e.g. taking on more of a family role) there may be an increase in the number developing eating disorders (Reid & Burr, 2000). Body image dissatisfaction can have the same negative effects on self-esteem as for females; Furnham et al. (2002) found that for both males and females eating and body image attitudes were highly correlated with self-esteem. However, the authors postulate that low self-esteem may be a precipitant to body image dissatisfaction rather than an effect.

2.4. The egosyntonic and Functional Nature of Anorexia

Chapter 1 highlighted the egosyntonic and functional nature of anorexia (partly because of the effects it has on sufferers' sense of control and their sense of self). These egosyntonic and functional roles mean that the person is often motivated to

maintain their eating disorder rather than recover. Indeed, sufferers of anorexia are normally resistant to treatment interventions (Cooper, 2005; Hepworth, 1999; Patel, Pratt & Greydanus, 2003; Roth & Fonagy, 2005), with a high number dropping out of treatment prematurely (Cooper, 2005; Eivors et al., 2003). One reason for the resistance in treatment is the fact that many with anorexia deny that their behaviours are problematic or perceive it as a solution (Garner & Bemis, 1982; Vitousek et al., 1998).

In 2003, Fairburn et al. developed the “transdiagnostic” theory of the maintenance factors associated with those with anorexia, bulimia and EDNOS. These include ‘clinical perfectionism’, ‘core low self-esteem’, ‘mood intolerance’ and ‘interpersonal difficulties’. Likewise, Schmidt and Treasure (2006) also consider four maintaining factors in anorexia, three of these, ‘perfectionism/cognitive rigidity’, ‘experiential avoidance’ and ‘response to close others’ are similar to the constructs developed by Fairburn et al. (2003) but, instead of ‘core low self-esteem’ they have included the factor ‘pro-anorectic beliefs’. This review has already discussed core low self-esteem and perfectionism as fundamental characteristics of the development and maintenance of anorexia. The roles of pro-anorectic beliefs and experiential avoidance will now be considered in more detail by drawing upon other work to complement. Interpersonal factors will be discussed later in the chapter.

‘Pro-anorectic Beliefs’

Garner and Bemis (1982) describe how anorexia is different from other mental health problems in that it is perceived positively by those who experience it: “*what makes the treatment of anorexia nervosa so difficult is that the system provides its own potent reinforcement*” (Garner & Bemis, 1982, p.128). They describe how treating anorexic patients can be difficult as they are often reluctant to give up the positive aspects they get, which is often thought to be the only way these they feel they can achieve happiness:

While the baseline is unhappiness, weight loss is the one pleasure that gives relief; patients have no wish to forgo this single gratification and they are incapable of seeing beyond it.

(Garner & Bemis, 1982, p.128)

There is an obvious paradox in understandings between the client who sees their behaviours as a solution and the healthcare professionals who see it as something to be cured (Gremillion, 2003; Vitousek et al., 1998). As seen in chapter 1, this can often cause sufferers to find understanding outside of the therapeutic context (e.g. Rich, 2006). Clinicians need to be aware of the positive roles that anorexia may play in the person's life (Miles, 1994; Vitousek et al., 1998) because ignoring this will result in them being unable to offer any useful treatment (Miles, 1994).

Cognitive-behavioural theories recognise the functional and egosyntonic roles of anorexia and the subsequent effect on its maintenance (Garner & Bemis, 1982; Vitousek & Hollon, 1990; Vitousek et al., 1998) leading others to consider the role of resulting 'pro-anorectic' beliefs (Schmidt & Treasure, 2006; Wolff & Serpell, 1998) in the maintenance of the disorder. As Wolff and Serpell state:

Pro-anorexia meta-cognitions (such as 'if I didn't have anorexia, my whole world would fall apart, I wouldn't be able to cope) enhance resistance to treatment whilst anti-anorexia meta-cognitions (such as 'anorexia stops me from having a life') can enhance motivation to change.

(Wolff & Serpell, 1998, p412)

Using the results from their qualitative study (Serpell et al., 1999 – see chapter 1), Serpell, Teasdale, Troop and Treasure (2004) developed the Pros and Cons of Anorexia Nervosa (P-CAN) scale to quantitatively measure the positive and negative aspects of the disorder. Results of the P-CAN identified that those with more severe anorexia had stronger beliefs about a positive function and had lower scores on the cons subscale. They found no significant difference between the beliefs of those who were currently ill and those who were recovering.

Similarly, drawing on the Transtheoretical model of changing behaviours (see later in the chapter), Cockell et al. (2002) developed and validated (ibid, 2003) a

questionnaire to measure the decisional balance (the weighing up of pros and cons) expressed by those with anorexia. They found that those considering changing their behaviours saw more burdens to the disorder. However, they did not find significant differences in beliefs about the pros of the disorder between those who were not contemplating recovery and those that were, supporting ideas that anorexia is highly valued by sufferers (Cockell et al., 2003). They therefore suggest that therapists need to be aware that patients may see benefits to anorexia until they have worked on new ways of coping and 'self-definition'. Furthermore, whereas decisional balance scales for other behaviours normally consist of two subscales: pros and cons, Cockell et al. (2002) found that the ambivalent nature of anorexia meant that a third subscale needed to be incorporated. The three factors for this questionnaire therefore consisted of benefits (or pros), burdens (cons) and functional avoidance. The concept of functional avoidance will be returned to later in the chapter.

There has been little research investigating to what degree pro-anorexia beliefs relate to the maintenance of the disorder (Schmidt & Treasure, 2006). It seems that pro-anorexia beliefs obviously play some roles in its maintenance as the popularity of pro-anorexia websites confirms and this will be considered further in chapter 3.

Feelings of Ambivalence

At the same time as receiving positive, egosyntonic effects from behaviours, those with anorexia may also acknowledge negative effects, causing strong feelings of ambivalence. Ambivalent feelings will also play an adverse role in treatment resistance. The term ambivalence describes the process of having “*conflicting motivations*” or “*feeling two ways about something*” (Miller, 1998, p.123). Miller (1998) describes how for those trying to change addictive behaviours ambivalent feelings can be detrimental to the recovery process:

Ambivalence is immobilizing. One thinks of the not-so-good things about a present situation, then about the good things, then again about the reasons to change, finally moving on to think of something less stifling.
(Miller, 1998, p.123)

Indeed, Vitousek et al. (1998) describe how the more ambivalent the anorexic is the more they will manipulate aspects of treatment in order to maintain behaviours. Miller and Rollnick (2002, p.14) present ambivalence as “*a natural phase in the process of change*” and argue that it is only when the individual gets ‘stuck’ in ambivalence that it becomes problematic.

Because of the strong ambivalence and resistance exhibited in those with anorexia, a number of researchers have applied the Transtheoretical model to investigate change behaviour. This model (see for example, Velicer, Prochaska, Fava, Norman, & Redding, 1998) can determine a person’s readiness and motivation to change a particular behaviour by assessing the person’s stage of change (consisting of five stages: precontemplation, contemplation, preparation, action and maintenance, see Velicer et al., 1998).

Ward, Troop, Todd and Treasure (1996) adapted questionnaires used in research on bulimia to look at the stages and processes of change in thirty-five inpatients (22 with anorexia, restricting subtype, 2 with bulimia and 11 with anorexia, binge/purge subtype). Although the study is limited by the small numbers, results showed that three were in the precontemplation stage, 14 in contemplation and 18 were in the action stage. The authors describe the difficulties of assigning a single stage to eating disorder patients: scores of 15 patients allocated to the action stage were tied between contemplation and action. However, it is interesting to note that the authors did not incorporate the preparation stage and perhaps this is why there was discrepancy here, something which is not drawn upon in the study.

Blake, Turnball and Treasure (1997) adapted questionnaires previously used for weight control and looked at stages and processes of change in 109 patients presenting at an outpatient clinic. The study found that half of the patients with anorexia were not ready to change their behaviours being more likely to present for treatment in a precontemplation or contemplation stage, whereas those with bulimia were in the action stage. The authors relate this to the egosyntonic nature of anorexia

and the fact that many are externally motivated to seek treatment (e.g. they are often taken by friends and family).

More recently, Rieger et al. (2000) have developed and validated (Reiger, Touyz & Beumont, 2002) the Anorexia Nervosa Stages of Change Questionnaire (ANSOCQ), a 20 item self-report questionnaire designed to evaluate readiness to recover in anorexia. When using the ANSOCQ, individuals are asked to choose one of five statements, with each one referring to the five stages of change. Answers referring to the pre-contemplation stage are scored with 1 and those referring to maintenance are scored 5. Thus, a score of between 20 and 100 can be achieved. The full questionnaire can be found in Rieger et al (2002). Although the ANSOCQ (Rieger et al., 2002) has been validated, one potential criticism of the questionnaire and the other studies listed above is that they are based on the original Transtheoretical Model or adapted from other measures using researcher's and healthcare professional's perspectives of what constitutes recovery rather than on sufferer's own experiences. Despite the fact, as was seen earlier in the chapter and expressed by Jordan, Redding, Troop, Treasure and Serpell (2003), there is no agreed definition of recovery for anorexia.

Another limitation of the questionnaire studies is that the complex, multi-symptomatic and ambivalent nature of eating disorders may mean that individuals fit into more than one stage of change, which would not be picked up with the use of a questionnaire (Geller & Drab, 1999; Sullivan & Terris, 2001; Ward et al., 1996). More generally, the stages of change have been heavily criticised for its arbitrary differentiation of stages, which causes difficulty in assigning people to a particular stage of change (West, 2005). For example, Etter (2005, p.1041) has stated that "*the concept of 'stage of change' is a haphazard mixture of current behaviour, intention to change, past quit attempts and duration of abstinence*". The stages of change model also assumes that individuals make clear plans about changing behaviours which is not always the case and does not take into account other processes of motivation such as perceived rewards and punishments which make habitual behaviours difficult to change (West, 2005). Indeed, the strong maintenance factors

considered in this section suggest strong reward motives for anorexic behaviours that may not be measured adequately using the stages of change model.

Functional Avoidance

Anorexia's role in enabling the sufferer to avoid emotions and responsibilities has been found in a number of studies (Cockell et al., 2003; Serpell et al., 1999, 2004; Troop et al., 1998). Indeed, Crisp (1995) theorises the onset of anorexia as being a way of avoiding adulthood and the emotions and responsibilities that come with it, through maintaining a pre-pubertal body shape.

People with anorexia become preoccupied with thoughts about food and weight because of a natural drive to eat and the strict dietary rules that are deemed important for the person. These preoccupations can override all other thoughts and emotions: “[t]he exclusive mental focus on food and eating is associated with emotions becoming less salient and clinically many patients report that they feel somewhat numb” (Schmidt & Treasure, 2006, p.347). The feelings of numbness are seen as a positive function of anorexia as they allow the anorexic to avoid difficult emotions. It has been suggested that those with an eating disorder suppress negative emotions (termed silencing the self) and instead choose to focus on the needs of others (Zaitsoff, Geller & Srikameswaran, 2002). Furthermore, high levels of alexithymia, characterised by difficulties in identifying and describing emotions, have been found in those with anorexia suggesting a lack of ability “to tolerate and modulate emotions” (Bourke, Taylor, Parker & Bagby, 1992, p.242).

This process of avoidance has been given different terms by different authors including ‘mood intolerance’ (Fairburn et al., 2003) ‘experiential avoidance’ (Schmidt & Treasure, 2006) and ‘functional avoidance’ (Cockell et al., 2002). Fairburn et al’s (2003) consideration of this fails to recognise the situational aspect of the avoidance and only focuses on the affective nature. Schmidt and Treasure (2006) acknowledge how anorexia functions as way of avoiding “the experience and

expression of intense negative emotions and the need to avoid close relationships, which trigger these emotions” (Schmidt & Treasure, 2006, p.335).

‘Functional avoidance’, a term coined by Cockell et al. (2002) is similar to Schmidt and Treasure’s (2006) ideas and relates to the functional use of anorexia as a means of avoiding negative emotions and/or situations and relationships related to leading an adult life. According to the authors, functional avoidance is related to the functional use of anorexia as a means of avoiding negative emotions or aspects to do with adult life. This is considered to be both a pro and a con as although the avoidance of problems can be seen positively this also prevents long term goals which is perceived negatively. This decisional balance scale further highlights the strong ambivalence those with anorexia have about their disorder. Functional avoidance was a strong theme in the empirical work and is discussed in relation to participants’ own experiences in chapters 6 and 7.

Motivational Issues in Anorexia

Motivation to change behaviours is essential for the recovery process. Those with higher levels of motivation have a better outcome and are more likely to complete their treatment programme (Jones, Bamford, Ford & Schreiber-Kounine, 2007). A number of authors have recommended the use of motivational interviewing (Roth & Fonagy, 2005; Treasure & Schmidt, 2001; Vitousek et al., 1998, Wolff & Serpell, 1998) in the treatment of anorexia due to the levels of ambivalence displayed by those experiencing it. Motivational interviewing looks at the perceived pros and cons of a behaviour and a person’s motivation to change, measured by their willingness, readiness and ability (or self-efficacy) (Miller & Rollnick, 2002). Being willing refers to how much a person wants to change and how important the change is considered, readiness relates to the level of priority given to change, and being able refers to the person’s self-efficacy and how confident they are to change.

Motivational interviewing is defined by Miller and Rollnick (2002, p.25) as “*a client-centred, directive method for enhancing intrinsic motivation to change by*

exploring and resolving ambivalence.” In other words, it uses a collaborative and individualised approach to explore the client’s own experiences and values to elicit ‘change talk’ and to improve self-efficacy; the therapist facilitates the client to discover the reasons for change by looking at the motivations intrinsic to self. This is dissimilar to extrinsic approaches like behavioural programmes that use punishments and reward systems to elicit change. Motivation interviewing advocates freedom of choice in treatment (Treasure & Schmidt, 2001) which is in keeping with sufferers’ concerns about the importance of control described in chapter 1 (Bell, 2003; Reid et al., 2008). Motivational interviewing was originally perceived as a way of preparing clients for further treatment and indeed, it can be used in this way. Additionally it can be used as a ‘communication style’ during other therapeutic approaches (such as Cognitive Behavioural Therapy) and can be used throughout treatment when the need to address motivational issues arises (Miller & Rollnick, 2002). Indeed, as Vitousek (2002, p310) explains “*resistance to change is not an initial barrier that is cleared as soon as anorexic patients are persuaded to enter treatment*”. Motivation should be an ongoing focus of care.

Treasure and colleagues (Treasure & Schmidt, 2001; Treasure & Ward, 1997) have looked at using motivational interviewing for anorexia. This has been derived from treatment approaches for changing addictive behaviours (e.g. Miller, 1998) and aims to identify the areas where ambivalence about anorexia and treatment arise. In particular, motivational techniques include looking at the functional and egosyntonic aspects of anorexia, the perceived pros and cons of both anorexia and treatment, and subsequently the patient’s resistance to change (Vitousek et al., 1998). By exploring clients’ perceived pros and cons of the disorder, work can begin on changing behaviours. According to Vitousek et al. (1998), there are often contradictions between the pros and cons that should be drawn out and explored in the therapeutic context. For example, a perceived pro for an anorexic may be the attention they may receive but a con may be the continual negative attention about weight loss.

Nordbo et al. (2008) used a phenomenological approach to explore participants’ motives for recovery. Motivation fitted into four areas: “sense of vitality” referring to

increased joy, concentration and energy; “sense of autonomy”, for example choosing to recover; “sense of insight” such as acknowledging the limitations of their weight goals; and negative consequences such as the effects on their health, social interaction or their future.

Although the results are limited by a small sample size (n=8), a study by George, Thornton, Touyz, Waller and Beumont (2004) suggests the efficacy of using motivational interventions with chronic anorexics. Patients reported increased motivation to change their behaviours. The motivational intervention also positively affected compliance with treatment and the ability to utilise treatments more effectively (George et al., 2004). Further research with larger sample sizes should be conducted in this area.

2.5. Addiction Theories of Eating Disorders

Chapter 1 recognised how some with anorexia felt that they were addicted to it due to feeling unable to stop their restrictive behaviours. Furthermore, the egosyntonic and functional nature of anorexia was also considered to suggest a connection between anorexia and addictions. These factors have also led some authors to suggest a relationship between eating disorders and addiction. References to the addictive nature of eating disorders have been made by different authors with different theoretical standpoints (Bordo, 2003, Brumberg, 2000, Garret, 1998; Vitousek et al., 1998). For example, Garrett (1998) expresses how both are concerned with dealing with emotional problems, both are habitual, and both require an acceptance of the problems that lead to their onset in the first instance if they are to be treated. Furthermore, Garner and Gerborg (2004) believe that applying an addiction model to explain eating disorders “*makes sense*” as both addictive behaviours and eating disorders consist of compulsive use, loss of control and continued use despite adverse consequences. Additionally, individuals with addictions or eating disorders can become preoccupied with their behaviours, are often secretive about them and use them as a way of coping (Garner & Gerborg, 2004).

A link with addictions has been considered in bulimic behaviours (Orford, 2001), obesity (Brownell, Marlatt, Lichenstein & Wilson, 1986) and eating behaviours in general (Hammersley & Reid, 2001). A number of authors have also described how anorexia could be considered an addiction to starvation (Davis & Claridge, 1998; Huebner, 1993; Marrazzi & Luby, 1986; Szmukler & Tantam, 1984). Using seven key criteria for alcohol dependence, Szmukler and Tantam (1984) argue how each criterion can be applied to anorexia nervosa:

- 1) Anorexics narrow their 'eating repertoire', by eating limited food types
- 2) Salience of self-starvation, anorexics are preoccupied with thoughts about food and weight and evading eating is of primary importance
- 3) 'Subjective awareness for the compulsion to starve': the anorexic gets to a point where they feel they cannot eat, have lost control over the ability to eat and if they do eat this needs to be compensated
- 4) 'Increased tolerance to restraint': the anorexic needs to lose more and more weight and needs to starve for longer periods to continue achieving positive effects
- 5) Withdrawal symptoms: eating causes distress for the anorexic whilst not eating has positive effects
- 6) Further restraint to avoid or relieve withdrawal symptoms including compensatory behaviours if they do eat to remedy withdrawal effects such as feeling guilty
- 7) 'Reinstatement of the syndrome after abstinence', anorexics often relapse after initial refeeding.

Davis (1996) describes how addictions are made up of physical and biological, psychological, and socio-cultural factors. He defines addiction as:

A **compulsion** or strong desire to engage in the behaviour; an overwhelming priority or **salience** being given to the behaviour; an impaired capacity to **control** the behaviour; and **distress** if prevented from carrying out the behaviour.

(Davis, 1996, p.11 [Bold as author's own])

Whether eating disorders can be explained using addiction theory has been contested. This contention relates to the idea that certain characteristics of addictions (at least using a biological explanation) are absent. The two main biological features of addiction are tolerance and withdrawal, which occur because of neuroadaptation (Davis, 1996). Therefore, in the example of a cocaine addict, the brain adapts to the repeated presence of the drug and therefore requires more of it to achieve the same effects (tolerance). When drug use is ceased, the adapted brain decompensates

resulting in withdrawal symptoms that are contrary to the effects of the cocaine such as lethargy and dysphoria. Some authors have argued how symptoms such as tolerance, withdrawal and cravings are noticeably absent in those with eating disorders (Klein & Walsh, 2004; Wilson, 1999). However, as Orford (2001) argues, it is questionable how essential the symptoms of withdrawal and tolerance are for the diagnosis of addiction. He explains how the propensity for those in the field to view drug addiction or substance abuse as central to the field has shaped the way that addiction is defined. As a result, other areas of addiction (or excessive appetite) have been sidelined (Orford, 2001). Orford (2001, p.3) sees eating as one of the “core addictions” (alongside drinking, gambling, drug taking, exercise and sex).

It is also argued that, rather than being a sign of addiction, preoccupations with food experienced by those with anorexia or bulimia should be seen as a response to the biological need for food (Wilson, 1999). However, preoccupations were discussed above as a functional way of avoiding difficult emotions (Schmidt & Treasure, 2006) and this function of modifying or ‘escaping’ negative emotions is considered a central feature of all excessive appetites (Orford, 2001). The role of anorexia in resolving negative emotions has also been implicated by other authors who associate it with a theory of addiction (Brumberg, 2000; Huebner, 1993).

This idea may also explain why not all those who restrict their intake go on to develop anorexia (Brumberg, 2000; Huebner, 1993). According to Huebner (1993), those who are initially depressed or anxious before dieting and have low self-esteem are more vulnerable to becoming addicted to the rewarding anti-depressant and anti-anxiety effects of the endorphins secreted through restriction. Conversely, the average dieter does not have a significant precipitating depressive mood and diets solely for social reward. These rewarding effects become a coping mechanism for the anorexic as although her situation has not changed (she still experiences the situations that caused her to become depressed or anxious) the positive effects increase her ability to cope with them. Brumberg (2000) explains how if restricting food causes emotional satisfaction (e.g. control, expression of identity) then it becomes more difficult to stop.

An addiction theory may also explain the maintenance of anorexia. Huebner (1993) describes how the anorexic has two minds: an addicted mind and a healthy mind. He describes a state of cognitive dissonance or ambivalence where on the one hand the anorexic *cannot* stop her behaviours, despite being worried about their health, yet on the other they *do not* want to stop the behaviours that are enabling them to feel better and more able to cope. The addicted mind corrects this cognitive dissonance through a number of cognitive mechanisms, including denial of a problem, change in values about food, weight and body image, social isolation, self-denial of pleasure but an increase in self-punitive behaviours.

An alternative explanation is provided by Woodman (1982), she takes a psychoanalytic approach to eating disorders and theorises them as a reaction to societal expectations for perfection. Rather than associating perfectionism as part of core self-schemata (as described above), she suggests that all addictions and compulsions (alcoholism, obsessive cleaning and eating disorders) are a result of a need for perfection in all areas of life. Drawing on Jungian theories of masculinity/femininity and persona/shadow, some of her ideas may be outdated. Nonetheless, the relationship between perfection and addiction and the consideration of the important roles of sociocultural expectations seem relevant to the experience of anorexia.

Similar to Huebner (1993), Woodman describes a separate part of the anorexic that demands them to continue their behaviours. The role of this other self seems to be one of maintaining anorexia, to continue the spiralling journey towards perfection, success and the 'ideal self'. Woodman says:

In an effort to be mature and independent, such a woman tries to be more and more perfect because the only way she can alleviate her dependence on that judgemental voice is to be perfect enough to shut it up.

(Woodman, 1982, p.62)

Participants in the current research often spoke of experiences of a judgemental voice and so these ideas will be returned to later in the thesis.

A relationship between anorexia and addiction may also be observed in the levels of comorbidity with addiction. High rates of substance abuse have been found in those with anorexia and bulimia (Jade, 2007; Wilson, 1999) although this may be more so in those with bulimic symptoms (Jade, 2007). O'Brien and Vincent (2003) report how women presenting for treatment for substance abuse also have a higher rate of eating disorders. Herzog et al. (1996) identified moderate rates of substance abuse in those with anorexia (12-21%), which were less in those with the restricting subtype than the binge-purge type. This can be related to impulsivity, where it is suggested that those with binge/purge behaviours engage in more impulsive behaviours such as purging, substance abuse, kleptomania, sexual promiscuity and more commonly, self-injury (Svirko & Hawton, 2007).

To investigate this relationship, Davis and Claridge (1998) measured the addictive personality traits of 83 female patients (34 anorexic/ 49 bulimic). They found that both groups showed similar overall scores on the addictiveness scale of the Eysenck Personality Questionnaire-Revised as earlier studies had shown for drug and alcohol addicts. Despite this, they found noticeable differences between the personalities of the anorexic and bulimic participants. Although both were negatively correlated with addiction and neuroticism, addictiveness in those with anorexia was also related to introversion but for bulimics the addictiveness was more related to impulsivity. This suggests that there may also be differences in the reasons and experiences of addiction in these two groups.

Orford (2001) provides a social-behavioural-cognitive-moral model to explain excessive appetites (his term for addictions). Although he does not pay much attention to the idea of anorexia as an excessive appetite, he does describe in detail the ideas relating to addiction to eating. Nonetheless, his model does seem to fit with a suggestion that anorexia can be linked to addictions. According to Orford (2001, p342-343) excessive appetites:

- (1) "Serve numerous personal functions" for the individual including modifying negative mood or facilitating self-expression – this is illustrated in the use of

anorexia for functional avoidance (Cockell et al., 2003) or a way of resolving low self-esteem (Vitousek & Hollon, 1990)

- (2) Are “dynamic” and may serve different functions for people at different time therefore effecting the levels of its use – people will increase their anorexic behaviours to try and gain increasing levels of control and or self-esteem (Duker & Slade, 2004; Fairburn et al., 2003)
- (3) Are developed through reinforcement; people learn to increase their behaviours based on positive and negative reinforcement, the rewards they receive and the development of “behaviour-enhancement” expectancies – as evidenced through cognitive-behavioural models of the maintenance of anorexia (Slade, 1982)
- (4) Increasing attachment to the appetite results in salience and preoccupation, the behaviour also begins to play even more far ranging purposes and become more automatic. The appetitive behaviour becomes further reinforced through new motivations such as “maintaining secrecy”
- (5) Incur costs that may be “physical or social, immediate or long-term, affecting the self or others” and results in ambivalence –negative effects of anorexia (Freedman et al., 2006; Serpell et al., 1999) and a strong feeling of ambivalence have been identified in those with anorexia (Vitousek et al., 1998)
- (6) Initial attempts in stopping excess often result in relapse back to the appetite following an attempt to change
- (7) “Giving up addiction” requires a cognitive decision to change before the behaviour can be changed. This often involves a moral evaluation of behaviours. This is suggestive of a need for motivation and has been implicated in the treatment for anorexia (Treasure & Schmidt, 2001).

2.6. Addressing psychological Issues in Treatment

Chapter 1 highlighted the importance of treatments to focus on the underlying psychological issues. However, many who treat anorexia believe that psychological interventions will not work until normal weight and metabolism is reached.

According to Comerici and Greydanus (1997) “*as weight is gained, thinking becomes clearer and less obsessional*”. Those involved in the treatment of anorexia unanimously agree that psychotherapy should not be attempted until the dangerous physical effects of emaciation have been treated (for example, Bruch, 1978; Vitousek, 2002; Wakeling, 1995). The idea that medical symptoms need to be treated before psychological aspects can be addressed subsequently means that weight gain is the primary goal of treatment (Hepworth, 1999; Patel et al., 2003; Comerici & Greydanus, 1997).

Behavioural approaches in the treatment of anorexia are commonly used in hospitals. This involves the use of reward systems where if the person gains weight, they are rewarded and if they lose weight, they are punished. Such rewards/punishments include the use of the telephone, access to visitors and being allowed to move around the ward rather than strict bed rest. Reviews of treatment programmes have indicated that approaches that are more lenient have been found to be more effective than stricter behavioural programmes (APA, 2006). Furthermore, the National Institute for Clinical Excellence (2004) does not recommend the use of behaviour modification approaches. Behavioural approaches have been heavily criticised by a number of theorists (Bruch, 1978; Gremillion, 2003; Hepworth, 1999; Orbach, 1993). Behavioural programmes focus exclusively on food and weight and can only serve to exacerbate the eating disorder (Gremillion, 2003) and foster treatment resistance.

For the healthcare professionals in a qualitative study conducted by Hepworth (1999) the primary goal of treatment was to establish weight gain in the patients. Patients were rewarded or punished depending on whether they gained or lost weight and were constantly supervised to ensure they were not employing behaviours that could threaten the treatment goal. These behavioural practises caused the patient to become “resistant” to treatment and impeded the therapeutic relationship. Similarly, a thematic analysis of interviews with ten nurses found that one of the key factors affecting the therapeutic relationship was a mutual power/control struggle between both staff and patients. The controlling effects of the behavioural treatment

programme caused patients to employ manipulative behaviours as a way of re-exerting their control and as a result both parties mistrusted the other (Ramjan, 2004). Ramjan (2004) believes that the hospital needs to be more aware of the psychological needs of the patients and should not employ behavioural programmes that take control away from the patient and hinders the therapeutic relationship.

Weight restoration was considered the highest priority for treatment in a questionnaire study of services in twelve different European countries (including Great Britain, France, Spain, Netherlands, etc) out of a list of a possible thirteen treatment aims (Gowers et al., 2002). However, "*Dietary counselling should not be provided as the sole treatment for anorexia nervosa*" (NICE, 2004). It is also important to remember that disordered eating arises as a result of underlying psychopathology and it is important that this is focused upon during the treatment process.

Vanderlinden, Buis, Pieters and Probst (2007) compared the elements of treatment that patients felt to be important to those that therapists considered important and found no significant differences. They put together a list of 20 items referring to the main components covered in the Cognitive Behaviour Therapy approach they used (e.g. 'learning problem solving skills'). Both therapists and clients believed the most essential element was improving self-esteem. Other high scoring components were 'improving body experience', 'learning problem solving skills' and 'enhancing motivation to give up the eating problems'. This research has some limitations. The 20 items were based on pre-determined items based on the views of the researchers and the components of an existing programme. A more informative result may be gained from allowing participants (both clients and therapists) to describe in their own words the elements they feel are most essential.

Randomised control trials (RCTs) comparing CBT to nutritional counselling have found much lower drop-out rates in the CBT groups than the nutritional counselling (Vitousek, 2002). One study (Serfaty et al. Cited in Vitousek, 2002) reported a 100% drop-out rate in the nutritional group. Vitousek (2002) cautions against any

conclusions based on the efficacy of CBT but suggests only that compared to nutritional care a psychotherapeutic approach has a better outcome. The 100% drop-out also suggests a strong aversion to treatments focusing only on food and weight, iterating the concerns of sufferers presented in chapter 1.

McIntosh et al. (2005) carried out a RCT of three psychotherapies (CBT, interpersonal therapy and “nonspecific supportive clinical management”). They found that the nonspecific therapy had a better outcome than the two specialised approaches. Interpersonal therapy was the least effective. Worryingly, 70% of the total sample dropped out of treatment or made no significant improvement. Only 9% had a “very good” outcome and 21% had “improved considerably”. The efficacy of a nonspecific, supportive approach is noteworthy, not least because this highlights the essentiality of an empathic supportive therapeutic relationship.

More research is needed to find effective treatment approaches for anorexia (APA, 2006; Fairburn, 2005; le Grange & Lock, 2005; Kaplan, 2002; Roth & Fonagy, 2005; Vitousek, 2002; Woodside, 2005). With no recommended treatment approach, healthcare professionals have difficulties to decide what therapies to use (Cooper, 2005; Stein et al., 2001). One difficulty in finding an evidence-based treatment approach is the low prevalence rates; this means that the studies that are conducted have such small sample sizes that the results are often not statistically significant (Fairburn, 2005; Kaplan, 2002; le Grange & Lock, 2005; Roth & Fonagy, 2005; Vitousek, 2002; Woodside, 2005). Treatment studies are made even more difficult by the fact that patients are often unwilling to receive treatment in the first place; this may also explain the lack of studies in this area (le Grange & Lock, 2005; Stein et al., 2001). Given the limitations in conducting treatment trials for anorexia, a number of authors have recommended that future research should conduct larger multisite studies (APA, 2006; Stein et al., 2001; Woodside, 2005). Reviews of the literature pertaining to the treatments of anorexia suggest that family therapy for adolescents seems promising. Although there are less data on the use of psychotherapy for adults, individual approaches based on CBT look promising and future research into this

area needs to be a priority (Bowers & Ansher, 2007; Bulik, Berkman, Brownley, Sedway & Luhr, 2007; le Grange & Lock, 2005; Stein et al., 2001).

Cognitive Behavioural Therapy (CBT)

CBT is concerned with the “maladaptive” cognitive functioning surrounding issues around food, weight and body image and thoughts regarding the underlying problems of the eating disorder such as low self-esteem or a strong need for control that cause the development and maintenance of maladaptive eating behaviours (Slade, 1982). It is the most appraised treatment approach for bulimia nervosa (Fairburn, et al., 1993; NICE, 2004) and in 2004 the National Institute for Clinical Excellence recommended that it be provided for every bulimic patient in the National Health Service (NHS). CBT is increasingly being used for anorexia and research suggests that it is effective in this population (Bowers & Ansher, 2007; Bulik et al., 2007).

In order to change the behaviours associated with psychological disorders it is required that the illogical thinking underlying the behaviours is modified. Beck (1976, p.214) states: “*In the broadest sense, cognitive therapy consists of all the approaches that alleviate psychological distress through the medium of correcting faulty conceptions and self-signals.*” The focus of CBT is the restructuring of maladaptive cognitions concerning weight, food, anorexia and the self that in turn assists behavioural change. These maladaptive cognitions may include the over-evaluation of weight, shape and eating, overemphasis on the need for control, perfectionist beliefs, low self-esteem, avoiding emotions (e.g. using anorexia as a coping mechanism) and interpersonal problems (Fairburn et al., 2003; Schmidt & Treasure, 2006).

An individual approach is recommended for CBT as it allows for individual beliefs to be explored (Fairburn et al., 2003; Vitousek, 2002). Different approaches to CBT may recommend slight variations in techniques but all seem to centre on four main areas. These are listed by Vitousek (2002, p309) as “(1) *the ego-syntonic nature of symptoms; (2) the interaction between physical and psychological elements; (3)*

specific beliefs related to food and weight; and (4) pervasive deficits in self-concept.” This is done through developing motivation, “managing eating and weight”, “modifying beliefs about weight and food” and “modifying views of the self” (Vitousek et al., 2002).

To summarise the main features of CBT for anorexia, the first stage focuses on the development of motivation to change. It identifies clients’ beliefs about their anorexia and discusses their perceived pros and cons (Vitousek & Orimoto, 1993; Wolff & Serpell, 1998), allowing therapists to address its perceived functional role (Schmidt & Treasure, 2006). Psychoeducation is also presented in the early stages. This includes educating clients about the physical and psychological effects of starvation, bingeing, purging and being low weight and the properties of foods and the importance of a balanced diet (Vitousek et al., 1998). Early phases also focus on nutritional and weight restoration, but unlike other approaches that focus only on this (nutritional counselling, behavioural approaches), CBT also explores the core beliefs about food and weight throughout this process. Wolff and Serpell (1998) describe an aim of therapy as letting go of an anorexic mindset. The idea is to create cognitive dissonance about anorexia and seeing it as “*an imperfect pseudo-solution worthy of attempts to change*”.

CBT incorporates many of the important aspects of an effective therapeutic relationship including collaboration, respecting the individual, and validating and recognising clients’ beliefs (see below). CBT appears a promising approach to treatment for anorexia.

Narrative Therapy

Narrative therapy is a relatively new approach to treatment for anorexia. Its use has been widely recommended by social researchers especially those with strong views about the pathologisation of anorexia as a disorder (Garrett, 1998; Gremillion, 2003; Hepworth, 1999). Narrative therapy recognises the sociocultural influences on anorexia, positing it as an exaggeration of cultural ideals of thinness,

accomplishment and perfection (Maisel, Epston & Borden, 2004), yet also recognises the individual beliefs about behaviours. Instead of locating anorexia as a problem within the person (which can reinforce the person's belief that it forms a significant part of their identity) narrative therapy externalises the problem as something outside of the person (Gremillion, 2003; Lock, Epston & Maisel, 2004; Maisel et al., 2004). The idea is that it is anorexia that is the problem and not the person. Externalising anorexia may be considered problematic, for example, it may be considered a way of victimising the person experiencing it (Gremillion, 2003; Vitousek, 2005) or could suggest the abdication of any responsibility or ownership for some cognitions or behaviours (Vitousek, 2005). However as Gremillion presents:

The point of engaging “externalizing conversations” with clients is to create a discursive space to name, unpack, and detail the relational and ideational contexts of problems so that clients can imagine and experience a sense of active agency, rather than passengerhood or inevitability, in connection with these problems.

(Gremillion, 2003, p.201)

In other words externalising anorexia from a sense of self can assist the exploration of its nature and roles in the person's life and then allow them to take control of the fight against it. Or as Hepworth (1999, p.123) posits, anorexia can be seen as “*an entity that she [sic] can act on and resist rather than anorexia nervosa being understood as an integral part of herself [sic], and an identity that is defined by psychopathology*”.

Thus, the basic premise of narrative therapy is to construct anorexia as a potential “murderer”, “bully” or any other negative entity (that may disguise itself as a “friend” who is trying to solve their problems) which attempts to “seduce” and “imprison” the person (Lock et al., 2004; Maisel et al., 2004). The idea is then to use “anti-anorexia” strategies, such as questioning an “anorexic voice” about its motives as a way of resisting it.

2.7. Helping relationships

Supportive relationships both within and outside the treatment environment was heavily advocated in the qualitative studies detailed in chapter 1. This section considered the importance of helping relationships in more detail.

The Therapeutic Relationship

Effective therapeutic relationships are important for the successful treatment of eating disorder patients (Bell, 2003; Comerici & Greydanus, 1997; Garner & Bemis, 1982; Kaplan & Garfinkel, 1999; Muscari, 1988) but this can be complicated by non-compliant behaviour and the subsequent distrust from the professional (Hepworth, 1999; King & Turner, 2000; Ramjan, 2004). Eating disorder patients are often viewed as “*deceitful*” (King & Turner, 2000) “*noncompliant*” (Kaplan & Garfinkel, 1999; Muscari, 1988) and “*manipulative*” (Hepworth, 1999; Muscari, 1988) as they employ behaviours that jeopardises their treatment and give the impression of weight gain. Consequently, healthcare professionals may deem their patients as distrustful and in need of constant surveillance.

Nurses interviewed by King and Turner (2000) held personal beliefs about what they felt constituted appropriate nursing standards, these included trusting patients, treating them all equally and not judging them, however, the non-compliance displayed by their anorexic patients meant that these standards were challenged and the nurses became distrustful of them. The nurses felt unable to form a therapeutic alliance with their patients causing them to feel angry, inadequate and frustrated. Garner and Bemis (1982) believe that anorexics are very untrusting of people and healthcare professionals should remember this when building up the therapeutic relationship. Patients should not be viewed as deceitful or manipulative; instead, professionals need to understand that these behaviours are part of the disorder.

The way that the healthcare professional feels about the patient will affect the therapeutic relationship. Countertransference is a psychoanalytic term used to mean “*all those reactions of the analyst to the patient that may help or hinder treatment*” (Slakter, 1987. p.3 [cited in Franko & Rolfe, 1996]). Franko and Rolfe (1996) explored the feelings expressed by 10 psychiatrists, 12 psychologists and 10 social workers who specialised in treating eating disorders. They were asked to fill in a questionnaire about the emotions they felt the last time they treated a person with anorexia, a person with bulimia and, as a control, someone with depression. The results found that higher levels of frustration and hopelessness and lower degrees of sympathy, empathy and success were felt by healthcare professionals when treating anorexia than when they were with bulimic or depressed patients. Professionals with less experience and larger caseloads of eating disorder patients also felt more negatively towards their patients.

A key factor affecting the therapeutic relationship between nurses and patients in a qualitative study of nurse’s perspectives was a lack of understanding about anorexia (Ramjan, 2004). Ramjan (2004) suggests that nurses need more training and education about anorexia to enable them to understand their patients and the disorder, this in turn will reduce some of the negative feelings that nurses have of their patients. The need for education about anorexia has also been discussed elsewhere (King & Turner, 2000; Muscari, 1988). Muscari (1988) states three principles that are required in order for nurses to effectively help eating disorder patients: firstly, the nurse needs to have sufficient knowledge of eating disorders; secondly, staff need to educate patients and their family about the disorder in order for change to occur; and finally, it is necessary to form a therapeutic relationship.

To reduce patient’s fears of a lack of control in treatment and therefore resistance, therapists need to take an empathic yet firm approach with their clients (Reid et al. 2008; Vitousek et al., 1998). Vitousek et al. (1998) advocate that therapists adopt a Socratic style of questioning. This involves a style of questioning that allows the client to verbalise information and conclusions rather than the therapist simply telling the client what needs to change. This approach should reduce resistance as it is the

client not the therapist who is presenting the ideas. Other recommendations for the therapeutic style include, respecting the client's individuality, collaboration and patience (Vitousek et al., 1998).

The therapist must recognise and value the client's beliefs and values about their self, life and disorder (Miller & Rollnick, 2002; Vitousek et al., 1998). In particular, it is essential for the therapeutic relationship that therapists recognise the perceived benefits that a client may have about their anorexia (Vitousek et al., 1998; Wolff & Serpell, 1998). Furthermore, Wilson (1996) acknowledges the need for patients to feel validated in their beliefs in order to encourage self-acceptance.

Relationships with Family and Friends

Parents are usually the first to seek help for their child's eating disorder (Comerci & Greydanus, 1997; Patel et al., 2003) and it is important that they are educated about its effects (Patel et al., 2003). A review of studies exploring treatment approaches for anorexia has suggested that family-based therapy may be the treatment of choice for adolescent anorexia (le Grange & Lock, 2005). Although caution should be made of the fact that there is a lack of research into other possible treatments (le Grange & Lock, 2005), these findings are supported by guidelines presented both by the National Institute for Clinical Excellence (NICE, 2004) and the APA (2006). Specifically the APA (2006) state, "*for children and adolescents, the evidence indicates that family treatment is the most effective intervention*".

Research has shown that family involvement in eating disorder treatment (especially amongst adolescent anorexics) is essential to the patient's recovery (Comerci & Greydanus, 1997; Patel et al., 2003). However, research has found that caring for those with eating disorders is difficult (Cottee-Lane, Pistrang & Bryant-Waugh, 2004; Treasure et al., 2001; Whitney et al., 2005); with carers feeling that they require a better understanding of eating disorders and recommendations for the best ways to deal with them (Cottee-Lane et al., 2004). This is important to consider, especially considering that unhelpful interactions can serve to maintain anorexia.

For example, anorexia can be positively reinforced by the positive comments given by others when the person begins losing weight and negatively reinforced by the concern of family and friends when weight loss is continued (Fairburn et al., 2003; Garner & Bemis, 1982; Schmidt & Treasure, 2006). Furthermore, Schmidt and Treasure (2006) recognise how the expressed emotions of significant others who are trying to manage a person with anorexia will influence the maintenance of the disorder. Too much comfort or reassurance may sustain the behaviours, whilst criticalness, hostility or attempts to control the individual may cause the person to become further ingrained in anorexic behaviours or embrace their anorexic identity (as seen in chapter 1).

Problems with family dynamics can be considered a contributing cause for the development of an eating disorder and therefore issues within the family should be addressed (Patel et al., 2003). Interpersonal therapy, based on psychoanalytic theories of the role of the family in personality development has been suggested for treating anorexia (Finelli, 2001; McIntosh et al., 2000). This approach explores four areas, interpersonal disputes, role transitions, abnormal grief, and interpersonal deficits. More research is needed to test the efficacy of interpersonal therapy in this patient group.

2.8. Chapter Summary

This review has provided a theoretical insight to the main areas perceived by sufferers to be important in their experiences of anorexia, recovery and treatment. The review has highlighted the problems with defining 'anorexia' and 'recovery' whereby current definitions appear somewhat inadequate and disconnected from the experiences described by participants in the studies reviewed in chapter 1. This has implications for the current research; participants of the research will be explicitly asked what their definitions of anorexia and recovery are. It is hoped that this will inform the understandings of those working with sufferers of anorexia.

The review also considered the precipitating and maintaining factors of anorexia, centring on the key constructs of control and self-worth highlighted in chapter 1. These constructs have been theorised psychoanalytically as adolescent fears of adulthood and ambivalence about one's mother, cognitive-behaviourally as core negative self-schemata that emphasises the need for perfection and control, and socio-culturally as a response to cultural meanings of restriction and the effects on a person's sense of self, particularly their body image. All of these theories have something to offer in the aetiology of anorexia as is perhaps evidenced by the egosyntonic and functional roles anorexia is considered to play and through the presentation of the addiction theories of eating disorders. Addiction theories seem a promising area in understanding the maintenance of the disorder, especially as they take into account the key theoretical standpoints (e.g. see Orford, 2001).

Treatment for anorexia was considered but it was suggested that, although such approaches as CBT and narrative therapy appear promising, further research into finding an evidence-based approach is required. What was clear was the overriding conflict between targeting the physical symptoms of weight and food and the psychological symptoms surrounding cognitions and weight. This conflict affected the therapeutic relationship, sufferers' resistance and the overall efficacy of treatment. The current research will ask participants about the experiences of treatment in detail. It is hoped that increased understanding of anorexia, recovery and treatment will help therapeutic and familial relationships, leading to effective recovery.

During this review, pro-anorexia beliefs or beliefs about the positive aspect have been implicated in the maintenance of anorexia and it is suggested that further research into these beliefs are needed (Schmidt & Treasure, 2006; Serpell et al., 2004). In particular, Serpell et al. 2004 recognises the need for perceived pros and cons to be explored using qualitative research. They also suggest that future work could compare the perceived pros and cons between those recovering from anorexia and those not. To contribute to this gap in research, the current research includes a study that explores the experiences of those who self-identify as wishing to maintain

their disorder and asks them what roles they perceive anorexia playing in their life. Furthermore, those who self-identify as wishing to recover will also be asked the same. Pro-anorexia will be explored further in the next chapter which explores the uses of the internet by those with anorexia.

3.1. Introduction

Up to date Internet World Statistics (2009) calculate that 1463 million people use the internet worldwide and that 21.9% of the world population is online. In North America alone 73.6% of the population have access to the internet, whilst 68.6% of those in the UK are internet users. Furthermore, it suggested that 90% of people aged 15-24 have used the internet, with 29% of 15-17 year olds having private access in their own bedrooms (Rideout, 2001, cited in Mastronardi, 2003). The internet is a commonly used and important medium for information and communication in today's world.

People are increasingly using the internet for reasons relating to health. For example, a series of surveys conducted by the PEW Internet & America Life Project showed that in 2000 52million or 55% of users had used the internet to seek information about a health issue (Fox & Rainie, 2000) whilst in 2005 this had risen to 95million or 79% of users (Fox, 2005). Table 2 exemplifies the types of health information sought online in 2000.

Table 2: Types of Health Information sought on the Internet. From Fox and Rainie (2000)

Percentage of site users	Type of information sought
91%	Sought information about a physical illness
26%	Sought information about mental illness
16%	Received information about a sensitive topic that is difficult to talk about
10%	Received advice from an online doctor
10%	Bought medicine or vitamins online
9%	Used email to communicate with a doctor
9%	Participated in an online support group

The abundance of online health information means that people can collate more information about their health problems before consulting a doctor and this may have an effect on the clinical relationship (Health on the Net (HON) Foundation, 2007; Kennedy, 2002). For example, Jadad, Sigouin, Cocking, Whelen and Browman (2001) report that over 90% of the physicians and nurses asked had experienced patients bringing information with them that they had found on the internet. Seeking information about health online can be especially problematic if the information is not credible (Kennedy, 2002) and this is something that is targeted by the HON Foundation (2007) who work towards ensuring patients and doctors who seek health information online find only that which is reliable.

The internet offers people a space for finding information, social support and even therapeutic interventions. One main appeal of the internet is its physical anonymity, which allows users to explore identity and express their views and opinions (some of which may be considered unacceptable in offline settings) in a safe environment (Bargh, McKenna & Fitzsimmons, 2002).

The online environment allows people to explore their own identity or create a new one (Turkle, 1995). For example, people may express their identity through the development of personal webpages and online journals (blogs; Schmitt, Dayanim & Matthias, 2008). Furthermore, as Livingstone (2008) found, social networking sites such as Myspace and Facebook are used by young people as a way of continuously recreating identity through the ever-changing nature of their pages. Younger teenagers tended to use more decoration on their sites, whilst older teens used plainer backgrounds, perhaps indicating a more established identity (Livingstone, 2008). This capacity to (re)create identities is also evident in online games, as one game player interviewed by Turkle (1995) expresses:

You can be whoever you want to be. You can completely redefine yourself if you want. You can be the opposite sex. You can be more talkative. You can be less talkative. [...] It's easier to change the way people perceive you, because all you've got is what you show them. They don't look at your body and make assumptions. They don't hear your accent and make assumptions. All they see is your words.

Furthermore, as Tierney (2006, p.184) expresses “*virtual communication means the body does not have to assume such a prominent role in discussions*” which can be considered advantageous for those with body image issues (Fox, Morris & Rumsey, 2007; Walstrom, 2000). It therefore seems unsurprising that a person experiencing anorexia, who may be searching for a new identity or who may have concerns with her body, may be drawn to an online environment. The following extract is from an online game (MUD) user interviewed by Turkle (1995) who is in treatment for anorexia.

In real life, the control is the thing. I know that it is very scary for me to be a woman. I like making my body disappear. In real life that is. On MUDs, too. On the MUD, I'm sort of a woman, but I'm not someone you would want to see sexually. My MUD description is a combination of smoke and angels.

The anonymity of the internet allow people to express a true self (Bargh et al., 2002) and one that may be “*considered to be unacceptable in real life*” (Adams, Gavin & Rodham, 2005, p.1295). As suggested in chapter 1, people with anorexia may turn to the internet for support because of a lack of understanding from those in their offline environment (Rich, 2006).

The rest of this chapter will review the literature on the current and potential uses of the internet for health information, especially those that may be utilised by those experiencing anorexia. Specifically the uses of the internet for support (through online forums and pro-anorexic websites) and for therapy will be considered. This chapter also aims to evaluate the strengths and weaknesses of using the internet in these various ways and considers the potential for using the internet as a research tool.

3.2. The Use of Online Forums

The internet offers a popular place for finding support about conditions that are relatively misunderstood and unrecognised in healthcare settings (Davison, Penebaker & Dickerson, 2000). For example, a survey study conducted by Berger, Wagner and Baker (2005) found higher levels of internet use with those with a

stigmatised illness, than those without, especially when the stigmatised illness was of a psychiatric nature (depression and anxiety). Those who feel stigmatised about their condition derive benefit from the anonymity that the internet affords (Tanis, 2008; Wright & Bell, 2003, cited in Malik & Coulson, 2008). Online forums exist for a host of stigmatised conditions including addictions (King, 1994), self-harm (Adams et al., 2005) and those with anorexia (Walstrom, 2000). People in online forums can obtain mutual support and can discuss their experiences in a frank and open manner (Kral, 2006) in a safe and physically anonymous environment (Walstrom, 2000). For example, a study of the use of mental health forums (Kummervold et al., 2002) found that 75% of respondents preferred talking about personal problems in an online environment than they did offline and around half of them told how they often did not discuss these problems offline.

Underlying the use of online forums is the desire for self-help, where those with the same experiences can come together to share and work on their problems (Castelnuovo, Gaggioli, Mantovani & Giuseppe, 2003; Davison et al., 2000). Thus, online forums can be considered empowering for patients (Kummervold et al., 2002; Malik & Coulson, 2008), as evidenced by Coulson and Knibb (2007) whose participants reported increased confidence communicating with healthcare professionals. Davison et al. (2000, p.206) state: *“a collective wisdom is born through the shared experience of participants rather than the professional training or style of the leader”*.

Finfgeld (2000) reviewed some of the existing studies on online support groups and identified the main advantages and disadvantage. Advantages included the convenience of having 24-hour access to the groups, the global accessibility of sites and the anonymity and reduction of social cues such as age and race. That participants can ‘lurk’ (view but not post) was also beneficial for those who may not feel ready to participate, whilst the reflexive ability to think and construct a message before posting allowed people to distance from destructive emotions. One disadvantage concerned the level of accuracy about the information exchanged. However, the most commonly reported disadvantage was the lack of nonverbal

communication but, as Finfgeld acknowledges, this may be offset by the advantages afforded by the lack of physical cues and that people can use online conventions such as emoticons.

One of the benefits of online groups is their ability to be accessed at any time of the day (Coulson & Knibb, 2007; Malik & Coulson, 2008). However, as Tierney (2006) points out this may also be disadvantageous as the lack of immediacy in receiving a response to a post may increase feelings of loneliness. Finfgeld (2000), however, argues that although this may be a disadvantage for distressed individuals, in comparison to face-to-face groups that, at best, only meet weekly this concern may be “unfounded”.

Most of the studies exploring the use of online forums have analysed the content and nature of posts. There is a growing body of studies on the use of discussion forums for physical and mental health issues and many report the same key themes. Researchers have reported that the central reason for using online forums for such issues as suicide (Kral, 2006), type 1 diabetes (Ravert, Hancock & Ingersoll, 2004), infertility (Malik & Coulson, 2008) and food allergies (Coulson & Knibb, 2007) is for the social support and ability to talk with others with similar problems. This can reduce feelings of isolation (Malik & Coulson, 2008).

Burri, Baujard and Etter, (2006) found that the most common type of messages posted in an online discussion forum for recent ex-smokers were those providing emotional support and encouragement. Other types of messages included those that described experiences and opinions, those that congratulated others, ‘commonplace remarks’, messages of gratitude, practical advice and tips on nicotine replacement therapy. Similarly, Tanis (2008) found that the most common use of a number of health related forums was as a way of coping. However, Tanis (2008) suggests that using the internet for coping can also be considered limited as people may only communicate with online contacts, breaking links with their offline social support network. This concern is also expressed by others (Finfgeld, 2000) but rejected by Malik and Coulson (2008) whose participants experienced an improved relationship

with their partner as the support group reduced the pressure of only having their partner to talk to. However, these participants already had used their partners for support prior to seeking it online.

Online Forums for Eating Disorders

Davison et al. (2000) explored the use of online and face-to-face peer support groups for a range of mental and physical problems. They reported that the number of support groups available for people with anorexia ranked fourth in both online and offline settings (groups for alcoholism ranked the highest in offline settings whilst multiple sclerosis sufferers had the most online support groups). The number of support groups for all cardiovascular problems are only marginally higher than for sufferers of anorexia despite the fact that prevalence levels for cardiovascular disorders is nearly 1000 times greater. This finding can be related to early suggestions that people are more likely to look online for information on more stigmatised disorders (Berger et al., 2005).

Although there have been a wide range of studies exploring the use of online forums in general, there are not many specific to the use of forums for eating disorders. Nonetheless, the research that has been conducted supports the results found in relation to other health problems, where anonymity and the subsequent perception of the internet as a safe environment enables those with eating disorders to connect with similar others to discuss and work on their problems (Walstrom, 2000).

Leiberich et al. (2004) looked at the benefits of a German-speaking online self-help group for eating disorders using an online questionnaire. The results showed that 72.9% of the 1006 respondents used the sites as a way of being around others in the same situation, 67.8% found the sites helpful for gaining advice and 47.2% used the sites to break the isolation of the eating disorder. Participants also reported that the site helped to deal with their disorder and make decisions about therapy. Similar results were obtained by Kral (2006) who reported that a high percentage (80.6%) had visited an eating disorder online support group in order to meet others in the

same situation. These results highlight a strong social function of the forums, which, considering that eating disorders are characterised by social isolation, seems to be of benefit to the users.

Again, support was the most common theme of posts in a study conducted by Winzelberg (1997) with around half of the posts providing support to assist each other to cope with such things as increasing weight gain, pressures from family and friends, cultural pressures for thinness, negative emotions and treatment decisions. By providing recommendations for treatment, outlining the benefits and helping others to cope with stopping their behaviours and gaining weight it is clear that the purpose is to support and advocate issues surrounding recovery.

Implications of Online Forums and Future Research

Kral (2006) explored the use of an online forum for eating disorders and one for self-harm. Around 27% of those in the eating disorder forum and 22% in the self-harm forum reported feeling motivated to use professional help after visiting the sites. While these numbers seem quite low, Kral (2006) believes that this is a positive outcome. Although not discussed by the author, both of these behaviours are considered stigmatised and sufferers may choose to hide these behaviours and are resistant to seeking help. Thus, these results are extremely positive and may suggest a role for online support groups for those who may be contemplating recovery. Kral (2006, p.30) believes *“linking online and offline support could be considered as an optimal care for people with health concerns”*.

Participants in a study of the use of mental health forums (Kummervold et al., 2002) believed that online forums were a useful adjunct to offline therapy with many expressing a wish for healthcare professionals to get involved with the provision of such forums. They recommend healthcare professionals to consider how their roles could fit into such a service. It has therefore been suggested that healthcare professionals should be familiar with, and be able to recommend high quality and useful online resources (Bell, 2007; NHS Quality Improvement Scotland, 2006) and

also be able to “*warn against dangerous information for patients and their families*” (NHS QIS, 2006).

It is suggested that through observation of online support groups, researchers and healthcare professionals can obtain insight into the issues that are important to site users (Davison et al., 2000; Malik & Coulson, 2008). However, to date research into the use of support groups has tended to only use observation or questionnaire methods, future research may want to engage site users through electronic interviews or online focus groups, such as this research aims to do with those who use eating disorder support groups.

3.3. Pro-anorexia Websites

Pro-anorexia is an online movement of websites designed with the purpose of continuing anorexic behaviours. Visitors to the sites can offer and receive support, tips and information on many different aspects of anorexic behaviours, but the main principle of pro-anorexia sites is the ability to talk about the perceived positive aspects of anorexia without the fear of being judged or stigmatised. ‘Pro sites’ also exist for the use of drugs such as heroin and cannabis, and those that focus on pro-self-harm, for those seeking support about their use of self-harm.

Other and perhaps more extreme sites also exist. A review by Bell (2007) reports how online communities exist for those who reject medical explanations of psychosis, instead explaining it as a result of mind control technology. There are also discussion groups available for those who want to be amputees (a condition known as apotemnophilia). Finally, sites exist for people to discuss suicide methods and make suicide pacts. Bell (2007, p.451) suggests that the presence of such groups illustrates how “*an individual interested in almost any behaviour, no matter how unconventional, is likely to be able to find like-minded others*” in the online environment. This can be linked to the anonymous nature of online communication and the subsequent capacity to discuss socially unacceptable thoughts and behaviours. The rest of this section will now focus on pro-anorexia or pro-eating disorder websites and review the literature regarding how these are used.

The Content and Nature of Pro-anorexia Websites

Pro-anorexia websites often include the same typical features. Most include ‘thinspirational’ images of thin celebrities and models and other anorexics intended to inspire viewers to continue with their behaviours. Sites also include tips and techniques where site users can share information on diets, exercise, brands of laxatives as well as ways of hiding behaviours from others. Most pro-anorexia sites also include a forum so that site visitors can communicate with one another.

A warning statement is usually pronounced on each site’s home page, informing potential users of the content within. These disclaimers explain how the sites may be triggering and claim that those who are recovering or do not have an eating disorder should not enter. However this warning page could be considered “*alluring*” (Peebles, 2005) or act as a “*dare*” for the visitor (Reaves, 2001), encouraging them to continue throughout the pages. Both Reaves (2001) and Peebles (2005) believe the websites are ‘dichotomous’ as although the site owners advise potential users about the dangers of anorexic behaviours and the triggering effects of the websites, they also convey how proud they are of their behaviours and support other members to do the same.

A content analysis carried out by Chesley, Alberts, Klein and Kreipe (2003) of three different types of site providing information on anorexia (pro-anorexic websites, pro-recovery sites and professional sites) found that: “*Pro-anorexic websites are better organized, comprehensive, and more numerous than sites based on recovery or professional services*” (Chesley et al., 2003, p.124). Similarly, Keller, Rosenthal and Rosenthal (2005) also explain how treatment sites have fewer images and are not as interactive as pro-anorexic websites. Chesley et al. (2003) found that pro-anorexic sites included much more detail on ways of maintaining anorexia including tips, ‘thinspiration’ and clinical definitions as ways of avoiding detection from healthcare professionals. Only 5% of the sites mentioned details of the mortality associated with anorexia compared to 38% on pro-recovery sites and 22% on professional websites.

Keller et al.'s (2005) content analysis used the Health Belief Model and Stages of Change Model to compare pro-anorexia and treatment websites. They found that pro-anorexic sites mentioned fewer benefits of recovery, gave little information about recovery and more information about maintaining anorexia than treatment websites. The results suggested that some treatment websites 'mentioned' common anorexic behaviours such as fasting, purging, diet pills and exercise, however, a lack of further information means that the context in which these behaviours were 'mentioned' is not clear. The authors were also surprised to find that the pro-ana sites did offer advice on taking vitamins and seeking psychotherapy.

A novel approach to analysing the content of posts to pro-anorexia forums was employed by Lyons, Mehl and Pennebaker (2006). They used linguistic inquiry to compare the linguistic styles employed on pro-anorexia and recovering anorexia homepages and forums. They found that pro-anorexics used more emotionally positive words and less self-preoccupation than those in recovery posts however, these findings are hard to evaluate without more contextual examples. Just because a posting had an emotionally positive word does not necessarily equate with positive mood. For example, it is unknown whether this approach accounts for the use of such phrases as "I used to be happy [...]" which would not mean a happy state at that time. The authors state that precise definitions of pro-anorexia and recovery anorexia were not used. Furthermore, if someone posts in a recovery site how can we be sure that they do not concurrently use pro-anorexia sites.

Pro-anorexic Identities and Social Support

Pro-anorexic websites follow some of the general premises of the pro-recovery self-help and support sites discussed above. As with the use of other online forums, users of pro-eating disorder websites reported social support as a key reason for site use (Brotsky & Giles, 2007; Csipke & Horne, 2007; Dias, 2003; Mulveen & Hepworth, 2006; Tierney, 2006, 2008). A common theme in the posts made to a pro-anorexic forum was the need for reassurance that feelings and behaviours were normal for

those with anorexia, a message that they did not get from others in their offline environment (Gavin, Rodham & Poyer, 2008; Tierney, 2006).

Connecting with others online alleviates the loneliness of experiencing an eating disorder and thus the use of pro-anorexia sites could be said to have a positive outcome on the psychological wellbeing of site users (Csipke & Horne, 2007). One of the main reasons for using pro-anorexic websites is for the support and understanding users will get from connecting with others who have similar beliefs in a safe and non-judgemental space (Gavin et al., 2008; Williams & Reid, 2007) or, as Dias (2003) conceptualises, in a “sanctuary”. Indeed, lack of understanding (from family, friends and healthcare professionals) and subsequent past negative experiences are considered factors for causing people to look online in the first instance (Brotsky & Giles, 2007; Dias, 2003; Rich, 2006; Tierney, 2006).

However, in a more negative light, being part of an internet community reinforces the person’s identity of being eating disordered (Gavin et al., 2008; Rich, 2006; Tierney, 2006) and in the case of pro-eating disorder communities this may make it difficult to leave the community behind and recover (Csipke & Horne, 2007). As Tierney (2006, p183) describes, “*visiting such resources could cement the positive association individuals derive from the label “anorexic”*”. An interpretative phenomenological analysis of postings to a pro-anorexic website (Gavin et al., 2008) indicated the role of participating in pro-anorexic sites in both reinforcing and normalising the pro-anorexic identity. Participants wanted reassurance that their experiences and feelings were normal to other pro-anorexics but liked having an ‘abnormal’ identity that made them different from others (Gavin et al., 2008).

People who use pro-anorexic websites may keep their behaviours a secret from ‘others’ in the offline environment for fear that they would intervene and attempt to ‘fix’ their disorder (Gavin et al., 2008; Williams & Reid, 2007). However, by normalising and supporting their anorexic identity any likelihood of ever seeking support offline is reduced. Thus, as Gavin et al. (2008, p331) state, “*The pro-ana*

forum therefore provides an ideal space for maintaining and validating a pro-anorexic identity.”

Pro-anorexia cannot be considered a unified identity and indeed with such negative connotations of the term some may not identify themselves as such (Brotsky & Giles, 2007). Research into the identities displayed in forums revealed a number of in-group and out-group identities (Giles, 2006). In-group identities ranged, from ana (those with anorexia), mia (those with bulimia), ‘half-way house’ identities (e.g. those that fit criteria for EDNOS) and newbies (those at the beginning of the eating disorder experience). These identities, although accepted by one another were hierarchal with anas as the top and newbies at the bottom. Mias were seen as subordinate to the ‘pure’ identity of being ana. Those with EDNOS saw themselves as not having a ‘real’ eating disorder or not being sick enough. Out-group identities included ‘haters’ (those who opposed the sites and posted hostile messages) and ‘wannabes’ (those who were using the site to obtain dieting tips). This latter group was seen as a threat to the pro-ana identity as they were seen as epitomising the stereotypical identities portrayed in the media of someone using the sites for a lifestyle choice.

A sense of community may be heightened with such paraphernalia as “ana bracelets”, these also act as a reminder to those wearing them of their commitment to anorexia (Norris, Boydell, Pinhas & Katzman, 2006). This can also be interpreted as a way of reinforcing their anorexic identity. As Norris et al. (2006, p.446) states *“[m]any of the websites aim to offer and promote a community of support for individuals with AN, allowing perpetuation of the eating disorder in the absence of treatment”*.

Csipke and Horne (2007) found differences between active users (those that participated in forums) and passive users (those who simply read others’ posts). They suggest that active users are more likely to obtain positive benefits such as increased self-esteem from the support they received, whereas passive users may obtain more negative, disorder-sustaining effects. Passive users tended simply to use the site for

tips to maintain and did not break the social isolation imposed by having an eating disorder.

Pro-anorexia as a Dangerous Lifestyle Choice?

A survey carried out by Peebles and Wilson in 2005 looking at eating disorders and internet use found that 40% of the 52 adolescents they surveyed had visited pro-eating disorder websites whilst 34% visited pro-recovery sites, 25% had used both site types and 50% had not used either (Peebles, 2005). Sixty percent of those using pro-eating disorder sites began using new behaviours, however roughly 25% of those using the pro-recovery sites also picked up new techniques. Those who used pro-eating disorder websites spent less time on schoolwork and more time in hospital but there was no evidence that their health was any worse than those who did not use the sites. In contrast, a preliminary pilot study, using a researcher-developed prototypical pro-anorexia site to measure the effects this had on a site user compared to more neutral sites (women's fashion or home decoration) found that the pro-anorexia site had a negative impact on participants' feelings about themselves (Bardone-Cone & Cass, 2006). This study can be criticised, however for its small sample size (n=24) and the authors recommend future research in the area. At present, there is no concrete evidence that viewing pro-anorexia websites is harmful or dangerous.

Despite this, pro-anorexia has received much attention in the media pertaining to the "dangerous" messages conveyed by positioning anorexia as a lifestyle choice. For example, pro-anorexia has been portrayed in the media as "*disturbing*", "*dangerous*" and even "*macabre*". (Gray, 2006; Jackson & Elliot, 2004; Reaves, 2001). In 2001, one eating disorder charity succeeded in causing Yahoo to delete the pro-anorexic websites on its server (Reaves, 2001). This portrayal in the media can backfire. A study by Csipke and Horne (2007) identified how over half of their sample reported visiting the sites after hearing about them through the media. Thus, the media's sensationalist depiction of pro-anorexic sites as dangerous actually serves as a precipitator to their use.

Those that use pro-anorexia sites have a much more positive view of their nature. According to most of those that visit the websites, they are places where they can belong and be around those that understand their views on anorexia. They are places where they can obtain support when they are not ready to recover but they are not places to encourage anorexic behaviours in others and some even support recovery if that is what the person is looking for. (Uca, 2004; 'Fat like me' website¹; 'pure*perfection' website²):

Pro-ED to me means understanding that there's no shame in how we are, and acceptance that this is how we will continue to be for an indefinite period of time. It means support for us so we don't have to deal with this alone. It means non-judgemental help so we can survive and remain safe and healthy as possible while maintaining the behaviors we still need to keep.

'Fat Like Me' website¹

Thus although a small number of sites do carry a message of anorexia as a lifestyle choice it appears these sites are not promoting eating disorders but acting as a place for sharing common views that cannot be expressed in another setting. Furthermore, the same views and group identity are expressed in offline settings between patients (Dias, 2003; Rich, 2006). Some authors have made a distinction between those who use pro-anorexia websites as a way of avoiding recovery because they are not yet ready to recover (due to perceiving benefits from continuing behaviours) and those who use the sites as an extreme way of dieting, rather than because of any eating disorder psychopathology (Mulveen & Hepworth, 2006; Uca, 2004). This latter group of site users have been termed 'wannabes' and are often criticised by those who consider themselves to have anorexia (Giles, 2006).

Pro-anorexic websites have also received attention from feminist authors, who posit pro-anorexia as a way of rejecting medical and pathological assumptions of anorexia as a disorder that simply needs to be cured (Dias, 2003; Mastronardi, 2003; Pollack, 2003). In particular, Pollack (2003) suggests that the pro-eating disorder

¹ What does pro-ED mean to me? Downloaded from the 'Fat Like Me' website, retrieved from the World Wide Web 20th February 2006. <http://jaoui.lunarpages.com/proed.html>

² Warning Page downloaded from the 'Pure*Perfection' website, retrieved from the World Wide Web 20th February 2006. <http://www.freewebs.com/ana/>

phenomenon is a way of moving the discourse of anorexia away from those ideas that posit it as a disease. She suggests that the pro-eating disorder message of adopting the disorder as a lifestyle is a political “*rejection*” of both medicalised and “traditional feminist” ideas of disordered eating and thin bodies. This conceptualisation of pro-anorexia sites is usefully summarised by Bell (2007, p.450) who describes the emergence of pro- sites as a “*process of building and reinforcing an alternative framework for behaviour pathologized by mainstream medicine and society*”.

Other researchers have identified that the views of those using pro-anorexic sites differ from the views held by healthcare professionals who view anorexia as something simply to be treated and cured (Davies & Lipsey, 2003; Fox, Ward & O’Rourke, 2005; Pollack, 2003). In particular, using ‘virtual participant observation’ and online interviews with site visitors of one pro-anorexic website, Fox et al. (2005) concluded that the pro-anorexia phenomenon opposes other explanatory models in that it is anti-medical and seeks to manage and maintain anorexic behaviours. Perhaps if treatment focused more on the psychosocial needs of the patient there would not be a need to reject these models. This also taps into some of the themes discussed in chapter 1, particularly the need for understanding in the treatment setting (Rich, 2006). This also highlights the disparity in views between healthcare professionals and those experiencing anorexia (Gremillion, 2003).

Feminist authors have honed into the ‘choice’ element of the idea that anorexia is a lifestyle choice, suggesting that the pro-anorexia phenomenon gives women a sense of agency. Mastronardi (2003, p.2) for example talks of the personification of anorexia (as ‘Ana’) as a way of “*shift[ing] the definitional framework of an eating disorder from a discourse of medicine to one of interpersonal intimacy [...] offer[ing] young women a greater sense of power*”.

The idea of pro-anorexia conveying a message of ‘lifestyle choice’ may not be as clear-cut as it seems. Some authors have recognised the differing beliefs of those who use the sites with some using it for a dieting lifestyle but others considering

themselves to have an eating disorder but not wishing to recover (Mulveen & Hepworth, 2006; Uca, 2004). Participants in a questionnaire study by Csipke and Horne (2007) were asked about their perceptions of eating disorders as a lifestyle or disorder and over half (54%) saw it as a disorder. Interestingly, the term lifestyle was perceived in different ways. Some respondents (7%) saw it as a lifestyle because it was a chosen behaviour whereas others (4%) believed it was a chosen behaviour but would lead to a disorder if continued. Others (8%) used the term lifestyle to mean that the behaviours had become engrained and a way of life for the individuals, rather than as a chosen behaviour. Some participants were undecided on their view of their eating disorder. This study could be criticised somewhat for its recruitment strategy, where, although the questionnaire explores uses of pro-anorexia sites links to the study were also provided on charity websites. This may have affected results as those recruited through these sites may have had different views than those recruited through pro-anorexia.

Nevertheless, similar results were identified by Norris et al. (2006). This study, a content analysis of twelve pro-anorexia websites, can be criticised due to its small sample, yet results indicated that only one website ascribed to the idea that pro-anorexia was a lifestyle choice. Again, as above, half the sites saw the websites as a way for those with an eating disorder to obtain support. As Giles (2006, p.464) identifies "*It is an oversimplification to regard the pro-ana community as reflecting a universally coherent standpoint*". Participants in the forums analysed by Giles (2006) often debated the nature of anorexia as a disorder or lifestyle, indicating a level of ambivalence, results that have been further supported by Brotsky and Giles (2007). Furthermore, Fox et al (2005, p.967) believe that:

Pro-anorexia is not a diet, nor is it a lifestyle choice. It is a way of coping and a damage limitation that rejects recovery as a simplistic solution to a symptom that leaves the underlying pain and hurt unresolved.

For participants in Giles' (2006) study, the diagnostic criteria served as a way of authenticating whether people could earn the identity of 'ana' or 'mia'. This use of the diagnostic criteria as a way of determining identity is interesting. In one way it seems to oppose feminist ideas that the pro-ana identity exists as a rejection of

medical views yet may also be seen to somewhat support them as these diagnostic criteria are seen as something to work towards rather than avoid.

Similarly, the idea that those who use pro-anorexic websites because they are 'anti-medical' (Davis & Lipsey, 2003; Dias, 2003; Fox et al., 2005; Mastronardi, 2003; Pollack, 2003) is not always supported. When people in the pro-anorexia groups told others of their decision to seek treatment this was encouraged just as strongly as their support for anorexic behaviours (Brotsky & Giles, 2007; Williams & Reid, 2007). Brotsky and Giles (2007) used participant observation whereby Brotsky participated in the sites with a pro-ana persona as if she too were experiencing anorexia. When she was planning to leave the sites, which she said was doing because she had decided to receive treatment, others responded with "overwhelming" encouragement and support.

A completely different explanation of the personification of anorexia as 'ana' is offered by Dias (2003). She relates the personification to ideas considered in narrative therapy (Maisel et al., 2004; see chapter 2) where this personification acts as a way of externalising their ambivalent thoughts about anorexia. Dias (2003) interprets some of the posts made in pro-anorexic forums as an illustration of the ambivalence about recovery that many with anorexia feel. This could also explain some of the results above (Csipke & Horne, 2007; Giles, 2006), whereby some were unsure of whether their behaviours were a disorder or a choice. Dias (2003) interprets pro-anorexia websites as "*sanctuaries*" where users can go when they are not ready to recover; the web communities offer a safe and supportive environment free from judgement. Using feminist poststructuralist discourse analysis she identified a number of recurring themes throughout the pro-anorexic information, including:

Not feeling understood by those around them; feeling out of control; feeling isolated and in pain; using the eating disorder as a form of coping and a security blanket; recognizing that they still need that security blanket even though they are aware of the potential dangers of anorexia; needing support and connection; feeling ambivalent towards both ana and recovery; and resisting dominant interpretations of the experiences of disordered eating.

Dias (2003, p.38)

This is reiterated in other research exploring the phenomenon of pro-anorexia that suggests that people have pro-anorexia beliefs and thus use the sites as a result of ‘needing’ (Hepworth & Mulveen, 2006) or ‘wanting’ (Williams & Reid, 2007) anorexia as a result of the positive functions it plays in their lives. For those not ready to recover from anorexia, there are perceived benefits from maintaining including feeling better about themselves, and being better able to cope with life situations (Dias, 2003; Mulveen & Hepworth, 2006; Williams & Reid, 2007).

Norris et al.’s (2006) investigation into the nature of the sites found ten common themes across websites including control, strength and perfection. The most common way that these themes were conveyed to users was through religious metaphor such as ana psalms and creeds. Although the authors do not discuss the implications of these metaphors, it could be suggested that such metaphors represent the strong beliefs site users have about their anorexia. As Williams and Reid (2007) discuss, this may also reflect earlier meanings of self-starvation, which were originally positioned within religious meaning before it became pathologised as a disease concept. The religious metaphor in Norris et al.’s (2006) study convey messages of control, starvation and self-hate and this can be considered synonymous with ascetic meanings.

Implications of Pro-anorexia and Future Research

Chapter 2 identified pro-anorexic beliefs as a maintenance factor in anorexia. According to cognitive behavioural theories, pro-anorexic beliefs stem from the positive roles that anorexia plays (Schmidt & Treasure, 2006) and this may lead to pro-anorexia meta-cognitions (Wolff & Serpell, 1998) such as the ideas that without anorexia their life would be much worse. These ideas are also iterated in qualitative studies on the reasons for using pro-anorexia websites. For example, Mulveen and Hepworth (2006) found that a key theme in discussion posts was participants’ perceived ‘need for anorexia’ where some members of the community felt that their anorexia helped them to cope. In a similar vein, Williams and Reid (2007) found that participants wanted their anorexia because of the positive perceptions they have towards it. Anorexia gave individuals desired results and subsequently made them

feel better about themselves, giving them positive feelings of empowerment, personal control and personal identity. Thus, individuals hid their anorexic behaviours from others and continued pursuing them despite the knowledge that they could be harmful. The positive values placed on anorexia also meant that individuals did not feel ready for or want recovery. However, sometimes the anorexia could be considered a problem for the pro-anorexics and it was during these times that the idea of recovery was considered, nonetheless, these individuals still felt compelled to continue the behaviours as they felt unable to stop because of feeling addicted or because they felt anorexia had become their identity (Williams & Reid, 2007).

The results of Williams and Reid's (2007) study iterate many of the themes considered in the previous chapters, particularly, the egosyntonic and functional nature of anorexia, ambivalence about recovery and a feeling of addiction. Furthermore, concurrent with the studies reviewed in chapter 1 (Colton & Pistrang, 2004; Elkins, 2000; Reid et al., 2008), researchers exploring the use of pro-anorexia websites have found that some members feel ambivalent about their disorder, sometimes liking the effects and other times wishing that they could recover (Dias, 2003; Mulveen & Hepworth, 2006; Uca, 2004). This suggests that perhaps pro-anorexia websites serve a purpose for those with conflicting beliefs about their disorder. By using sites designed to discuss positive views about the disorder they are likely to reinforce their positive beliefs about it. This may momentarily reduce ambivalence but may also serve to maintain behaviours.

Healthcare professionals should be aware of the presence and nature of pro-anorexia websites (Bell, 2007; Chesley et al., 2003; Norris et al., 2006). A number of authors believe that healthcare professionals need to be made aware of and address the reasons why people use pro-anorexia sites (or have a positive view towards their disorder), rather than unsuccessfully attempting to shut the sites down (Csipke & Horne, 2007; Tierney, 2006). Similarly, if healthcare professionals considered eating disorders as "*more than a medical complaint*" concerning food and weight there may be less reason for people to use pro-anorexia sites (Tierney, 2008, p341). Indeed,

negative experiences with healthcare professionals and hospitalisation is a common theme on pro-anorexia sites (Mastronardi, 2003). Indeed:

Practitioners have to assist those with an eating disorder to consider the damaging nature of their behaviours and attitudes, encouraging them to modify their thoughts and activities, whilst recognising the benefits they can acquire through self-starving. It may be wise to ask patients about their use of online resources to see if they are accessing pro-anorexia sites.

(Tierney, 2006, p186)

Fox et al. (2005) believe that pro-anorexic site users are 'experts' in the disorder, not necessarily in medical and psychological terms, but through their own experiences, for example they say, "*pro-ana emerges as a coherent system of understanding grounded in the shared experiences of being anorectic, as opposed to externally-imposed models of disease*" Fox et al. (2005, p.965). In other words, those experiencing anorexia are able to offer more understanding regarding it than theories proposed by those without the disorder. Davies and Lipsey (2003) believe the information contained within the pro-anorexic web pages should be used by healthcare professionals to provide insight and understanding into the people that they treat, a view that is also shared by many other authors (Chesley et al., 2003; Fox et al., 2005; Peebles, 2005; Tierney, 2006; Williams & Reid, 2007). More research clearly needs to be conducted to explore the experiences and perceptions of those who use pro-anorexia websites and this is one of the aims of the current research.

So far, research into the views of those who use pro-anorexic sites seem limited. Researchers need to move beyond the conception of pro-anorexia as symbolising a lifestyle choice. Instead they need to look at the why people using the site may not feel ready to recover. Much research has been done on the content of such sites, i.e. using content analyses (Chesley et al., 2003; Keller et al., 2005) or through analysing posts made in forums (Gavin et al., 2008; Lyons et al., 2006; Mulveen & Hepworth, 2006; Williams & Reid, 2007). Furthermore, these studies all seem to have centred on four main aims: exploring the content/nature of sites, exploring pro-anorexia as an online identity, determining why people may use the sites and determining the impact of viewing the sites on people's health and wellbeing. These all centre on the experience of the internet rather than utilising the use of the internet to explore

experiences of anorexia. The authors above posit the study of pro-anorexia as a way of understanding the experience of anorexia but there seems to be an essential gap in the literature. To date little research has utilised the internet as a means of interacting with those with pro-anorexic beliefs. Fox et al. (2005) did interview pro-anorexia website users and Brotsky and Giles (2007) interacted with users under a pro-anorexia persona but both studies centred only on maintenance behaviours and internet use. So far no research has utilised the pro-anorexia phenomenon as a way of engaging this population in exploring their experiences of anorexia rather than internet use and this is an aim of the current research.

3.4. E-therapy

A number of researchers have begun to consider the potential of using the internet for therapeutic reasons for those with eating disorders (Schmidt, 2007; Williams, 2003; Yager, 2002). E-therapy³ seems to come in three different forms: (1) stand alone, self-help interventions, (2) therapist-led individual or group counselling, and (3) adjunct therapy in conjunction with face-to-face approaches. This section reviews some of the current literature on the uses of the internet for therapy purposes. As will be seen, many of the advantages and disadvantages to this use are similar for the use of the internet for research purposes.

E-therapy is practical. Online communication can reach across geographical distances, which is especially important when some areas do not have the resources to provide the treatment that some need (Castelnuovo et al., 2003; Hamilton, 1999; Schmidt, 2003, 2007; Williams, 2003). Similarly, the convenience of online resources can be advantageous to busy professionals or those who are housebound, as Hamilton (1999, no page) explains this “*can make the difference between seeking help or not.*” Another advantage to online therapy is the cost efficiency where face-to-face therapy is more expensive to provide than online alternatives (Alleman, 2003; Schmidt, 2003). Linked to this is the idea that online self-help interventions may reduce the number of face-to-face sessions provided later (Williams, 2003).

³ also called online therapy, cybertherapy, webcounselling or online counselling

People may prefer to disclose information on a computer (Joinson, 2001; Schmidt, 2007) and this can be efficacious for therapeutic purposes. As Hamilton (1999, no page) describes, *“too embarrassed, ashamed or self-conscious to look a therapist in the eye, some find typing onscreen as direct and honest as writing in a journal.”* Hamilton (1999) refers to the case of Elizabeth whose use of e-therapy for her eating disorder helps her not to focus on weight and instead on the feelings associated with binging. Elizabeth describes feeling “safer” in the online environment due to her body image concerns. Thus, suggesting that a lack of physical presence in the online medium may be perceived advantageous for those with body image concerns. As Skarderud (2003) explains, those with eating disorders feel a certain amount of shame about their bodies and their eating disordered behaviours but the anonymity of the online environment allows the patients to “conceal” themselves and feel safe and protected in disclosing sensitive information to a computer screen. Skarderud (2003, p.164) believes that e-therapy *“may stimulate more people with eating disorders to seek help sooner”* which, could result in a better prognosis.

Griffiths, Lindenmeyer, Powell, Lowe and Thorogood (2006) reviewed the literature relating to online interventions to ask the question ‘why are health care interventions delivered over the internet?’ The internet was often seen as a unique way of resolving the difficulties in providing care for people in traditional settings such as reducing costs (both for users and health services), convenience for users, ability to reach hidden and stigmatised groups and the ability for users to have some element of control over their care. Williams (2003) considers that the internet can be utilised for providing self-help CBT to people with eating disorders in the absence of enough professionally trained therapists, such interventions are currently being piloted (Schmidt, 2007). Williams (2003) also suggests that this approach allows users to be involved in their own treatment and thus having a sense of control over it. Control within interventions is thought to be an important factor in eating disorder care (Bell, 2003; Eivors et al., 2004; Reid et al., 2008).

Furthermore, internet based treatment can bridge a gap in eating disorder treatment provision as a first step when waiting for face-to-face treatment and can reach hidden populations who may not usually present for treatment (Schmidt, 2007). Jeanne Rust who answers questions on a number of recovery websites describes how she decided to help people, despite the possible professional risks, as “*some of these people would never get into therapy if I didn’t help them*” (quoted in Hamilton, 1999, no page).

One of the biggest concerns of the use of technology for e-therapy is the lack of nonverbal communication that comes with face-to-face interaction (Alleman, 2003; Holmes & Hampton, 1998). This is particularly pertinent when working with patients who may feel suicidal (Holmes & Hampton, 1998) Suler (cited in Castelnouvo et al., 2003) describes the pros and cons to using synchronous or asynchronous communication in online therapy. In synchronous communication, the therapist and client will meet at a defined time giving a “feeling of presence” by being with a person and may have the feeling of commitment, yet scheduling sessions that are mutually convenient can be difficult. The real-time nature of the synchronous communication could lead to more “spontaneous”, “uncensored disclosures” but there is less time for reflection between exchanges. Conversely, asynchronous communication allows both client and therapist to reply at convenient times and allows for more reflection on answers but this can lead to “reduced feeling of presence” and commitment.

The immediate nature of being able to log onto a website or to compose an e-mail may aid people’s motivation for seeking help. Alleman (2003) describes a scenario whereby a person lying awake at three in the morning unable to sleep because of his problems is able to log onto the internet and find an appropriate site. The person can then opt to send an e-mail, carefully composed to say what he wants to convey, to an online counsellor who endeavours to respond with 24 hours. If that person did not have that option to seek help online they would have to wait until the morning, find a therapist, make an appointment for a mutually convenient time that may be several days away, travel to an unknown place and meet a stranger to discuss the problem

face-to-face. Chapters 1 and 2 highlighted the ambivalence and subsequent lack of motivation that those with anorexia may have (Garner & Bemis, 1982; Vitousek et al., 1998). Thus, the ability to go online and seek help at the moment they are feeling ready and willing to attempt recovery could be of great benefit. Perhaps with waiting for an appointment for an offline intervention, motivation may decline and a person may begin to feel more positive about their disorder. This suggestion is supported by an analysis of questions posted to an online counselling service for people with eating disorders. The study found that most of the questions were from very young women who up until that moment had not felt motivated to seek any help (Grunwald & Busse, 2002, cited in Kral, 2006).

Yager (2002) reports his experiences of providing adjunct e-mail therapy with his eating disorder patients between sessions. This had positive effects on the therapeutic relationship, reducing the formality of the relationship (one patient often greeted him as “Dr Yagermeister”). The e-mail communication allowed patients to write down their concerns there and then rather than having to wait until their next face-to-face session. This is also allowed them to better track their recovery progress.

This review has highlighted many of the advantages of using the internet for providing therapy. Specific to eating disorders, the option of e-therapy may be particularly beneficial considering the difficulties relating to motivation highlighted in chapter 2. The 24-hour availability of such services may make the difference between taking the first step towards recovery or not as it allows for immediate action from the user. As this review indicates, people with eating disorders already seek information and support online (through online forums and pro-anorexia sites) suggesting that therapeutic interventions in this same space may be highly utilised.

A review of the use of the internet for mental health (Bell, 2007) suggests that online CBT interventions for depression such as MoodGYM⁴ are just as effective as offline versions. More research is needed to explore the efficacy of providing interventions online compared to offline through randomised control trials (Griffiths et al., 2006;

⁴ <http://moodgym.anu.edu.au/>

Laksmna, 2002). Other recommendations for future research include the use of larger sample sizes and long-term follow-up studies (Laksmna, 2002). Before more research is conducted, healthcare professionals should remain cautious of their efficacy.

3.5. The Internet as a Research Tool

Online data collection methods are considered a new approach in health and social science research and have recently been used in studies of self-harm (Adams et al., 2005), nurses decisions to change job roles (Kenny & Duckett, 2005) and the experiences of pregnant women on bed rest (Adler & Zarchin, 2002) amongst other things. Data can be collected online in a number of ways including electronic surveys, virtual ethnography, e-mail interviews or online focus groups.

Many of the advantages and disadvantages of using the internet as a research tool are similar to the use of the online environment for the support and therapeutic purposes discussed above. Anonymity of participants can aid communication, as participants feel more comfortable in disclosing information especially regarding sensitive and personal topics (Adams et al., 2005; Chen & Hinton, 1999; Cher Ping & Seng Chee, 2001; Illingworth, 2001; Kenny, 2005; Stewart & Williams, 2005; Turney & Pocknee, 2005). This physical anonymity of the online environment also allows for equal participation, whereas in face-to-face situations social power amongst some group members may affect others' responses or may mean that some members dominate the discussion (Cher Ping & Seng Chee, 2001; Illingworth, 2001; Stewart & Williams, 2005).

There are also advantages regarding the practicality of the online approach. A lack of geographical boundaries increases accessibility (Chen & Hinton, 1999; Cher Ping & Seng Chee, 2001; Illingworth, 2001; Stewart & Williams, 2005), as does the practical issues of cost and time (Chen & Hinton, 1999; Illingworth, 2001; Kenny, 2005). The convenience, for both researcher and participants, of being able to log in at suitable times and places rather than arranging a mutually appropriate meeting is

also considered advantageous of research using asynchronous methods (Cher Ping & Seng Chee, 2001; Kenny, 2005; Turney & Pocknee, 2005).

Online focus groups are particularly suited to research where participants are hard to find or obtain (Turney & Pocknee, 2005) and existing online groups can be utilised for participation (Illingworth, 2001; Turney & Pocknee, 2005). This could be considered particularly advantageous for research involving those with experience of anorexia.

As with the disadvantages of e-therapy, the main limitations of using the internet for research centre on interaction and communication. Some researchers identify that a lack of physicality or loss of non-verbal information such as a lack of facial expression can be disadvantageous to data collection (Chen & Hinton, 1999; Illingworth, 2001; Stewart & Williams, 2005) and it is considered that this may affect the researcher-participant relationship (Illingworth, 2001). To counter this, participants and researchers can use written conventions to inject the tone and expression lost. The use of capital letters (I AM SHOUTING), punctuation marks (!), emoticons (☺), colour and words in between asterisks (*participant 1 nods*) can be used in the online environment to express emotion and other non-verbal cues (Kenny, 2005; Stewart & Williams, 2005). Furthermore, as with the provision of e-therapy, online research is also restricted to those who have adequate skills and access to a computer and the internet (Kenny, 2005; Turney & Pocknee, 2005).

Some potential advantages and disadvantages are unique to the use of the internet for research purposes. Validation of participants is a big concern for some researchers (Chen & Hinton, 1999) and may cause ethical issues (see chapter 4).

Fox et al. (2007) recognise the potential for using synchronous online focus groups with young people who already utilise such methods in their own communications (e.g. using instant messaging techniques and chatrooms) in engaging these populations in research. However, for studies using a more diverse group in terms of ages perhaps slower-paced asynchronous methods are more suited. Fox et al's (2007)

reflections on using synchronous online focus groups throw up two important limitations that would be addressed in an asynchronous approach. First, arranging a suitable time for all participants seemed just as problematic as conducting a face-to-face focus group; participation was subject to the focus group fitting with their offline commitments. Furthermore, this approach limited the opportunity to have a group consisting of people from a range of geographical regions and timezones. Second, the “*fast, furious and chaotic*” (p.543) nature of the synchronous approach may have implications for the type of data collected. For example, threading⁵ problems may occur when participants reply at the same time, those with more typing experience could dominate and the “*race to type and send responses*” can result in less reflective responses that may not be particularly focused on the question asked. It therefore seems that an asynchronous method of communication may be better suited for research purposes.

3.6. Chapter Summary

This review has highlighted multiple reasons for the uptake of internet resources that may be particularly important for those experiencing anorexia such as support groups for both maintaining and recovery reasons and for therapy purposes. A key advantage of online communication is the anonymity it affords which gives users a sense of ‘safety’, allowing for increased disclosure on issues that may be uncomfortable or unacceptable to discuss in an offline setting. Furthermore, the anonymity means that physical factors such as the body cannot be seen, a factor that may be particularly valued for those with body image concerns. Another key advantage is the accessibility of the internet; it can be used 24 hours a day, accessed from any computer and users can connect globally with others with similar interests or concerns. A potential disadvantage is the reliance on written communication that can result in miscommunication between users (an important consideration for therapeutic uses). However, written communication may be preferred by some users and allows for greater reflection.

⁵ Threading refers to the process of posting; when a new message is added to a discussion this becomes ‘threaded’ onto the end of the ongoing communication.

Research using online anorexic communities has looked at people's opinions and experiences of using web communities such as their experiences of using pro-anorexia websites (Mulveen & Hepworth, 2006; Williams & Reid, 2007). With the exception of Keski-Rahkonen and Tozzi (2005) who explored the meanings of recovery expressed through an online message board (see chapter 1), no other research has used online participants to explore their offline experiences in the online domain. In addition, no research studies to date have used online approaches (such as online focus groups and e-mail interviews) to interview people who use online communities about their experiences of living with anorexia. This is the purpose of this research. This thesis intends to contribute to current understandings of anorexia by exploring the lived encounters of those who have experienced anorexia and recovery using an 'online phenomenological' approach.

This review has highlighted the acceptability of using the internet to communicate about experiences of anorexia. One of the aims of the current research is to utilise pro-anorexic and pro-recovery websites to recruit those with varying beliefs to take part in online focus groups based on their experiences of anorexia and treatment. Unlike previous research, the study will not be asking about their use or views of sites but on their experiences and understandings of anorexia. Tierney (2006, p.187) has suggested how the use of the internet for exploring eating disorders "*can give voice to those who, in the past, have been missing from research, enabling investigators to explore the lived experiences of these individuals*" (Tierney, 2006, p.187). The decision to use asynchronous online focus groups arose for a number of reasons. First, online focus groups take place in online forums or discussion boards and it is suggested that this approach will emulate the online support group and pro-anorexia forums that participants will already be familiar with. Second, people utilise online discussions as a way of connecting with others in a similar situation, a one-to-one approach with only a researcher may not be desirable to participants who may position the researcher as another person who may not understand or who may judge them. Furthermore, a chance to talk to similar others may be seen as an incentive for participation. Finally, previous research has relied on passive methods of using the internet for research with those with eating disorders (e.g. observation, surveys) and

it is considered that an interactive approach may be a novel yet informative method of data collection. The following chapter will further consider the uses of the internet as a research tool by explaining the methodological approach employed in the current research.

4.1. Introduction

This research used an ‘online phenomenological approach’ and aimed to (1) determine the experiences and understandings of anorexia, recovery and treatment by those who have experienced it, and (2) identify how these understandings may affect pathways to and through treatment. The research explored the lived experiences of people with different attitudes towards anorexia and was split into three separate studies with three distinct groups: those who wished to maintain anorexia (pro-anorexic), those who wished to recover (pro-recovery) and those who had recovered. Participants were recruited through their participation in websites pertaining to anorexia and were asked to take part in one of three online focus groups or an e-mail interview. The term ‘online phenomenology’ has been coined for the purpose of the current research as a way of locating the methodological and epistemological underpinnings of the study design. This chapter has three aims: (1) to consider the online phenomenological approach; (2) to review and pilot the online focus group method and (3) present the method for the empirical work.

4.2. Phenomenological Psychology

Qualitative Psychology

The aim of the current research was to try to gain a better understanding of anorexia, the recovery process and the treatment experience. Thus, it seemed imperative for this to be done by allowing participants to tell, in their own words, their own stories and meanings of anorexia and recovery. Therefore, it was necessary, in order to meet these aims, for the research to employ a qualitative approach.

Qualitative research is “*concern[ed] with human experience in its richness*” (Ashworth, 2003, p.4). Qualitative researchers focus on the meanings of experience that are important to research participants. This is in direct contrast to quantitative research that aims to examine existing theory through testing variables that are

pre-defined by the researcher (Tindall, 1994; Willig, 2001). According to Willig (2001, p9) “*The objective of qualitative research is to describe and possibly explain events and experiences, but never to predict.*”

In contrast to quantitative research, qualitative research, which is typically inductive, allows for new insights from research participants to be discovered. Quantitative researchers aim to test “*a preconceived hypothesis on a large sample*” (Smith, 2003, p.2) in order to generalise results in support of a truth about experience (Parker, 1994; Willig, 2001). In contrast, qualitative researchers do not aim to conduct studies that can be replicated or generalised to all people who have shared a similar experience but instead “*an attempt is usually made to try and understand a small number of participants’ own frames of reference or view of the world*” (Smith, 2003, p.2). Thus, rather than attempting to test and measure variables to try to reach a “scientific law”, qualitative researchers believe that:

[R]ather than the world being a unitary environment in which people act in their different ways it should be seen that a world for each person exists which must be understood from each person’s perspective.
(Ashworth, 2003, p11)

Another clear difference between quantitative and qualitative research is the concentration on objectivity and subjectivity. Quantitative research attempts to produce objective findings through controlled experiments and the measurement of confounding variables that could affect the ‘validity’ of the research such as attempting to avoid demand characteristics and experimenter effects and to try to maintain ecological validity (Parker, 1994). In contrast, a qualitative approach embraces subjectivity through reflexive practice (Parker, 1994; Elliott, Fischer & Rennie, 1999). Qualitative research can be considered more naturalistic because instead of attempting to conduct research in an entirely controlled environment set up by the researcher it acknowledges and works with the effects that the research will have on the participants, researchers and the overall findings (Parker, 1994).

Despite these obvious differences between the two types of research approach, many traditional researchers accustomed to positivist ideas about research have tried to assess qualitative research based on ideas of reliability, validity and the ability for

research to be generalised (Tindall, 1994; Smith, 2003; Willig, 2001 – also see Chamberlain, 2000 for an example). Given the massive differences between the two methods, this is inappropriate. The “*quality of qualitative research*” (Smith, 2003) needs to be assessed in ways that are sympathetic to the aims of the research. Thus, whereas a quantitative study may be assessed on its ability to be replicated in future studies a qualitative study should be assessed on its ability to accurately interpret and present the experiences and views of those involved in that particular study. So, rather than assessing research based on ‘reliability’ and ‘validity’ a qualitative researcher will aim for ‘sensitivity’ and ‘rigour’ (Yardley, 2002 cited in Smith 2003).

Sensitivity refers to the ways in which the research is sensitive to the context of the phenomenon being investigated. This involves being sensitive to the data by ensuring that concrete examples from the data are provided alongside the interpretations in order to ‘ground’ the findings in participants’ accounts (Elliott et al., 1999). According to Elliott et al. (1999), it is also important for findings to be presented in a way that they ‘resonate’ with readers as an accurate account of participants’ experiences. Readers must also be presented with enough detail about participants and their circumstances to enable the reader to do this (Elliott et al., 1999).

Qualitative researchers should show ‘commitment, rigour, transparency and coherence’ by conducting the research, analysis and write-up in a thorough manner and providing a detailed description of the whole process (Smith, 2003). Elliott et al. (1999, p.223) recommend presenting findings as “*a data-based story/narrative*” to ensure coherence, and indeed, this can be considered a step in the data analysis process (Braun & Clarke, 2006). Triangulation serves as ways to ensure rigour (Tindall, 1994). This can include any number of ways that are felt to be relevant to the particular investigation, including investigating a phenomenon from a number of viewpoints (different participant groups), using multiple qualitative methods, or asking another researcher to ‘audit’ or provide feedback on the study.

Reflexivity is another important way of assessing quality research (Elliott et al., 1999; Parker, 1994; Tindall, 1994; Willig, 2001) and can be thought of as addressing issues

of both sensitivity and rigour. In a broad sense, reflexivity involves the researcher acknowledging the ways in which their own subjectivities, the subjectivities of the participants and the relationship between the participant and researcher shape the research (Finlay, 2003a). All qualitative approaches include some level of reflexivity but each will differ in the amount. Two forms of reflexivity are recognised, ‘personal reflexivity’ and ‘epistemological’ or ‘functional’ reflexivity (Tindall, 1994; Willig, 2001). Personal reflexivity involves acknowledging the ways in which the researcher influences the research (and the ways in which the research influences them) whilst being careful not to deflect away from the participant’s experiences. Epistemological reflexivity involves reflecting on the ways in which the methodology used has influenced the findings. Full consideration of reflexivity will be made in chapter 9.

Qualitative research can be split into two main branches: approaches that explore individual experiences and a person’s individual lifeworld (a phenomenological position); and approaches that explore how people’s language is socially constructed (social constructionist approaches). Whilst phenomenological approaches are concerned with the individual, social constructionist approaches aim to generalise findings to the society/culture it is examining. The current research takes a phenomenological approach as this is appropriate for the research question ‘how do people with anorexia experience and understand their disorder?’

Introducing Phenomenology

Phenomenology is “*the study of human experience and the way in which things are perceived as they appear to consciousness*” (Langdrige, 2007, p.10). The aim of phenomenological research “*is to capture as closely as possible the way in which the phenomenon is experienced within the context in which the experience takes place.*” (Giorgi & Giorgi, 2003). Central to phenomenology is the individual ‘lived experience’ and a person’s perception of their lifeworld or, expressed another way, as the meanings people place on their experiences. In order to locate the epistemology of the current research it is important to discuss some of the theoretical underpinnings of phenomenology. Therefore, this section begins by drawing

principally from Darren Langdrige's (2007) explanations of the theoretical underpinnings of phenomenological psychology. As will be seen, although the phenomenological movement is rooted in the early philosophy of Husserl, over time variations of phenomenology have been taken up, espousing the ideas of existentialism and hermeneutics.

In phenomenological research, the researcher attempts to explore the lived experience as perceived by the participant. This requires a certain level of what Husserl termed epoché, or 'bracketing off' one's own perceptions and preconceived ideas about the phenomena to be open to discovering the phenomenon as experienced by a participant (Spinelli, 1989). However, it is debateable as to how much a researcher can bracket off their ideas. The phenomenological movement is essentially split between early phenomenologists who believe that experience is transcendental (e.g. Husserl), and later phenomenologists who believe it is existential, (e.g. Heidegger and Merleau-Ponty, see Langdrige, 2007 and Spinelli, 1989). Transcendental phenomenology relates to the belief that a person can step outside of their experience and 'view the world from above', and thus believe that epoché is possible. However, existential phenomenologists believe that experience is embodied and we exist only through 'being-in-the-world', thus we can only perceive things through our subjective experience of being-in-the-world. Existential phenomenologists, therefore believe that a person cannot completely achieve epoché.

Existential phenomenology also recognises both the temporal and social nature of experience. Our sense of being-in-the-world is understood through our concept of time where "*we all live in time in a verb-like way, as meaning-making machines seeking to realize ourselves*" (Langdrige, 2007, p.39). Furthermore, we exist in a world with others therefore all experiences occur in relation to other people; being-in-the-world can thus be thought of as being-in-the-world-with-others.

It is also important to remember the idiographic nature of experience. Each person's experience of a phenomena will be different thus there is no 'correct' interpretation. We cannot know the truth about phenomena because one person's truth will not

necessarily be another's (Spinelli, 1989). Similarly, As Finlay (2003a, p.107), drawing on the ideas of Heidegger, notes "*each person will perceive the same phenomenon in a different way, each bringing to bear his or her lived experience, specific understandings and historical background.*" Moreover, experience is ever-changing, as an example from Spinelli (1989), the first time I see a painting in a gallery that I have been meaning to see for a while will be a different experience when I see it for a second time. "*Our interpretations of the world, therefore, are not only unique, they are also unfixed ('plastic') in their meaning*" (Spinelli, 1989, p.9).

Phenomenological psychology also employs the use of hermeneutics (meaning the 'art of interpretation' – Smith, 2007). Phenomenological research is considered a co-creation between the researcher and the participant and the meanings that both bring to the data through their individual subjectivities (Finlay, 2003b). Thus, phenomenology acknowledges the important role that the researcher and their fore-understandings play in the interpretation of the research (Finlay, 2003b, Smith, 2007) yet, at the same time, recognises the need to remain open to the insights obtained through the participant's experience. The researcher's fore-understandings may work to block the participants' meanings from appearing yet also serve to open up the interpretation. Thus, 'tension' between reduction and reflexivity occurs in phenomenological research whereby the researcher must "bracket" their fore-understandings yet also utilise them as a "source of insight" (Finlay, 2008).

This complex nature of interpretation may best be understood as a hermeneutic circle, whereby "[t]o understand the part, you look to the whole; to understand the whole, you look to the part" (Smith, 2007, p5). Interpretation is seen as a moving back and forth between the part and the whole to reach the interpretation. Each time one looks at the part one's understanding of the whole becomes strengthened and with each strengthening of the whole, new questions and new understandings of the part becomes apparent. The same explanation can be applied to the co-construction between participant and researcher. Before data is collected, the researcher already has a fore-understanding of the phenomenon under investigation, which inevitably becomes modified through hearing the experience of a participant. This new

understanding causes new questions and understandings of the participant's experience to be formed. Thus the research process involves a constant moving back and forth between the researcher's and participant's subjectivity until a plausible interpretation is reached (Finlay, 2003a; Smith, 2007).

The complex role of the researcher's understandings in the interpretation of data renders it essential for the phenomenological researcher to be reflexive throughout the research. Reflexivity can be defined as:

[T]he process of continually reflecting upon our interpretations of both our experience and the phenomena being studied so as to move beyond the partiality of our previous understandings and our investment in particular research outcomes.

(Finlay, 2003a, p.108)

...and should involve:

[R]eflecting upon and understanding our own personal, political and intellectual autobiographies as researchers and making explicit where we are located in relation to our research respondents. Reflexivity also means acknowledging the critical role we play in creating, interpreting and theorizing data

(Mauthner & Doucet, cited in McKay, Ryan & Sumsion, 2003, p.52)

To summarise, phenomenological psychology acknowledges that lived experience, and the meanings we place on that experience, is a result of 'being-in-the-world-with-others'. Experience is embodied, ongoing and a result of our interactions with the world and others. Phenomenological psychology also involves a process of interpretation (hermeneutics) and acknowledges the co-constructed meaning-making process between the researcher and participant. The researcher must constantly reflect on their own experiences and understandings regarding the phenomena under investigation from the outset and throughout the research process through reflexive notes or a reflexive journal. The characteristics of phenomenological psychology will be returned to later in this chapter when consideration is given to how such an approach can be applied to online research. First, interpretative phenomenological analysis, the particular phenomenological psychology approach chosen for this research will be explored.

Interpretative Phenomenological Analysis (IPA)

Interpretative Phenomenological Analysis (IPA) is a phenomenological approach developed by Jonathon Smith for psychological research. It is commonly used in health psychology but may also be used in areas such as social, clinical and counselling psychology (Brocki & Wearden, 2006; Reid, Flowers & Larkin., 2005; Smith, 2004). As with all phenomenological approaches, the focus of IPA is the study of individual experiences of a particular phenomenon and the meanings participants attribute to these experiences. As Smith and Osborn state:

The aim of interpretative phenomenological analysis (IPA) is to explore in detail how participants are making sense of their personal and social world, and the main currency for an IPA study is the meanings particular experiences, events, states hold for participants.

(Smith & Osborn, 2003, p.51)

The decision to use this approach for the current research arose as a result of previous work (Williams & Reid, 2007), which used a grounded theory approach. This work highlighted the diverse nature of anorexia nervosa and emphasised the need to study individual cognitions and experiences. The current research aims to understand participants' meanings of anorexia through their lived experiences of it and therefore a phenomenological approach is suited. Grounded theory, an approach that originated from sociology is appropriate for phenomenological research but its emphasis on generalising findings to whole populations means that any differences in individual accounts may be missed. As Willig recognises:

Grounded Theory aims to identify and explicate contextualized social processes which account for phenomena. By contrast, IPA is concerned with gaining a better understanding of the quality and texture of individual experiences; that is, it is interested in the nature or essence of phenomena.

(Willig, 2001, p.69)

At present, qualitative research on understanding the experiences of anorexia, recovery and treatment (reviewed in chapter 1) has tended to use a grounded theory approach (e.g., D'Abundo & Chally, 2004; Lamoureux & Bottorff, 2005; Weaver et al., 2005) and there is currently a dearth in the number of studies employing a

phenomenological approach in this area. However, as Colton and Pistrang (2004, p.315) state: “A *phenomenological approach has the potential to enrich both our understanding of anorexia and the debate about how best to treat it.*” It seems that only two studies use ‘phenomenological’ approaches to investigate the phenomenon of living with anorexia (Garrett, 1998; Nordbo et al., 2006) and only three have used IPA (Colton & Pistrang, 2004; Gavin et al., 2008; Mulveen & Hepworth, 2006).

A number of studies aiming to ‘understand’ anorexia have employed feminist, discourse analyses (Dias, 2003; Malson, 1998; Rich, 2006). These studies also miss the individual experience and cognitions as the discursive approach is focused on the social construction of anorexia rather than the individual’s interpretation. In addition, by taking a feminist stance such authors could be criticised for not ‘bracketing’ off their own subjective biases regarding anorexia. In contrast, the current research, which attempts to bracket off such researcher biases and does not take a particular stance could be said to get closer to the participants’ own lived world.

Social approaches to data analysis (e.g. grounded theory and discourse analysis) aim to generalise research findings to a society rather than focusing on the individual’s subjective meanings. Grounded theory employs devices such as data saturation (when no more new themes can be generated), constant comparison (constantly comparing findings from participants for differences and similarities) and theoretical sampling (to go back to more participants to try and confirm emerging theory) to generalise findings to a larger population (Charmaz, 2003). Discourse analysis (including discursive psychology and Foucauldian discourse analysis) is concerned with the role language plays in constructing social reality (Willig, 2003). In other words, it is concerned with the ways in which a society constructs particular phenomenon, rather than how an individual may construct this. These approaches have been criticised for only providing claims at the group level and not “*being able to say anything substantive and specific about the particular individuals who, in fact, provided the data for the study in the first place*” (Smith, 2004, p.42).

Contrastingly, phenomenological research (including IPA) allows a more individual approach. So rather than aiming for nomothetic, generalised research findings, IPA is concerned with idiographic experiences and understandings and how the individual interprets phenomena, rather than how it is socially constructed. Only when each individual's experience has been interpreted can the researcher move to shared understandings across the group (Smith, 2004). Nonetheless, it also important to consider that although IPA focuses explicitly on the individual experience it also (like discourse analysis) recognises the role of sociocultural and historical influences in the way people experience and understand their lived world (Eatough & Smith, 2008)

Related to this, another difference between IPA and other approaches to data analysis is the focus on cognitions. IPA shares with mainstream cognitive psychology a focus on cognitions in that it is concerned with the meaning making process of participants, however unlike mainstream cognitive psychology IPA uses qualitative analysis as opposed to quantitative analysis (Smith, 2004). Therefore, this focus is not the same as that used in a cognitive science sense, which uses positivist measures of cognitive functioning. Rather, IPA enables the researcher to explore participants' own cognitions through the interpretations of their own meanings and understandings. In this way, IPA "*afford[s] us a deeper understanding than traditional psychological methods*" (Reid et al., 2005, p20). For example, whereas grounded theory analysis simply asks what is happening in a particular phenomenon, IPA asks how people make sense of what is happening in a particular phenomenon, thus incorporating the person's own cognitions. A focus on cognitions is also another way in which IPA is distinct from discourse analysis. Smith (1996) describes IPA as a middle ground between the opposing stances of social cognition (which draws on positivist approaches to look at cognitions) and discourse analysis (which uses qualitative data but does not consider cognitions):

Where such researchers [using a phenomenological approach] would typically differ from discourse analysts is in having a concern with cognitions, that is, with understanding what the particular respondent thinks or believes about the topic under discussion.

(Smith, 1996, p.263)

One final difference between grounded theory analysis, discourse analysis and IPA is the focus on the researcher. By discussing the researcher's own interpretations of the participants' own meaning (a double hermeneutic approach), IPA is explicit about what the researcher brings to the analysis (Smith, 1996; 2007). Reflexivity is also apparent in grounded theory with the use of memos throughout the analysis but the final presentation of results does not include this focus, instead the research findings are presented as completely data-driven. Discourse analysis also does not present research findings as a meaning-making process between the researcher and the participant but links participants' discourses with institutions and current social explanations and practices (Willig, 2003). An interpretative approach to data analysis, therefore, does not mean that themes can simply "emerge" or "be discovered", rather data analysis requires the researcher to "actively" work with the data (Braun & Clarke, 2006). The use of the term "emerging":

...can be misinterpreted to mean that themes reside in the data, and if we just look hard enough they will 'emerge' like Venus on the half shell. If themes 'reside' anywhere, they reside in our heads from our thinking about our data and creating links as we understand them.

(Ely et al., 1997: 205-6 cited in Braun & Clarke, 2006)

IPA goes beyond simply using participants' own words to describe a particular phenomenon it then uses these own words to interpret the meanings expressed by the participants. IPA uses a double hermeneutic as the researcher is making sense of the interviewee making sense of their experiences (Smith, 1996; 2007). IPA uses hermeneutics of empathy in that it is trying to understand a person's experience from their own perspective. This can be differentiated from discursive approaches (e.g. discourse analysis and conversation analysis) that use the hermeneutics of suspicion by examining why people say things and why they have said it in a particular way (deVisser, 2007).

Smith (2004) outlines three characteristic features of IPA; it needs to be 'idiographic, inductive and interrogative'. IPA's commitment to the individual account has already been discussed above. The idiographic nature of IPA allows the researcher to identify participants' distinct meanings and experiences of a phenomenon but also allows for the identification of the areas where these meanings and experiences are shared by a

group of participants (Shaw, 2001; Reid et al., 2005). Therefore, the results of an IPA study will look at the shared meanings and understandings of a subject but will also demonstrate aspects that are unique to individuals (Shaw, 2001).

IPA is *inductive* as it allows unanticipated areas of experience to be explored (Smith, 2004). In this sense, it is important to employ a semi-structured approach using open-ended questions, which allow participants to discuss areas of importance for them. Once the results of an IPA study are obtained, they are then discussed with reference to the existing psychological literature on that topic. In other words, the results of the IPA study are then used to inform, support or problematise findings from previous work from mainstream psychology and it is in this way that IPA is *interrogative* (Smith, 2004).

Reid et al. (2005) also outline three characteristic features for a successful IPA study, they believe it must be ‘interpretative’, ‘transparent’ and ‘plausible’. To be *interpretative* the researcher must subjectively and reflexively work with the data to interpret the meanings the participants hold, these interpretations can be based on theoretical perspectives as long as they are *transparently* linked to the participants’ words (“grounded within the data”). Furthermore the analysis needs to be *plausible* to the participant, those working on the data and to those reading the analysis, in other words the interpretations need to resemble what it is actually like to live those experiences.

4.3. Methodological considerations

Although guidelines for IPA have been published (Smith, Jarman & Osborn, 1999; Smith & Osborn, 2003), it is important to recognise the flexibility that IPA affords (Smith, 2004; Smith & Osborn, 2003; Willig, 2001). For example, Smith and Osborn (2003, p66) recognise that IPA “*is there to be adapted by researchers, who will have their own personal way of working.*” Similarly, although IPA studies have predominantly been conducted using traditional semi-structured interview methods (Brocki & Wearden, 2006) researchers using this approach are encouraged to “*push*

the boundaries in terms of populations and data collection methods” (Smith, 2004, p.51).

The current research definitely takes up this challenge by sampling from online populations and adopting online data collection methods that employ the use of online focus groups and e-mail interviews and it is important to consider how this may affect the IPA research. This section considers the methodological choices in more detail by relating them to the phenomenological tradition, by considering the online approach before moving onto issues of sampling and then the data-collection method of online focus groups.

The Phenomenology of the Internet

The two concepts of ‘online’ and ‘phenomenology’ may not seem, in traditional phenomenological philosophy, to link naturally because “*the Internet transforms human experience across dimensions of temporality, embodiment, spatiality, and sociality*” (Garza, 2002, p.185). However, recent research into the phenomenology of technologies suggests a need to rethink what is meant by experience (Ihde, 1993; Murray & Sixsmith, 1999; Richardson, 2005). This section explores the phenomenology of the internet by drawing on the phenomenological concepts of embodiment, spatiality, temporality and sociality and argues that an online phenomenological approach is valid.

Research combining online methodology and IPA has been employed to look at such experiences as identity in self-harm (Adams et al., 2005) the experience of prosthesis use (Murray, 2004) and the experience of using pro-anorexia websites (Gavin et al., 2008; Mulveen & Hepworth, 2006) yet none of these papers acknowledge the relationship between phenomenology tradition and online communication. This section attempts to do this.

Online Embodiment (Technosoma)

The typewriter snatches script from the essential realm of the hand – and this means the hand is removed from the essential realm of the word.

(Heidegger, 1982, cited in Ihde, 1993)

It is clear that a sense of embodiment is essential to a person's experience of being-in-the-world and that this needs to be explored in phenomenological research. Finlay (2006) believes that it is important for phenomenological researchers to think reflexively about the bodies of both the researcher and participant during the interview process. In an online interview or focus group the physical body of both are absent (unless interviews are conducted using a webcam). Does this mean, therefore, that online data collection is "*a form of comprised research practice*" (Langdridge, 2007, p.70) because it eradicates the physical bodies of the participants and the researcher? A consideration of postphenomenology may help answer this question.

Ihde (1993) proposed the term 'postphenomenology' as a way of locating phenomenology within a postmodern context. Postphenomenology concerns the philosophy of technology and the roles technologies play in human experience and existence. According to Ihde (1993), technologies are "*non-neutral*" in that they shape "*quality, field and possibility of human experience*" (Ihde, 1993, p.33). Ihde (1993, p.34) believes that technologies need to be understood phenomenologically, as a human-technology relationship, in that rather than being "*mere objects totally divorced from human praxis*", technological artefacts can only be understood through the experience and embodiment of the person that interacts with them. Thus, technologies shape lived experience in a number of ways. Postphenomenology may help link the phenomenological philosophy to the online approach. However, it is important to remember that this thesis is concerned with the lived experiences of anorexia as 'told' *through* online medium not on the participants' experience *of* the online approach.

By drawing on Ihde's (1993) ideas of human-technology relationships, online communication in an online interview or focus group can be understood as two human-technology relationships between the researcher and the computer and the

participant(s) and their computer. It is undeniable that the technology affects the lived experience of the online interview or focus group in many ways but this may also be said of the technologies (e.g. tape-recorder or pen and paper) used in an offline, face-to-face interview.

In her work on the phenomenology of mobile phone media, Richardson (2005) acknowledges how in today's culture with "*our increasing remote interaction with the world*" through technologies we need to think of new ways of thinking about our lived experiences that incorporates our experiences of technologies. She believes that embodiment is continuously altered through technology and we consequently need to alter the way we think about embodiment, we need to "*think through other ontologies, other ways of being-in-the-world, and in a Heideggerian sense, of being-with-equipment*". Richardson (2005) uses the term 'technosoma' to describe the technological nature of the body being in the world.

Drawing on the work of Heidegger, Langdrige (2007) discusses the distinction between corporeality and embodiment whereby "*[t]he corporeal thing stops and is bounded by the skin, whereas our sense of embodied selfhood may extend beyond this 'bodily limit'*" (Langdrige, 2007, p.71). The classic example given by Heidegger is the experience of pointing where our sense of 'bodiliness' extends past our finger and to the object we are pointing at. Bodiliness can also be experienced through technologies. Murray's (2004) research focusing on the embodied experience of a particular technology - artificial limbs - found that some participants came to see their artificial limb as an extension of their own body. Langdrige (2007, p.72) purports that the same should be true in online interviewing through an "*ability to conjure up a sense of embodied subjectivity in text*". Thus, drawing analogy with Heidegger's example of pointing, we could say that the sense of bodiliness extends past our finger through our typed text.

Today, contact means a telephone number, not touching each other through our senses, our skin.

(Irigaray, 2000, p.97)

French philosopher, Luce Irigaray (2000) questions the spatiality, sociality and embodiment of technology in her poetic and metaphorical essay on long-distance communication entitled "*How can I touch you if you are not there?*" Irigaray's message seems to imply a technical versus a natural argument whereby technologies such as the television and telephone transform our natural perceptions of touch, sight and sound. As the above quote illustrates the term 'contact' no longer refers to the physical contact of two bodies but the exchange of means of communication that do not require physical interaction.

The act of using technologies such as the internet can be said to be both physically and emotionally embodied; however, when we consider the spatiality of the experience of the internet, we see that the meaning of embodiment is challenged. Garza (2002, p.191) has argued that the lack of corporeality in cyberspace renders online use as 'disembodied': "*The ability to "go anywhere" with the Internet comes at the price of doing so in a disembodied manner*". However, Richardson (2005), just as Heidegger and the pointing example, recognises the embodied nature of telecommunication, believing that "*a sense of presence can be felt beyond the location of the physical body*". Online communication can be considered disembodied in that the interaction is not with a corporeal being but with a technosoma. Yet at the same time it is embodied in that the sense of body can be "*extend(ed) beyond [...] bodily limit*" (Langdrige, 2007, p.71); the body is physically used in the experience of using the internet and can be emotionally represented through the text it produces. As Alapack, Blichfeldt and Elden (2005, p.59) state: "*Over the net, 'no body' does not equal 'no presence'.*"

The internet can be understood as a 'telepresent' experience (present at a distance) in that a person is both here and there; or near and distant (Garza, 2002; Richardson, 2005) which may affect a person's experience. For example, a conversation on a

mobile phone may evoke emotional reactions that are unsuited to the physical location of where we are having the conversation and in this occasion, the person has to be present in both the here and now of the conversation and the environmental context (Richardson, 2005). Thus, the same could be true from reading an e-mail (how often have you opened an amusing e-mail at work and had to stop yourself from laughing aloud?) where a person may be momentarily caught up in the 'there' of the e-mail whilst also being aware of the 'here' of the environment in which the e-mail is being read.

Embodied presence may also occur when people have never physically met each other. Alapack et al. (2005) investigated the experience of online dating to find that *"online flirting often triggers physical and sexual reactions stronger than in a regular conversation"* (Ibid, p.54). One participant, in particular, describes her experiences of forming a close relationship with someone despite never meeting face to face, suggesting how even without physical presence rapport can be built. In a similar yet unrelated vein, research into pro-anorexia websites has recognised a sense of connection between site visitors who convene in the online space for the same purposes (Dias, 2003; Mulveen & Hepworth, 2006; Uca, 2004). Furthermore, a lack of physical presence in the online environment may be particularly advantageous for those who have appearance related concerns (Fox et al., 2007; Walstrom, 2000). As Walstrom (2000, p.761) identifies, *"[t]he 'bodiless' nature of online support groups helps ensure participants' sense of safety, because judgements relating to physical appearances are largely decreased"*.

Rapport between a researcher and participant(s) is important for disclosure of experiences. In light of the research conducted on telepresent communication (Alapack et al., 2005; Richardson, 2005) it is suggested that a telepresent relationship between the researcher and participant can be formed. It is proposed, therefore, that a description of the embodied experience of anorexia given by a participant through the embodied interaction of the human-technology relationship could produce a strong embodied reaction through the researcher's reading of the text in their human-technology relationship.

As highlighted in chapter 3, one positive aspect of conducting social science research online is that the physical anonymity may result in a reduction of power relationships. For example, it was seen how online communication between a doctor and patient reduced the normal conventions of a doctor/patient relationship (Yager, 2002). The same can be said in online research between a researcher and participant (Fox, et al., 2007). Furthermore, the anonymous online environment allows for equality amongst participants in a group situation. So, whereas in face-to-face situations social power amongst some group members may affect others' responses or may mean that some members dominate the discussion this is reduced online (Illingworth, 2001; Stewart & Williams, 2005). This reduction of power relationships also has positive implications for the ethicality of online research and these will be discussed later in the chapter.

The Temporal Nature of the Internet: Asynchronous or Synchronous Communication

Synchronicity is important to understanding mediated communication because once the pressure to reply immediately is removed, the person has the opportunity to move scarce cognitive resources from the management of the conversation to the actual message.

(Joinson, 2003, p.22)

Online communication can be conducted in real-time (synchronous) or in non real-time (asynchronous). The asynchronous nature of much online communication (e.g. in e-mail or discussion boards) also changes the temporal and spatial nature of communication. People no longer need to be in the same space at the same time to communicate, which has the added benefit of convenience for both the researcher and the participants (Cher Ping & Seng Chee, 2001; Kenny, 2005; Turney & Pocknee, 2005).

As the above quote from Joinson (2003) illustrates the removal of the immediacy of communication can allow people to devote more 'cognitive resources' to the content of their message rather than to the process of merely replying. Thus, asynchronous communication affords both participant and researcher more time to reflect on the

interview. The participant has more time to reflect on the answer they wish to give whilst the researcher has time to reflect on the previous answer before asking the next (Hamilton & Bowers, 2006; Murray & Sixsmith, 1997; Wood, Griffiths & Eatough, 2004). For example, Murray's (2004) study, which employed the use of both asynchronous e-mail and synchronous face-to-face interviews, found that those interviewed via e-mail "*were more frank about their experiences, remained more focused on the research questions, and provided more reflectively dense accounts than their face-to-face counterparts*" (Murray, 2004, p.965). This illustrates that the asynchronous, telepresent nature of the methodology gave participants more time to think about their experiences before providing a focused answer. Wood et al. (2004, p.515) recognise that the asynchronous, reflective nature results in a "*loss of spontaneity*" in the research but discuss how this is only a "*minor and inevitable drawback*".

The Spoken and Written Word

Human communication is always ambiguous. Whether we are writing a letter, shouting face-to-face or whispering in the dark, we never catch all nuances. Something always gets lost in translation [...] Users, plopped in front of a screen, try to clarify expressions of sarcasm and irony, just as do writers of traditional letters...or two intimates standing in front of each other, wagging tongues.

(Alapack et al., 2005, p.54)

Online communication relies entirely on written language and, as discussed in chapter 3, some have questioned the implications of this on expressing and interpreting emotion (Illingworth, 2001; Stewart & Williams, 2005). Spoken language includes non-verbal cues such as pitch, tone, facial expression and body language that provide a sense of emotion. However, online conventions are commonly used that allow communicators to inject some sense of emotion in their text (Alapack et al., 2005; Fox et al., 2007; Kenny, 2005; Stewart & Williams, 2005-see also chapter 3).

The differences between the written and spoken word has been discussed by authors who describe how through transcribing spoken language into written language a sense of meaning and context is lost (Langdrige, 2007). Langdrige (2007)

acknowledges how the spoken conversation shared by the researcher and participant differs in the intention of the written transcription, which becomes fixed and detached from the speaker. However, data collected online begins in written form; thus, one could argue that in fact this data is closer to the participants original meaning as it does not require treatment by the researcher in order to be analysed. In online data collection, data is simply used in the same format in which it was collected.

Sampling

Most research into anorexia, recovery and treatment has been carried out with samples drawn from treatment services. The literature review has identified how for many people their restrictive and exercise behaviours are not seen as problematic. Many often do not present for treatment and if they do they may not comply, may drop-out or have a negative experience that prevents them from seeking treatment in the future (e.g. Eivors et al., 2004). Furthermore, some who do think their behaviours are problematic may be turned away from treatment because they do not meet the strict diagnostic criteria or may not be able to receive treatment because of practical problems with treatment provision such as waiting lists or financial implications (e.g. Reid, Williams & Burr, under review). Therefore, research that limits samples to those currently receiving some kind of professional support or treatment are intrinsically biased to a small proportion of those who have experienced anorexia and/or self-identify as anorexic.

The current research uses a sample recruited through their involvement in websites related to anorexia. It is recognised that, although this sample could also be considered biased to those using websites, the potential reach to those who may or may not have received treatment and those who may or may not feel their behaviours are problematic would mean that the sample is still more inclusive than a sample restricted only to problematic patient groups.

Researchers have recognised the potential of the internet for studies involving participants who are hard to reach (Turney & Pocknee, 2005) and existing online groups are considered a useful source of recruitment (Illingworth, 2001). The online environment also offers a potentially global sampling pool, therefore increasing accessibility to potential participants (Chen & Hinton, 1999; Mann & Stewart, 2000). This is advantageous when considering the low prevalence rates of those with anorexia. Finally, the anonymity of the online environment may also allow those who may not feel comfortable discussing their anorexia face-to-face to become involved in research (Adams et al., 2005; Kenny, 2005; Stewart & Williams, 2005). Of course, this level of anonymity may also cause issues with validity and this will be considered later in the chapter.

IPA allows the researcher to obtain detailed accounts of individuals' experiences of living with a particular disorder (Shaw, 2001) and therefore participant samples are purposive and are recruited due to their "*expertise*" on a particular subject, subsequently:

Participants are experts on their own experiences and can offer researchers an understanding of their thoughts, commitments and feelings through telling their own stories, in their own words, and in as much detail as possible.

(Reid et al., 2005, p.20)

Reid et al. (2005) describe how by conducting comparison studies by looking at a phenomenon from multiple perspectives the researcher can obtain a thorough account of it. Thus, by engaging the three participant groups (those wishing to maintain, those in recovery and those who have recovered) a more thorough understanding of anorexia can be obtained.

Low sample sizes are normally recommended for phenomenological research as the aim is to provide detailed, in-depth accounts of participants' lived experience (Smith, 2004). Reviews of IPA studies (Brocki & Wearden, 2006; Reid et al., 2005) have found samples ranging from one to thirty, with most employing small sample sizes. Nonetheless, Reid et al's (2005) review identified a mean sample size of 15 participants. Asynchronous online research has the potential to employ a larger

sample size (Mann & Stewart, 2000), however, as the review presented later in the chapter indicates, online focus group studies tend to range in number between 4 and 57 participants per group with a mean group size of 14. Although a pragmatic attitude to recruitment needs to be taken, it can be postulated that a sample size of 14-15 participants should be aimed for, for each of the three online studies.

Procedure: Implications of Online Focus Groups

Because of the idiographic nature of the research, IPA is more commonly used and recommended for interview data (Brocki & Wearden, 2006; Eatough & Smith, 2008; Millward, 2006). Indeed, in a review of 52 IPA studies Brocki and Wearden (2006) found that 42 used the traditional semi-structured interview technique, with a further three employing email interviews. Eatough and Smith (2008) recognise that it is not essential for IPA research to use this method for data analysis suggesting that diaries and written personal accounts could be useful alternatives. However, they argue that *“the real-time interaction with the participant gives major flexibility for the researcher in facilitating the participant in exploring their lived experience”* (Eatough & Smith, 2008, pp187-188). In contrast to methods devoid of researcher input such as a diary study this could well be true. However, as seen in the above section, an asynchronous yet interactive approach could have the potential for even more flexibility as the ongoing nature of the research can allow for a deeper exploration of lived experience.

Although a one-to-one approach is favoured, Millward (2006) recognises that IPA research may be combined with a focus group approach, she acknowledges:

[...] there may be instances where people find it easier to talk openly about their personal perceptions and experiences in a context in which these experiences can be shared with similar others. [...] In such instances, the individual perceptions and experiences need to be parsed out from the group discussion

(Millward, 2006, p.295)

As discussed in chapter 3, the decision to use online focus groups for this research, is to emulate naturalistic online discussion forums that recruited participants may be

used to. Those recruited from websites and forums with the intention of discussing eating disorders are used to discussing their experiences in a group situation and one of the main reasons people use pro-anorexic websites is for the support and understanding that they can obtain by talking to others in the same situation (Dias, 2003; Mulveen & Hepworth, 2006; Rich, 2006). Therefore, to ensure a naturalistic approach to the research it is imperative that a group interaction approach should be taken. As Pollack (2003, pp249-250) suggests, it is important for researchers to investigate pro-anorexia beliefs by “*engage(ing) with these women [sic] in their chosen community of cyberspace.*” Thus, it follows that research investigating the experiences of those recruited through pro-recovery websites should also be conducted in the natural environment of cyberspace.

IPA has been successfully used with face-to-face focus group research in the past (Dunne & Quayle, 2001; Flowers, Knussen & Duncan, 2001; Jordan, Eccleston & Osborn, 2007) and Adams et al. (2005) have employed IPA in their online focus group study of self-harm. In particular, Dunne and Quayle (2001) and Flowers et al. (2001) recognises the effects that group dynamics may play on the data, and both emphasise how being already well-known to each other in the group and having a shared concern with the topic under investigation enabled suitable discussion and therefore data. On a similar note, Smith (2004) suggests that those using IPA with focus group data should check the transcripts for both group dynamics and for idiographic accounts:

If the researcher is convinced that participants are able to discuss their own experiences in sufficient detail and intimacy, despite the presence of the group, then the data may be suitable for IPA

(Smith, 2004, p.51)

The participants in the current studies will not know each other prior to their participation but will share a concern with the topics of anorexia, recovery and treatment. Furthermore, the fact that the online environment offers anonymity should enable participants to feel more comfortable in disclosing information regarding personal topics even in a group interaction. As Adams et al. (2005, p.1295) state “*The anonymity of cyberspace allows Internet users to express themselves in ways that might be constrained in their real-world interactions.*”

On a cautionary note, it is important for research using focus groups as a data collection method to retain the idiographic approach to analysis. A number of focus group studies employing IPA (for example Rubin's (2004) study into the social context of men's Viagra use and Earle, Davies, Greenfield, Ross, and Eiser's (2005) study into the advantages and disadvantages of using follow-up services for child cancer survivors), seem to have forgotten to address the fundamental aspect of IPA; the individual lived experience. Instead, both studies concentrated on generalising their findings to the group as a whole without addressing the issues of importance for the individual participants.

On a final note, although it is important to consider 'epistemological reflexivity' or the ways in which the methodology used may affect the research (Willig, 2001) it seems essential to remind oneself of the creativity of qualitative research and the importance of not allowing the research project to get caught up in methodological issues. It is thus important to keep in mind Chamberlain's (2000) cautions of becoming "*overly concerned with method*" to the detriment of the research topic. This has been termed by other researchers before him as "methodolatry" defined as "*a combination of method and idolatry, to describe a preoccupation with selecting and defending methods to the exclusion of the actual substance of the story being told*" (Janesick, 1994, cited by Chamberlain, 2000, p286). With the exception of more practical issues surrounding methods (as opposed to methodology), any further discussion of methodological or epistemological issues will be 'bracketed' and reported at the end of the thesis (chapter 9) so as to ensure sufficient focus is given to the research topic at hand, the experiences and understandings of anorexia.

4.4. Review of Online Focus Group Studies

A number of practical questions still linger regarding the online focus group method including what is a recommended sample size? How long should the online focus groups last and how many topics should be included? What is the researcher's role in conducting a focus group online? What sort of data can this method produce? Where

can online focus groups be held? And where can participants be recruited? It is hoped that by answering these questions a suitable method for conducting online focus groups can be developed.

As the online focus group is still relatively novel there are currently no specific recommendations for using this method. Therefore, a review of existing studies that utilised online focus groups in the fields of health and social sciences was conducted to aid in informing the design of the present research. Twenty-one asynchronous online focus group studies were identified and reviewed and these are summarised in table 3.

Table 3: Review of Asynchronous Online Focus Groups

Author/s (Year)	Sample size/ Participants	Study length	Study site	Number of discussion topics/ [total posts by participants if stated]	Method of Data Analysis
Adams et al., (2005)	2 focus groups – (1 with 13 participants and 1 with 9 participants) with people who self-harm	Unknown	Self-harm discussion board	Not stated	IPA
Adler & Zarchin (2002)	7 pregnant women on bed rest	4 weeks	E-mail list	6 questions [33]	Thematic content analysis
Boshoff, Alant & May (2005)	2 focus groups (consisting of 7 and 6 participants) with occupational therapy managers	1 week	Insufficient details	5 topics [total of 99 posts for both focus groups]	Identification of preset codes
Bruening & Dixon (2007)	Seven focus groups with 5 participants in each group, two with 4 (43 in total) – Sports coaches who were also mothers	18 weeks	Closed site (Specific type e.g. VLE or forum was not stated.)	1 per week minus two weeks = 16	Thematic Analysis
Dattilo et al. (2008)	8 adults with cerebral palsy	Not explicitly stated but can assume 9 weeks	Unsure	1 question per week = 9	Thematic Analysis
Dickerson & Feitshans (2003)	4 focus groups (with 3, 5, 5, and 19 in each group- total 32) with self-identified frequent internet users	3 weeks	VLE ¹ (Blackboard)	Not stated	Hermeneutical Phenomenology approach
Hanley (2006)	9 UK Counsellors	One month	Customised online forum	[41]	Grounded Theory

Im (2006)	29 white cancer patients	6 months	Online forum	9 topics [291]	Thematic Analysis
Im et al. (2007a)	16 Cancer patients (investigating attitudes towards internet cancer support groups)	1 month	Online forum	6 topics	Thematic Analysis
Im et al. (2007b)	15 Hispanic cancer patients	6 months	Online forum	10 topics -1 was included as a result of participant feedback [227]	Thematic Analysis
Im et al (2008a)	15 midlife women	1 month	Online forum	17 topics [average 26 posts per participant]	Thematic Analysis
Im et al. (2008b)	16 Cancer patients (investigating gender and ethnic difference in cancer care needs)	1 month	Online forum	1-2 topics per week	Thematic Analysis
Im et al (2008c)	23 midlife white women with experiences of menopause symptoms	6 months	Online forum	7 discussion topics in total with participants allowed to add their own topics	Thematic Analysis
Im et al (2008d)	27 Asian American cancer patients	6 months	Online forum	Unsure	Thematic Analysis
Kenny (2004)	38 Nurses	8 weeks	VLE ¹ (WebCT)	[263]	Not stated ²
Moloney et al (2003)	Four focus groups, 5-6 in each group (total=22) with perimenopausal women experiencing migraines.	3-5 weeks	Customised discussion board	Not stated	Not stated ²
Murray (1997)	6-8 health professionals with expertise in computer-mediated communication	4 weeks	e-mail list	Not stated	Not stated ²
Robson (1999) cited	57 Inflammatory bowel disease sufferers	8 weeks	Closed e-mail list	Not stated	Not stated ²

in Stewart and Williams, 2005)

Turney & Pocknee (2005)	3 focus groups, one with 4 men's rights activists, 6 women who had been paternity tested and 9 stem cell study patients (Parkinson's disease or spinal injury).	1 week each	VLE ¹ (Blackboard)	Not Stated	Not stated ²
Watson, Peacock & Jones (2006)	5 focus groups (total of 57 participants)	10 days each	VLE ¹ (WebCT)	Not stated [702 total, average 140 per group]	Phenomenological Thematic analysis
Williams (2003, cited in Stewart and Williams, 2005)	Compared a focus with 45 participants with one that comprised of 15 participants.	8 weeks	Not stated ²	Not stated but same topics used in both groups. ²	Not stated ²

¹ VLE = Virtual Learning Environment; common learning technologies employed by universities for learning purposes

² These details were not given as the paper reviewed was based on methodological findings rather than study findings

Sample Size

Online focus groups have the potential to use larger sample sizes than their face-to-face counterparts (Robson, 1999, cited in Stewart & Williams, 2005) and indeed this has been recommended by some. Williams (2003, cited in Stewart & Williams, 2005) compared a focus group consisting of 45 participants with a group that was comprised of 15 and found that members of the smaller group ceased posting despite further questions being introduced, whereas the large group carried on posting throughout the entire study. According to Williams, a smaller group size may result in less of a group identity and a casual attitude towards the research.

With no concrete recommendations, some researchers have chosen to simulate the numbers recommended for face-to-face focus groups (Boshoff et al., 2005; Im et al., 2007b, 2008b). For example, Im et al. (2007b, p862) describe how “*6-10 participants are adequate for a focus group discussion. Thus, 15 participants were considered more than adequate for the online forum discussion*”. Their argument for this sample size seems unjustified and confusing considering their sample is almost double that recommended for a face-to-face group. Murray (1997), who ran focus groups online to investigate the feasibility and potential issues of using the internet in this way, used the same sample sizes recommended for traditional focus groups (6-8 participants). Although Murray (1997, p.545) believed that this sample size was appropriate he warns, “*the off-line group size may not be appropriate in all circumstances, and a larger group may be needed to promote the level of discussion and interaction the researcher seeks*”. Mann and Stewart (2000), although recognising the internet’s potential for larger group sizes, warn that for the discussion to be “*comfortable, permissive and conducive to ongoing self-disclosure,*” a small group size is more appropriate.

There are obviously conflicting views regarding an optimum number of participants for an online focus group and this is illustrated well in table 7.1 where the sample sizes for individual studies range between 3 and 57, with most consisting of small

numbers of four, five or six participants per group (mode = 5). This calculates as a mean number of 12 participants per group, double the recommendation for a face-to-face focus group study (Willig, 2001). Clearly, there is no fixed recommendation for sample size and it therefore may be wise to take a pragmatic approach depending on the number of participants that come forward to take part.

Study Length

The studies in table 7.1 illustrate study lengths ranging from one to twenty-four weeks resulting in a mean study length of nine weeks. However, when account is taken of the fact that only one group of researchers use 24-week studies (six month studies conducted by Im and colleagues, 2006, 2007a, 2008b, 2008c) it is apparent that the median which calculates as four weeks, best reflects an average study length. Again, there does not appear to be a recommended study length for an online focus group and this may be dependent on such factors as how many question topics the researcher wishes to cover.

However, there does not seem to be any consistency in the amount of topics that can be covered over a specific amount of time. With some researchers choosing to post one new topic per week (Bruening & Dixon, 2007; Dattilo et al., 2008), others posting five in one week (Boshoff et al., 2005) and others still posting seven topics over six months (Im et al., 2008c). It is important to consider that a discussion topic can consist of one general topic for participants to discuss and several prompting or follow-up questions as the discussions progress. Furthermore, participants may post discussion questions to the rest of the members of the group outside of the researcher's topic schedule (Bruening & Dixon; 2007; Im et al., 2008c; Kenny, 2005).

Murray (1997) experimented with how he presented the discussion topics to his participants; either asking them all at the start or by introducing them throughout the study. He found that asking all questions at the start meant participants felt under pressure to answer them all at once and tended not to interact with other focus group

members whereas introducing questions over time gave participants more chance to interact (Murray, 1997). Thus, a longer period with questions asked intermittently seems to work well.

Participant Recruitment

When recruiting participants it is essential to consider the need for participants to have access to and appropriate skills in using the internet (Adler & Zarchin, 2002; Im et al., 2007b; Kenny, 2005; Moloney et al., 2003; Murray, 1997). Owning a computer and being able to use the internet may relate to other participant biases including being “*educated, middle class, healthy, married, white*” (Im et al., 2007b, p.867). However, as Kenny (2005) discusses this bias may be becoming reduced as internet access in such places as schools and libraries is increasing.

Researchers have emphasised the use of existing discussion groups as a good source of recruitment (Illingworth, 2001; Stewart & Williams, 2005) and indeed this was utilised by a number of the studies reviewed here (e.g. Adams et al., 2005; Im et al., 2008c; Oringderff, 2004). Others have utilised both online and offline sources (such as treatment centres) for recruitment (Adler & Zarchin, 2002; Moloney et al., 2003; Turney & Pocknee, 2005). One of the potential benefits of using an online focus group is that there are no geographical boundaries, allowing for a more diverse sample (Adler & Zarchin, 2002; Bruening & Dixon, 2007; Illingworth, 2001; Moloney et al., 2003). For example, Turney and Pocknee (2005) used an online method because their samples were considered “*difficult-to-access populations*” due to geographically dispersion. Finally, as Oringderff (2004, p.4.) emphasises, “*subjects who might feel uncomfortable revealing themselves for political, religious, or social reasons*” may be more likely to participate in the research when it is conducted online due to the anonymous nature.

The convenience of asynchronous groups and the ability to access them at any time and any place allows those who lead busy lives to get involved when it is suitable for them (Moloney et al., 2003). For this reason, Adler and Zarchin (2002) were able to

conduct research with women on bed rest for preterm labour and therefore would not have been able to participate in a face-to-face focus group. They also report the benefits of how participants can contribute to the study at any time of night or day (Adler & Zarchin, 2002).

The Study Site

Where a focus group is hosted will have important ethical implications regarding both confidentiality and safety. In studies that explore sensitive or personal issues it is important that “*secure methods of discussion*” are chosen (Murray, 1997, p.545). For example, researchers ensured that only registered users, who had been given access via a password, were allowed to enter their online forums (e.g. Bruening & Dixon, 2007; Im et al., 2007b).

Turney and Pocknee (2005) recommend the use of a Virtual Learning Environment (VLE) as it “*takes advantage of existing university infrastructure*”. Although originally designed as educational course tools, VLEs have been successfully employed to collect research data (Dickerson & Feitshans, 2003; Kenny, 2005; Turney & Pocknee, 2005; Watson et al., 2006). In particular, Kenny (2005) used WebCT (one type of VLE) in her study exploring nurse’s experiences of a conversion programme for changing job role. Kenny (2005) describes WebCT as easy to use and accessible as participants do not need access to nonstandard software to use it. Although Kenny (2005) lists a number of advantages and disadvantages regarding the use of online focus groups, one specific advantage to the use of WebCT is the closed and controlled access whereby people need to be given a password in order to access the site. This ensures confidentiality and participant welfare and guarantees that only desired individuals have access, as Adams et al. (2005) experienced, open-access discussion boards can lead to unfavourable interactions, in the form of ‘flaming’ (hostile comments) from non-participants. This is especially important to consider, given the sensitive nature of the research.

What Sort of Data can Online Focus Groups Produce?

A focus group can be defined as ‘*A research technique that collects data through group interactions on a topic determined by the research*’ (Morgan, 1997, cited in Watson et al., 2006, p551). Turney and Pocknee (2005) compared their online groups to the main characteristics set out by Krueger (1994) as important factors for evaluating a focus group. These include the assumptions that they involve a somewhat homogenous group of people who are unfamiliar with one another, they are methods of qualitative data collection, and they comprise a focussed discussion. They concluded that their online focus groups were “*theoretically sound and met key criteria of traditional focus group methods*” (Turney & Pocknee, 2005, p7). Likewise, Watson et al. (2006, p.555) believe that the online method had “*more similarities than differences to FTF groups*” and that online groups should be seen as a suitable variation to the offline method.

Despite this, some researchers may be wary of the types of data that online methods elicit (Stewart & Williams, 2005) and it is essential to acknowledge that conducting research online may only be appropriate for particular types of research topics with certain participants (Illingworth, 2001; Watson et al., 2006). However, some have found that the online environment allows for the generation of rich and detailed responses (Adler & Zarchin, 2002; Kenny, 2005) and believe it makes a “*feasible alternative to traditional face-to-face focus group*” (Im et al., 2008c). Furthermore, the written nature of online communication should be considered simply as a different, rather than inferior, method (Watson et al., 2006).

As evident in table 3, researchers have used either a thematic analysis or a more detailed phenomenological or grounded theory approach to the analysis of data obtained through the online focus groups. However, this does not tell us anything of the types of data obtained as it may simply reflect the subject area of the research with nursing studies typically using thematic analysis and those from a psychological or sociological background using phenomenological or grounded theory approaches.

Finally, as expressed earlier in the chapter, the data collected through online focus groups is already written and therefore there is no need to transcribe data, thus increasing the accuracy of the transcripts and eliminating the potential for error (Adler & Zarchin, 2002; Moloney et al., 2003; Oringderff, 2004).

Interaction in Online Research

As addressed previously in chapter 3, the anonymity and physical distance between researcher and participants may be of benefit. As Illingworth (2001) discusses, the physical distance between the researcher and participants can reduce any power relations that may come from such physically visible biases as race or gender. In this same sense, there are also reduced power relations amongst the participants (Kenny, 2005; Oringderff, 2004) which may allow quieter participants to feel comfortable in getting involved. Related to this, researchers using an online approach have found that participants do not feel pressured to answer every question (Moloney et al., 2003) and suggest that they may find it easier to withdraw if they wanted to (Kenny, 2005).

On a more unhelpful note, the lack of physical presence also makes it easier for participants to “lurk” (e.g. read others’ posts) rather than contribute (Moloney et al., 2003). The anonymity of the online environment can also mean that participants have a greater likelihood of expressing negative views and/or communicate with “less discretion and tact” (Oringderff, 2004). Oringderff (2004) therefore recommends the use of a netiquette guide (how participants should behave on the study site) or the provision of ground rules for how the site should be used (Oringderff, 2004).

Little has been written about the roles of the moderator in the online focus group situation although Turney and Pocknee (2005) do report how the role of the moderator was not as dominant as it would be in a face-to-face group. The role of the researcher seems to centre around the aim of ensuring an interactive discussion based on the research question through maintaining a comfortable and conducive environment. As with offline focus groups, the researcher must therefore ensure the

research questions are answered through introducing discussion topics, using prompts, and initiating follow-up questions at appropriate times. Im and colleagues (e.g. 2007b, 2008c) used a number of methods to ensure participants got involved in the discussions. These included asking them to visit the forum at least twice a month, e-mailing those who had not contributed in a while to check there was no participatory issues and trying not to get too involved in the online forums so as not to interrupt participants' discussions.

To increase rapport between participants and therefore facilitate detailed discussions, some researchers included an introduction topic as their first discussion (Adler & Zarchin, 2002; Bruening & Dixon, 2007; Dattilo et al., 2008; Im et al., 2007b). This may also serve as a way of giving participants an opportunity to practice posting messages (Dattilo et al., 2008).

Review Summary and Implications for the Present Research

At present, there does not appear to be any clear recommendations regarding the sample size, study length or number of discussion topics for an online focus group and it appears that these decisions depend on such things as the research question, structure of the focus group and the sensitive nature of the research. Thus, it can be supposed that a study exploring opinions of a training programme will be less sensitive and may use more structured questions than this phenomenological study looking at the sensitive topic of the lived experience of anorexia. So, it could be suggested that this research will require a smaller sample size to ensure an appropriate environment for self-disclosure (Mann & Stewart, 2000) may include fewer, more open-ended discussion topics but may last longer to give participants a chance to build rapport and become familiar with the topics before posting.

It also seems imperative for this research, and indeed any project requiring self-disclosure of sensitive topics to include a chance for introduction as the first discussion topic (e.g. Adler & Zarchin, 2002; Bruening & Dixon, 2007; Dattilo et al., 2008; Im et al., 2007b). It also clear that the study environment needs to be

confidential, secure and therefore have restricted access. Accordingly, the recommendations from Turney and Pocknee (2005) and Kenny (2005) suggest that a VLE, as is available at Queen Margaret University, will be a suitable site for hosting the group and this will be platform for this research. Furthermore, a netiquette guide (Oringderff, 2004) will be utilised.

4.5. Pilot Study

As online focus groups are still a new and developing approach to data collection, and there are no specific rules or recommendations as to how they should be conducted, a pilot study was carried out. The pilot study aimed to: a) give the researcher experience in facilitating and moderating a focus group online; b) evaluate the WebCT site and the role of the facilitator/researcher within this; and c) aid the planning of the procedure for the three studies with the participant groups.

Method

Participants. An opportunity sample of people who defined themselves as interested in eating behaviours was recruited for the purpose of this pilot study. Potential participants were recruited through a snowball technique whereby friends and colleagues were contacted and asked to recommend others they thought would be interested. Potential participants were sent an e-mail giving brief details of the study. Attached to the e-mail was an information sheet for those who were interested to get more details (appendix 1.1.) and a consent form should they wish to participate (appendix 1.2.). As the aim of the pilot study was to test the online focus group method detailed information about participants were not required.

The WebCT site. The focus group was hosted on the institution's virtual learning environment, WebCT. WebCT was chosen for the current studies for a number of reasons. First, the researcher could control access to the site, which is important for both confidentiality reasons and participant safety. Second, the researcher could control the design and content of the site, for this research it was

important for the site to look professional to be taken seriously for research purposes but neutral enough for participants to contribute. Third, WebCT was free for the researcher to use, whereas setting up an online private discussion board elsewhere would have cost money. Finally, designing and maintaining a bespoke discussion board requires technical expertise and using an institutional software package meant that support was available for the researcher, through the university's e-learning team.

The WebCT site consisted of the discussion board plus pages to describe, 'General Rules and Netiquette' for using the site; 'Information about the Study'; and the ways and reasons in which the researcher could be contacted. There was also a 'Web Links' section with links to websites that participants might find of interest.

The main page on the WebCT site was the discussion board because this is where the online focus groups took place. The main discussion page displayed all of the topic areas available for viewing and contributing. Participants could click on the title of the discussion and read or/and contribute to the ongoing discussion. Each topic thread started with a question from the researcher followed by the participants' replies. The researcher also asked probing questions when participants began talking about a particularly interesting subject as a way of steering the discussion towards those areas. To get an impression of the format of the WebCT pages, screenshots have been provided in appendix 2.

Procedure. The focus group was asynchronous and lasted for two weeks. On the first day, those who had agreed to participate were sent a username, password and a guide to logging on and using the discussion boards (appendix 3). The username and password was based on a participant number to ensure anonymity (e.g. participant one, participant two, etc). When the participant logged onto the site for the first time they were asked to change their password to something more personal so that only they would know what it was.

On the first day, a welcome message and the first discussion question was already posted. The researcher posted further questions as was appropriate over the two weeks. The researcher visited the site roughly ten times a day to moderate participant activity, check for new posts or to ask further questions. Discussion topics were centred on participant's interests and views on eating behaviours and eating disorders in the UK (see appendix 1.3. for the topic guide).

Towards the end of the two weeks, an evaluation form was posted for participants to assess the WebCT site, the role of the researcher and to answer questions pertaining to their use of the site (appendix 1.4.). A debrief form was e-mailed out the day after the focus group had ended to thank respondents for participation, notify them that the discussions had ended and to provide contact information for the Eating Disorders Association (appendix 1.5).

Evaluation of the Pilot Study and Implications for the Empirical Work

The pilot study was relatively successful in the beginning stages, resulting in research data that could be considered rich and useful. However, as the discussions progressed participant activity and involvement declined. This section considers the possible reasons for this by combining the reflections of the researcher and the results of the participants' evaluation.

Participation. Thirteen respondents consented to participate in the group and were therefore registered onto the WebCT site. Of these, only nine participants entered the site and only eight contributed to the discussions (2 male, 6 female). Four participants took the opportunity to fill in the evaluation form.

Participants contributed 42 posts to the online discussions, with individual contributions ranging from 2 – 11 posts. Of those who filled in an evaluation form, all accessed the WebCT site at least once every couple of days. Participants 3 and 5 chose to access the site during the day, participant 12 used the site during the evening and participant 8 chose to participate during the evenings and weekends. This result

illustrates the convenience of an asynchronous site whereby participants can chose to take part at the times felt most suitable for them.

As described above, an opportunity sample of participants who described themselves as interested in eating behaviours was recruited for this study. This sample was selected from friends, friends of friends and colleagues, therefore a limitation of this study is that some may have taken part just to help the researcher rather than because of a genuine interest. The participant samples for the empirical studies will consist of individuals who are unknown to the researcher and will be recruited through their involvement in websites relating to anorexia and therefore should have a genuine interest in the discussion topics.

Another limitation to this pilot study was the lack of homogeneity amongst participants. Participants consisted of people who were interested in eating behaviours for various reasons including for academic purposes (including a professor in the field), for health and social reasons and because of previous experiences with disordered eating, dieting or having a friend with a previous eating disorder. This lack of homogeneity had an effect on the data collected. For example, near the end of the study the researcher had asked a question about people's definitions of disordered eating to which there was little response. Although anecdotal, conversations with some participants indicated that although unaware of the professional background of the participant, the nature of the first response, (made by the professor), "summed it all up" and some (lay) participants had felt they had nothing to contribute or were worried about "saying something wrong".

In contrast, the empirical focus groups will be homogenous in that they will be made up only of people from one group (e.g. there will be an online group for those wishing to maintain behaviours (study 1), one for those wishing to recover (study 2) and one for those who have recovered (study 3). Similarly, participants will be recruited from similar websites so will also be somewhat homogenous in that sense. Additionally, participants will have to fill out questionnaires prior to their involvement in the focus group to validate eligibility (see section 4.7); this will also help ensure homogeneity. For example, questions relating to participants' attitudes to

anorexia will identify whether participants belong in the focus group for those wishing to maintain behaviours or those wanting to recover.

A further limitation of the study was the online identity of the participants. In her evaluation form, participant 3 expressed how it was sometimes difficult to relate to other group members due to the usernames they were given. Participant 3 recommended giving participants a pseudonym instead. Using this information, the participants in the empirical studies will be given an opportunity to choose their username, which should give them more of an online personality and may help participants to relate to each other and become involved in discussions.

Participants were given the opportunity at the end of the evaluation form to give any comments on the use of the internet in conducting focus groups. In line with previous research (Illingworth, 2001; Kenny, 2005; Oringderff, 2004) participant 5 remarked on the fact that sometimes in group situations people may tend not to say anything whilst others may dominate the conversations but “*this method ensure(s) everyone has their say and it is confidential*”. Participant 12 explained how he felt “*that it [the use of the internet] provides a more innovative and efficient medium for communication than conventional techniques*” Similarly, participant 3 explained how:

I felt more comfortable participating in this type of focus group than I think I would a face-to-face group. It enabled me to contribute more openly I believe. Also, the fact that the discussions took place over a period of times allowed me to think more about the issues before contributing to the discussion.

(Participant 3)

Study length and discussion topics. As this was a pilot study the online focus group was conducted for a period of two weeks. As stated above, there are no explicit recommendations for how many discussion topics can be covered over any amount of time. The researcher devised a topic schedule of five discussion topics (comprising of an initial question and possible prompts) as a way of exploring how many topics may be covered (appendix 1.3). When the study was designed, the researcher had not anticipated the involvement of participants and the length of time

it takes to have a focussed discussion and in reality, only a small number of the study questions were covered. This needs to be considered in the design of the empirical studies and it is suggested that a longer study period with more allowance given for the discussion of topics will be more effective.

The questions that worked best, and allowed for greater interaction between participants, tended to be more open-ended allowing participants to focus on their own personal experiences (e.g. 'How would you describe your interests in eating behaviours'). This is also in line with IPA's focus on personal understandings and experiences and is also important to consider.

The WebCT site. The participants who filled in an evaluation form (n=4) felt that the WebCT site was easy to use and were able to log on and use the site with no problems. For example participant 12 described how the site had a “[n]ice layout and [was] fairly easy to navigate”. Participants agreed that the web links, ‘information about the study’ and ‘general rules and netiquette’ pages were useful and informative. However when asked about the harshness of the ground rules there was a mixed response: two participants neither agreed nor disagreed with the statement ‘The general rules were too harsh and formal’, one participant disagreed with this statement and another completely agreed. These results need to be carefully considered when re-designing pages for the participant groups, for example for the pro-anorexic participants these rules may need to be tightened so as to ensure participants are clear that they may not trade tips or information that may trigger others to increase anorexic behaviours or learn new ones. All four respondents agreed that focus groups could work well online, although one also agreed that they preferred face-to-face focus groups.

The roles of the researcher/participant and the type of data collected. All four respondents who evaluated the study agreed that the discussion topics were interesting and that the researcher successfully facilitated the discussions and was able to successfully post discussion topics at appropriate times, draw discussions together and generate debates between focus group members.

In many ways, the researcher effectively guided the discussions using a number of techniques including, using participants' responses as a way of introducing new questions or as a way of expanding on the topic and using questions posed by the participants to further the discussion. However, in other respects the involvement of the researcher may have hampered the discussion of participants. This possible over-involvement of the researcher may be apparent when considering the total number of posts to the discussion board, as although the participants contributed 42 posts, the researcher added 20 more. A number of these were made up of important study announcements (including details of when the study would end, a reminder to participants of their right to withdraw and detailing the features of the WebCT site) however, other posts aimed at facilitating discussion seemed to affect the data provided by participants. For example, on reflection, some of the new discussions may have been introduced too early, meaning that some discussions were cut short. On one occasion, an interesting debate was occurring between two participants that had the potential to turn into an involved discussion with other members of the focus group, which may have resulted in rich data had the researcher not introduced a new topic.

Fox et al. (2007), in their methodological reflections on conducting synchronous online groups, describe their experiences of 'researcher anxiety', whereby they felt a personal responsibility to ensuring participants had others to discuss with and had adequate discussions to contribute to. Although their experiences are of conducting a synchronous focus group which is reliant on immediate communication, some of their anxieties can be applied to asynchronous groups. Fox et al. (2007, p.543) "*found it challenging to decide whether a contribution from the moderator was required to move the discussion forward.*" Similarly, in the current study the researcher felt anxious about participants logging in, not having anything to do and consequently losing interest. It seems that the researcher is caught in a difficult dilemma of becoming involved and risking the cessation of a potentially rich discussion or not contributing and risking a decrease in participation. From Fox et al's (2007) experiences it seems that a certain level of confidence and patience on the

part of the researcher is essential which is something to consider in the empirical work.

To overcome some of the problems of participants losing interest in the focus group because of not having anything to contribute to a discussion, further focus groups will have more than one ongoing discussion at any time. In the empirical studies, participants will also be aware of the general focus of the discussion topics and the frequency of how often new topics will be introduced.

This pilot study also highlighted the need to ensure participants are aware of their role in the group and what they are expected to do. For many participants, contributing to a focus group study will be a new experience and they will be unaware of their role or of what the researcher expects of them unless this is explicitly stated. Information about the nature of focus group research and expectations of the researcher will be introduced from the outset and will be included in the information sheet (which will be sent out when participants first express an interest) and in the welcome message (which will be posted on the first day of the study).

The pilot study was effective in enabling the researcher to obtain key skills in using the WebCT site and for aiding the design of the empirical work which will now be presented, alongside other methodological aspects in the following chapter.

4.7. Method for the Empirical Work

This section outlines the method employed in the three online studies that make up the empirical work of the research. This method has been informed by the methodological and practical considerations discussed earlier in the chapter.

Participants

The research consisted of three online studies with three distinct participant groups. Study 1 included those who wished to maintain their anorexia (did not want to recover). This study consisted of 14 participants recruited through their involvement in pro-anorexia websites which, as seen in chapter 3, are websites set up especially for those who wish to maintain their behaviours.

Study 2 included 14 participants who wished to recover from their disorder and who were recruited through pro-recovery websites. Pro-recovery websites, as the term suggests, advocate recovery for anorexia. These sites are designed to encourage their visitors “*to strive for recovery*” (Something Fishy, 2007), others may warn about the dangers of anorexia, advocate eating disorder awareness and provide support for those wishing to recover. For the current research, pro-recovery websites meant those that carried a recovery message and included peer-led recovery orientated sites, charity-run sites and recovery blogs. A study page was also set up on MySpace, a social-networking site that includes numerous links to charity and peer-led pages detailing recovery from anorexia.⁶

Finally, study 3 included 15 participants who had recovered (or were in “long-term recovery”, see chapter 7) from their disorder. Some of these contacted the researcher during recruitment for study 2 whilst the rest were recruited through pro-recovery sites as above. The exact recruitment procedure differed for each study and detailed descriptions are provided in the respective chapters.

Just because a person used pro-anorexic websites did not mean that they did not also visit pro-recovery sites. Participants’ attitudes about anorexia and the way they described themselves were taken into account. Recruitment was advertised asking for people “*who wish to maintain their anorexic behaviours*” (study 1), those “*who wish to recover*” (study 2) or for those “*who have recovered*” (study 3) and these descriptions were reiterated during initial e-mails and in the information sheet sent

⁶ This webpage can be found at <http://www.myspace.com/understandinganorexia>

out before the study. Furthermore, a pre-study questionnaire (see below) asked participants about their attitudes and current behaviours.

The research aimed to understand the views of those who use online resources relating to anorexia and participants were not required to have a formal diagnosis. Participants were eligible to take part if they were 18 years old or over, had regular access to a computer and the internet, and self-identified with one of the participant groups described above. Detailed information about participants is provided in the respective chapters.

Measures

After a participant consented to take part, they were e-mailed self-report questionnaires to fill in electronically via Microsoft Word to return to the researcher attached in an e-mail.

The Pre-study Questionnaire

Participants were asked to fill in a pre-study questionnaire, which had been designed by the researcher with four specific purposes: to collect demographic information; to collect information regarding their eating disorder and mental health history; to identify website use pertaining to eating disorders; and to determine attitudes about anorexia to ensure participants met eligibility requirements. The questionnaire used open questions that encouraged participants to discuss aspects of their eating disorder that they felt important. The pre-study questionnaire was split into four sections:

Demographic Information. Participants were asked about their age, sex, marital status and employment and education status. Due to the online approach, this was an international study therefore participants were also asked about their location and ethnicity. It is important to consider a participant's location and ethnicity as cultural differences may affect their experiences, for example, a participant's location may affect the treatment options available to them and therefore their

opinions of it, for example, some countries may have higher prevalence rates of anorexia and therefore more services.

Information about your eating behaviours. Participants were asked whether they thought they had an eating disorder or any other comorbid mental health problems and then whether they had ever been diagnosed or treated for these. The literature review has highlighted how those with anorexia (especially those using pro-anorexia websites) may have never been professionally diagnosed or treated for a number of reasons. For example, they may not see their eating as problematic, may be hiding their behaviours from other or they may have not been recognised as having a substantial eating problem by a doctor. Similarly, those in the process of recovery or those who have recovered may do so without professional interventions. It was important to be aware of these situations when considering the individual's life story but was not important for inclusion in the study.

Internet Use. Participants' use of both pro-anorexia websites and those designed for recovery purposes was also examined by looking at the frequency of using the sites.

Attitudes towards Anorexia. Questions relating to participants' attitudes towards anorexia were formulated from previous work carried out into why people use pro-anorexic websites (Williams & Reid, 2007). This research found that people use these sites because they want to maintain their anorexic behaviours and feel their behaviours give positive results. The questionnaire therefore asked participants about their attitudes towards maintaining or recovering from their disorder and their attitudes about living with it. Participants were also asked whether they described themselves as pro-anorexic, pro-choice, pro-recovery or none of the above and then were asked to describe why they felt that way.

As the research progressed, a number of additional questions were incorporated into the pre-study questionnaire. These changes included:

(1) Adding a question relating to participants' age of onset

After study one it became apparent that a limitation of the questionnaire was that participants were not asked how long they had been experiencing anorexia (which may have had an effect on the experiences that they reported), thus a question was added to the pre-study questionnaire that asked about age of onset.

(2) Asking participants about their behaviours and whether they felt addicted to them

The results of study 1 suggested a link between anorexia and addictions and concluded that further investigation of this relationship could be advantageous.

(3) Asking about length of recovery

Participants in study 3 were also asked how long they had been recovered.

A copy of the final version used for those who had recovered from anorexia can be found in appendix 4.1.

The Eating Disorder Examination-Questionnaire (EDE-Q, Fairburn & Beglin, 1994)

Participants were asked to fill in the Eating Disorder Examination Questionnaire (EDE-Q, Fairburn & Beglin, 1994) to identify levels of eating disorder psychopathology. The EDE-Q is straightforward to fill in and only takes 15 fifteen minutes to complete (Fairburn & Beglin, 1994). It is also a beneficial tool for the researcher as it is free to use and permissible to be administered electronically. As this research used an online approach, permission was obtained to administer the questionnaire electronically via a Microsoft Word document for participants to fill in and e-mail back to the researcher (C. Fairburn, personal communication, 26th September 2006). The EDE-Q is a self-report version of the interviewer-led Eating Disorder Examination, which is “*devised to provide a standardized instrument for the assessment of the specific psychopathology of eating disorders*” (Fairburn & Cooper, 1993, p.217).

The EDE-Q measures people's current state as it is concerned with the person's attitudes and behaviours over the last 28 days. It consists of 23 items over four subscales: restraint, eating concern, shape concern and weight concern. The restraint subscale measures efforts to restrict food intake and includes items relating to food avoidance, avoidance of eating and dietary rules. Eating concern includes items such as those relating to preoccupation with food, eating or calories, fear of losing control over eating or guilt about eating. The shape and weight concern subscale relate to such areas as preoccupation, dissatisfaction and the importance of both shape and weight respectively. A subscale score is calculated by summing the ratings for each item and dividing by the total number of items in the subscale. If data for a subscale is missing, a score can still be calculated if at least half the items are rated. A global score is calculated by summing together the scores for each subscale and dividing by four. The highest score possible for each subscale, and thus the global score, is six.

The EDE-Q also asks about episodes of behaviour (binging, vomiting, exercise and laxative use) over the last 28 days by allowing frequency data to be collected. It also asks about height and weight (allowing for Body Mass Index (BMI) to be measured) and menstruation. A full version of the questionnaire can be found in appendix 4.2.

Fairburn and Beglin (1994) compared the use of the EDE-Q with the interview version. They found no differences in the reporting of behaviours such as self-induced vomiting, laxative use and dietary restraint but found significant differences in the reporting of more ambiguous items such as loss of control and binge eating. This is because in an interview situation, an interviewer can explain such terms. In a more recent study, Wolk, Loeb and Walsh (2005) compared the EDE and EDE-Q in assessing 60 women with anorexia and found that the EDE-Q sufficiently assessed eating disorder diagnosis and specific symptoms and can be used in place of the interview version. According to the EDE-Q 86.7 % of patients met diagnostic criteria for anorexia nervosa, whilst only 71.7% were reported to have the eating disorder with the EDE. All patients (100%) had been diagnosed with anorexia when interviewed by a clinician using the DSM-IV.

The Beck Depression Inventory-II (Beck, Steer & Brown, 1996)

The Beck Depression Inventory-II (BDI-II, Beck, Steer & Brown, 1996) was included in the battery of questionnaires after study 1. The purpose of this was twofold: to measure depression rates because a high proportion of participants in study 1 reported depression as a co-morbid symptom and to act as a risk assessment tool.

The BDI-II is a 21 item measure that provides an estimate of the overall severity of depression. Items relate to cognitive, affective and physical symptoms of depression and include such items as sadness, worthlessness, changes in appetite, concentration difficulties, and suicidal thoughts or wishes. Each item is rated from 0-3 indicating gradual levels of severity. A BDI-II score is calculated by summing the total for all items. A maximum score is 63. Scores are interpreted as follows: 0-13 = minimal depression, 14-19 = mild depression, 20-28 = moderate depression and 29 or above indicates severe depression (Beck, Steer & Brown, 1996). The BDI-II has been considered an adequate measure of depression in those with eating disorders (Pulos, 1996). A copy of the BDI-II is provided in appendix 4.3.

Procedure

Those who were interested in participating in the research were asked to e-mail the researcher for more information. They were then sent an information sheet providing details of the research and inviting participants to contact the researcher should they have any further questions (see appendix 5.1). At the same time, a consent form was sent out for them to fill in electronically and e-mail back to the researcher (appendix 5.2).

Online Focus Groups

The procedure was designed with the results of the review and pilot study in mind. WebCT was used to host the focus group as it was considered both practical and

ethical to use (Kenny, 2004). The WebCT site consisted of a discussion board for hosting the focus group, details of a netiquette guide, details for contacting the researcher (appendix 6) and a list of websites should a participant require more information about eating disorders or recovery. Each focus group was asynchronous and lasted between four and five weeks. This duration was chosen as a result of the pilot study and the literature review of existing focus group studies.

During recruitment, participants were asked to choose a username that they wished to be known as for the duration of the study and an account was set up for them to have access to the WebCT site. On the first day, participants were given password details and instructions for accessing and using WebCT (appendix 3). When logging in for the first time, participants could change their password to something more familiar. Participants were asked to get involved in the topics and to discuss answers with the other members. At the beginning of the focus group, participants were reminded of their right to withdraw or refuse to answer a question.

Participants were asked to log in at least three times a week to remain updated and involved. The researcher checked the WebCT site at least three times a day to keep updated with the progression of the discussions. This meant that the researcher could determine when new discussion topics, further questioning or any encouraging responses were required. If any of the participants had not contributed to the discussions over the course of a week a gentle reminder of the study was e-mailed to them asking if they were having any problems (e.g. with accessing WebCT) that was preventing them from getting involved. This only had to be performed on a few occasions with the principle reasons for missed participation usually as a result of other commitments in the participants' life (e.g. jury duty, family issues). At the end of the focus group, discussions were locked to prevent participants accessing the site after the study period, debrief information was e-mailed out (appendix 5.3) and data from the WebCT discussion boards was downloaded into a Microsoft Word document to be printed for analysis.

E-mail Interviews

During the focus group for study 1, the researcher was contacted by others who were interested in participating. As the focus group was already underway and it was felt that new participants would find it difficult to catch up with ongoing discussions they were offered an e-mail interview instead. This also created an opportunity to triangulate data by using two methods of data collection (Tindall, 1994). Thus, to maintain consistency e-mail interviews were also conducted in studies 2 and 3.

E-mail interviews involve multiple e-mail exchanges over an extended period in a one-to-one format between a researcher and participant (Meho, 2006). Murray and Sixsmith (1997) acknowledge that e-mail interviews can be utilised for the same reasons as face-to-face interviews and can be especially beneficial when face-to-face interaction is impossible (e.g. geographical or time constraints). They also recognise, based on their own experiences, how e-mail interviews may be of potential benefit over face-to-face versions for communicating sensitive information whereby *“divulging sensitive information to a computer may feel much less threatening than recounting it directly to another person”* (Murray & Sixsmith, 1997, p.107).

The e-mail interviews for the current research covered the same question topics as the online focus group and worked much the same way as traditional e-mail communication. The e-mail interviews were also asynchronous and worked by e-mailing back and forth between the researcher and participants until all topics in the schedule (and any others that arose) had been covered. The decision to e-mail one question at a time was to allow for the opportunity for unanticipated areas to be explored further. If a participant had not been in contact for a period of two weeks, they were e-mailed a gentle reminder and asked if there were any problems preventing them from participating. As with the focus group, the resultant data was downloaded into Microsoft Word documents for analysis.

The Topic Schedule

Questions were designed to explore participants' understandings of anorexia based on their lived experiences and therefore used a semi-structured approach to allow them to discuss aspects of their experience which they felt to be important. As recommended by Smith and Osborn (2003) questions were neutral, jargon-free and open-ended. The topic schedule was informed by the work of other IPA authors (Adams et al., 2005; Smith & Osborn, 2003). For example, Adams et al. (2005) asked their self-harming participants what role their self harm played in their life and it was thought useful to similarly ask participants what role their anorexia played in their life. The topics covered areas considered important for the study aims and stemmed from the results of the literature review and from our previous research which concluded that further investigation into individual cognitions about anorexia was needed (Williams & Reid., 2007).

On the first day of the focus groups, three discussion topics were already set up. The first, a welcome topic, allowed the researcher to welcome participants, remind them about the purpose of the study, of their right to withdraw and introduce them to the features of the WebCT site. The second consisted of a discussion topic where the researcher introduced herself and asked participants to do the same as a way of building rapport amongst participants and with the researcher (Adler & Zarchin, 2002; Bruening & Dixon, 2007; Dattilo et al., 2008). The third was the first in the topic schedule and was an open-ended question asking participants to give a history of their anorexia.

Further discussion topics were introduced throughout the following four weeks. Questions were designed to explore participants' experiences of living with anorexia, their experiences of maintaining and/or recovering from it and any experiences with treatment they may have had. These questions covered areas such as: definitions of anorexia and recovery; the role anorexia was thought to play in the person's life; the factors influencing/contributing to maintaining and/or recovering; and experiences of treatment and healthcare professionals including the helpful and unhelpful aspects.

At the end of each study, participants were also asked if there was anything they wanted to add or topics they were expecting to be covered. Towards the end of each focus group, a summary of the discussions was posted and participants were invited to add or discuss as appropriate. Participants in the focus groups of studies 2 and 3 were also asked how they found participating in the focus group and these answers are considered in chapter 9. A full topic schedule for each study is presented in appendix 7.

Participants in the focus group for study 3 also posed their own questions to the rest of the group. These covered topics such as social recovery, difficult treatment experiences since they were recovered relating to their past diagnosis, finding inexpensive treatments, whether anorexia was an addiction and whether full recovery was possible. The researcher ensured that any unanticipated areas of importance brought up by participants, across all three studies, were probed with further questioning.

Data Analysis

Adams et al., (2005) refer to guidelines presented by Smith et al. (1999) for their IPA analysis of data collected from online focus groups and e-mail interviews and these were employed for the current research. The guidelines by Smith et al. (1999) allow the researcher to analyse the data at the individual level before looking at similarities and differences across the group. Table 4 lists the processes involved in the analysis. Stage 1 has been incorporated due to the focus group method (as opposed to an interview method) whereas all other stages are based on the recommendations by Smith et al. (1999).

To summarise, the full focus group transcript was read through a number of times to determine the context of the discussions and initial notes were made regarding preliminary themes. For the focus groups, posts were numbered in the order they occurred in the group discussions and then individual responses were ‘parsed out’ into separate transcripts so that the participants’ idiographic accounts could be

explored. The numbers allowed the researcher to go back to the full discussion if further context for a statement was needed. For example, if a person stated, “I agree with the above post” the researcher was able to go back to the original discussion for context.

Taking each transcript at a time (including those from the e-mail interviews), the researcher analysed the data making notes of any initial thoughts or ideas, whilst remaining descriptive and close to the participants’ own words. These annotations may be quite descriptive and close to participants’ own account and may focus on initial ideas for themes, comments on the use of language and any connections or contradictions throughout the transcript (Smith & Osborn, 2003). Next, the transcript was analysed again but this time more interpretative themes based on psychological terms were noted. Although these themes use psychological terms they must still be grounded in participants own experiences (Smith & Osborn, 2003). These interpretive themes were then clustered together into related groups of themes. This process was carried out for each participant before the clusters from every participant were brought together to identify broad themes across the group. These broad themes were then formed into corpuses whereby the researcher went back to the transcript to find every example of that theme and bring them all together for a more detailed analysis. Appendix 8 provides examples of data analysis for each study including details of descriptive and interpretative coding, example clusters, and the list of final numerical codes and themes.

Table 4: Process of Analysis for the Current Research

Stage	Procedure
1 <i>Parsing out individual's responses</i>	<i>Each post in the online focus group was numbered in the order in which they were posted and each person's responses from the full focus group transcript were separated out into individual transcripts. The numbers on the posts allowed the researcher to go back to the full transcript if any context was required.</i>
2 Descriptive codes	The first transcript was read a number of times and then notes were made in the left-hand margin regarding any initial thoughts that arose.
3 Interpretative coding	The first transcript was analysed more thoroughly, writing down more interpretative themes in the right-hand margin.
4 Clustering	The theme labels were clustered together into groupings that reflected the connections between them.
5	Stages 2-4 were repeated for each transcript until theme clusters for each participant had been generated.
6 Generating corpuses	All theme clusters were grouped together to identify broad general categories across them. Looking at one category at a time, the researcher returned to the transcripts to ensure that all examples of the theme had been found and "a 'complete' corpus of data" was formed (Smith et al., 1999).
7 More detailed analysis	The corpuses were analysed in more detail and examined to identify if any of these more detailed themes could be grouped together.
8 Numerical coding (optional)	Numerical codes were used to label the themes in more detail.

Ethical Considerations

Ethical approval for the current research was obtained from Queen Margaret University's ethics committee and at all times ethical guidelines presented by the British Psychological Society (British Psychological Society (BPS), 2006) were followed. To summarise, the BPS guidelines are based on four principles: respect, competence, responsibility and integrity. Accordingly, researchers using these principles must respect participants' individual differences (e.g. gender, age), ensure confidentiality, seek informed consent wherever possible, avoid intentional deception and state at the outset participants' right to withdraw from the research and the right to decline to answer any questions. The researcher has a responsibility to ensure no harm to the participant and to debrief them appropriately once the study has ended. The researcher must not mislead the participant and should present the findings in an honest fashion. Finally, the researcher has an obligation to keep up to date with appropriate ethical recommendations concerning their practice.

A number of researchers have identified how the nature of online research may require additional ethical consideration and guidelines for conducting ethical research online have been proposed (BPS, 2007; Ess and the AOIR Ethics Working Committee, 2002). These guidelines are useful but not exhaustive. For example, the BPS (2007) guidelines list the types of research that could be conducted online but fail to mention the idea of online focus groups or e-mail interviews. It is therefore suggested that a pragmatic attitude to the ethicality of the current research is taken by applying the principles expected in offline research and by drawing on the experience and advice of people who have carried out work online.

Much of the debate and concerns regarding the ethicality of online research has centred on the use of existing online forums as a source of data through non-participant virtual ethnography, in other words entering sites and downloading and analysing the information posted without the consent of the people who posted it (King, 1996). This debate regards whether such material is considered public or

private material. The current research does not employ virtual ethnography and so a full discussion of this debate is not needed.

Undoubtedly, the key concern with online research is the lack of physicality between the participant and the researcher, which “*restricts the researcher’s capacity to monitor, support, or even terminate the study if adverse reactions become apparent*” (BPS, 2007, p1). Of course, as with offline research, this relies on participant cues being picked up by the researcher. Clearly, precautions need to be in place. When researching sensitive issues it is recommended that the researcher provide appropriate details for ways of obtaining support and ensure that they do not provide any “*advice that is beyond their professional knowledge*” (Wood et al., 1004, p. 516). In line with this issue, Adams et al. (2005) argue how participants recruited through online sources pertaining to the topic of the research have already placed themselves in that environment:

Our respondents were already users of the Web site [site set up for those who self-harm], and therefore participating in our discussion forum would not expose them to a level of risk higher than that associated with their normal use of the site.

(Adams et al., 2005)

Similarly, as seen in chapter 3, the online environment is already the platform of choice for discussing experiences of anorexia for the participants in the current research and it may be seen as more ethical to engage them in their chosen environment that offers them physical anonymity. The lack of physicality also poses important implications for the verification of online participants where it can be difficult to substantiate that a participant is who they say they are. This issue is especially apparent when considering studies requiring participation from specific groups (e.g. adults over the age of 18). It is recognised that the actual age of the participant cannot be verified in online research (BPS, 2007; Ess et al., 2002; Wood et al., 2004), but of course, this may sometimes be difficult to confirm in face-to-face research too. Wood et al. (2004) recognise that although researchers can never be sure participants are who they say they are, it is still important for them to be asked about age and researchers should bear in mind the implications that having minors in

their study may have. In the current research, eligibility is dependent on participants being over the age of 18 and this will be made clear from the outset.

The rest of this section lists a number of procedures that were taken to ensure ethical practice throughout the studies. As will be seen these procedures reflect the issues considered for offline research and the processes involved in ensuring these are maintained in the online environment:

Informed Consent: Participants were asked to provide informed consent before any data was collected through sending electronic information sheets and consent forms before the study began.

Confidentiality: Participants' anonymity and confidentiality were maintained at all times. Participants were asked to choose a pseudonym (username) to be known as throughout the study. The researcher then changed the username again to another pseudonym in the reporting of results to avoid recognition had participants chosen the same username that they often used in other online communities.

Right to withdraw: Participants were made aware of their right to withdraw or choose not to answer any questions from the outset, as outlined in the information sheet. Participants were reminded of this when questionnaires were sent out, on the first day of the study and throughout the focus group or e-mail interview.

Participant Safety: As with any research, this was ensured as much as within the researcher's capabilities. This was done in the following ways:

- a) The study site was only accessible by the researcher and study participants, ensuring no harmful comments or behaviour from others. For example, people with strong negative views regarding ideas of maintaining anorexia could not enter the online focus groups. Furthermore, the use of pro-anorexic websites as a source of recruitment and the results of the pre-study questionnaire checked participant attitudes to anorexia and ensured a purposive sample was obtained.

- b) Ground rules for using the focus group site were enforced insisting that any pro-anorexic tips or any information that could be considered triggering to other users were not traded. These ground rules were stated in the information sheet and provided on the study site. The researcher moderated the focus groups regularly to ensure these rules were followed.
- c) Participants were provided with links to appropriate online resources for information and support for eating disorders should they have needed it, through both the study website and the debrief sheet.
- d) Only people over the age of 18 were eligible to take part. Although it is recognised that people may have provided a false age this was considered out of the control of the researcher and it is hoped that by setting this criteria from the outset (during recruitment) that participants adhered to this.
- e) The research was directed by a supervisor with clinical experience of treating people with eating disorders and could be consulted for any assistance when required.

Deception: The researcher did not deceive the participants at any stage throughout the studies. The information sheet provided detailed information of the expectations of the participant from the outset.

Debrief Information: On ending the online focus groups or e-mail interview, participants were e-mailed debrief information detailing additional details of the study and a list of appropriate websites for support and information that the researcher had checked beforehand (appendix 5.3).

Chapter 5, Study 1, Maintainers' Ambivalence about their Anorexia: "Ana is my Friend, my Foe"

5.1. Introduction

This chapter reports the results of an online study looking at the experiences of those who wish to maintain their anorexia. As the literature review illustrated more research is needed to investigate why those with anorexia may wish to maintain it (Serpell et al., 1999; Williams & Reid, 2007). One of the main places where those wishing to maintain anorexia can convene is through pro-anorexic websites and forums. Although a small number of studies have been conducted on the experiences of those who use pro-anorexia websites (Fox et al., 2005; Mulveen & Hepworth, 2006; Williams & Reid, 2007) these studies have focused on people's experience of pro-anorexia and not at looking at their experiences of living with anorexia and/or receiving treatment. Therefore, the aims of this study were first to determine how those who wish to maintain their anorexia understand their disorder by looking at their experiences and how they make sense of these experiences, and second to begin to understand how these understandings affect their pathways to and through treatment.

5.2. Recruitment Procedure

Participants were recruited through pro-anorexic web pages and forums. The search engine 'Google' was used to locate pro-anorexia sites, as at the time of recruitment this was the most popular search engine. For example, in July 2006 60.2% of all web searches conducted in the United States used Google, compared to 22.5% using Yahoo (Sullivan, 2006). The search term pro-anorexia was used, resulting in 348,000 results (number of results were for the 25th September 2006). The first result linked to an online journal (or blog) which required visitors to register, the second result did not describe itself as pro-anorexic or for people wishing to maintain their behaviours and the third result was an Open Directory of the pro-anorexic websites running at the present time. This directory is powered by DMOZ and is described as

*“the largest, most comprehensive human-edited directory of the Web”*⁷. This site linked to the 23 most popular pro-anorexic sites therefore these sites and links from these sites were used for identifying people that could be contacted for recruitment. Ninety-four websites were used for recruiting participants.

Potential participants were contacted by an initial e-mail giving a few details about the study and asking them to contact the researcher if they would like further information. E-mail addresses were typically found in the ‘Contact me’ pages, in guest books and attached to posts in forums. E-mail addresses were only used if the message or guestbook entry had been posted within the last six months and in the case of web administrators, these were only contacted if they had updated the site within the last six months. This is in recognition of the changing situation of experiencing anorexia. People posting these messages may now be in recovery or now have a different attitude towards their anorexia. Posts were read to check that the authors were not anti-pro-anorexia before they were contacted, similarly authors of messages that simply asked members to help them lose weight were not contacted either. A total of 244 e-mails were sent out to website administrators and site visitors. An additional 33 messages were posted in site guest books. These are pages on the websites that give visitors an opportunity to post a comment for any subsequent visitor or the site administrators to read.

E-mails were sent to addresses left on the sites under the assumption that these addresses were left for people to be contacted regarding their pro-anorexia. The idea of posting in forums was considered but was felt to be more imposing as the forums were a place for members to talk openly and anonymously and therefore was not a place for researchers to be. It was also felt to be ethically deceptive to post in the forums, both for the reason mentioned above and because many forums required the visitor to become a registered member. Pages that required registration for the user were not used.

⁷ <http://dmoz.org/about.html>

If someone requested further information, a formal information sheet and a consent form were sent out. On receipt of a consent form, a person was then considered a participant and asked to fill in two self-report questionnaires and arrangements were made to set up an account for them for the online focus group (see chapter 4 for full procedure).

From the 244 e-mails and 33 guest book entries, 36 responded and requested further information. Four people requested further information once the focus group had begun and because it was too late to join the focus group as the discussions were already under way, they were offered an e-mail interview, two of them accepted. Of the 32 who requested further information, 15 filled in and returned a consent form and were therefore considered a participant, however, one was later removed from the focus group as she later revealed she was under the eligible age, one never entered the site and another only posted a quick introduction. Therefore, only data collected from twelve focus group participants and two e-mail interview participants was considered in the analysis.

5.3. Information about Participants

Participants consisted of 13 females and 1 male aged 18-36. This study was an international study with participants located in the USA (n=5), Canada (n=2) and one each in Spain, South Africa, Australia, New Zealand, Romania and India. Results from the pre-study questionnaire identified how all participants used pro-anorexic websites with frequencies ranging from around five times a month to 10-15 times a day, whereas use of pro-recovery websites ranged from never to twice a day. All participants believed that they had anorexic behaviours at the time of the study and wished to maintain them, however, and ambivalently, three participants also wished to recover from their eating disorder and five wanted to receive treatment.

Participants were also asked to fill in the EDE-Q. This indicated that all participants had high eating disorder psychopathology and with the exception of two all had a low BMI (one BMI was unknown and one was in the normal weight range).

Demographic, eating disorder characteristics and EDE-Q scores are demonstrated in table 5.

Table 5: Participant Characteristics for Study 1

Name	Age	Eating Disorder History	Treatment History	Body Mass Index	EDE-Q Subscales				
					Restraint	Eating Concern	Weight Concern	Shape Concern	Global Score
Emily	23	Diagnosed AN(R)	Unknown	17.4	6.0	5.0	6.0	5.6	5.7
Emma	18	Self-diagnosed AN(B/P)	Never	16.7	5.2	5.2	5.8	5.9	5.5
Maria	36	Diagnosed AN(R)	Never	17.8	6.0	-	5.7	5.8	5.8
Gabriella	18	Self-diagnosed EDNOS	Never	Unknown	5.0	5.5	5.7	5.8	5.5
Taylor	30	Diagnosed AN(R)	Past	14.2	6.0	-	5.2	5.5	5.6
Jack	18	Diagnosed AN(R)	Current	17.9	5.0	2.4	4.8	3.9	4.0
Cristina	20	Self-Diagnosed AN(R)	Never	17.2	4.0	2.2	4.8	5.4	4.0
Abigail	21	Self-Diagnosed EDNOS	Never	17.9	5.0	4.5	4.7	5.6	5.0
Grace	22	Diagnosed EDNOS, previous: AN(R) and BN	Current	18.0	5.4	4.0	6.0	5.6	5.3
Ashley	18	Self-diagnosed EDNOS	Past (for AN)	17.7	5.0	3.8	5.8	5.4	5.0
Anita	18	Self-diagnosed EDNOS	Never	17.0	5.0	4.6	5.0	5.4	5.0
Hailey	20	Diagnosed AN(R)	Past	16.6	-	-	-	-	-
Charlene	21	Self-diagnosed AN(B/P)	Never	18.1	5.8	4.8	6.0	6.0	5.7
Lily	19	Self-diagnosed AN(R)	Never	19.5	6.0	6.0	5.6	6.0	5.9

5.4. Results

The online focus group was successful in yielding rich data regarding participants' experiences. In total, participants posted 162 posts of varying length. Interestingly, participants in the e-mail interviews gave shorter and less detailed answers. One e-mail participant described a preference for communicating in a group situation, supporting the initial decision to use an online focus group approach to researching this sample, as this is familiar to participants. As with existing online discussion boards some participants contributed more to the discussions than others where some chose to contribute to every topic and others chose those most relevant to their experience. The levels of group interaction amongst participants varied. Some participants simply replied to the researcher's questions whilst others communicated with one another and formed their own discussions. Some also quoted each other or replied to other's posts agreeing with a statement and then providing further elaboration based on their own experiences. However, because of the idiographic nature of the data analysis (Smith, 2004) each participant's responses were 'parsed out' of the focus group discussion and looked at independently (Millward, 2006), therefore the differences in group interaction were not seen as a problem.

The IPA analysis yielded two overarching themes: ambivalence and conflict about anorexia; and barriers to recovery. As will be seen, both themes contribute to participants' maintenance of anorexia.

Ambivalence and Conflict about Anorexia

Participants expressed often having two conflicting emotions regarding their anorexia. It could be a positive role and a negative role, a way of having control over an area of their life that they felt no control over and something that controlled them, and was thought of as something to maintain yet, at the same time, something to recover from. A number of participants described this conflict with anorexia in terms of a battle or a struggle: "*My battle with anorexia started when I was 13.*" (Hailey) and "*I've struggled with an eating disorder for almost 7 years.*" (Grace).

As in previous studies (Colton & Pistrang, 2004; Reid et al., 2008), participants' experiences of anorexia were fraught with ambivalence. Underlying this ambivalence was a conflict between the belief that anorexia provided a sense of control yet also, at the same time, was in control of them. This ambivalence about control is expressed by Emma when she explains the positive and negative roles of anorexia, both of which encompass control:

Emma: The main way I can really think of in which anorexia is positive is that it helps me survive with my day to day life with a slight sense of control... I guess in a way it helps me live. It is negative in the fact that it controls my thoughts and behavior.

This conflict led to further ambivalence about whether anorexia was a functional, controllable tool and therefore something to maintain, or whether it was a disease or enemy that was out of their control and should be ceased. For example, Emily distinguishes between a disorder that can be controlled (managed) and a disease that controls when she says, "*Anorexia can be both a disease and be a manageable disorder.*" Gabriella and Charlene express their ambivalence regarding whether or not to maintain or recover: *Sometimes, I hate it so much I just wish I could end it... Then others, I can't imagine myself without it (Gabriella)* and "*Your emotions are in a whirlwind... one day you cant see life without Ana, the next day, you just want to be normal, or whatever that is!*" (Charlene).

Ambivalence and conflict was also underlined by a sense of futility for participants; they were striving for a thin body but never felt thin enough, they wanted perfection but perfection was never achieved, they maintained their behaviours for a sense of control but deep down knew that the disease controlled them, yet they still continued maintaining their behaviours. Abigail questioned why she still continued with her behaviours, she described how although she can see the futility of continuing her anorexia, expressed as "regret", a waste of time and only a short-term happiness she still pursues:

Abigail: Any happiness I get is short term so why do I keep doing it if I only look back and regret the time I wasted... spent so much time trying to be perfect and never ever achieving it.

For Taylor, she “*feel(s) larger the smaller I get*” she recognises that reaching a goal weight will not cause the feeling of thinness that she wants and so she therefore needs to set another weight goal. “*You think reaching a goal weight will make you feel thin, yet it only leads to another weight goal....*” and from Anita’s experiences the futile efforts of losing weight to feel thin can only be seen retrospectively. However, despite both girls’ recognition of this futility of continuing their behaviours they both continue to restrict:

Anita: I recently found some photographs of me at my lowest weight, and i was horrified at what i looked like... but i kept thinking that it couldnt have been me because not for a moment do i remember thinking i was thin...

The remainder of this theme will focus on these opposing experiences by further exploring anorexia ‘as a functional and controllable tool’, as a ‘friend and foe’ and ‘anorexia as uncontrollable disease’.

a. Anorexia as a Functional and Controllable Tool

Participants iterated the results of previous studies that saw anorexia as playing a functional and egosyntonic role (Garner & Bemis, 1982; Serpell et al., 1999; Williams & Reid, 2007; Vitousek et al., 1998). Anorexia could be used as a multi-functional tool as a way of feeling in control, achieving something and as a form of coping. Anorexia was also used as a way of feeling safe, a way of expressing emotion, as an escape or a focus to avoid negative situations and emotions, a way to disappear, to feel strong and successful, to feel happiness, a way of fighting puberty, and a way of punishing themselves or others. Furthermore, anorexia was used to fix the person’s life problems, for example Hailey believes “*thinness will fix everything*”. Similarly, Cristina feels that “*I can't adapt myself to this world, that I am rejected, and my answer to this rejection is anorexia*”. These responses echo earlier suggestions that eating disorders are not problematic for the individual but a solution. If anorexia is perceived by the person as providing the answer to their problems then why would they wish to give this up? Table 6 further illustrates how, when looking at the contributing factors to the onset or maintenance of anorexia and

then looking at the perceived positive effects, it can be seen as a tool for fixing their problems.

When anorexia was given the meaning of a tool that they could use when needed, participants felt in control of the disorder and felt it was egosyntonic. Furthermore, participants expressed how the sense of control that came with restriction led to increased positive emotions. This was expressed in relation to eating and not eating, where not eating led to positive feelings of control and being good and eating led to feeling bad, fat, out of control and feelings of self-hatred: *“If I don’t eat, I’m good...If I eat, I’m a fat, out of control eejit, and I hate myself.”* (Maria) and *“Yes that is so true cause when I’m starving I feel control and when I eat I feel bad”* (Hayley). This is further exemplified by Maria when she says:

 Maria: Some days, when I do not eat at all, I get a triumphant sort of feeling, because, hey, I can actually control SOMETHING of the many things that are thrown at me! Although when I feel weak physically, I realise I’m not actually in control, because then I would eat properly...It’s so hard, though!!

Table 6: Anorexia as a Functional Tool

Contributing Factor	Effects of anorexia	Examples from the data
a) Lack of control over life/ A need for control	Restraint as control	<ul style="list-style-type: none"> - “It's the control factor. Food seems to be the only thing in my life that I can control.” (Emily) - “If I slip up in other areas of my life anorexia means that I still have some control.” (Abigail) - “There are so many things that I feel are way out of my control, and I am too scared to go without the small bit of control I find in my behaviors.” (Emma) - “Sometimes, I think its not even about the weight, but so many things in your life, in the past, have happened, that you feel your eating is the only thing that u can control... to me that’s all its about.” (Charlene) - “I dont think I have ever felt in control of my own life... And this disease gives me the control over my life to do with it as I so desire.” (Jack)
b) A desire for perfection	Thin body perceived as perfection	<p>“The desire to be perfect: I’m a perfectionist, and that’s a reason why I want to be thin.” (Maria)</p>
c) Self-hatred/negativity about self	Anorexia as an achievement	<ul style="list-style-type: none"> - “Anyway I maintain my behaviour because it gives me control and makes up for the things I don't acheive in my life... if I don't do well in a paper or at a job I can always think "well I stayed under 300 cal today" (Abigail) - “I want to be as perfect as possible on the outside, so that maybe I wont always be rejected, and il be more loved. I am such a disappointment, I just want to be good at one thing!” (Charlene)
	Anorexia as self-punishment	<ul style="list-style-type: none"> - “That (control-own insertion) and punishment. If something happens during the day, or my thoughts wonder back to past failures, and experiences, then I get so frustrated, that I just go home, exercise till I hurt, and don’t eat!!!” (Charlene) - “Self-hatred and the need for self-destruction. i loved being sick bcoz of my ed, i loved it when people told me i looked like death.” (Anita) - “I was too stubborn and afraid to ever let anyone SEE my weakness so i just took punishment out on myself and my own body.” (Taylor)

d) Stressful situations/ difficult emotions	Anorexia as a coping mechanism	<ul style="list-style-type: none"> - "Its how I cope and get through!" (Charlene) - "Everyone has a way of dealing. Its just that the anorexic person, starves, exercises counts cals and worrys about food.etc" (Hailey) - "Positive role becuase it helps me through strenuous emotional periods." (Lily)
	Anorexia as an escape and avoidance of negative emotions and situations	<ul style="list-style-type: none"> - "To me my ed is the one thing in my life I use to suppress all my feelings. There are just somethings I still can't deal with. My ed protects me from certain feelings." (Hailey) - "It allows me to exscape from everything that i can't face, and it makes me happy." (Grace)
e) Inability to express true emotions	Anorexic body as a way of expressing emotions	<ul style="list-style-type: none"> - "I feel like i am dying inside and it just feels like the right thing that i shud look like that too..." (Anita) - "It's my way of talking to the world. it tells everyone what i can't. it allows me to show them how much i am hurting, how scared i am, how much i feel i am without." (Grace) - "When I look sick, when I look terrible I feel as though i am finally one person within and without...I look as I feel, I feel as I look." (Taylor)
f) Unhappiness	Anorexia as happiness	<ul style="list-style-type: none"> - "And depression also plays a role. It makes you less happy with yourself and more willing to do something to try and make yourself feel better." (Ashley) - "I'm only happy when I'm hungry." (Hailey) - "My behaviours are the way i can achieve happiness, so they are very important for me." (Cristina)
g) Changes during puberty	Anorexia as a way of "fight(ing) puberty"	<ul style="list-style-type: none"> - "In the face of the possibilty of puberty, I had this fear that if I started showing signs of 'growing up' it might make my parents feel "old" I did not want my parents to feel old or like they were losing me so i sought to 'fight puberty' by not eating." (Taylor) - "At the same time, I started getting curves and attracting the wrong comments for a little girl ... So I wanted to stop getting curves, and I ate even less." (Maria)

As suggested in the pre-study questionnaires, participants had ambivalent feelings regarding whether they wanted to recover from anorexia or maintain their behaviours. Respondents perceived their anorexia to play such a significant role in their life that they felt that they did not want to (or perhaps could not) give this up. For example, Maria explains how anorexia “*plays a massive role in my life. Everything I do or think, I relate it to anorexia in some way.*” Similarly, Anita’s anorexic behaviours are important as they mean “*everything to me*”. Whilst Jack’s anorexia is also highly important as for him it has become his identity: “*My anorexia is my life. It is who I am.*”

Positive emotions from restraint, the role of anorexia as a tool and an answer to underlying problems, and a perceived importance attributed to their behaviours caused many to feel positive about their anorexia reinforcing its maintenance.

b. Anorexia Nervosa: Friend or Foe?

When participants felt in control of their anorexia, they ascribed the meaning of a friend that they could depend on, subsequently when they did not feel in control it was seen as an enemy. They therefore described an ambivalent relationship with anorexia: “*Its become my friend! And yet not! Ana is something that is there for you when no one else is!*” (Charlene) and “*Ana is my friend, my foe, I love, yet hate her*” (Hailey).

Some participants personified their anorexia using the pro-anorexic term ‘ana’ or by referring to it as ‘her’, however as the next three extracts illustrate, this personification and description goes beyond a simple pro-anorexic convention and expresses participants’ beliefs about anorexia as something capable of performing actions and having emotions of its own. Here anorexia is expressed as another entity; something that is able to take control of the sufferer and to enforce behaviours upon them.

Anita experiences her anorexia as “*the voice in my head*”. It is a negative entity that controls all of her actions and makes her feel depressed; it has “*expectations*” that she needs to meet through her behaviours, she no longer makes her own decisions, and instead she makes her decisions to “*satisfy*” her anorexic voice:

Anita: It makes me depressed and suicidal because i am never good enough to meet my expectations or rather the expectations of the voice in my head. (...) i wouldnt be able to make any desicions because i forgot a long time ago what i wanted... now all my desicions are made to satisfy the voice in my head.

For Grace and Jack anorexia is both a positive and negative influence. For Grace, anorexia plays a triple role of her best friend, a teacher and something capable of killing. As a friend and teacher it is capable of “*telling*” her what she needs to know to pursue her behaviours, although she uses the inanimate pronoun ‘it’ she describes how it “*holds*” her hand and “*sleeps*” next to her, actions that an inanimate object is unable to do, illustrating the role of anorexia as an entity. This extract, exemplifies the ‘guardian’ theme suggested by Serpell et al. (1999) where for many individuals anorexia plays a role of a friend that is always there and can always be depended upon for protection:

Grace: My anorexia plays the role of my best friend. it is always there for me. it makes me happy and always tells me the truth...that i am fat, and underserving and that food is not what's going to make me happy. it teaches me what i need to know...how to lose weight, how to lie to people, how to avoid feeling by not eating. it holds my hand when i need to feel safe. it sleeps next to me every night. it makes me feel safe and secure.

However, later on Grace describes the role of anorexia as a deadly disease yet at the same time it is also implied that it has a motivation of “*trying to kill*”.

Grace: It's just like cancer in that one moment your fine and then something else is inside you, something you have no control over and it is trying to kill you.

Jack also describes his anorexia as a friend. His friend plays the ‘guardian’ role of being something to depend on “*no matter what*” but his friend is also one that causes many negative consequences: it “*causes*” his grade to drop, “*isolates*” him from those around him and “*forces*” him into a “*stressful*” relationship:

Jack: And if I may personify it, it is the friend that is there no matter what through thick and thin, I always have my anorexia to turn too [...] It causes my grades to drop in school. You cant pass out in class and maintain high grades. It isolates me from my parents and sisters, it takes my friends. It forces me into a relationship between just it and I which as one can imagine is pretty stressful at times.

In all three cases, anorexia is described in a way that it is able to control the persons' actions, which combined with the anorexia's functional role as a tool for control causes conflicting and ambivalent emotions for the person. This theme is considered in more detail in chapter 6, where participants in study 2 further discussed experiences of an anorexic entity, often described as an "anorexic voice".

c. Anorexia as an Uncontrollable Disease

Authors such as Pollack (2003) and Fox et al. (2005) describe how the pro-anorexia movement is anti-medical and oppose explanatory models that see anorexia as a disease that needs to be treated, however, the beliefs expressed by participants in this study suggests otherwise. Despite their involvement in pro-anorexic websites, participants in this study described their anorexia as a "disease", "disorder" or "illness" and recognised the negative effects on health a disease causes. For example, "*It's a disease no different from cancer, or multiple personality disorder.*" (Grace) "*Anorexia is a potentially fatal disease. It's like cancer. You don't treat it you're gonna die of it*" (Anita). Furthermore, Jack describes how despite being an "*active member*" on pro-anorexic sites he still sees anorexia as a "*serious*" disease that requires treatment and can lead to death. Interestingly, Jack's use of the word "consumes" effectively illustrates the lack of control he has over the disease. This description is also far removed from his earlier accounts of anorexia as a tool for control and a friend.

Jack: I do believe that anorexia is a disease, however, I am a very active member on a couple of (pro?) anorexia forums [...] I would feel that anorexia is a serious but treatable condition. Without treatment it completely consumes the life of its host and eventually leads them to death.

Similarly, Hailey also uses the term ‘consumed’, for her this feeling of being consumed (or controlled) by anorexia leads to her not wanting it: *“I do wish to not have this poison that consumed my mind”* (Hailey). However, this lack of control also means that stopping behaviours is not easy to do as Taylor describes, *“I find myself talking to myself in my head begging myself to stop things and I cannot.”*

Pro-anorexia has been said to be promoting a lifestyle choice for the individual, however, Taylor does not agree with this concept: *“Anorexia is NOT A “LIFESTYLE CHOICE”⁸ It’s a disease.”* Although some participants did describe anorexia as a lifestyle or a way of life, this lifestyle had not been deliberately chosen by the individual. Rather, this way of life is due to being entrenched in the disorder for a long length of time, which causes many to believe that recovery is not possible. For example, Cristina describes how anorexia has become a way of life and therefore she feels unable to give it up: *“I think i got used so much to this way of living, that i wouldn't be able to live in another way.”*

Related to this, Maria says to the other users of the focus group, *“I would say to you girls, if you can help it, don’t fall into this illness at all, because then you’re in too deep, and it can kill you.”* Here she describes a number of stages of anorexia, one where to begin with the person can have some control over, or choice to stop anorexia (*“if you can help it”*) and another where the individual can become *“in too deep”* where they do not have control over or a choice to stop. Maria also expresses the importance of anorexia as an illness that *“can kill you”*, and it is this fear that may also lead to a wish to recover. Later, she says,

Maria: I don’t want to die, but I don’t want to recover, though-not yet...mostly because of fear, and a small bit of me wants to get better sometimes, but I wouldn’t know how.

This extract further exemplifies the feeling of ambivalence about recovery where in the exact same sentence she talks about both wanting and not wanting to recover. Maria also describes how she *“wouldn’t know how”* and in this next extract we can see that she believes that there is lack of services available to her, however, if the option was there then she would choose to get treated. We can therefore see that

⁸ It is important to note here that capital letters in online communication represents shouting.

although she is contemplating recovery and treatment there are barriers for her to do so:

Maria: If I lived in a city that offered proper treatment and I thought my life was going to be in danger, I would probably have to think a bit about it, but in the end, I'd choose to get treated...

Barriers to Recovery

Theme 1 has already highlighted some of the barriers to recovery including the positive results gained through using anorexia as a tool, the perceived importance that anorexia has in the person's life and the positive emotions experienced through restriction. The feeling of being unable to control anorexia and therefore unable to stop can also act as a barrier to recovery. Participants also expressed three other barriers including fears, inability to recover, and attitudes and perceived limitations of treatment. These three areas will be looked at here.

a. Fears

DSM-IV criteria for anorexia nervosa requires an anorexic to have an "*Intense fear of gaining weight or becoming fat, even though underweight*" (APA, 2000, p.554) and this was also expressed by participants. Respondents also described a fear of losing control which was associated with ceasing restraint and gaining weight. "*Gaining weight is a big fear for me.*" (Emily) "*I guess I can't stop now because I'm scared of "letting myself go" mentally and physically.*" (Abigail); "*I'm terrified of losing control and becoming massive or something*" (Maria).

Understandably, participants were afraid to recover because this would inevitably lead to weight gain and a sense of lost control. Emily describes how those with anorexia (herself included) all want to "*get better*" but they are too scared to do so:

Emily: But I do NOT discourage recovery, because ultimately that is what we are all seeking: to get better. But we are all scared of getting better, because we are all messed up.

Similarly, Grace expresses that maintaining anorexia feels safer to the person than giving it up: “...and realize that the only reason they're holding on so tight is that it feels safer to them than letting go”.

b. Inability to Recover

It is suggested that the earlier anorexia is treated the better the outcome (NICE, 2004) and as one participant describes “it has been proved that the sooner anorexia is discovered the easier it is to recover.” (Grace). Participants detailed how the length of time that they had experienced anorexia meant that they now felt unable to recover. As discussed above this was a result of feeling out of control of their anorexia and now feeling “in too deep” (Maria). As Charlene describes, “It’s as though you are stuck in something you cant get out of!”

As mentioned above, participants described how their anorexic behaviours had become so entrenched that they were a routine and way of life for them, this caused fear of stopping the behaviours and a feeling that, for them, this was the only way that they can live. For example, Grace explains how the length of time she has had anorexia is a contributing factor for maintaining her behaviours, for her giving up anorexia is akin to losing all of her important possessions, she would feel “lost” without the behaviours that have been such a large part of her life:

Grace: Part of it is also the length of time I’ve been anorexic. It’s pretty much all I know...I can’t imagine waking up one day without it...it’d be like losing my car, my cell phone and my puppy all at once...I’d be lost.

Maria also believes that she would feel lost without her behaviours “They are the routine by which I live, without which I would feel terrified, lost and out of control”. Cristina describes how she has got used to living with anorexia and therefore feels unable to give it up: “I think i got used so much to this way of living, that i wouldn't be able to live in another way” (Cristina).

Participants’ inability to recover was also expressed as being in “a really huge, never-ending cycle.” (Emma). This cycle, as described by Taylor, is a relapse cycle

of being treated and recovering, and then relapsing and going back to behaviours, only to end up back in hospital: *“Hospitalized, treated, recovered, relapsed, repeat. Cycle never ending.”* Lily describes how she has not chosen to maintain her behaviours, rather, she is in a cycle: *“I guess it isn't a conscience [sic] decision to maintain my behaviours, it just is a continuous cycle.”*

c. Attitudes and Perceived Limitations of Treatment

Participants described numerous negative attitudes towards treatment. For some these attitudes had come from their own past experiences of trying to recover or seek treatment whereas others' attitudes seemed to be based only on perception, perhaps from researching on the internet and listening to others experiences in the pro-anorexic forums, either way, having these attitudes were barriers to seeking or attempting recovery. One common attitude was a sense that recovery was not needed because their anorexia was not perceived to be severe enough *“i dont think its gotten bad enough to require treatment”* (Anita). For Gabriella it seems that she is attempting to achieve specific goals before she feels she would need to recover, however, it is not clear whether these are personal goals to obtain a sense of achievement or what she feels she needs to accomplish before she would be considered anorexic by a healthcare professional:

Gabriella: I'm not thin enough I still have my stupid fat lumps (boobs) I still have my period I haven't been hospitalized I have yet to have someone worry about my size. All in all, I'm just not there yet.

Taylor also does not seek treatment because she doesn't feel it is needed. However, she had experienced past treatment attempts and expresses a lack of confidence in the treatment centres available to her: *“The reason I do not seek treatment at the moment is because i a) think treatment centers are a load of crap b) dont think i need it yet.”* (Taylor). Later she describes how treatment focused too heavily on weight gain and not on the psychological problems or what is happening *“inside”*: *“IP treatment facilities really only serve to fatten you up so that they can collect their exorbitant fees based on you "looking healthier" while inside youre still a mess.”* This view has been expressed by participants in previous studies (Bell, 2003; Colton & Pistrang,

2004; de la Rie et al., 2006; le Grange & Gelman, 1998) yet this is still a problem. Charlene, who has never had treatment for her eating disorder, does not even contemplate treatment because it will not focus on her psychological problems: *“I don’t want to go into treatment. Because I feel, it doesn’t get to the root.”*

It has also been suggested that a supportive relationship during treatment is imperative for it to be effective (Bell, 2003) yet from participants’ descriptions this was not always experienced. In particular, both Hailey and Grace questioned staff motivations, from their experiences it seemed that staff only worked for wages and did not care about the patient: *“Doctors don’t really care they just fake it for money.”* (Hailey); *“The counselors did not give a fuck about you and were only there for a paycheck.”* (Grace).

Similarly, participants felt that healthcare professionals had a limited understanding of anorexia. For example, Jack, who was currently in the process of treatment, felt that more research needed to be conducted about *“proper treatment”*:

Jack: There really doesn’t seem to be a lot of knowledge among medical professionals about proper treatment, and I think that this is another area that could use a lot more research.

Some participants also acknowledged that anorexia was a difficult disorder to understand. Charlene, for example, felt that unless a healthcare professional had experienced an eating disorder themselves then they were unable to understand it *“I think, unless they have actually had, or gone through it themselves, they don’t have that understanding.”* Anita describes how she finds it difficult to understand her disorder so can therefore see how difficult it is for someone who hasn’t even experienced it:

Anita: But i dont blame them for it. i can hardly understand why i wanna weigh 75 lbs, i can imagine how difficult it must be for someone on the outside to really understand.

Although only a limited number of participants had experienced treatment for their eating disorder, some of these experiences were perceived so negatively that it had caused them to not want to seek professional help again. For example, Hailey

expresses how the forced approach of her treatment experience was more painful for her than her anorexia causing her to “*hate*” eating disorder treatment.

Hailey: First of all I've done the whole fighting myself to get well thing. I hate ed clinics, I hate the hospital. They forced a tube into my throat and an iv in my hand. I hate the fact that I was force feed it hurt me more than ana.

Grace details how her negative experiences only acted to enforce her behaviours; making her more determined to maintain them and not let anybody else find out about them:

Grace: It was the most wretched experience i have ever had and i vowed to never ever let anyone find out about my ED ever again, so instead of getting better, i just found better ways to cover it up, and more reasons to have it because of the way they treated me.

The extracts above illustrate the roles of unhelpful treatment experiences and negative relationships with staff in the maintenance of anorexia suggesting that interpersonal as well as intrapersonal factors are involved. Treatment experiences are further considered when exploring the experiences of those in the process of recovery and those who had recovered (studies 2 and 3).

5.5. Study Summary

This study aimed to identify how those self-identifying as wishing to maintain anorexia experienced and understood their disorder. Anorexia was experienced as a ‘battle’ of conflicting emotions and experiences. On the one hand, anorexia is perceived positively as a tool for achieving desired results and fixing underlying problems, for some it is also seen as a reliable friend that can be constantly depended upon. On the other hand, anorexia plays a negative role; it is a disease that negatively influences sufferer’s health, relationships and life and an entity capable of controlling their thoughts and behaviours. Anorexia can be both positive and negative, a friend and an enemy, a tool for achieving control and an entity or disease that controls them, it can be some or all of these things at different times or at the same time. The positive emotions reinforce feelings of wanting to pursue and maintain anorexia,

whilst the negative emotions cause many to contemplate recovery. Again, at the same time, individuals can want to do both: recover and maintain.

Participants expressed a strong desire to engage in their anorexic behaviours because of the egosyntonic and functional nature of anorexia motivating them to want to maintain. Participants felt their anorexia was important and it had become a way of life for them. They had feelings of being unable to control their anorexia, they feared recovery and had negative attitudes, and distressing past experiences of recovery. These feelings have also been suggested in those with addictions. Similarly, ambivalence about behaviours and about changing these behaviours is common in addictive behaviours and the results of the current study suggest a possible relationship between these two conditions.

5.6. Limitations of the Study and Suggestions for Study 2

Participants varied in the level of ambivalence that they had regarding anorexia and treatment. Those with less ambivalence reported more positive effects from their disorder and did not even seem to be contemplating the idea of recovery. Similarly, those showing more areas of ambivalence could see more benefits to recovery and were more likely to have attempted to recover in the past, however they still saw many barriers to recovery and many positive effects of continuing the disorder. Although two participants were actively in treatment they were both still using pro-anorexia sites, they wished to maintain their anorexia and could see numerous positive effects of their disorder. Participants' experiences of anorexia were diverse and this is reflected in the reporting of results. One limitation to the study was that participants were not asked about how long they had experienced their eating disorder. It is important that participants are asked this in following two studies as the length of time someone has experienced anorexia may affect their ability to discuss their experiences in detail.

This study also aimed to look at individuals' experiences and understandings of treatment for anorexia, however, as only a small number of participants had received

treatment for their eating disorder (n= 5), a limited amount of discussion was raised on the subject. In addition, the way the topic schedule was presented meant that all questions relating to treatment were discussed at the end, which caused some participants to lose interest in the focus group (this is important, as there was still ongoing discussion about experiences of anorexia that they could have contributed to). The next study in the project looks at the experiences of those who describe themselves as wishing to recover from anorexia and it is suggested that for this focus group the presentation of topics is revised. In particular, as it is possible in online focus groups to have two ongoing discussions at the same time, questions regarding experiences of anorexia and those for experiences of treatment will occur simultaneously.

Chapter 6, Study 2: Pro-recovery Perspectives of Anorexia: “It’s like there are two people in my head”

6.1. Introduction

Study one has already explored the experiences and meanings of anorexia and recovery from the perspective of those self-identifying as wishing to maintain anorexia. In contrast, this chapter reports the results of an online phenomenological study of the lived experiences of those who wish to recover. Previous research into the perspectives of those who are recovering from anorexia have drawn their sample from treatment services. To my knowledge, this is the first piece of research to engage visitors of pro-recovery websites in online discussions regarding their experiences of anorexia and recovery through the online medium.

The study aims were twofold: first, to determine how those wishing to recover from anorexia experienced and understood both anorexia and the recovery process; and second, to identify how these experiences and understandings affected pathways to and through treatment. Thus, the research questions were what do anorexia, recovery and treatment mean to those in the process of recovery? Moreover, what motivates participants’ decision to recover?

6.2. Recruitment Procedure

Participants were recruited in four ways. First, advertisements were put on four pro-recovery websites including, Anorexia Nervosa and Related Eating Disorders (ANRED), Beat, Something fishy, and the South West Eating Disorders Association (SWEDA), these websites were chosen as they provided links about current research studies. Second, owners of personal websites pertaining to recovering from anorexia were contacted. Third, details of the research were spread by site owners themselves where some posted information about the research in their own blogs or web forums for their site visitors to read. Finally, a research webpage was designed by the researcher and hosted on Myspace. This website gave background information about

anorexia and the study and information about how interested people could get involved.

Advertisements and study information asked for people who were recovering from anorexia to e-mail the researcher if they were interested in taking part in an online focus group to discuss their experiences of anorexia and recovery with others in the same situation.

Eleven people consented to take part and filled in questionnaires, however only five contributed to the online focus group. One withdrew from the focus group and the other five did not enter the site. Reasons for this could be that the time between collecting questionnaires and sending out password and log-in details was too long and participants had lost interest. Another explanation could be connected to the complex nature of anorexia as these dropout rates for participation in this study resemble dropout rates for treatment (e.g. Eivors et al., 2004). Of the five who contributed to the online focus group, only four gave sufficient data to be included in the study, with the fifth only contributing to one discussion topic.

As the advertisements and study website was still running, the researcher continued receiving e-mails from others interested in taking part and as the focus group had already begun these were offered an e-mail interview. In total, ten e-mail interviews were conducted. This study therefore reports data from fourteen participants (four focus group participants and ten e-mail interviews).

6.3. Information about Participants

Participants were a purposive sample of fourteen people who were currently experiencing anorexia but wished to recover. Two were male. Participant ages ranged from 21 to 50 years. Participants were located in the USA (n=8), the UK (n=4), Canada (n=1) and Australia (n=1). All described their ethnicity as White or Caucasian with the exception of one who was Chinese (Jon), one who described themselves as White Hispanic (Kelly) and one whose ethnicity was unknown (Cara).

All participants had used pro-recovery websites, with eleven using them weekly and three who described using them within the last year. Ten of the participants had also used pro-anorexic websites, although one tells how this was not on purpose. Four had used pro-ana sites over a year ago, four within the last year and two within the last month. All participants described how they had experienced anorexic behaviours within the last 24 months and 12 told how they had behaviours at the time of the study (the remaining two participants did not answer this question).

Full details of participants' characteristics including EDE-Q and BDI-II scores are summarised in table 7.

Results relating participants' feelings of addiction are presented in table 8. This table indicates that participants felt most addicted to self-harming behaviour (a common co-morbid symptom of anorexia: Svirko & Hawton, 2007). Furthermore, half of the participants felt addicted to heavy exercise, six out of thirteen to strict dieting and five out of eight felt some addiction to using laxatives. Only two participants reported no feelings of addiction.

Table 7: Participant Characteristics for Study 2

Name	Age	Age of Onset	Current Eating Disorder	Treatment Status	Body Mass Index	EDE-Q subscales					Beck Depression Inventory
						Restraint	Eating Concern	Weight Concern	Shape Concern	Global Score	
E-mail Interview Participants											
Jon	27	17	AN(R)	Waiting list	17.6	5.6	3.8	5.6	5.1	5.0	39
Laura	24	11	EDNOS	Current	19.1	5.2	3.6	5.8	5.9	5.1	33
Mary	37	16	AN (R)	Past	19.0	3.2	1.0	4.0	4.1	3.1	16
Cara	24	-	EDNOS	None	20.5	3.4	3.0	3.8	5.0	3.8	-
Lisa	32	31	AN(R)	Current	17.8	3.0	4.0	5.0	4.6	4.2	44
Elizabeth	30	20	AN (R)	Current	19.5	6.0	3.0	3.2	3.8	4.0	28
Angela	21	12	EDNOS	In between treatment	18.6	5.0	4.2	6.0	6.0	5.3	39
Pete	24	21	AN(R)	Current	21.0	2.8	2.0	0.8	2.1	1.9	23
Kim	50	12	EDNOS	Current	22.1	6.0	0.2	4.2	4.4	3.7	19
Chloe	21	13	AN(R)	Current	16.6	2.6	1.6	3.2	4.9	3.0	21
Focus Group participants											
Natalie	26	14	EDNOS	Current	18.1	4.0	2.8	5.0	5.1	4.2	25
Debra	41	13	AN(R)	Current	17.4	6.0	4.4	5.5	5.8	5.4	34
Kelly	27	7	AN(R)	Past	17.2	5.2	3.8	5.0	4.6	4.7	31
Beth	24	12	EDNOS	Current	19.6	3.2	-	6.0	5.8	5.0	49

Table 8: Number reporting various anorexic behaviours and feeling addicted to those behaviours (total n=13 - with one not providing this information)

Anorexic Behaviour	Number feeling addicted to it/Number reporting behaviour
Strict Dieting	6/13
Episodes of bingeing	2/8
Self-induced vomiting	2/6
Laxative use	5/8
Use of diet pills	2/8
Use of diuretics	2/6
Heavy Exercise	6/12
Deliberate Self-harm e.g. cutting, burning or skin picking	5/7
Violence towards others	0/2
Caffeine use ⁹	1/1

6.4. Results

The four focus group participants posted a total of 99 messages to the discussion board. Despite, or perhaps because of, the small sample size, participants in the focus group interacted well with one another, often discussing the discussion topics between them. E-mail interviews ranged in length from one to four months although this did not reflect the level or depth of data but rather was a result to other commitments in the participants' life.

The researcher ensured that any unanticipated topics that the participants addressed in their answers were probed with further questions. This resulted in the introduction of two new discussion topics in the focus group: 'Relapsing' and 'Anorexia as a contradiction'. In the e-mail interviews, many participants drew analogies between their situation and alcoholism and therefore this was pursued through further questions. Respondents also openly discussed experiences of having an anorexic voice or an internal struggle in their minds and this was another concept that was explored throughout the interviews.

⁹ This behaviour was not included on the original list but one participant expressed feeling addicted to this behaviour

The IPA analysis resulted in two overarching themes and their subthemes pertaining to participants' experiences of anorexia and recovery: "The function of anorexia" and "The meaning of recovery". Together these themes explore participants' journeys from the onset of anorexia, through the positive functions, the negative functions, the decision to recover and then their recovery experiences.

The Function of Anorexia

Participants in this study experienced three functional roles of anorexia: as a coping mechanism (or method of avoidance), a way of changing their identity and a method of control. As well as an egosyntonic role, participants described an egodystonic aspect of the experience of anorexia as an "anorexic voice". These experiences will be explored through the following four subthemes:

- a. Anorexia: "My faithful companion"
- b. Changing the self through the body
- c. Striving for the perfect self
- d. Battling the "anorexic voice"

a. Anorexia: "My Faithful Companion"

Participants felt that one of the functions that anorexia served was as a "coping mechanism": "*I think it's a way of coping*" (Kelly); "*My mother passed away from Lupus, and I coped by the anorexia.*" (Chloe) and "*I realize my ED is only coping mechanism I have to deal with stress. I see no other way.*" (Kim). As Kim alludes to, anorexia is considered the "only" way she feels she can cope with stresses that occur in her life. This could be, as Lisa expresses, because she had not learnt alternative, healthy ways of coping: "*Anorexia is a coping mechanism because I suppose I didn't learned [sic] or hadn't been taught to cope with things in a non destructive manner growing up.*" (Lisa).

Part of the role of coping was participants' belief that anorexia enabled them to "survive" their unpleasant experiences, which saw anorexia as a predominantly

positive role: *“I consider the role the ED played to be positive so that I did make it in my younger days to survive a crazy home life.”* (Kim); *“When it all began I adored it. I needed it in my life and saw it as the only way I would survive.”* (Debra) *“I feel like it is the only way I can and will survive...”* (Beth).

Another meaning ascribed to the role of coping was the ability to avoid both negative aspects of their lives and future responsibilities. For example, Debra’s anorexia is a *“retreat from the tough situations I can’t face”* whilst Chloe’s biggest theory of why she has anorexia is that she *“wanted to stay a child forever”*. Cockell et al. (2002, 2003) used the term functional avoidance to describe the ways that people with anorexia use it to avoid negative emotions or avoid aspects of adult life. Functional avoidance is considered both beneficial and detrimental for the sufferer as although it enables them to avoid negative emotions and adulthood it also disables the achievement of long-term goals and does not allow the negative emotions to be addressed (Cockell et al., 2002).

Schmidt and Treasure (2006) discuss how this avoidance role is one way that anorexia is maintained. They describe how by focusing all thoughts on food and eating the person can avoid negative emotions, producing a “numbing” effect. This is supported by participants’ descriptions: *“Food was all I could think about. I used it to comfort myself and run away from my life.”*(Chloe); *“[F]or the most part, it STOPS me feeling. It numbs out pain, fear, anger, rejection. Takes away anything/everything except it in itself”* (Beth).

Participants also illustrated the role functional avoidance played regarding fears of adulthood. For Angela, anorexia enables her to avoid adult, sexual relationships *“It stops me caring about men and wanting relationships or sex or whatever.”* Whilst Debra, has ambivalent fears, which can be interpreted as a rejection of adult responsibilities where her fears of recovering, living, success and love are because she will have to face adult responsibilities and relationships that she has been avoiding through self-starvation. Yet, although she fears the idea of her adult,

responsible self this is also something she strives for and can be interpreted in her fears of not recovering, dying and starving:

Debra: Fear of absolutely everything and everyone, of living, of dying, of failing, of succeeding, of eating, of starving, of love, of recovering, of not recovering.

Similar to participants in study 1, during the early stages of the eating disorder, participants were only aware of the positive aspects of the coping and avoidance roles of their behaviours and because of this anorexia was metaphorically ascribed the meaning of a “friend” and “confidant”:

Natalie: A became a friend. When I was alone (or felt alone), I knew that at least I had A, and so things would be okay... I was never completely alone. She was a comfort.

Chloe: Anorexia was my best friend, my confidant, my support system, and my "lover."

Central to the meaning of anorexia as a friend was the belief that the person could rely on it at the times they most felt they needed a coping mechanism. As noted in chapter 1, a previous study conducted by Serpell et al. (1999) asked participants to write two letters to anorexia, one as a friend and one as an enemy. They found that almost all of their participants described feeling protected, looked after and as if they could rely on their anorexia. Serpell et al. (1999) ascribed the term ‘guardian’ to this theme. Although it was questionable, whether this theme arose due to the nature of the task (writing a letter to anorexia as a friend), the participants in the current study also ascribed this meaning to their anorexia, suggesting that the ‘guardian’ theme is important to sufferers. As Natalie says, “*it was my rock in hard times*”. Similarly, Cara felt that “*I can count on them [anorexic behaviours] to always be there. Whenever things get tough, I can fall back on them*” and Chloe describes how “*It was always there for me, and it never let me down.*” Anorexia’s function as a ‘guardian’ meant that some became dependent on it whenever life circumstances meant that they needed a coping mechanism, as Angela says:

Angela: I feel I need it in case anything else goes wrong in my life. I can always fall back on anorexia kind of thing! It probably sounds strange but it's comforting in a way.

Anorexia was described by Cara as a “crutch” and by Pete as a “handle”, exemplifying that they may draw on anorexia in the future and indicating their dependence on it.

Cara: There are times when I felt in control of my life, well, enough to loosen my grip on my crutch. I've never put down the crutch, though, and I wonder if I ever will.

Pete: I think I've got off the roundabout now, but sometimes I can't help worrying that I still have one hand on the handle still.

Over time, anorexia, which at first offered survival and a coping mechanism, became something else to survive and cope with. As Jon says, *“The only thing I can say is that Ana saved my life when I couldn't cope, but is now killing me...and I know it, but can't stop it.”* The original positive experience of anorexia as a friend soon turned into an experience of an enemy: For example, for Debra anorexia is *“an unyielding tyrant out to destroy me - and I hate it”*, whilst Laura experiences it as her *“worst enemy and biggest nightmare”*. Similar to those in study 1, although participants could see the negative effects of anorexia, they felt ambivalent and still maintained it. This was often described metaphorically in regards to the person's relationship to anorexia. For example, Laura describes “a love-hate relationship” between herself - “an abused woman” – and her “abuser”:

Laura: I still have my eating disorder because I know what to expect from it and it is something that I can rely on. I stay with my ED like an abused woman stays with her abuser. It is truly a love-hate relationship that I cannot escape.

This negative relationship with anorexia will be explored further later on in the theme.

b. Changing the Self through the Body

Consistent with existing theories, participants in the current study described how life experiences precipitating their anorexia resulted in a need to change their identity and/or to feel a sense of control. For example, Jon describes an unhappy home life

and unhappiness with his identity (because of bullying) and because these were both problems that he could not control he resorted to finding control in other aspects of his life (food):

Jon: I was not happy at home and I was not happy with the way I was (mainly thanks to being bullied at school for the way I was). For both, I felt there was nothing I could [sic] about it. Not sure why, but one day I realised I had some form of control over food.

Laura's unhappiness with her identity was a result of childhood illnesses and a reaction to an imposed "sick child" identity. Laura's illnesses included food allergies that she believed "*set the stage for [her] ED*" and medications, which caused weight gain and "*led to poor body image and self-esteem*". In contrast to a "sick child" identity that she "*had no other choice*" over, anorexia gave her a sense of power, which can be interpreted as a sense of control.

Laura: Looking back on my life, I can realize that I hated being the "sick child" but at the time, I had no other choice so I dealt with my situation to the best of my ability – I took the attention that came with being the "sick child". I think that it was when I was tired of being the invalid that I started my eating disorder. Although in retrospect I was trading in one disease for another, it felt that I was beating the image of the "sick child". At the time, Anorexia was power, not a weakness.

As with Laura's reasons for wanting to change the self, Natalie and Elizabeth's experiences also centred on negative experiences regarding their bodies. Both Natalie and Elizabeth experienced traumatic events that consisted of "a complete violation" of their bodies and their self. In both cases, (although this is only explicit in Natalie's case but may be interpreted in Elizabeth's experience) this led to a sense of lost control (or power) over their bodies and an "eating away" of "self-esteem". It is therefore unsurprising, as will be seen later in this theme that attempts to change identity is targeted towards changing the body.

Natalie: [I] was subjected to what people commonly [sic] refer to as "holding therapy". AKA being pinned down/sat on my 2 parents, while I screamed and raged to be let go. [...] I experienced it as extremely [sic] traumatizing, and liken it to rape; I had no power over my body or my space - it was a complete violation of my body, my self, my feelings...

Elizabeth: I was being sexually abused by the father of a friend. I was desperate to get away from him and the place where I had been living. [...] The knowledge of what had happened just sat inside of me, slowly eating away at my self-esteem.

Although the above experiences are different, they all illustrate the need for control and a wish to change their current identity. The method of changing identity through the body is common to all participants even if the experiences leading up to and the reasons for wanting to change are different. This is because the body (through restricting and exercising) is perceived as the only aspect of their life that they could have direct control over:

Beth: it has proven to be the ONLY thing I have that is predictable. [...] With everything else, other people control aspects and as cliché as it sounds, there is some truth in the whole "anorexia is about control" thing.

Restricting food intake is interpreted as control over food, which results in a controlled, thin body, a cultural symbol of control that also carries connotations of a controlled life. These feelings of control over food, weight and life can be seen in the following extract from Jon:

Jon: Not sure why, but one day I realised I had some form of control over food: what I ate, when I ate and if I ate at all. [...] It was a way to control what was happening to me on a day to day basis, and also my weight.

Furthermore, Jon felt that control over his body meant that he had “direct control” over his identity:

Jon: By not eating, I feel like I have direct control over myself and therefore what others see. Whether to fit in, or be different, I would not eat in order to have a say.

Participants’ experienced a dualistic relationship between their self and their body, whereby food restriction was a disembodied experience. Participants saw their body as something that could be controlled by the self through food restriction and other behaviours, “*I feel proud of my ability to control my hunger, to keep my needs under control*” (Elizabeth). This relationship is also seen in Debra’s view of her body when she says: “*I’ve become more sophisticated in my ways of fooling my body into believing that it’s OK to starve*”.

Consistent with theories of the maintenance of anorexia (Fairburn et al., 1999), the body was considered as a threat to the control the self was imposing on it as the body symbolised their natural but uncontrolled desires of hunger. The concept of the body as uncontrolled or a threat to control was exemplified in participants' descriptions of eating and the resultant emotions and behaviours that followed. Elizabeth and Jon describe how when they did eat, it was uncontrolled. Eating was considered as the body's way of "rebellious" (Elizabeth) and "coping" (Jon) and was accompanied by negative emotions of regret (Jon), desperation and disgust (Elizabeth). Because of eating and the momentary perceived loss of control, participants had to compensate by 'punishing' the body through running (Elizabeth) and self-harm (Jon) as a way of re-exerting control.

Elizabeth: I took a job as a waitress, and the tide started going the other direction for me, into binge eating. I also took up running as a way to keep my weight in check. As I was literally starving to death, my body began rebelling. [...] I knew I was gaining weight and felt desperate. I ran for miles, trying to burn off everything I'd eaten. My feet and body ached from all the exercise of running and being on my feet waitressing. By the end of the summer, I was back up around 110 pounds. I felt disgusting.

Jon: The other night when I ate something, I found that I couldn't stop. It was like I was on auto-pilot. Probably my body's way of coping with starvation, I don't know. [...] When I did eat, I would binge at times or eat until I felt sick - mainly because I'd lost the feeling of what it's like to be full up. [...] Afterwards, I'd regret it though. Self harm became a way of punishing myself for what I'd done. It's weird to think that my eating was a way to control my life, but stemmed from that self harm became a way to control my feelings about eating.

The conflict of control between the body and the self was also exemplified in participants' descriptions of their relationship with food. This was characterised by ambivalence about eating where on the one hand, they enjoyed food and cooking, yet this enjoyment was counteracted by fears of eating and thoughts about how to "get rid of it":

Mary: I would order something fattening and then only have a bite or two and say it wasn't that good. It was so good but as I ate it, all I could think about was if only I could get rid of it somehow or I can try and work it off tomorrow.

As with the results of study 1 and our previous research (Reid et al., 2008), participants initially felt a sense of control over their bodies but over time felt that they were no longer in control of their anorexia. As Jon explains, “*I’ve lost control of my only form of control. If anything, it controls me*” and as Lisa alludes to, “*if we actually had the control we think we have, it wouldn’t be such a struggle to recover.*” This experience will be explored further in subtheme d. battling the anorexic voice.

c. Striving for the Perfect Self

Another aspect central to many participants’ self-schemata and subsequent need to change their identity and life situation was a need for perfection. Some participants felt that they had a perfectionist personality, which predisposed them to the development of anorexia. For example, Beth illustrates that the perfectionist attitude involves the belief that both life and identity needs to be the “best” it can.

Beth: For me, I think it [anorexia] was a natural progression. I have always been a high achiever and perfectionist. Never got to grips with the fact that I couldn’t always be the best. [...] Guess I thought if I couldn’t be the best musician/top of my class/prettiest/whatever, I could maybe be the thinnest.

One reason for the need for perfection was a response to parental expectations. For example, Lisa’s striving for perfection is considered a way of making her parents “proud”:

Lisa: I wanted my parents to be proud of me. I did everything I could to prove I was worthy. Best student, best athlete, best musician....but it was never enough--I was and still am "a horrible daughter".

Similarly, Mary believes her anorexia developed, in part, because of “perfectionism tendencies” “brought out” through the expectations of her parents: “*I think overly critical parents and a mothers obsession with appearances played a role. It brought out some of the perfectionism tendencies*” (Mary).

Participants held strong beliefs about what perfection meant. For example, Natalie believes that being perfect would equate to being loved by others. Perfection is

understood by Natalie as being both the “perfect person” and the “perfect”, “thin” body.

Natalie: I believed so strongly that I needed to be perfect... to be loved, to be liked, I needed to be perfect, and that involved the "perfect" body (at that time I thought that meant "thin"), the perfect person (compliant, restrained, considerate, polite, always putting others first, brilliant grades, etc, etc). I strived so hard for this... and anorexia was part of that striving.

The perfect identity could be interpreted as a ‘thin’ body because of weight-related schemata based on both personal and cultural beliefs about weight (Vitousek & Hollon, 1990). Consistent with socio-cultural theorists (Bordo, 2003; Orbach, 1993), participants felt a certain amount of pressure to conform to a socio-cultural ideal of a thin body:

Mary: I think if there was more tolerance in society for being a woman over a size 4, that would help also. Some have said it's the environment that I live in, Denver or Boston and perhaps if I lived in Kansas or Nebraska, expectations might be different. I've thought I could never live in Los Angeles or Miami due to the focus on appearances and plastic surgery.

There was an element of the thin body as being important for feminine attractiveness. For example, Elizabeth feels that she has implicitly learned socio-cultural expectations of how she should “look”, “act” and “make a man like [her]” through the mass media.

Elizabeth: I read a lot of magazines. I usually skip over the parts that show models modelling clothing because the clothing is rarely anything I like or could afford. However, I am always reading about how to make a man like me, how I should look, how I should act, etc., etc.

However, the constant scrutiny of the body and the messages regarding gender (e.g. how to “look”, “act” and “make a [potential mate] like me” is not restricted to the female body. As Bordo (1999) analyses in ‘The Male Body’, males too are under pressure to “look” and “act” a certain way in order to “make a [potential mate] like me” and to succeed in other areas of life. Furthermore, an increased focus on the male body in mass culture (Crosscope-Happel, 2000; Soban, 2006) may mean that more males are feeling pressure to conform to certain body shapes. Pete ascribes the

need for a perfect identity and perfect life to sociocultural expectations to be perfect, where he needs to “get good grades”, “earn money” “feed [the] family” and “look good”:

Pete: I do think society's obsession with thinness is unhealthy and dangerous (although it's not the root cause of course). More important is the 24 hour a day, constant pressure to do better, work harder and be perfect which is felt by far too many people these days. The need to earn money, save money, feed your family, look good, get good grades, etc is just too much for many people - but there is no way "off" the roller coaster of life without losing "face". So people turn to things like EDs instead.

Woodman (1982) explains eating disorders (and alcoholism, workaholism, obsessive cleaning) as an addiction to perfection because of socio-cultural expectations, which provides a theoretical explanation for Pete’s description above. Writing in 1982, Woodman focuses on eating disorders as a feminine problem, however, the key element of her theory, that perfection is at the heart of all addictions, can offer an explanation to why the participants in this study, including Pete and Jon may have developed anorexia.

Essentially I am suggesting that many of us – men and women – are addicted in one way or another because our patriarchal culture emphasizes specialization and perfection. Driven to do our best at school, on the job, in our relationships – in every corner of our lives – we try to make ourselves into works of art. Working so hard to create our own perfection we forget that we are human beings.

(Woodman, 1982, p10)

Concurrently, Pete describes his experience of anorexia as an addiction because of the “constant seeking to get the perfect body image”; his extract demonstrates some of the key characteristics of perfection including continuous striving through the setting of new standards and goals and the fear of failure:

Pete: I guess it's like an addiction because of the way sufferers tend to have perfectionist tendencies. They are always constantly seeking to get the perfect body image or to be as thin as possible. [...] The basic point though is that once you have pushed yourself that little bit further, you can't go back (to do so would be failure), so you have to push yourself on and on and on.

Part of the experience of anorexia was the constant striving for self-enforced high standards and goals. This striving means that a solution can never be achieved as the goals are constantly moved and thus, restrictive behaviours are maintained. This is evident in Elizabeth's changing weight goals:

Elizabeth: The weight came off easily. Within a month, I was at my goal weight of 112. My next goal was 110...and when I reached that, 105and then a "perfect 100" ...and then anything below 100.

d. Battling the "Anorexic Voice"

Participants described a point in time when their restrictive behaviours "*became something else*" (Jon). This is the point at which what could be considered 'normal' dieting becomes a disorder, as Laura states, "*anorexia is a disease which evolves from the initial choice to control eating habits*". The use of the word "*evolves*" suggests that this change is not chosen by the individual as the original restricting behaviours may have been. Similarly, Natalie and Laura used the word "*morphed*" to describe the transition, further illustrating the fact that they did not have control over this change: "*[I] went on "diet", quickly morphed into anorexia*" (Natalie) and "*but the diet did not end, instead it morphed into a full blown obsession with food, appearance and exercise*" (Laura).

Consistent with our previous research (Reid et al., 2008), participants' experiences suggest that there is a point at which 'normal' dieting becomes a disorder and controlled restriction becomes controlling. This switchover from controlled dieting to controlling disorder is seen as a change in cognitions, this was described by Lisa as "*my brain changed drastically overnight*" and by Jon as "*the kinda struggle I have going on in my head*".

During this switchover, participants experienced a split between their self and their anorexia, which was experienced as a "battle" between two minds or two separate voices. This experience was described by participants in varying terms, for example; "anorexic voice", "anorexic mind", "Ana", "anorexic thoughts", "anorexic mode",

“negative tape in my head”, the term anorexic voice will be adopted throughout the rest of this discussion to encompass all of these aspects:

Elizabeth: I have a constant battle in my head between my voice and the voice of anorexia.

Jon: it's like there are 2 people in my head: the part of me that knows what needs to be done and the part of me that is trying to lead me astray. Ana is the part that is leading me astray and dominates me. I think being caught in between and trying to do the right thing whilst being pulled in the other direction is one of the struggles...a mental struggle to resist or fight it.

It is clear that participants' experience of the self/anorexia conflict was between two minds, two selves and two sets of cognitions. As Lisa says, “*I would like to describe my experiences with anorexia as a major conflict in my thinking, processing and perception.*” Participants viewed the anorexic thoughts as external (or alien) to the thoughts of their self. Anorexia was perceived as a separate entity that ‘took over’ and ‘consumed’ the person’s life and identity. As Chloe expresses “*Anorexia catches you at your most vulnerable moments, and if you DON'T have the proper knowledge, it WILL take you over.*” Whilst Elizabeth describes anorexia as, “*an all-consuming disease that oozes its way into every facet of a person's life. Once you have it, there's no escaping it.*”

Laura metaphorically personified anorexia as a “*monster*”, “*leech*”, “*virus*” and “*parasite*” as ways of symbolising the control that she felt it had over her and her life, whilst Lisa used the description of “*the demon*” to signify the self-deprecating motivations of anorexia and the control it had over her:

Laura: The way I see it is that I have this “thing” (this disorder, this monster, this leech – the ED) clinging to me and I am trying desperately to shake it off but it will not let go – it is stuck on me, digging its nails in deep so that it will not fall off.

Lisa: I call my anorexia "the demon" who controls my thoughts, feelings, emotions, and actions. Anorexia is controlling and loves to see me fail when I try so hard to recover. Anorexia laughs in my face when I fail, tears me down, steps on me, pulls me apart, and ruins my life.

Except for the narrative therapy literature where an anorexic self is created to externalise anorexia from a person's sense of self as a way of fighting against it (Maisel et al., 2004), there appears to be limited reference in the literature of such a description. Nonetheless, Bruch (1978) describes her patients' experiences of "being a split person". Her examples demonstrate the "powerful", "dictat[ing]" and therefore controlling nature of this "other self". This "other self" is theorised as parts of the self that the person disapproves of and this may go some way to interpreting why participants externalised these thoughts, attributing them to anorexia rather than to their sense of self:

Others speak of feeling divided, as being a split person or two people. Most are reluctant to talk about this split. Sooner or later a remark about the other self slips out, whether it is "a dictator who dominates me" or "a ghost who surrounds me", or "the little man that objects when I eat". Usually this secret but powerful part of the self is experienced as a personification of everything that they have tried to hide or deny as not approved by themselves or others. When they define this separate aspect, this different person seems always to be male...

(Bruch, 1978, p55)

A contrasting description of the anorexic mind has been provided by Huebner (1993), who believes anorexia arises through an addiction to the endorphins released through starvation. He explains the split between anorexia and the self as a conflict between the anorexic's "healthy" mind and their "addicted" mind whereby:

A split occurs in her subjective experience and attitude: As the addiction increasingly takes control of her thinking and behavior, the healthy part of her mind loses ground.

(Huebner, 1993, p.33)

According to Huebner (1993), the addicted mind must employ "mental defence mechanisms" to maintain the restrictive behaviours. This theory offers a useful explanation of the "anorexic voice" or "anorexic mind" as a cognitive mechanism for maintaining restriction.

This interpretation of the anorexic mind as cognitive mechanism for maintenance is represented in the self-deprecating nature of the anorexic voice that serves to strengthen feelings of low self-esteem, reinforcing the negative self-schemata:

Laura: Anorexia is [...] a constant nagging, demanding, controlling, aggressive... voice which criticizes everything that you do and reminds you daily that you are undeserving, unloved, worthless, pathetic... which does not disappear even when you succumb to what the voice tells you to do.

Elizabeth: The voice of anorexia constantly tells me, "You can't do that, you shouldn't do this, you're not good enough, you're not thin enough, no one will ever want you, you have no friends, you're boring, you're 'damaged goods', you have to exercise or you're a failure," and just about every other negative message you can think of.

The anorexic voice as a mechanism for maintenance is further exemplified in Lisa's experiences of the "anorexic mind" who as part of her interview typed out a conflict as it was occurring. In the following extract the symbols [s], [a] and [b] have been inserted to illustrate the researcher's interpretations of the voices of the self, anorexia and the body.

Lisa: For an example I will type out exactly what my mind is thinking (green is my "right" mind and red is my **anorexic** mind): *It is 10am here and I haven't eaten breakfast. I should have had breakfast and one snack by now [s]. I have to meet with someone for lunch which means I have to eat in front of them. So, I'm not going to eat until then [s]. I have to eat because it will make me healthy [s]. You are going to gain weight and get fat [a]. It's not getting fat, stop saying that..you are going to get healthy [b]. When my body is nourished so will my brain [s]. You aren't even hungry. Don't eat! [a] If I can get my weight up then I will be able to think clearly, get back to work, heal broken relationships, and get my life back [s]. Why even bother, everything you've tried hasn't worked. No one believes what you say either, so what's the point [a]. The point is I need to eat because if I don't my organs are going to start to shut down, my heart could fail[s]. Give me a break, you aren't that bad. Remember that lady from the hospital--now that is bad. She is the one who needs to eat [a]. You are hurting yourself and everyone else around you [b]. Do you really care? [a] Yes, I do care because I finally can see that people actually love me and care about me. I need to care for my self like I care about everyone else [s]. But, I don't want to get fat [s]. Everyone tells you that you are too thin and you look unhealthy. Why aren't you listening?[b] Because when I look in the mirror I don't see how they can possibly think I'm skinny*

[s]. *Alright, anorexic mind.....go away.....I hate you! I'm going into the kitchen right now and finding something to make me healthy. So, stay away from me!*[s]

What makes this extract so interesting is the use of the pronouns 'I' and 'you', which is used by both her "anorexic mind" and her "right mind". It is suggested that there are in fact three 'voices' in the example: the controlling, irrational anorexia, which emphasises the need for thinness and not eating; the body, which emphasises the need for nutrition; and the rational self which moderates between the conflicting messages. The self, 'I', is ambivalent about these messages. It is torn between doing the right thing for the body and self "*I need to eat because if I don't my organs are going to start to shut down*" and the socio-cultural messages of eating and the fat body "*I don't want to get fat*". Lisa's extract illustrates several mechanisms which can be interpreted as ways of reinforcing anorexia including: ambivalence, a weight-related self-schemata, a lack of interpersonal support "*No one believes what you say*", under emphasis of the seriousness of the situation "*you aren't that bad*", and body image distortion "*when I look in the mirror*".

Some participants experienced an increase in the volume and aggression of the anorexic voice if they try to "recover" or become "free" as a maintenance factor. Interestingly, Kelly also describes her wish to recover as a way of "*becoming a whole person*", further exemplifying the feeling of the sense of self being split by the experience of the anorexic voice:

Kelly: Basically - for me, when I listen to the negativity and live the negative lifestyle (aka anorexic life) then the negative tape in my head lessens. It has nothing to fight against. When I ignore it things in my head get really loud and it's horrible for a long time [...] When I start to go against the negativity and want to recover and become a "whole" person, then the thoughts get worse and worse.

Moreover, as Kelly demonstrates, the anorexic voice also reinforces the need for achieving perfection through the body through the continuous setting of higher goals:

Kelly: It tells us if we lose weight, we will be perfect and we will be happy. So we lose weight, trying to accomplish it. We don't feel it so we

keep losing weight, in search of that happiness the ED promises us. One bite is too much and yet never enough.

Striving for the perfect, thin body is reinforced by the constant demands of anorexia. Similar to Laura's earlier description, Woodman (1982) has also described a "demon" who "demands perfection":

Their "I" is possessed by some demon over which they have no control. The demon who wears the mask of respectability during the day shows his real face at night. He demands perfection – perfect efficiency, perfect world, perfect clean, perfect body, perfect bones, but they being human and not prime-time TV advertisements, falter into perfect chaos and perfect death.

(Woodman, 1982, p.13)

Epston (2000), a narrative therapist, describes an oxymoronic function of anorexia, whereby the search for the perfect life can only lead to the perfect death. Thus, by attempting to succeed at perfection the person with anorexia can only fail:

It seems that once a person is taken in by anorexia, anorexia assesses them relentlessly as 'bad', 'unworthy', 'undeserving' and the only way out is to drop out. Anorexia sets a myriad of tests of perfection and ironically, only their death can ensure their success, e.g. 'the perfect failure'.

(Epston, 2000)

Participants strived for perfection in the belief that it would give them a perfect identity and a perfect life but as Debra explains, "*Perfection isn't really possible*". As Natalie and Pete have discovered the solutions that anorexia offers are also the same things that it "takes away". Thus, experiencing anorexia reinforces and exacerbates the original search for a different identity that precipitated its development to begin with. At this realization, sufferers have two choices; continue behaviours in the hope of achieving the goals they have set, or change.

Natalie: You may use it to seek perfection or love or competence or admiration or confidence... But these are the very things it takes away....

Pete: It's all very much a vicious circle - bullying and so on causes low self-esteem, which increases the risk of anorexia, which lowers self-esteem even more.

Themes 1-3 have considered three egosyntonic and functional roles of anorexia as a coping mechanism, a search for the perfect identity and a method of control. However, over time, anorexia was experienced as egodystonic and as an “anorexic voice” that controlled the person and caused negative feelings that precipitated the anorexia in the first instance. The realisation that anorexia could not provide the solution they were looking for contributed to a decision to recover and this will be the focus of the next theme.

The Meaning of Recovery

This theme explores participants’ meanings and experiences of recovery. It draws on three subthemes:

- a. What is recovery and is it Possible?
- b. Acceptance
- c. Barriers to Recovery

a. What is Recovery and is it Possible?

It was apparent that participants vehemently disagreed with weight gain as a definition of recovery. It is clear from Natalie and Debra’s accounts that weight improvement was too arbitrary to define recovery, especially as Debra explains; even if weight improves, the person may still experience continuous cognitions regarding weight, eating and exercise.

Natalie: One can have been “anorexic” by official definition for years, but then decide to embark on recovery, or may have undergone forced weight gain... As soon as she crosses that weight threshold or starts menstruating, is she no longer anorexic? I think not.

Debra: And what about the lines drawn in the sand? Am I not anorexic when I’m able to fight back for awhile and my weight improves? If not, what am I then? Am I just nuts because all I can think about is my weight or what I’ve eaten or how soon I can exercise?

Reiterating previous qualitative research, participants described how the biggest lack of understanding in treatment for anorexia was the strong focus on physical

symptoms and weight, rather than on the psychological issues. Participants believed that anorexia was ultimately a mental health disorder, which resulted in physical “side effects”: *“And it doesn't matter what weight you are currently at, or whether you get your periods or not. They are just side effects”* (Angela).

Furthermore, as medical symptoms were considered “side effects” of the psychological disorder, some participants believed that people could be considered “mentally” anorexic. In clinical terms, this is considered EDNOS (APA, 2000) and these beliefs from participants illustrate how important it is for this patient group to receive effective treatment early on, despite not meeting full diagnostic criteria. This also suggests that perhaps current diagnostic criteria is ineffective and should include more cognitive aspects so that those with EDNOS are considered just as in need of psychological treatment. It is clear from participants’ definitions of anorexia as a “way of thinking” rather than “a way of looking” or a “physical” disorder, that recovery needs to address the person’s cognitions.

Chloe: I believe someone can be anorexic and be at a normal body weight, as long as they have those constant thoughts telling them they are fat or that they need to lose weight. They may not be "physically" anorexic, but they are "mentally" anorexic.

Kelly: Anorexia, to me, is a way of thinking, not so much a way of looking. Yes, it has the physical signs, but it's more to do with internal pressure than the external shell. [...] Does losing that one extra pound to become 15% under IBW make you any sicker than the day before? Does not having a menstrual cycle make you any sicker than someone who continues to, even though they are a low weight?

Furthermore, participants describe how their experiences of treatment that focused heavily on weight and food served only to “motivate” or “exacerbate” behaviours:

Cara: The nutritionist worked with me on meal plans, which I didn't follow, and kept tabs on my weight and body fat percentage, which was excellent motivation to keep losing, or at least not to gain.

Pete: Too often medical professionals' attention is focussed on the weight of the sufferer, rather than the underlying causes (although if a person is dangerously thin they obviously need specific care) and this can exacerbate the problem!

Participants talked about the meaning of recovery in regards to whether full recovery from anorexia is possible and there were diverging views. These views ranged from the belief that full recovery is possible to the idea that the person will always have an eating disorder. Natalie, holds onto the idea of full recovery, she outlines some of the consequences of the perspective that full recovery is not possible which can result in losing hope and giving up “fighting” for recovery.

Natalie: The hope that it is possible to completely recover... I don't care if it is false hope or not - I have needed it to FIGHT (and when people have questioned the possibility of full recovery and talk about "maintenance" or "living with" or "functioning".... I see no point in fighting; they don't understand what they are asking or saying, or they never would ask for one to accept such a thing...)

Contrastingly, Laura believes that the goal of “stabilization” of behaviours would be more beneficial than aiming for full recovery and this is because of the inevitability that relapse will occur.

Laura: In terms of recovery - I think that instead of "recovery" people should be more focused on stabilization so that if (or rather when) they relapse, it won't be such a blow to self-confidence. It is really hard having someone tell you that you are now "well" and then a week later be back at square one.

Similarly, Cara is uncertain about the possibility of full recovery due to the long-lasting effects of the behaviour and, again because of the possibility that relapse may occur. It is clear that this attitude can be detrimental to the recovery process as Cara says “why bother?”

Cara: I'm not sure it's possible to completely recover. Even if you succeed in recovery, there will always be part of your soul that is scarred, and you may suffer the physical consequences for the rest of your life. Furthermore, you'll always need to watch yourself to make sure you don't fall off the proverbial wagon. Why bother.

Finally, Chloe, who uses Overeaters Anonymous (OA), believes that recovery is a life-long process. OA is a twelve-step programme adapted from the twelve steps philosophy of Alcoholic Anonymous. The twelve-step perspective of recovery suggests that a person will always be considered an alcoholic or eating disordered.

Chloe anticipates that this life-long process will be “hard” which could be interpreted as due to the possibility of relapse: *“I will be in recovery everyday, and it's always going to be hard.”*(Chloe).

Similar to study 1, some participants expressed how they went through cycles of relapsing back into anorexia and working on recovery, which could be interpreted as a result of their ambivalence and their fears: *“Thing is, I tend to go round in cycles - so I start eating again, then put on weight, get scared and drop back down.”* (Angela); *“It's cyclical for me: starve, "recovery", change it for another negative behaviour (ie running, other form of exercise, etc) and recover and then back to square one”* (Kelly).

Theme 1 identified how anorexia played the role of a coping mechanism therefore indicating from participants’ experiences that part of the recovery process needs to incorporate the acquisition of new coping mechanisms. For example Beth explains how *“we need HELP to learn healthier/more effective ways of coping”* whilst Cara recommends that treatment should include *“learning to replace the ED as a coping mechanism (for ordering a chaotic world, for avoiding adult responsibilities, whatever) with another coping mechanism.”* Stressful situations were often given as the reason why participants had experienced a relapse, further exemplifying the need to learn new coping mechanisms in recovery. For example Kim *“relapsed yesterday, because of dealing with lots of stress in my life.”*.

Both Laura and Elizabeth describe feelings of distress and feelings of lost control because of weight gain, which led them to relapse. For Elizabeth this is only a temporary slip in the recovery process, whilst for Laura this led to feelings of ambivalence about whether to continue her recovery or maintain her anorexia. *“Sometimes when I felt my weight was getting out of control, I would slip back into my old patterns of calorie-counting, but that usually doesn't last long”*(Elizabeth).

Laura: I returned home and two weeks later relapsed. I began restricting and purging and even began using laxatives again. I was distraught about my weight gain and failure to remain in recovery – I was torn between fighting for recovery and holding onto my ED.

It is evident from the extracts presented above that people will have different understandings of what they should be aiming for in the recovery process and it would be useful for these to be discussed and worked towards in therapy. At the same time the therapist should work with the client on why they feel full recovery cannot be gained. It is also imperative that treatment addresses relapse and considers techniques (such as those learnt through Cognitive Behavioural Therapy) that can be used when setbacks occur, clients should be made aware that slips may occur but that these can be overcome (Fairburn & Wilson, 1993; Freeman, 2002).

b. Acceptance

D'Abundo & Chally (2004) looked at the patient's perspective of recovery, using a grounded theory approach and found that the recovery process is characterised by the 'Circle of Acceptance'. This involves three areas that work together to produce feelings of self-worth for the person and aid recovery. These three areas include accepting the disease (or acknowledging the severity and negative aspects of the disorder), accepting spirituality (the sufferer's realisation that they wanted a life beyond the eating disorder) and accepting others (building or re-establishing relationships). These three areas of acceptance, and the resulting self-worth, which, in the current study, is termed 'self-acceptance', were also expressed by participants in the current study. This subtheme therefore expands on D'Abundo and Chally's (2004) findings by looking more in depth at these four concepts.

Accepting the Disease

Accepting anorexia, and therefore accepting the notion of recovery, was only experienced once participants recognised the problematic nature of anorexia and this meant overcoming denial: "*From the time I stepped out from denial I have wanted to recover.*" (Lisa). Without accepting that behaviours are problematic, the sufferer will not attempt to recover, as Kim says, "*Once you realize you have a problem, you can begin to get better.*"

For some participants accepting that their behaviours were problematic came after an experience that highlighted the negative consequences on their health: *“As my health deteriorated, I sought counselling...”* (Mary); *“At the end of 2000 i got very ill and decided i was either gonna get better or die. no question.”* (Kelly). Another physical factor that affected some participants’ decision to recover was the fact that they had become tired of being ill: *“I am sick of being sick!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!! [..] If I don't recover I will die.....I have to recover and I want to.”* (Lisa); *“I got sick of being sick.”* (Natalie); *“I'm sick and tired of being sick and tired.”* (Kelly).

Recognising the negative effects of anorexia was also experienced due to interpersonal factors. Some participants felt that the negative effects that their anorexia was having on their relationships was a sign that they needed to recover: *“This went on a while until I had a big argument with my wife, and I realised that I needed help.”* (Pete); *“My husband gave me an ultimatum--your going for treatment or I'm leaving you. So---I went for treatment.”* (Lisa).

A key factor in accepting anorexia as problematic and accepting the need to recover was participants’ motivation to change, as Cara says, *“Perhaps one of the most important factors in the success of a treatment is the patient's desire to get well.”* Similarly, Chloe believes, *“Treatment won't "fix" people who don't want to be fixed.”* Motivation to change includes a person’s willingness, readiness and ability (or self-efficacy) to change (Miller & Rollnick, 2002). Study 1 has already highlighted the ambivalence felt about wanting to maintain or recover from anorexia and this is related to the person’s willingness to change. The following extract from Debra incorporates the three aspects of motivation. Presently, Debra does not feel ready to live without her anorexia but is “willing” to try even though she “struggle(s)” to want to change. Part of not feeling ready is because of the perceived positive roles of anorexia; it “serves a purpose” and is an “old friend”. Furthermore, Debra is fearful of the “terrifying unknown of recovery” which as will be seen in further extracts is suggestive that she feels unable to change.

Debra: I fight with whether or not I'm ready to give up my ED every day, but at least now I'm willing to consider it and maybe even take steps in

the right direction. That wasn't always the case, though. Not all of my treatment experiences were voluntary. At times I felt like I'd been pushed into something I didn't want. No matter how bad my ED is to me, it definitely serves a purpose and I've never found anything that can do its' job nearly as well. I'm afraid that I'll never find anything to fill up the huge void in me that would be left if the anorexia was gone. So even when I've gone into treatment because I wanted to, I've often wound up realizing I wasn't ready to say goodbye to my old friend. I guess what I'm trying to say is that I struggle with wanting to let go of my ED while not knowing how to live without it and I don't always feel ready to face the terrifying unknown of "recovery"

Debra's extract illustrates how at times she felt she was "pushed into" treatment at a time when she had not wanted to recover. If a person is not motivated to change their behaviour then they are inevitably going to be resistant to treatment:

Natalie: I knew in those times that I did not want to give my ED up, and that unless I was ready to at least give it a try, treatment (hospital, residential, whatever) would be useless... It's like, "why do (sic) to the hospital with a broken arm if you're just going to refuse to have it plastered?"

Related to low self-efficacy is the concept of fear, which has also been described in detail in study 1. This fear stemmed from having to adjust to a new way of life, to change, and to lose the eating disorder that had been a part of their life for a significant amount of time. Again, paradoxically, part of the reason patients wish to recover is because they wish to live a new, meaningful life, which means having to let go of anorexia. Therapists could address both the fears and benefits of change to aid patient motivation: "*A part of me is still so scared about something so new to me.*" (Jon); "*I am afraid of everything, especially change, the unknown.*" (Debra); "*Really, I am just scared of the unknown...*" (Beth).

Beth describes how a course of Motivational Enhancement Therapy (MET) was valuable to her recovery process. This approach consists of looking at the clients own values and what they perceive as the pros and cons of both continuing and changing their disordered behaviours. For Beth, this resulted in feelings of empowerment, which seems to boost her motivation for treatment even further:

Beth: Motivational Enhancement Therapy: this literally saved my life. It's used mostly for drug addictions, but really helped me to look at both the pros and cons of recovery/staying sick. I had been 'forced' into treatment/to gain weight so many times, that I really felt empowered to know that I could choose for myself what I wanted to do.

Accepting Life

Accepting life was experienced once participants recognised that there was 'more to life than anorexia' where having anorexia meant that participants were not living a fulfilled life. For example, Beth describes how *"I had literally lost everything. I had no friends, no education, no hobbies/interests, no life. [...] My life had NO meaning, NO purpose."* Whilst Elizabeth realises that she cannot fulfil her accomplishments whilst she has anorexia. *"I have a very exciting life ahead of me and many, many things I want to accomplish in my life, and being anorexic isn't going to get me there."*

Some participants described a turning point in accepting recovery where they "woke up" or realised the negative effects on their life that their eating disorder was having and this spurred them on to change their behaviours. *"When I finally woke up and realized that I was losing everything that mattered to me because of my disorder, I knew I had to do something."* (Debra) and *"It may sound strange to say but it is almost as if one day I woke up and said "I am wasting my life away" (Mary).*

Part of the meaning of 'wanting to live' was to have a 'normal' life or, in other words, to have a life that others who do not have anorexia have: *I wanted to be a normal person again or at least live that way."* (Mary). Therefore, an important element of the recovery process means letting *"life get in the way of [...] anorexia"* (Elizabeth), and to understand that *"There is no room in [...] life for anorexia anymore"* (Natalie). This acceptance of life is further considered in study 3 where those who had recovered described a sense of living as a key determiner that recovery had been reached.

Accepting anorexia through recognising the negative physical effects on health and the acceptance of a life with more meaning were often interrelated for participants. Thus, participants wanted both to live physically and spiritually. This is exemplified in participants' wish to start a family where having children was considered a future life ambition yet participants acknowledged that to bear children they needed a healthy body: "*I didn't want to die, and I really wanted to stay healthy to have children.*"(Chloe); "*I also want children and I'm worried that if I don't get better I won't be able to.*" (Angela) "*I want to have a family. As long as I'm sick, I can't*" (Lisa).

Accepting Others

The importance of trusting, helping relationships both in the therapeutic relationship and with family and friends have been posited as essential for recovery (Bell, 2003) and this was reiterated by participants. These relationships played many roles for participants. Chloe, for example, talks about helping relationships from a number of sources. First, her boyfriend provided "emotional support": "*He was definitely my biggest emotional support I had during my stint in inpatient as well as my journey with anorexia.*" Therapists, "recovery friends" and those in Overeaters Anonymous (OA) provided understanding and aided motivation "*Nobody will truly understand what I've gone through except them. They are truly helpful in my recovery because they keep me motivated.*" In addition, the spiritual approach of OA meant that Chloe also had the support of her "higher power" to help in her recovery: "*I still have negative images of my body right now, but I'm looking at my higher power to help me with that. (Higher Power meaning God of my choice)*".

Other participants also expressed the importance of helping relationships from family and friends. These relationships provided "support", faith, encouragement and, in Pete's case, a reminder that there is "more to life" than anorexia:

Pete: The influence of my wife, my children, my grandfather, and to a small extent, my parents, have all reminded me of the fact that there's more to life than worrying about food and punishing myself etc.

Accepting others was also required for an effective therapeutic relationship. Being able to open up, be honest, and talk things through was considered a vital aspect of the therapeutic relationship as this enabled participants' experiences and emotions to be "validated" and also meant that they felt "listened to" and "valued", therefore trust and understanding between the therapist and client is essential. *"The therapist needs to establish trust with the patient, first and foremost, so that the patient feels safe to talk about her issues."* (Elizabeth); *"It felt good to talk to someone about it and actually have my feelings validated, because Lord knows they weren't being validated at home"* (Chloe).

Participants also described a number of aspects that would make the therapeutic relationship more conducive for individual recovery. First treatment should follow an individual, "customized" treatment plan: *"I think treatment should be customized for the patient beginning with the diagnosis."* (Mary) and *"More individualized treatment plans would be better, too. [...] Having only one (treatment or meal or whatever) plan for everyone just doesn't work."* (Debra).

Second, the therapeutic approach needs to be personal and recognise that is more to the person than the anorexic identity: *"I am a person. I might have a disease, but I am still a person. I am not a disease."* (Kelly)

Elizabeth: Treatment has worked for me when my providers have taken the time to get to know me as a person and to really listen to me. I like it when they let me have a say and to explain my perspective.

Third, and as found in previous work (Reid et al., 2008) a collaborative approach that enabled patients to be involved in treatment planning was desired by some: *"Allow us to be involved in the treatment plan."* (Lisa). Beth found it helpful to be involved in her treatment as "part of a team". As she describes, a lack of involvement causes increased symptoms, which may be a way of regaining control as a result of feeling a lack of control when treatment decisions are made for her.

Beth: It helped me when I felt I worked as PART of a team, not UNDER a team. It was about MY recovery and MY life, and I wanted input/to be listened to (which is where my current treatment is going wrong...) I find that when I feel like I have no voice, my symptoms get worse as a way

of...I don't know. Showing that I am in control at the end of the day maybe?

Correspondingly, some participants criticised behavioural approaches, which offers little or no involvement in treatment and works on a reward and punishment system to facilitate recovery: “*many are based on the rewards system which I HATE! It's very demeaning and, to me, counterproductive.*” (Debra); “*the whole reward/punishment method made me feel like i had to do something to be worthy and basically...well, really didn't work for me.*” (Kelly)

Finally, participants expressed how the therapeutic approach needs to be balanced between compassion and empathy on the one hand and expertise and authority on the other iterating previous research findings (Reid et al., 2008).

Elizabeth: Not just anybody can treat an eating disorder patient. You really need to know what you are doing. You have to understand how we think and feel. You have to be patient and empathetic, yet also firm enough to set boundaries and expectations. We as the patients have to feel that we have a voice and are being heard. We need to know that our treatment team cares about us. The treatment team has to want to treat ED patients, not just do it because it's a good source of revenue.

Self-Acceptance

Accepting anorexia, life and other people all link to participants' acceptance of themselves (D'abundo & Chally, 2004). Part of self-acceptance was the recognition of the importance of eating. Some participants regularly reminded themselves how important it is to recover and that the fears and struggles associated with recovery were worth it, as this would lead to a better way of life:

Mary: I convince myself that I wasn't happy during that dark period and I need to remind myself of being positive and not obsess about my body but it's a struggle.

Angela: But when I don't feel like eating I try to remember that I can't play my harp if I don't eat, and I really want to be a good harpist.

These continuous reminders could be interpreted as a way of counteracting the negative thoughts imposed by the anorexic voice. For example, theme 3 saw an

example of how Lisa's anorexic mind relates weight gain to getting fat whilst her healthy mind recognised the importance of nutrition for mental functioning. The importance of putting on weight is affirmed in the following quote, which suggests this is Lisa's 'right mind' talking:

Lisa: I have to remind myself all day--you aren't getting fat you are getting healthy. I have to remind myself when I get healthy my brain will start to work right. I have to remind myself, you have to recover or you are never going to be able to start a family.

Furthermore, Debra describes how, for her, treatment approaches that enabled self-discovery were felt to be of particular benefit:

Debra: I seem to do best in programs that allow for self-exploration in a safe environment. Art, music, and dance therapy, yoga, mindfulness training, discussion groups – all ways that allow me to get in touch with myself at my own pace, in my own way- work well for me. I can learn more about myself in an afternoon with a paintbrush or camera in my hand than I ever will from a rigidly structured schedule or meal plan.

As described above, participants sometimes felt that the anorexia had become their identity, feeling that their own voice/thoughts were “taken over” by anorexic thoughts, or as Kelly stated “*it [anorexia] doesn't allow you to become the person one was meant to be.*” Therefore, one important aspect of recovery was finding the self and the person's own voice. As described earlier, narrative approaches to therapy may be considered an effective way of doing this (Maisel et al., 2004). As the following quotes illustrate, participants recognised that beneath their anorexic identity there is a self or “own voice” who is “waiting for the opportunity to shine” (Debra) and as Elizabeth and Beth describe through their recovery they are able to “figure out” their own identity and become more ME again”:

Elizabeth: It's [anorexia] what kept me from finding my own voice and making my own decisions about my life. I'm just now, within the past year or so, starting to figure out who I am and what I want to be.

Beth: Along the way, as I got better nourished, I felt sparks inside me as *I* started to become more ME again. [...] It sounds cheesy but I really started to connect more to reality than the shadows in my head.

c. *Barriers to Recovery*

Many of the internal barriers to recovery have been discussed previously in the study including the reinforcing, egosyntonic effects of control and thinness, listening to the anorexic voice and the continuous strive for perfection that can never be achieved. Furthermore, low motivation to change and associated low self-efficacy was also recognised as a barrier. Similar to study 1, participants also described experiences of service limitations that acted as barriers to recovery. These external barriers encompassed accessibility of services and included financial issues, lack of services and waiting lists. These service limitations can be detrimental to the recovery process and may exacerbate the eating disorder.

Financial issues were a huge problem for people regarding eating disorder treatment especially those in America and Canada, who had to either pay for their own treatment, find insurance or both. For example, *“The high cost of even a short stay in a treatment facility can be financially crippling. And insurance? Good luck getting them to pay for treatment!”* (Debra); *“The financial burden is HUGE... and such an enormous cause of guilt, stays ended prematurely, not accessing it (or the level or type needed) at all... Huge, huge Issue...”* (Natalie). Financial issues were a key barrier to treatment, with some not being able to access appropriate treatment, which resulted in some “axe(ing)” the idea of treatment “quit(ing)” or feeling “really discouraged”: *“Money was tight, and I didn't want to ask my dad for help, so I had to axe that idea”* (Chloe) and *“I quit treatment because of insurance payments stopping.”* (Kim). Because of the financial issues surrounding treatment, Elizabeth has had to support her own recovery process, which as we can see from the following quote, is a “struggle”:

Elizabeth: The problem is, no one will pay for it. It's prohibitively expensive for me personally, and my insurance won't cover it (I've asked.) So I struggle and wage war with myself on how I want to approach recovery on a daily basis. Some days are good, some days are not.

Lisa and Kim describe having to “fight” with their insurance companies so that they can afford treatment: *“I've been fighting with my insurance for months trying to get*

them to understand my needs and to cover my treatments. We are still working on that.” (Lisa) *“I am still fighting with the insurance company and I owe the latest treatment ED unit lots of money.”* (Kim). This can be stressful and therefore detrimental for someone in recovery for an eating disorder, who as shown earlier may relapse back into their behaviours.

A number of participants described how a lack of appropriate services in their own area meant that they had to travel long distances. *“Currently living in the US after giving up on treatment in the UK!”* (Beth); *“There are no treatment centers in [location]¹⁰, not even outpatient partial programs in my state which makes getting help even harder.”* (Lisa). As discussed earlier, helping relationships with family members were a key component of recovery but this can be difficult if the sufferer has to move away for treatment. For this reason, Laura did not take up the recommendation by her doctor to be hospitalised, as this would be too far from her husband: *“All he could offer was admission back into hospital immediately – I did not take that offer because of the distance from my husband.”*

Long waiting lists were another barrier to treatment. Participants’ experiences of waiting for treatment illustrate the detrimental effects on recovery. Waiting for treatment was de-motivating, *“constantly being on waiting lists and being told that you can’t be helped just knocks all the hope and motivation out of you.”* (Angela), and exacerbated the eating disorder *“By the time I could get in, I was often too sick to be there.”* (Debra). Jon was on a waiting list at the time of being interviewed and talks about feeling “disappointed”, frustrated, helpless and out of control. Feeling out of control caused him to further use his eating disorder as a way to cope. Jon also describes how the long waiting list gives sufferers the impression that healthcare professionals do not “care enough” and carries the message that it is acceptable to maintain behaviours.

Jon: I feel really disappointed and let down that there is a waiting list on [sic] NHS. [...] The really weird thing is that allowing such long waiting times almost promotes ED's...like they don't care enough to help you sooner or are saying it's ok to carry on with it in the meantime. For me

¹⁰ Area has been left out for participant’s anonymity.

personally, the fact that it frustrates and annoys me so much makes me feel helpless - as though I'm losing control...that's when I then find Ana stepping in to help me cope with it.

It is essential that effective treatment is provided early on in the disorder. As seen in theme 1, the longer participants experienced anorexia the more it became seen as part of their identity and was felt to overtake their life. Participants recognised the need for early treatment but as Angela experienced, accessibility issues due to referral criteria, “*you can't get immediate treatment unless you're at death's door*” and having to “*fight to get any help*” can be detrimental to recovery as Angela explains “*The longer people suffering from them are left, the harder it is for them to get better.*” The following quote from Beth further exemplifies the detrimental effects of delayed treatment:

Beth: For me, I think if I had had access to specialized treatment at the beginning, things would have turned out very differently. Instead, I was shipped from one inappropriate facility to another, where often, the way I was treated made things worse. My symptoms became such a huge part of me that by the time I went to a specialist clinic, I had lost sight of what life without an eating disorder could be like, and had long since given up hope that there were people out there who really could help me.

6.5. Study Summary

The aims of the study were to explore the experiences and meanings of both anorexia and recovery from the perspective of those who use pro-recovery internet resources, and to determine how these experiences and meanings affect recovery and treatment processes.

Participants' experiences of anorexia developed from negative self-schemata (low self-esteem, need for perfection) and a perceived need to change their identity and gain some control over life. Accompanying weight-related schema formed from personal and cultural meanings of weight and body shape meant that the vehicle for this identity change was the body as the body was felt to be the only aspect that participants felt that they could have complete control over. During the initial stages of restriction, participants experienced anorexia as positive, egosyntonic and functional, increasing participants' ability to cope with emotions, increasing self-

esteem and providing a sense of control. Thus, participants attributed positive meanings (or pro-anorexic beliefs) to their anorexia.

These pro-anorexic beliefs, accompanied by a continuous strive for perfection served to motivate behaviours, meaning that they were maintained and even increased. This increase in behaviours could only go on for so long until participants reached a point where their cognitions and behaviours no longer seemed logical or worthwhile. Participants reached a point where their controlled dieting became controlling and the cognitions and behaviours that were initially perceived as egosyntonic came to be seen as egodystonic. This shift was experienced by participants as a split in cognitions between their own voice or set of thoughts and the anorexic voice. The interpretations and implications of the experience of an anorexic voice will be discussed further in chapter 8.

One of the aims of the study was to identify how participants' understandings and experiences affected pathways to and through treatment. This study has highlighted the roles of perfection, low self-esteem, pro-anorexic beliefs, and the functional nature of anorexia as motivating factors of anorexia therefore illustrating how the experience of anorexia negatively affects the processes of recovery and treatment.

Acceptance of the disease, recognising there was more to life than anorexia and positive relationships were essential parts of accepting recovery but could be impeded by internal barriers to recovery, which included motivation to change, fears, understandings of recovery and relapse. It was clear that participants desired a personal, collaborative approach in the therapeutic relationship that recognised the individual experience and did not impose control on them.

It was also evident that the main barriers to treatment were external and related to the inaccessibility of services due to waiting lists, lack of services and financial issues. Furthermore, a perceived lack of understanding from healthcare professionals was also thought to influence recovery outcome.

Chapter 7: Study 3, Perspectives of Those who had Recovered: “Living” versus “Existing”

7.1 Introduction

The previous two studies have explored the understandings of those who were experiencing anorexia at the time of the study, by investigating the experiences of those who wished to maintain anorexia and those who wished to recover. In contrast, this study explores the experiences and meanings of those who describe themselves as recovered. To my knowledge, this is the first study to use an online approach to explore the understandings of those who have recovered.

As with the previous two studies, there were two study aims: first, to determine how those who have recovered from anorexia understand anorexia and the recovery process; and second to identify how the experiences affected pathways to and through treatment. This study therefore explores two research questions: what does recovery mean for those who have recovered? and how do participants describe their experiences of having anorexia now that they are recovered?

7.2 Recruitment Procedure

During recruitment for study 2, four people who were recovered from anorexia contacted the researcher interested in participation. The dropout rates from study 2 indicated that a long waiting period between recruitment and the start of the study has the potential for a reduction in interest. Therefore, as the researcher was not yet ready to begin a focus group with this sample, these people were invited to take part in an e-mail interview. A further person contacted the researcher once the focus group for the study was underway and she took part in an e-mail interview too. Thus, five e-mail interviews were conducted.

As with study 2, recruitment for the focus group was conducted in a number of ways. Advertisements were posted on six pro-recovery websites (ANRED, Beat,

Gurze.com, Pale Reflections, Something Fishy and SWEDA). Owners of personal websites were contacted and this led to a snowball effect whereby some website owners passed on information to others they felt would be interested or posted details of the study in their forums or Web Logs (Blogs). Finally, the information on the research page on MySpace was updated to advertise for participants who considered themselves to be recovered from anorexia. Advertisements and initial information asked those who were interested in participating in an online focus group to e-mail the researcher for more information. The researcher then replied via e-mail with an attached information sheet and consent form. On receipt of a consent form, participants were sent questionnaires to complete electronically and return before the focus group began. Eleven people consented to take part in the focus group and filled in questionnaire data, however one participant did not give sufficient data (replying only briefly to two topic threads) thus the study reports data from ten focus group participants.

During the recruitment phase of the study, the researcher received e-mails from those describing themselves as 'in recovery' despite the request for those considering themselves 'recovered'. Many were e-mailed back to say that the study was actually looking for people who were 'recovered' and that their e-mail addresses could be retained for future contact if the person agreed. However, it became apparent that the terminology used in recruitment was problematic; many people considered that recovery from anorexia was a life-long process and therefore considered that they were still "in recovery" or in "long-term recovery" (Helen). For example, during recruitment one respondent expressed how:

I think I consider everyone who has suffered as IN RECOVERY, because I am not sure if we ever really are recovered. Just like alcoholics, are they ever fully recovered?

Therefore, based on this, those that described themselves as 'in recovery' but did not currently have anorexic symptoms were also included in the sample.

7.3: Information about Participants

Fifteen female participants took part in this online study (ten in the focus group and 5 e-mail interviews). Participant ages ranged from 20 to 54 years. This was an international study with participants located in the USA (n=8), the UK (n=2), Canada (n=4) and Australia (n=1). The majority ethnicity was white or Caucasian (n=10) with a further three describing themselves as mixed white, one described herself as Jewish Caucasian and one labelled herself as European. All participants described themselves as recovered at the time of the study and none believed themselves to have a current eating disorder, despite this, two participants reported having minimal behaviours at the time of the study due to a temporary lapse. The main participant characteristics are summarised in table 9.

Participants were asked about their internet use pertaining to eating disorders. Regarding pro-anorexia websites, eight had never used these sites, five had done so over a year and two reported using them within the last month for research purposes. The majority (n=11) used pro-recovery sites at least once a week, with some owning their own sites. Two had used pro-recovery sites within the last month, one over a year ago and another reported never using pro-recovery sites despite somehow obtaining details of the research. Either the term 'pro-recovery site' is ambiguous and the respondent did not associate the sites she used with this term or she had been made aware of the study from someone who had seen the details online.

Table 9: Participant Characteristics Study 3

Name	Age	Age of Onset	Length of Recovery	Body Mass Index	EDE-Q subscales					Beck Depression Inventory
					Restraint	Eating Concern	Weight Concern	Shape Concern	Global Score	
Focus Group participants										
Fiona	23	13	¹¹	18.0	0.0	0.4	1.4	3.1	1.2	19
Ali	54	13	7	22.6	1.0	0.0	0.6	0.8	0.6	0
Alice	31	12/13	2.5-3	23.4	0.8	1.0	4.8	4.5	2.8	20
Karen	49	14	5	22.5	0.0	0.0	0.2	0.0	0.1	3
Linda	50	15	2	30.1	1.2	2.2	2.0	1.5	1.7	28
Clare	27	9	5	17.6	0.4	0.2	0.8	0.1	0.4	2
Naomi	29	?	3	18.6	0.0	0.0	0.8	0.9	0.4	3
Samantha	20	15	1	19.6	0.2	0.0	0.4	0.9	0.4	2
Sue	43	28	10	18.5	2.4	0.4	0.6	0.6	1.0	3
Maggie	32	12	5	22.8	0.0	0.0	0.0	0.3	0.1	0
E-mail interview participants										
Helen	36	10	Unknown ¹²	19.5	0.0	0.3	0.2	0.0	0.1	6
Ruth	30	16	Unknown ²	21.4	0.0	0.0	0.2	0.1	0.1	0
Ann	25	16	Unknown ²	21.5	0.0	0.0	0.0	0.0	0.0	1
Lyndsey	35	18	Unknown ²	17.2	0.8	0.6	0.6	0.6	0.7	9
Jane	24	13	1	¹	1.2	1.8	5.0	4.6	5.9	5

¹¹ Participants chose not to answer this question

¹² Participants were recruited before this question was added to the pre-study questionnaire

As with study two, participants were also asked whether they had ever felt addicted to any of their anorexic behaviours. This question was asked in an open-ended way allowing respondents to respond in their own words. This was sometimes problematic when trying to analyse results as some answers did not always seem to refer to a feeling of addiction. For example, Linda's response details only the frequency of her behaviours: "*enemas daily, laxatives daily, very picky eating with a lot of extreme rules*" (Linda). Nonetheless, some of the answers indicated a strong belief in feeling addicted to their behaviours, as Helen describes, "*I consider eating disorders to follow the addiction model extremely closely*" whilst Ruth explained:

Ruth: I believe that an eating disorder is by its very nature an addiction to a set of behavioural patterns that offer escape mentally from upsetting thoughts, memories and situations that nonetheless harms the person... and keeps that person pursuing a lifestyle that is unsustainable. I've done all of the things indicated to the extent that I felt unable to stop.

Participants' responses are tabulated in table 10. Only one participant reported no feeling of addiction. Similar to the results of study 2, participants reported feeling strongly addicted to self-harming behaviours with 7 out of 8 participants reporting this. The implications of this are discussed in detail in chapter 8. A further 11 out of 15 participants reported feeling some addiction to strict dieting and this lends support to the strong need to maintain anorexia (which is a strong theme throughout all three studies). Feeling addicted to anorexia was discussed in depth and spontaneously by many of the participants during the online focus group and e-mail interviews and this topic will be returned to later in the chapter.

Table10: Number reporting various anorexic behaviours and feeling addicted to those behaviours (total n=15)

Anorexic Behaviour	Number feeling addicted to it/Number reporting behaviour
Strict dieting	11/15
Episodes of bingeing	3/9
Self-induced vomiting	2/7
Laxative use	5/12
Use of diet pills	2/5
Use of diuretics	3/7
Heavy exercise	6/14
Deliberate self-harm e.g. cutting, burning or skin picking	7/8
Violence towards others	2/2
Low body weight or “being minimal sized” (Ali) ¹³	1/1
Self-deprecating thoughts (Alice) ³	1/1

7.4 Results

Participants in the focus group posted a total of 174 messages. As with the previous studies participants varied in the levels of posting with some choosing to post more than others. Participants interacted with one another and often posed questions to the rest of the group to discuss, highlighting the co-research nature of the approach. Serendipitous topics included social recovery, finding inexpensive treatments, whether anorexia was an addiction and whether full recovery was possible. E-mail interviews varied in length between 2 weeks to 5 months (this was due to unexpected events in the participant’s life). Again, the researcher ensured that any unanticipated topics in the interviews were covered.

As participants in this study had recovered from their anorexia, the resultant data was more complex and detailed their experiences from every stage of the anorexic

¹³ These behaviours were not included on the original list of behaviours but were described by participants as addictive

journey. This is a retrospective data narrative detailing participants' experiences backwards from being recovered to deciding to recover to experiencing anorexia.

Living versus Existing

Participants made a clear distinction between their current situation as a recovered anorexic (described as a sense of 'living') and their previous experience of having anorexia (described as merely 'existing'). For example, "*For years I was only "existing", now I'm alive!*" (Ann), "*I want to live now not just exist.*" (Naomi):

Sue: I guess I could define this [recovery] as "now I have a life" – I don't really consider when I was in the illness that I was really living, just existing, in a coma life.

As with study 2, the idea of living meant an acceptance of life and a desire to engage actively in living a fulfilling life full of enjoyment. This newfound acceptance of life is described by Karen as "*the fog has finally lifted*", this fog that Karen described could be a metaphorical description of the barrage of anorexic thoughts and rules that had governed her life previously. This is also described in Jane's extract as not "*having every waking minute thinking about [...]*". These ideas will be considered more thoroughly later in this theme.

Karen: The fog has finally lifted and I can enjoy the one life that I have been given, and I now know that I have the right to do just that.

SW: *What would your definition of "recovery" be?*

Jane: [...] being able to enjoy all the things you used to enjoy and more without having every waking minute thinking about your next meal or what you have just eaten, or how much exercise you need to do that day. I think recovery is taking part in life again.....instead of hiding in the shadows.

A sense of 'living' was tied up with a number of other factors. First, people needed to feel that they deserved to live a full and enjoyable life. This is inherently tied up in self-acceptance and a recognition and gratification of their needs and desires. Second, 'living' also encompassed an active engagement with other people, this often required a form of social recovery and an acceptance of others and, as food is such an integral part of most social occasions, a positive relationship with food.

Finally, 'living' was also related to an emotional recovery, this involved the adoption of healthy and alternative behaviours in place of previously used anorexic behaviours for dealing with strong emotions. The remainder of this theme will now focus on the main factors that participants believed contributed to their recovery and ultimately a sense of "living". These will be discussed as three subthemes:

- a. Acceptance and (Re)discovery of Self
- b. Acceptance of Others
- c. Acceptance and Discovery of Emotions

A final subtheme further explores the contrast between living and existing by exploring participants' experiences of 'existing':

- d. Existing through anorexia

a. Acceptance and (Re)Discovery of Self

As seen in study 2 and will be reconsidered in theme 3, anorexia is often precipitated by an unhappiness with the self and a wish to change. For some participants recovery from anorexia was characterised by a re-discovery of their former self before their identity crisis: "*I also found me again*" (Sue). For others, this was characterised by discovery of a sense of self for the first time. "*Recovery is starting to find out who I really am, looking for a partner to share the rest of my life with, and trying new adventures.*" (Fiona). Karen describes her experience of self-discovery as moving from a position of "darkness into light" which strongly exemplifies the extent of her newfound insight into her identity:

SW: How has your life changed since you have recovered?

Karen: [...] Living with clarity about who I am. From darkness into light.

Life is great!

Whether the person was re-discovering themselves or finding themselves for the first time, recovery from anorexia required self-acceptance, as Sue conveys, recovery involved "*Learning to accept and understand me, even like me.*" Self-acceptance, in the case of anorexia, involves an acceptance of a whole self made up of both a bodily and spiritual self. The following extract from Naomi details her progression to self-acceptance through alternative methods such as massage and yoga that helped her

reduce her body image issues and “connect” her mind and body into a coherent sense of self. Other participants also described helpful, alternative methods that assisted in the discovery and acceptance of the self and this may be suggestive of a place for such practices in eating disorder care.

Naomi: At college I studied massage and we used to practice on each other. The first time I had to get undressed I felt so sick as I never let anyone touch me. After around three weeks I noticed how comfortable I was becoming with it. I used to go home and cry after the sessions but this was partly due to relief at the fact somebody had touched me and wasn't repulsed by my body. It made me think maybe I wasn't as awful as my anorexia told me I was for so many years. Another thing that helped was yoga. I had always seen my body and mind as being separate [sic] things at war with each other and this helped me feel they were connected.

Self-acceptance is characterised by a “*compassionate self-awareness*” (Ali) which can be considered an ability to know the self, to understand one's temperament and to recognise individual needs, as the following quote from Ali emphasises, this “*compassionate self-awareness*” is an essential aspect of the recovery process described as “*the missing link*” and “*the key to recovery*”:

Ali: I now define complete recovery as a state of compassionate self-awareness: I understand my genetic temperament -- what makes me anxious, idealistic, focused, stubborn, and genuinely happy; I recognize that perfection is an unattainable illusion; I accept my limitations while seeing just how immense my true possibilities are. [...] I believe that the key to recovery is allowing myself to feel compassion for my body and for my mind, without judgment, without criticism, without shame or blame. Replacing criticism with compassion is a tall order for anyone with a history of anorexia, but I have found it to be the missing link.

Compassionate self-awareness requires a person to be understanding, sympathetic and even positive about their traits and needs and to attend to them appropriately. This is in direct contrast to the beliefs of self-denial and low self-esteem that characterises the person's negative self-schemata before and during their experience of anorexia. A rejection of self-denial includes recognition and gratification of individual needs, whether these are physical, emotional or social needs or simply a need for an element of pleasure. The following quote from Linda illustrates her acceptance of her needs and desires and her gratification of them. From this example we can see that she now does things for pleasure not for deprivation. She also accepts

her individuality, doing things that others may see as unconventional but which makes her feel better about herself. Linda's self-acceptance now also means she feels comfortable allowing others to see her individuality, which also relates to her need for others and plays into the next subtheme of acceptance of others.

Linda: I have come to see that I can nurture myself in other ways...instead of punishing and depriving myself...e.g. enjoy listening to music, dancing in my apartment for enjoyment, putting body butters all over my legs and arms...for the pleasure of it, keep my fan on all night to soothe me to sleep, be unique in how I live my life and not feel inferior about it. [...] I have dared to invite friends into my apartment. I used to feel too afraid and ashamed to do so.

Similar to study 2, one of the key areas of recognising needs for the participants was the recognition and acceptance of the need for food. This was evidenced by the identification of hunger and a positive relationship with food and eating.

Lindsey: It took quite a while for me to get back my biological signals for hunger, but I am proud to say that I eat when hungry and stop when full.

Alice: being able to hear & listen to my body-when im hungry, i need to eat, when not, i dont need to eat, and in social situations i eat what i feel like eating

Self-acceptance can be interpreted as change in the negative self-schemata that people with anorexia hold which includes low self-esteem, evaluating the self based on weight and beliefs about the need for self-denial and perfectionism. Thus, compassionate self-awareness requires a complete change in attitude about the self (or a modified self-schema). As the following quote from Ann illustrates:

Ann: it's something that happened within, it was my attitude that changed. [...] To give you a simple example about the attitude changing thing -- for eight years, whenever I looked into the mirror I started crying. I didn't even have to "force" it, it just happened. I felt so ugly. And now, I love what I see when I look in the mirror, I like the way I look. And the funny thing is, I look the same as I did before.. same face, same hair, same everything.. what has changed is my attitude and how I see myself.

As well as a change in attitude about the self and the cessation of self-denial, participants also described a change in attitude about the need for perfection. For

many of the participants “compassionate self-awareness” requires acceptance of the fact that nobody, including oneself, can be perfect and that this is “ok” as Jane explains:

Jane: Recovery is learning to love yourself as you are and being happy with yourself and knowing that your not perfect and that your not supposed to be, and being ok with that.

Self-acceptance and the acknowledgement that perfection is unattainable can be facilitated by an unconditional acceptance from significant others in the person’s life, whether this be a spouse, children, parents, friends, or a trusted therapist. As Karen describes, unconditional love from her husband and children, despite her imperfections, is helpful in allowing her to accept and express her true self: *“It helps to have grown children and a husband remind me of my imperfections, but loving me anyway. I can even laugh at myself!”* (Karen).

Self-acceptance can also be fostered through the treatment experience. In order for self-acceptance to occur, the therapeutic relationship must recognise the client as an individual and foster the development of self-worth. This takes many forms: listening to the person and validating their concerns and experiences; seeing the person as a person rather than a patient/diagnosis; and respecting and attending to their individual needs for recovery. In relation to this, the therapist must show interest in the values and experiences of their client

Helen: The ones [psychiatrists] that I like and end up seeing long-term are the ones who recognize my strengths and intelligence. [...] And I can tell that he really, honestly cares about me as a person and that matters a lot. When I was at college I had a shrink who could never even remember my name without looking at the chart- I don't know that he ever looked at me, myself.

Fiona: While others told me “[Fiona], you're just gonna crash and burn”, he realized that nursing was so important to me that it could well be the one thing that keeps me going. So we focused on that for a long while... [...] This program was great. Much more flexible, and I was treated like a HUMAN BEING with DIGNITY!! Very different than my previous experience.

In contrast, as will be discovered in theme 3 (maintenance), treatment experiences which do not cultivate a sense of self-acceptance can actually replicate emotions and

beliefs that precipitated anorexia in the first instance and serve to reinforce the maintenance of it.

b. Acceptance of Others

As noted above, relationships with others (both personal and therapeutic) can foster self-acceptance. For this to occur, the person must also accept others. This acceptance of others and acceptance of the self may sometimes go hand in hand whereby accepting and relating to others may involve allowing others to see one's true self (as opposed to a reconstructed, masked self) with the knowledge that this true self will be valued and accepted.

Ali: You need someone who cares, who listens with open and genuine attention, and who has the ability to hear and value your true voice and self.

Participants described a social aspect to their recovery whereby part of their sense of 'living' meant that they were now interacting with others. This is in direct contrast to the experience of social isolation and withdrawal that is characteristic of existing with anorexia. Recovered anorexics could meet up socially with friends and colleagues without worrying if this social interaction would involve food and as Fiona discusses, she can now dedicate time to being with others as she no longer has to spend this time thinking about calories and weight.

Fiona: When I could eat what I wanted, when I wanted and where I wanted, and able to go out with friends, eat lunch with my colleagues, etc. [...] Recovery was when I had time to hang out with friends, meet new people, and do my favourite leisure activities, because I was no longer using up so much time obsessing over calories, weight, and the rest that comes with anorexia.

Acceptance of others also requires a certain amount of trust and faith especially during the early stages of recovery where the person may have to "surrender" their own (maladaptive) ideas and beliefs about eating and begin to listen to others' suggestions. This can be difficult, especially if the person has been existing through these maladaptive beliefs for a while. This also requires the person to give up a

certain level of control over their behaviours, which is extremely challenging considering the high importance ascribed to feeling a sense of control:

Helen: [...] I would continue my downward spiral by continuing to rely on my own ideas or take a blind leap of faith and give someone else a shot at running my life. They told me that I could always take back control by resuming the eating disorder, but that maybe it was time to give something else a try.

Lyndsey: It also takes a tremendous leap of faith to trust your treatment team enough to make sure you are not going to get "fat" if you persist with treatment--some girls are just too scared to take that leap, especially given the cultural messages out there that thin is beautiful and desirable.

Acceptance of others allows the person to form or rebuild positive relationships. Positive relationships with others are extremely important for the recovery process (e.g. Bell, 2003), and in some situations can actually be a substitute for professional help (Protinsky & Marek, 1997). Two participants, Ruth and Ann describe how their recovery was only possible because of their relationships with others. Both had no experience of any formal treatment but expressed how relationships with others had ensured their recovery. Ruth had decided to recover without professional treatment after numerous unsuccessful visits to doctors and their lack of acceptance of any problem had left her with no other option. She set up an online forum and formed connections with other sufferers and together they helped each other to recover:

Ruth: How do did I change this for myself? I build [sic] a proactively positive recovery community online and started building friendships and relationships again... with a strong sense that if I build positive ties, it would help me get stronger... healthier... happier. And it has.

Ann's experience of recovery was a result of continued support and communication with her husband whose unconditional acceptance of her as a person allowed her to open up and discuss her experiences. As Ann states, this would not lead to recovery for everybody (they would need to be motivated for recovery and also ready to accept others). Nonetheless, Ann's experience illustrates how important positive relationships with others are in helping people to accept themselves. It also illustrates the important functions of communication (about behaviours, cognitions and emotions) and support in the recovery process.

Ann: And I was able to tell him everything that I was doing and what I was going through, and he never judged me or made fun of me. [...] I recovered with the help of my husband. Every single day we would talk about what I did, what I ate or didn't eat, how much I exercised, or any other eating disorder behaviour that I did... he was kind of my therapist and ask me why I did certain things, how they made me feel, and so on. I cried every day, and he was there, comforted and supported me. He never gave up on me. And we also celebrated my successes, when I was "healthy" for a day or so, he was so proud of me and I was proud of myself too. I recovered without professional help, but this was not a conscious decision, it just happened this way. [...] help and support from others is essential and needed in order to successfully get out of this struggle! One has to be ready and willing in order to accept the help and support offered.

c. Acceptance and Discovery of Emotions

The last area of recovery that participants discussed in relation to their sense of living was an acceptance and discovery of emotions. As also seen in studies 1 and 2, anorexia can serve as a way of avoiding emotions and the relationships and situations that may provoke these emotions (Cockell et al., 2002; Schmidt & Treasure, 2006). Cockell et al. (2002) discuss 'functional avoidance' as both a positive and negative role for the person with anorexia because although the avoidance of negative emotions can be seen as positive this also means the avoidance of positive emotions and situations that may lead to the attainment of life goals. Whilst captivated by the experience of anorexia, the person may only see the positive side of reducing the negative emotions but now that these participants are recovered, they realised the negative impact that this avoidance had on their life. As Clare explains, "*I started feeling again and was able to feel positive emotions as well, which was very rewarding.*"

Participants believed that learning to express emotions in a healthy way was an important part of the recovery process. Participants in the online focus group were asked if they had any advice for those in the process of recovery, their family and friends and for healthcare professionals and a number of these answers emphasised the need for the person with anorexia to express their emotions. For example:

SW: Now that you have recovered, what advice would you give to those in the process of recovery?

Clare: Crying and feeling are good; don't feel bad or ashamed of your emotions.

SW: [...] what advice would you like to give to healthcare professionals working with patients with anorexia?

Linda: The less communicative a patient is, the more likely that s/he is unable to express what is inside. Try to find ways to draw out her experience using tools such as creative therapies [...] Keep in mind that a person with an ED may have HAD to shut down all communication, even with herself..at a very early age...and therefore may not be able to know, even herself, what is really going on inside.

As Linda's quote above exemplifies, life events may have caused the person to be unable to relate to or recognise their emotions, thus one of the aims of treatment should be to enable the exploration and expression of emotions in a safe environment.

In study 2, the functional avoidance role of anorexia is interpreted as a coping mechanism where not having to deal with negative emotions enables the person to cope. One of the key requirements of recovery is thus to adopt alternative and healthy coping mechanisms in place of the maladaptive eating behaviours. As Helen describes, this can be difficult and the new mechanisms may not feel adequate at first:

Helen: I believe in working hard at developing new methods of coping and being honest that at first, they will not feel adequate to take the place of ED behaviors. On a scale of things, the intensity of using an ED behavior to cope is a 10 while using most other coping methods will feel more like a 3. Gradually, with work at getting emotions out in healthier ways, there won't be the need to express those emotions at a rate of 10, but rather at a 5.

This theme has already discussed the importance of (re)developing positive relationships. Communication with others and talking through problems can be considered an alternative coping method. Other coping mechanisms described by participants included relaxing meditation and the creative expression of emotion through writing, art or dance. This may have some implications for the use of creative art therapies and, again, alternative therapies in the recovery process.

Jane: I think being recovered means being able to express your feelings in a healthy way - IE by talking or through art or writing instead of allowing things to build up in your mind.

Samantha: i really enjoyed (and gained from) art and movement therapy because i'm a very 'hands-on' type person and i'm into both dance and art. they were really expressive ways of getting out emotions as opposed to just talking.

These creative methods allowed participants to express their emotions safely. They served as a way of releasing emotions rather than allowing them to “build up”. In the extract below, Helen describes her use of writing as “*a safe way of purging!*” illustrating the strong release that writing allows. Etherington (2003) values the use of writing as a healthy way of expressing, exploring and understanding emotions. Although not discussed by participants, this may suggest a role for the use of online support groups, personal web pages and online blogs in the recovery process, whereby sufferers can write about their emotions in a safe and anonymous environment and future research may want to explore this further.

Helen: I learned to do what I now call "free-journaling." I pull up a blank word document and just start writing without stopping. If I don't know what to write, I write that I don't know what to write. I don't worry about spelling, punctuation, grammar, or anything else that would make a teacher cringe. Just get it all out~ it's a safe way of purging! I stop when I feel like I'm completely done. Sometimes I just delete it, sometimes I e-mail it to my sponsor or therapist. Just knowing that someone who understands has read it helps. Mainly, the act of getting it out of me is the best part.

Exploring emotions and experiences that provoke these emotions may be particularly important for those whose anorexia was precipitated by a childhood trauma. Two participants (Maggie and Alice) described treatments that allowed them to explore their childhood experiences, process and express these emotions, and then move on. This is metaphorically conceptualised as the “rescuing” of their childhood selves. This may also have other implications, as by rescuing themselves they are able to see themselves as a caregiver; one who meets their emotional needs. Even if the caregivers during the childhood trauma did not meet these needs then the person can now feel that they are able to do so. This may transfer to other areas of the person’s

life and may help them to see themselves as able and worthy of meeting their various needs.

Maggie: We had very intense groups there and I was able to process a lot of difficult feelings. For the first time, I physically rescued 'little Tamie'. Dad yelled and screamed; I stopped breathing. They told me to breathe and that I could not leave her there anymore. I fought for my life and I saved her. My life has not been the same since.

Alice: we worked on healing childhood traumas. [...] she [therapist] would suggest i try something like being talking to myself (the little kid self) as a grown up telling myself id be ok, that i would take care of my little girl self whenever i would feel overtaken by my need to binge, burge [sic], control food...

d. Existing through Anorexia

In contrast to a sense of living, 'existing' was expressed as having an anorexic life determined by the preoccupations, obsessions and strict anorexic rules characteristic of anorexic thinking which greatly affected respondents' ability to live a full and 'normal' life. Participants expressed feeling controlled or consumed by the anorexic thoughts that governed their existence. This is interestingly described by Sue as a "death life", a term that clearly distinguishes between a 'normal' life without anorexia and a "death life" with anorexia. This state of existence can therefore be considered a middle ground between death and life, whereby the person is not quite living to the extent that they should be but not quite dead either. Furthermore, as detailed by Helen, the all-consuming nature of anorexia can leave a person feeling trapped by it and feeling unable to live a full life.

Sue: what role didn't Ana play in my life. It was the all consuming life (or death life that was my life). It consumed my thoughts, about eating, not eating, friends, no friends, controlling my environment, lying about what I did or didn't eat etc.

Helen: there were also times that I really wanted to go someplace or do something and the rules of my anorexia just wouldn't allow for that so I felt very trapped by it.

Living a life through anorexic rules and thoughts (existing) was considered to have a detrimental effect on a number of aspects of a person's life. So much so that Helen defines anorexia as: "*practicing anorexic behaviors to a degree that it interferes substantially with a person's life and the person becomes underweight.*" The effects on a person's ability to lead a 'normal' life and the contrast between living and existing are illustrated well by Naomi who expresses:

SW: Based on your own experiences what are your personal definitions of anorexia?

Naomi: The main thing for me though is when it becomes a way of life. When your eating disorder is put before family, friends, work, college or anything else of value in life, that's when I knew I had anorexia.

SW: From your own experiences, what would be your definition of recovery?

Naomi: For me this would be the flip side of what I defined anorexia as. When the disease no longer takes preference over the other things in life.

As discussed earlier, anorexia may serve a functional avoidance role and this is also described by Alice in the following extract. As can be seen this avoidance enables the person to "simply exist" implying that without emotional expression a person cannot fully experience "living". In the early stages of anorexia this avoidance is perceived as a positive role as it enables people to cope, but as stated by Cockell et al (2002) this can also be perceived negatively. This is implied by Alice whose use of quote marks suggests that actually anorexia does not help her deal and in fact this state of existing is not desirable. The idea of anorexia as functional avoidance will be discussed further in theme 3.

Alice: it seems pretty obvious to me now that anorexia AND bulimia both played the role of keeping me safe...keeping me above water...keeping my feelings just below the surface so that i could "deal" with simply existing.

Furthermore, 'existing' is tied up with the person's identity whereby living a life revolving solely around anorexia may cause some to adopt an identity based only on having anorexia. This experience thus has implications for self-acceptance as if a person sees their identity as based solely on their anorexia then they are not recognising their true sense of self. As can be seen from Ruth's example, anorexia

could be seen as a negative influence on her own identity that did not allow her to be herself:

Ruth: In the past it was a negative thing that took away from who I am. I was only able to get past this by turning weaknesses into strengths and pro-actively keeping a positive mindset when dealing with this issue.

D'Abundo and Chally's (2004) qualitative study of the experience of recovery discusses the circle of acceptance as an essential component towards recovery. This circle of acceptance involves the acceptance of others, the acceptance of spirituality (or importance of life) and the acceptance of the problem in order that self-acceptance can be reached. The experiences of participants lend support to this model. Theme 1 above has already highlighted the need to accept life, others and ultimately to accept themselves. However, before acceptance of these factors can occur a person must accept that their anorexia is problematic and this is the topic of the next theme.

Acceptance of Problem/Recovery

As described in the recruitment procedure (and in study 2) participants were unsure of whether 'full' or 'complete' recovery was achievable. Nonetheless, events in a person's life (usually centring on a life or death situation) lead to an acceptance that at least a 'meaningful' recovery should be attempted. Beliefs about recovery and beliefs about relapse could sometimes be problematic for the acceptance of recovery but motivation and a connection with other sufferers could be helpful. These ideas will now be discussed further under two subthemes:

- a. The "Light Switch" Moment
- b. Is full recovery possible? (Part 2¹⁴)

a. The "Light Switch" moment

The light-switch moment was a term used by participants in the online focus group to describe their decision to recover. This can be conceptualised as a light switch being

¹⁴ This subtheme revisits and builds on a subtheme of the same name in study 2.

turned on in their heads and relates to a change in attitudes about recovery. As Karen, the originator of the phrase says “*For me it boiled down to my deciding to get better. Like a light switch*”. This light-switch moment was often triggered by an event that could be interpreted as a threat to existence such as the recognition of the harmful effects of their anorexic behaviours or the realisation that they are not living their life to its full potential (see theme above):

Clare: The "light switch" moment for me was when I walked into my therapist's office one day and she told me that she was unable to keep working with me because my situation had gotten so serious.

Helen: As my physical condition worsened and it became clear, even to me, that things were nearing a life or death choice, I had to decide if I would continue my downward spiral by continuing to rely on my own ideas or take a blind leap of faith and give someone else a shot at running my life.

The recovery process is not always precipitated by this light switch moment and may be a “*slow and gradual*” process (Linda). As Sue describes, her light did not begin to switch on until she had become nutritionally stabilised and could begin to see a life for herself again:

Sue: In my instance, if I had waited for a light to switch on before I started recovery I would probably sadly no longer be alive.[...] But if I had waited to "decide" to recover until I wanted to - it may not have happened. The light really seemed to switch on as my refeeding had occurred and life returned to me.

Although effects on physical health played a role in accepting recovery, it is important to recognise that participants did not feel this was part of recovery or that anorexia was a physical disorder. Rather, physical consequences were seen as symptoms of the psychological disorder and something to be addressed before a more meaningful recovery targeting the areas discussed in theme 1 could be attempted.

Acceptance of recovery could be aided by the connection with others on the recovery path. Connection with others allows sufferers to recognise the benefits of recovery by showing them that a more fulfilling life can be achieved. It also allows them to see that they are not alone, that others understand their experiences and that recovery is

possible. Furthermore, connection with others who understand can provide the often-needed support and encouragement that many people need.

Helen: I found 2 people in that program who had similar histories with their eating disorders to my own and were in solid recovery. They had what I wanted.

Ann: One of the most beneficial things I have seen that works extremely well for sufferers is to be in touch with someone who is recovered. They get so much out of this conversation, they feel understood, inspired and it gives them hope that they can get better too.

As expressed by Linda, this connection can also come through reading books published by those who had previously had an eating disorder, *“Encourage reading of stories of other people with ED’s to help the person identify with someone else and realize that they are not totally alone.”* The experiences described by participants suggest that peer support groups and bibliotherapy can be useful ways of enabling sufferers to accept that their eating disorder is problematic but can be changed. Healthcare professionals may wish to offer such services to people especially during the early stages of recovery when motivation may be weak. Furthermore, the connection with other sufferers and the sense of support and hope may suggest a positive role for the use of pro-recovery support forums.

b. Is Full Recovery Possible? (Part 2)

As the recruitment process identified, some people with anorexia are unsure of what recovery means and whether a full recovery is possible. Despite this, some participants believed themselves to be fully recovered: *“I call myself completely and fully recovered because this is how I feel and what I am experiencing.”* (Ann), *“I consider myself recovered - I struggled with an eating disorder for 14 years of my life and I have been free from it for 5 years.”* (Maggie) and *“I am fully recovered.”* (Sue). However, as Ann expresses, she did not always believe in a full recovery

Ann: Individuals with eating disorders usually know that recovery exists and that there are people who managed to get out of it, but come up with all these reasons why everyone else can recover but them. I have come across this attitude many times and also had it once myself.

Some participants questioned whether full recovery was possible because despite making progress in many other areas of their recovery, they were still often plagued with anorexic cognitions. As Helen remarks, "*I believe that I will always be anorexic in a way because much of the thinking is very ingrained.*" Others believed that full recovery was possible but they had to remain alert to the situations that may trigger their eating disordered thoughts. This has implications for the meaning of recovery, where perhaps a full cognitive recovery is not an attainable goal and may not be perceived as an important determiner of recovery. Participants discussed the ability to manage or dismiss residual thoughts rather than act on them as an indication that they had reached some level of meaningful recovery.

Clare: I truly feel that full recovery is possible. That's not to say that the occasional eating disorder thought won't pop into one's head from time to time, but the ability to dismiss the thought and not act on it is indicative to me that full recovery is possible.

Sue: Full recovery is definitely possible. However we need to be wise about what traps we have previously fallen into.

Managing cognitions also goes hand in hand with relapse prevention. Participants described relapse prevention strategies that involved targeting cognitions and reminding themselves that their thoughts are a response to other factors in their life (not food and weight) and working on this instead of using food thoughts as a means of avoiding the situation.

Lyndsey: I have times when under stress where I worry about my body and calories more, but I can talk myself out of it by reminding myself that I am just stressed and it's not about the food.

Alice: when im feeling emotionally off, i dont turn to food / think about food to suffocate the feelings but i actually acknowledge how im feeling & why, if i can and work on the actual feeling.

The beliefs that people had about lapses and relapse also influenced the recovery process. As with study 2, participants discussed the inevitability of (re)lapsing. However, unlike some in study 2 who saw this as a deterrent to attempting to recover, participants here had a more positive attitude. For them, knowing that lapses

were inevitable and part of the process allowed them to move on. Unlike participants in study 2, lapsing was not seen as a failure but simply something to learn from:

Clare: Setbacks are bound to happen; learn from them and work thought [sic] them. As time progresses you'll be better able to sidestep setbacks. Each day gets a little easier.

As Ruth indicates, perfectionist beliefs (such are characteristic of anorexic thinking) can affect people's attitudes towards lapsing. This may explain the discrepancies between views held by those in study 2 who were still in the recovery process and those in this study who were much further along. Ruth suggests conceptualising eating disorders as "a set of behavioral patterns" which may be a beneficial suggestion for treatment. It is clear that beliefs about relapse should be targeted early on in therapy.

Ruth: Viewing an eating disorder as a set of behavioral patterns allows for slip-ups and errors along the way, so that it doesn't become yet another area to become a perfectionist - another way to "fail". (The concept of failing in recovery - it's a fear when you're in the disorder - that you won't ever be able to get out.)

Related to the uncertainty of whether full recovery is possible is the idea that a person may feel addicted to their behaviours. Participants in the focus group spontaneously initiated a discussion regarding whether anorexia can be considered an addiction due to the difficulty to recover. This discussion centred on three main areas. First, anorexia as *addictive* and therefore something that was difficult or perhaps impossible to fully recover from. Second, in contrast some discussed how anorexia was not addictive but *obsessive* or *compulsive*. Finally, the discussion explored anorexia as *addiction*, where participants drew parallels between the roles of anorexia and (other) addictions. This final area will be discussed in more detail later in this chapter (see theme 3, maintenance) as for now the focus is on the acceptance of recovery rather than the functions of anorexia.

For some participants, feeling addicted meant feeling out of control of their behaviours and feeling unable to stop them, this is considered a key criterion in addiction theory (Davis, 1996). Others, such as Fiona preferred the term, obsession to describe their experiences but nonetheless referred to the same feeling of being

unable to control or stop behaviours. These feelings suggest a low self-efficacy for change and thus it is unsurprising that participants felt unable to recover. The following run of quotes is an extract from the spontaneous discussion initiated by participants.

Alice: ive often wondered if eating disorders are like alcoholism in that "they" always say recovering or dry alcoholic, but always an alcoholic. are eating disorders like addictions?

[...]

Fiona: [A]norexia is more like an obsession, much like OCD, only the eating behaviours are the OCD behaviours. The illness starts off as perhaps "I'm going on a diet" and being in control, to all of a sudden the illness is in control, not you... and you feel completely helpless over your own decisions. Would you agree?

Sue: I think for myself the whole ED lifestyle and anorexic way of being was extremely addictive, the controls the secrecy the deceptions and the lies were all addictive. When I started to take the road to recovery it was very hard to let go of the "ways of the ed".

Some participants spoke of recovery as “giving up” anorexia. For example, “*I was not ready to admit that I had problem with alcohol and I was not ready to give up my eating disorder*” (Maggie) and “*I did not know if I wanted to give up my starving body because it was all I had to identify myself with*” (Linda). This language is interesting. Its use can be synonymous with that used when stopping other addictive behaviours, for example ‘giving up smoking’ or ‘giving up drugs’ and may illustrate the feelings of addiction towards anorexic behaviours. The use of “giving up” also connotes meanings of resolution as in ‘giving up chocolate for New Year’ or ‘giving up meat for Lent’. This resolution suggests a new start, whilst also signals a sense of motivation, determination and willpower. This idea of “giving up” demonstrates the nature of recovery from anorexia (and addictions) as changing a set of habits or learnt behaviours that may at times be considered positive. Thus, recovering from anorexia requires motivation to change.

Maintenance

This theme explores the experience of anorexia for those who have recovered, thus these experiences are retrospective. Nonetheless, this theme revisits many of the themes generated by those in the midst of the disorder interviewed in studies 1 and 2. As found in the previous two studies, participants' experiences of anorexia were characterised by its maintenance. For participants, anorexia was precipitated by some kind of crisis (either an identity crisis, emotional crisis or a combination of both) which at first could be alleviated through anorexia. However, as also seen in the other two studies, over time anorexia became seen as less of a solution and more of a problem. During this time, a number of reinforcing factors such as an anorexic voice, feelings of ambivalence, sociocultural reinforcement and unhelpful treatment experiences may serve to exacerbate, reinforce and sometimes replicate the original crisis and result in the maintenance of anorexia. This theme is split into three subthemes:

- a. Crisis
- b. Anorexia as solution
- c. Replication and reinforcement (of crises)

a. Crisis

Although participants all had different experiences and events that precipitated the onset of anorexia these all seemed to revolve around a type of crisis. Some had experienced an identity crisis that contributed to feelings of low self-worth and a wish to change their identity in some way. Others experienced an emotional crisis that resulted in the wish to shut down their emotions. For others still their crisis could be a combination of the two.

Often the identity crisis was a result of a transitional time for the person; a time where from that moment on they are no longer the person they were before the change. This change is often out of the person's control and thus the person may not feel ready for such a change to occur, resulting in crisis. A number of authors

identify how transitional stages such as puberty may precipitate this crisis (e.g. Bruch, 1978) and this was also iterated by a couple of participants in the current study, for example: *“i think my anorexic behavior started when i was 12/13, right around the time when i first got my period.”* (Alice). Although identity crises are normally discussed in the literature in relation to adolescent change, a number of participants discussed how middle age also caused them to question their identity. As Linda explains:

Linda: Then, aging does bring in new aspects of living, and maintaining recovery. There are natural changes that occur and I am finding this to be both interesting, sometimes challenging and frightening, and at other times freeing.

Karen describes how, for her, middle age was problematic, causing the same self-deprecating feelings to return: *“Just when I began to feel whole, boom, middle age hit and the same feelings of inadequacies came creeping back in.”* As Ali’s reply emphasises, this is because the bodily changes that occur are uncontrolled. Furthermore, these bodily changes (physical reminders of the change in identity) do not fit in with hegemonic beauty ideals.

Ali: But I completely agree with you, [Karen] that aging is both challenging and liberating. It's like adolescence, in that the body's aging process is involuntary and very physical, and really messes with our culturally-set notions of "beauty."

Sue’s eating disorder can also be interpreted as a reaction to a transitional period. Her anorexia began in adult life soon after the birth of her second child. Sue, who was suffering from postnatal depression, had also just moved to a new town with her husband who had a successful career. Sue’s parents were *“high achievers in their field”* and Sue *“felt the need to perform and be at least as good as mum”*. The birth of the second child can be seen as confirming her identity as a mother rather than a career woman especially as there seems to be a sense of jealousy regarding her husband and parent’s success. The move to a new town (especially one so focused on bodily appearance due to the beach location) that she feels she doesn’t fit into also affects her sense of identity. Now that Sue has recovered, she no longer feels a sense of crisis regarding her identity as now she recognises she *“just need[s] to be ME”*.

Sue: I was an adult woman of 24 with a brand new baby - suffering slight case of ante natal depression, we moved to a new town, and my husband

was in a position of prominence. It was a beach side community. My desire to fit in led me down the path of dangerous dieting, laxative abuse and eventually full blown anorexia, with starvation and purging. [...] She [her mother] was always on one diet or another, and also both of my parents were high achievers in their field. I felt the need to perform and be at least as good as mum -- when I know now that I don't need to be as good as mum - I just need to be ME. The perfectionistic behaviour patterns, and the dieting after my 2nd child when we were in a new role, and I felt the drive to FIT IN, led me on this path.

Just as not everybody exposed to the same cultural expectations of thinness will develop anorexia, not everyone going through transitional life stages (puberty, mid-life, motherhood) will experience an identity crisis. Thus, the identity crisis should be interpreted as a result of the negative self-schemata that a person holds about themselves. Cognitive behavioural theories posit anorexia as a result of negative beliefs about the self including a need for perfection, low self-worth and the over-evaluation of the self based on weight. It was clear from participants' responses that these used to be important factors in measuring their sense of self. As Linda's quote emphasises, her beliefs centred on ideas of ascetic austerity:

Linda: I considered becoming a nun with Mother Theresa, so that I would live without desires, including hunger. On my own I began to deny my own hunger signals. I felt extreme guilt and shame for eating every time I ate anything.

Emotional crises were experienced due to traumatic experiences (e.g. abuse, loss, sense of abandonment, or incapacity to express emotions) that left participants unable to process these often overwhelming emotions. As Maggie's quote below shows, this can result in the development of an eating disorder as a coping skill.

Linda: That same year my father announced to me, with no emotion, that my mother was going to die within 5 years, and he told me not to tell others about it. This began my secretive emotional life which within a year was extreme confusion, depression, anxiety, guilt and shame.

Maggie: My anorexia began @ age 12 or 13 - with restricting - a reaction to abuse in my home and also other sexual abuse. [...] My eating disorder had been so ingrained in my trauma and coping skills that I had to do a lot of trauma work to get better.

b. Anorexia as a Solution

Solution to Identity Crises

Theme 1 has already identified how during recovery an anorexic identity is considered to take away from a person's potential to be their own person. However, during the early stages of anorexia, this new identity can be considered a solution for the individual who before restricting their food did not even have an adequate sense of identity. This idea of anorexia as a solution invariably means that people view their behaviours positively and as something to maintain.

Jane: It gave me an identity when I didn't feel I had one - I made the illness into my friend, it made me feel like I had amazing will power and determination.

Lindsey: After awhile, being "eating disordered" takes on an identity of its own--it can be very hard to give up being the "best" at something if you feel so lousy about yourself that there is nothing to replace it.

As some participants expressed, food restriction gave them a sense of superiority, difference and power because they were able to do something that most others could not, restrict. In some ways these identifiers were seen as a solution to their identity crisis (e.g. giving them a sense of identity) and increased their self-esteem, as Helen says, "*I wanted to re-create myself into a different person because who I already was would never be good enough.*" However, as Naomi expresses these feelings may be short-lived as the "inner self-hatred" (negative self-schemata) still exists. Thus, a person may maintain behaviours as a way of achieving some positive aspects in response to the incessant low self-esteem.

Naomi: I walked around feeling as if I had discovered the secret to life and I even felt superior to others for my self control, not realising I was the real victim to the anorexia. It was odd because this superiority combined with an inner self hatred and lack of confidence.

It is unsurprising that participants used food restriction and weight loss as their way to change their identity given the sociocultural messages they receive about dieting and having a slim figure as a solution to their problems. As Helen's quote illustrates

many people believe that a “magical weight” can result in all kinds of benefits, although this is not reflected in reality:

Helen: I see it all the time that people think that their depression will evaporate once they hit some magical weight, social discourse will become easy, societal acceptance will be theirs, they will become economically successful, etc. So much magical thinking all linked to an arbitrary number (weight) that, once reached, is never quite the right number because those dream things don't materialize.

The meanings that participants ascribed to a thin body were numerous and often contradictory. These meanings ranged from a thin body being seen as unwomanly, nonsexual and childlike yet also attractive and beautiful, some participants saw having a thin body as a way of achieving some kind of acceptance from others whilst others believed that it would enable them to push people away and avoid them. Although these meanings were used by many of the participants, the following quote from Helen usefully sums up these contradictions:

Helen: Since I was sexually abused as a child, anorexia served in one way to remove signs of a woman's body from me, along with the adult roles and expectations that I thought went with that. Being an adult alone was a scary thought, but adding a sexual body into the equation was just too much. I thought of myself as "asexual." [...] On the other hand, I was also trying to make myself more attractive and desirable by becoming sheek thin. [...]I also used it to keep people at a distance while at the same time, I desperately wanted their attention.

The cultural representations of food restriction and thinness as acceptable for women in the cultures that these women were living undeniably reinforced their behaviours, whether they learnt these attitudes through peers, family members or simply through being in that cultural environment. As these quotes illustrate, this social acceptance normalises the behaviours further reinforcing the view that they are non-problematic:

Ann: I was in denial and thought what I was doing was "normal" (every woman/girl is always on a diet and you really get the impression that it is normal to not be happy with yourself).

Clare: I was a gymnast and everyone else was doing the same thing, so it didn't seem that abnormal.

Solution to Emotional Crises

As seen previously, anorexia was seen as a solution to participants' emotional crises and was perceived as a coping mechanism. The constant preoccupations with food and feelings of hunger served as an escape and distraction from the real problems in participants' lives. It allowed them to cope with their emotions by not having to deal with them. As these quotes exemplify, the functional avoidance role allowed sufferers to "simply exist", to feel invisible to the rest of the world. In the beginning, this was seen as a solution rather than a problem. However, as Linda's quote shows these feelings of safety and coping were an "illusion" as over time the harmful effects of anorexia become apparent.

Maggie: For me, the role of anorexia in my life was a metaphor for my real life. I felt invisible and neglected as a child and I started to disappear on my own. My anorexia started around 12 or 13. It was the way I learned not to cope with anything. My whole world revolved around eating, not eating, exercise, weighing myself, that there was little room for anything else. This was my core coping skill in my life that went on and off for 14 years.

Linda: For me personally...anorexia allowed me to actually believe that I was invisible...which gave me an illusion of being "safe" from harm because to be invisible meant that I really did not exist. This I understand now was how I coped with prolonged overwhelming traumas throughout my childhood and adolescence, and also into some years of my adulthood.

As described earlier, the functional role of anorexia as a coping mechanism caused many to draw parallels between anorexia and addictive behaviours. Behaviours can cause "highs" or numbing effects. These numbing effects allowed participants to cope with their emotions in a similar way that an addict may use drugs or alcohol. For example Naomi describes how *"I do think Eating Disorders are like addictions because I think behind all addicts is a lot of pain they are trying to numb."* As Helen, a participant who also had co-morbid addictions mentions how she often "used" her eating disorder in the same way she used drugs.

Helen: I spent much of my time either on a starvation high or numbed out from bingeing and purging- I was rarely feeling my feelings without some sort of filter. [...] When I was feeling depressed, the numbness that

vomiting gave me helped me not feel so much pain. My eating disorder was very much like a drug and I used it that way.

Anorexia was ‘used’ by participants as a way of solving their emotional and identity crises but over time this solution became recognised as another problem. However, as will be seen in the next subtheme other reinforcing factors meant that they still maintained these behaviours.

Clare: I wanted to use it to numb pain and solve my problems, but it was largely causing the pain and the problems and I was working not to use it anymore.

Ann: Anorexia was supposed to be my best friend, it was supposed to give me power and control, it was supposed to make me beautiful but all it did was make me feel worse about myself, it made me lonley and depressed, and even though I was slim and fit into small sizes, I still felt ugly...

c. Reinforcement and Replication (of Crises)

The Anorexic Voice

As seen in previous studies (Reid et al., 2008, and studies 1 and 2) although anorexia may initially give people a sense of control over their life over time it can become controlling. As Naomi says, “*I felt back in control of my life with the anorexia but of course it soon was in control of me.*” As the following two quotes illustrate anorexia can be experienced as a self-deprecating voice separate from a person’s sense of self. In study 2, this was interpreted as a cognitive mechanism for maintaining the person’s existing negative self-schemata as a way of maintaining anorexic behaviours. This can also be interpreted here, whereby the anorexic voice is described as constantly demanding the person to sustain behaviours. Even if the person does what the voice demands (lose weight) it does not give up and demands more. As Ann and Ruth explain, the anorexic voice can take over the person so that they find it difficult to differentiate their own sense of self from the disorder until they may no longer know their own self. This could further be interpreted as a replication of an identity crisis that caused people to develop anorexia in the first instance. Ruth, a former pro-anorexia website owner, relates the idea of the anorexic

voice to the personification of the disorder as 'Ana'. This idea will be further considered in chapter 8.

Ann: This voice is in your head, beating you up, all the time. It's telling you you are fat, you are ugly, you are worthless... and all kinds of negative things about you. It also tells you what to do and what not to do -- ie. don't eat this, exercise more. You start obeying this voice. [...] but no matter what you do, the voice is never happy. Even when you "obey", the voice always finds a way to still beat you up. (ie. you lost weight -- which is what the voice wanted you to do --- instead of saying "congratulations. you look good. keep up the great work. you look beautiful" it says thing like "well, you lost weight, but not enough. look at yourself, you are still fat." and so on) [...]The more an individual is lost in their eating disorder (the eating disorder has taken over so much, made them "blind" in a way) the louder the eating disorder voice is and the more quiet the "real" voice is, sometimes an individual is so much in their eating disorder that they don't hear their real voice anymore at all.

Ruth: This is one reason why the idea of Ana personified took off. It explained the voice inside which urged towards greater destruction that was somehow dissociated from an individual's self. A person argues with the self. A person argues with the disorder. A person doesn't know if the disorder and the self are the same, or if they are two separate things... but the disorder demands certain things that the person may or may not want to do but may do anyway out of fear. Fear of getting fat. Fear of failure. Fear of being alone. And so on.

Reinforcement of Crisis through Treatment

As mentioned above, unhelpful treatment experiences and upsetting encounters with healthcare professionals can serve to replicate participants feelings of crisis. As Eivors et al. (2004) found, this can serve to reinforce people's behaviours through treatment resistance or dropout. Jane's use of language in describing her experience of hospitalisation (based around that which may be used to describe a prison experience) illustrates the strong controlled approach employed. Words such as "accused", "forced" "use it as fuel" and "threaten me with sending me to a maximum security hospital" does not suggest a helpful therapeutic environment and it is unsurprising to learn that she soon dropped out. Jane recognises that this approach was informed by staff having a lack of understanding about the disorder.

Jane: As I was hospitalised in a mainstream general mental health hospital my behaviour was not understood by many of the staff - they

were at a complete loss and often accused me of 'acting out' or 'attention seeking' to my face.....or to my parents. I found it very hard in the general hospital because I was forced to sit in the dining hall when everyone was eating - even though it caused me obvious distress. If I did eat anything then the next day they would say 'well you ate a banana yesterday' and would use it as fuel to say that I was not eating just to be awkward. I think the staff were at a loss of what to do with me - they used to threaten me with sending me to a maximum security hospital.

People with anorexia already have low self-worth and a tendency to evaluate themselves on their restrictive behaviours and this should not be replicated in treatment experiences. After not hearing any news on the scheduled care she had been offered Naomi decided to contact her treatment service only to be told that she shouldn't "*be bothering them as they were busy people*" resulting in her feeling "*so angry and humiliated by this I vowed not to ask them for any more help*". Related to the need for treatment to foster self-worth, it is essential for this to focus on the (whole) person and not just the diagnoses that they present with:

Linda: I have so often felt completely invalidated or "erased" by professionals. I don't understand why they expect me to fragment myself into pieces in order to fit into their "definitions" of illness, "dysfunctions" and recovery. It goes against being a whole person, in my opinion to have to divide myself into parts: anorexic, trauma survivor with PTSD [...]

Furthermore and as discussed in detail in study 2, participants in the current study also described treatment barriers that affected the accessibility to appropriate services. Similarly, these accessibility issues centred on financial problems, waiting lists and a lack of appropriate services in the area. These issues caused de-motivation and exacerbation to sufferers and could therefore be considered factors in the maintenance of the disorder. These accessibility issues are exemplified in the following quotes: "*Then I finally had to stop counselling, as I had run out of funds to pay the counsellor. I felt deeply abandoned, and went into a severe depression again*" (Linda) and "*I live in a very rural part of **** and there are a notorious lack of services for any type of mental health problem in this area*" (Jane).

7.5. Study Summary

This study aimed to determine how those who had recovered from anorexia understood the disorder. Although participants' views of experiencing anorexia were retrospective, they still highlighted a strong theme of maintenance. As with the experiences explored in studies 1 and 2, anorexia began as a solution to the problems people had in their life and resulted in its continuation. However, eventually it became seen as problematic. Even when participants accepted that their behaviours were problematic there was often other strong reinforcing factors such as feeling controlled by an anorexic voice and unhelpful treatment experiences that meant it was maintained.

Nonetheless, acceptance of a problem motivated people to attempt recovery. This can be further facilitated through supportive relationships with family and friends, other sufferers (through a sense of connection) and with healthcare professionals. Acceptance of and by others can help people come to accept themselves which was considered the principle goal of recovery. Other goals included the uptake of alternative behaviours and coping mechanism to help in the expression and exploration of emotions. An ability to target any residual anorexic cognitions also contributed to a meaningful recovery and suggests the importance of relapse prevention strategies.

The study also aimed to understand perspectives of the recovery process. Recovery was perceived as a sense of 'living' due to increased social interaction and emotional expression a direct contrast to the state of 'existing' experienced whilst anorexic.

This study has important implications for the recovery process and the provision of treatment. From participants' perspectives it is essential for recovery to target self-acceptance (both spiritually and bodily), acceptance of others and from others, the exploration and expression of emotions through alternative behaviours and the ability to manage residual anorexic cognitions. Nutritional and weight restoration was not considered essential to the recovery process but as something that, in the case of emaciation, needs to be targeted before a 'meaningful' recovery can be attempted.

Chapter 8: Theoretical Implications

8.1. Introduction

The aims of this research were a) to determine the understandings of anorexia, recovery and treatment through participants' lived experiences and b) to identify how these understandings and experiences affected pathways to and through treatment. This was done by employing an online phenomenological approach to explore the understandings of those with lived experience of having anorexia. The research found that participants experienced anorexia as a process, not a state. To begin with it was considered as positive and something to maintain, but over time it developed into something negative to recover from. Thus, the anorexic process can be conceptualised as involving two areas; the maintenance of anorexia and the experience of recovery. These are referred to as 'areas' rather than 'stages' because there could be considerable overlap in time between the two areas and people could be oriented towards maintenance and recovery at the same time, or in a cyclical fashion. This chapter discusses these two areas by pulling together the results of the three distinct studies and discussing the implications for both theory and treatment alongside suggestions for future research.

As a reminder, this research consisted of three online studies with three distinct groups: those wishing to maintain anorexia and recruited from pro-anorexic websites (study 1); those wishing to recover from anorexia and recruited through their involvement in pro-recovery websites (study 2); and those who have recovered (study 3). As would be expected, participants differed in BMI and their levels of eating disorder psychopathology (as measured by the EDE-Q, Fairburn & Beglin, 1994). Those who had recovered had a higher BMI and lower level of psychopathology than those wishing to maintain. Interestingly, the groups also differed in age with those who wished to maintain their anorexia being on average seven years younger than those wishing to recover (means of 21.6 years and 29.1 years respectively). This lends support to the qualitative findings of the study where the experiences of anorexia was seen as a process where attitudes towards anorexia changed over time.

Summary of Findings

The experience of anorexia as initially positive and then negative was expressed by participants in all three of the studies and maintaining anorexia was a key theme throughout the project. Participants across the three studies described a number of cognitive mechanisms that worked to reinforce the maintenance of the eating disorder including: (1) pro-anorexic beliefs resulting from the egosyntonic and functional nature of restriction (which could sometimes be likened to an addiction), (2) the feeling of ambivalence and (3) the experience of an anorexic voice. Along with strong maintenance factors, participants in all three groups discussed other difficulties and barriers in the attempt to recover including other internal barriers such as motivation, denial of a problem and fears. Furthermore, participants described a number of external barriers including accessibility of treatment services (waiting lists, financial issues and lack of services) and negative experiences of treatment and healthcare professionals.

Studies 2 and 3 also focused on the experience of recovery and although there was some discussion regarding whether 'full' or 'complete' recovery was ever possible participants tended to agree on the factors considered essential in determining whether a 'meaningful' state of recovery had been reached. These include self-acceptance or self-discovery, the development of alternative coping methods and the healthy expression of emotions, an ability to deal with relapse situations and any residual anorexic cognitions and an ability to live a fulfilling and 'normal' life through interaction with others and social situations rather than previous attempts to avoid such events.

The research findings thus fitted into two main areas: the maintenance of anorexia and the experience of recovery. These will now be discussed further in relation to the implications these results have on the theory, treatment and future research into anorexia nervosa.

8.2. The Maintenance of Anorexia

Pro-anorexic Beliefs and the Concept of Ambivalence

Anorexia initially developed as a solution to emotional and identity crises. The resultant feelings played egosyntonic and functional roles. These included: an increased sense of identity, through the identity as ‘thin person’, ‘dieter’ or ‘anorexic’; increased self-esteem, through a sense of achievement and sometimes a sense of superiority; initial feelings of control; and an increased ability to cope, through the numbing of negative emotions. Thus, it is understandable that pro-anorexic beliefs add to the maintenance of behaviours. For instance, seeing anorexia as a positive role or, as Wolff and Serpell (1998, p.412) describe, feeling that without anorexia the person would not be able to cope or their “*whole world will fall apart*”.

Serpell et al. (2004) highlighted the need for more qualitative research to explore the perceived pros and cons of anorexia and to examine how these differed between those in the recovery process and those who were not. By employing a phenomenological approach and exploring the experiences of those wishing to maintain and those wishing to recover this research has contributed to the current gap in the field. This research has emphasised that the perceived pros of anorexia do not diminish between those who are recovering and those wishing to maintain. Although people wishing to recover accept that their behaviours are problematic, and recognise the cons, they still feel ambivalent about changing and hold pro-anorexic beliefs (e.g. that they need anorexia to cope/achieve a perfect self/control). It is only when those recovering recognise how illogical (or maladaptive) their beliefs are (e.g. anorexia has “consumed” their identity or that anorexia is in control of them) that they can begin to feel motivated to change.

Schmidt and Treasure (2006) suggested that pro-anorexic beliefs play a role in the maintenance of anorexia but state that there is little research to determine to what degree this may be so. The current research has indicated that these pro-anorexic beliefs are highly motivating. The egosyntonic and functional role that anorexia

plays means that is perceived as a 'guardian' (see also Serpell et al., 1999). For example participants across the three studies likened it to a friend that they could rely on when needed. This dependence on anorexia as a way of producing positive effects greatly affects its maintenance. In particular, participants in study 2 likened it to a 'crutch', 'rock' or 'handle' that they could depend on in times of need and it is this that motivated its maintenance (see page 193). Even when the negative effects of anorexia were identified, participants also held strong pro-anorexic views resulting in ambivalence and further motivating the maintenance of anorexia.

A person with strong pro-anorexic beliefs during the early stages of anorexia will not accept the help that is offered and will interpret attempts to change behaviours as misunderstanding, controlling and unnecessary (see Eivors et al., 2004; Gremillion, 2003; Rich, 2006). For example, Eivors et al. (2004) identified that when clients felt misunderstood and controlled by those around them they reasserted their feelings of control by dropping out of treatment. Similarly, ethnographic research conducted by Rich (2006) identified how feeling misunderstood by parents, teachers and the treatment team meant that participants sought understanding from other anorexics in the treatment environment and worked to maintain their anorexic behaviours and identity. Reiterating the views of previous authors (Mukai, 1989; Vitousek et al., 1998), healthcare professionals need to recognise that those with anorexia will not initially perceive it as a problem but as a solution. Without this understanding an effective therapeutic relationship cannot be achieved. Therapists need to work with the beliefs and values of their clients because without this they will undoubtedly resist the treatment plans that are offered. Therefore, motivational techniques such as those used during cognitive behavioural therapy are considered of benefit, especially during the early stages of care (Vitousek et al., 1998).

This research identified how sufferers' acceptance of a problem and motivation to change could be increased through the connection with others who were going/had gone through the recovery process. This connection with others served as recognition that if others were experiencing recovery it was possible that they could too, therefore often serving as the support and understanding that they needed. This

finding implicates the role for support groups (either community or electronic) and group therapy in the treatment of anorexia. Indeed, as seen in chapter 3, the main reason for accessing online forums pertaining to other physical and mental health issues is for the social support and ability to talk to others with similar problems (Malik & Coulson, 2008).

Support groups would need careful thought as a negative effect could occur whereby connecting with sufferers who also believe that recovery is not possible or beneficial at that time could increase motivation to maintain rather than recover. Participants in study 3 described how reading stories and being in contact with those who considered themselves to be recovered was especially helpful. Many of them were involved in ways of helping others by writing their own books, running their own websites, publicly speaking about eating disorders or through active involvement with eating disorders charities (and of course participating in this research which some felt was their way of helping others). This suggests a possibility for utilising bibliotherapy and peer support as a stepping-stone to treatment as another way of enhancing motivation for recovery. Future research may want to explore the benefits of peer support further.

Although anorexia initially began as a solution, over time it became problematic. Thus, participants reached a point when they began to feel ambivalent about their situation; seeing it as both positive and negative. Similar to recent findings reported by Reid et al. (2008), ambivalence encompassed a 'control paradox'. On the one hand, anorexia was seen as a tool for control and a way of coping with problems yet on the other it was seen as being in control of them. This 'control paradox' led to other areas of ambivalence including what role anorexia played in participants' life (tool, friend or disease) and whether anorexia should be maintained or treated. Participants used their anorexia as a tool to obtain a feeling of control but felt at times that the anorexia had taken them over and was in control of them.

Although evident throughout all three studies, the experiences of participants in study one in particular centred around a strong feeling of ambivalence. These

feelings of ambivalence are interpreted as a ‘double approach-avoidance conflict’ (Miller & Rollnick, 2002) where people feel both positive and negative emotions about both recovery and anorexia. Both options, continuing anorexia or attempting recovery have strong positive and negative aspects, causing conflicting emotions and therefore ambivalence.

Ambivalence was therefore considered a barrier to recovery, and a motivating factor in the maintenance of anorexia, as it can affect a person’s motivation to change their behaviours. The treatment team need to utilise their clients’ ambivalence by engaging them in discussion regarding both the pros and cons of anorexia (Vitousek et al., 1998). Again, this can be done through motivational interviewing techniques (Treasure & Schmidt, 2001) or as a component during CBT (Vitousek, 2002; Wolff & Serpell, 1998).

The Anorexic Voice

As mentioned above, participants experienced a control paradox. They felt that anorexia gave them a sense of control; something which they did not feel in other areas of their life yet at the same time believed that their anorexia was in control of them. The idea of anorexia as providing a sense of control has been well-documented in the eating disorder literature (e.g. Bruch, 1978; Fairburn et al., 2003; Malson, 1998) however, the experience of a ‘control paradox’ warrants further attention in future work.

Anorexia was thought to be in control of participants due to the ever-present anorexic cognitions and anorexic rules that governed their behaviours, identity and their life. Participants who had recovered (study 3) likened this experience to the idea of simply “existing” rather than living a fulfilling life, emphasising the extent to which they believed anorexia to be in control. When anorexia was thought to be in control it was experienced as another entity capable of motives and demands. This was often conceptualised by participants across the three studies as an ‘anorexic voice’, an ‘anorexic mind’ or another entity. Some participants described how at times this

anorexic voice became so strong that they were unable to separate their own sense of self from their anorexia. This also served to maintain anorexia as participants felt they were unable to separate themselves from the disorder.

Although a common experience described by participants across the three studies, this concept of an anorexic voice has not been readily discussed in the eating disorder literature and therefore this research offers an important contribution to the field. It may be that the online approach, as opposed to offline communication, allowed participants to feel comfortable in describing such experiences without feeling stigmatised. Bruch (1978) and Woodman (1982) have mentioned client's experiences of feeling "split" and feeling like they are controlled by an "other self" whilst Huebner (1993) has described a split between two minds; an 'addicted mind' and a 'healthy mind'. However, their descriptions of a separate self do not adequately theorise the experiences described by participants. Bruch (1978) suggested the other self was a representation of the parts of the self that the person disapproves of and may go some way towards explaining why participants externalised these thoughts. Woodman (1982) theorises the other self in psychoanalytic terms and as a representation of the "duality" between masculinity and femininity, however, these gendered themes were not captured in participants' descriptions. Finally, Huebner (1993) theorises the split as a result of an addiction to starvation, whereby the person becomes addicted to the endorphins released during starvation and their mind splits into an own mind and an addicted mind. This split, according to Huebner (1993) is a cognitive mechanism for maintenance.

This anorexic voice was experienced by participants as continuous, negative self-deprecating thoughts and interpreted by the researcher as an extreme representation of participants' existing negative self-schemata and thus, in accordance with some of Huebner's (1993) ideas, a cognitive mechanism of maintenance. The anorexic voice is interpreted here as an extreme representation of the sufferer's existing weight-related self-schemata. Participants described how they increased their behaviours as a way of trying to satisfy the voice. In line with the ideas of a negative self-schema (Fairburn et al., 1999; 2003; Vitousek & Hollon, 1990), the anorexic voice

encompassed aspects of the need for perfection, the need for control and low self-esteem. If a participant reached a goal imposed by the anorexic voice this was met with increased negative thoughts (further decreasing self-esteem), a new goal (suggestive of perfection) and the promise that if they continued their behaviours self-approval, perfection and control would be achieved.

It is suggested that these schemata become personified and externalised from a person's sense of self for a number of interlocking reasons. First, as a reaction to the increased nature of the negative self-schemata and increased demands for higher standards and goals in the pursuit of perfection that the person no longer recognises as their own thoughts. Second, through the recognition of the futility of the continuation of the behaviours since characteristically of a perfectionist attitude a solution can never be achieved (Shafran et al., 2002). Third, through an increased motivation to change behaviours the person develops a new and conflicting recovery schema that emphasises all the things the anorexic schema did not such as self-acceptance and an acceptance of life and health. The anorexic voice can paradoxically be interpreted as either a maintenance factor, through choosing to listen to the voice, or a motivating factor for change, through choosing to fight it.

Narrative therapy, a fairly new therapeutic technique, utilises the idea of an anorexic voice as a way of externalising anorexia as a problem separate from the person's sense of self (see Maisel et al., 2004). This technique does not work with the assumption that the person already experiences an anorexic voice but instead creates the idea as a therapeutic tool as a strategy to combat it. It is recognised that externalising anorexia may be problematic because it may remove a sense of ownership of cognitions or through emphasising a victim role (Gremillion, 2003; Vitousek, 2005). However, the fact that participants report a natural process of externalising their eating disorder suggests strong support for the uptake of narrative therapy. The principles of narrative therapy tap into many of the experiences described by the participants in the current research (especially regarding participants' experiences of an ambivalent relationship). It suggests that anorexia initially presents as a 'friend' or solution to ongoing problems, "seducing" the person

into believing its promises. The person then becomes imprisoned by the anorexia as they continuously try to meet the promises. One of the aims of narrative therapy is to reposition anorexia as an enemy or “murderer” and therefore to work against it (Maisel et al., 2004). As yet there have been no clinical trials of the efficacy of narrative therapy but the results of the current study suggest that such an approach may be promising and in keeping with sufferer’s existing experiences of having anorexia.

Pro-anorexia Websites

The results of the current research also suggest implications for the motivation to use pro-anorexia websites. Previous research has reported site visitors’ ambivalence about whether anorexia is a lifestyle choice or a disorder (Brotsky & Giles, 2007; Csipke & Horne, 2007). Others have reported how some users may use pro-anorexia websites for obtaining a dieting lifestyle whilst others believe they have a disorder but do not wish to recover (Mulveen & Hepworth, 2006). This ambivalence was also somewhat apparent in participants’ accounts whereby they saw anorexia as playing both the role of a functional tool (which could be likened to using anorexia as a lifestyle) and a disorder. It is therefore suggested that the over-simplified explanation (often presented by the media) of pro-anorexia as a lifestyle choice cannot be supported.

Previous authors have highlighted the anti-medical views of those using pro-anorexia websites, however, participants’ beliefs about anorexia as a disease, ambivalence about recovery and unsuccessful attempts at recovery do not support these views. The results from study one, and previous research (Williams & Reid, 2007) suggest that this is a result of not being motivated (ready) for treatment rather than being opposed to the idea.

Pro-anorexia websites often present the idea of ‘ana’ a fictional entity that they must obey to obtain their goals. This may sometimes be presented through religious metaphor through ana psalms and creeds that convey messages of control, starvation

and self-hate (Norris et al., 2006). This suggests some relation to participants experiences of an 'anorexic voice' or 'mind' which participants described as something that controlled them as they needed to live by its rules. This is highlighted by Ruth (study 3, see page 253) who describes 'ana' as a representation of the voice that many with anorexia experience. Indeed, Dias (2003) has previously related the personification of 'ana' to the ideas considered in narrative therapy.

The views expressed by those who have visited pro-anorexia websites, presented in the current thesis, suggests the motivation behind the creation of such sites is a way of replicating (and perhaps coping with) the experiences of anorexia by expressing their ambivalence, lack of motivation and experience of anorexia as a controlling separate entity.

Anorexia and Addictions

An important theme, and one not yet fully considered in qualitative research, was participants' descriptions of anorexia as addictive. Many of the participants described a relationship between their experience of anorexia and the experience of addiction for two key reasons. First, because of the role anorexia is thought to play in enabling the person to cope or avoid certain situations participants felt this was synonymous to the role an addiction plays. Second, participants related the difficulties in defining and reaching recovery from anorexia to perceived difficulties of recovering from an addiction.

The relationship between anorexia and addictions is currently under-researched. Various authors have recognised similarities between the two by mapping the key criteria for addictions onto the experiences of eating disorders (Garner & Gerborg, 2004; Hammersley & Reid, 2001; Smukler & Tantem, 1984) whilst others contest that certain biological factors associated with addiction, such as craving, tolerance and withdrawal, are missing in the experience of anorexia (Klein & Walsh, 2004; Wilson, 1999). As in the literature, there was some contention amongst some participants regarding the relationship between anorexia and addictions. Some

participants vehemently argued that anorexia was an addiction, some simply believed they were 'like' addictions and used this analogy as a way of explaining their experiences and others believed that anorexia could not possibly be an addiction. Those who argued against anorexia as addiction cited the inability to abstain from food and the fact that they were more like "obsessions". However, both ideas of anorexia as addiction and as obsession focused on the lack of control over behaviours; a key criterion in the experience of addiction (Davis, 1996).

Due to the similarities between addictions and anorexia found in study 1 the researcher added a question to the pre-study questionnaire asking people about their anorexic behaviours and then asking if they have "*ever felt addicted*" to these. The results of all those who answered the pre-study questionnaire are presented in the relevant chapters. Although there are methodological concerns with these results (for example, a small sample size (n=29) and the fact that the question is not based on existing addiction literature) the results are nonetheless informative.

It is interesting to note that half of those who filled in the questionnaire also reported co-morbid self-harm behaviours (n=15), with 12 of these reporting "feeling addicted" to these behaviours. This relationship between addiction, self-harm and anorexia may reflect the level of impulsivity of such behaviours (Svirko & Hawton, 2007). Svirko and Hawton (2007) explored the association between self-harm and eating disorders and found that binge/purge types (bulimia and the binge/purge subtype of anorexia) are linked with other impulsive behaviours such as self-harm, substance abuse, sexual promiscuity and kleptomania. Interestingly, eight of the twelve participants who reporting feeling addicted to self-harm also engaged in bingeing behaviours. Further research should further investigate the relationship between self-harm, anorexia and feelings of addiction.

In total 17 out of 28 of the participants reported a feeling of addiction to the strict dieting of anorexia. Even if anorexia does not fit with an addiction model, the very fact that people 'feel addicted' must be recognised. This research suggests that 'feeling addicted' to anorexia may be an important influence on the effects of

recovery or treatment and needs to be acknowledged in therapy. Perhaps those involved in the treatment should check for these attitudes in the early stages of care and tailor approaches appropriately. For example, those who do 'feel addicted' may benefit from a heavier focus on motivational techniques. Furthermore, these beliefs about being addicted can be targeted through cognitive behavioural approaches by targeting unhelpful cognitions. Support groups exist for eating disorders based on the 12-step approach for alcoholics (e.g. Eating Disorders Anonymous, EDA and Overeaters Anonymous, OA). However, twelve step approaches work on the philosophy that someone will be in recovery for the entirety of their life and so could be problematic in motivating people to change. Furthermore, OA can be criticised for its promotion of abstaining from certain foods which may only serve to maintain the eating disorder (Wilson, 1999).

At present, there is limited empirical research into the relationship between addiction and anorexia. However, participants' experiences seem to fit with Orford's (2001) social-behavioural-cognitive-moral model of excessive appetites. In particular, anorexia serves a number of functions, including one of modifying mood, which are positively reinforced and maintained. A link between anorexia and addictions based on an avoidance function has also been presented by other authors (Brumberg, 2000; Huebner, 1993). Furthermore, anorexia is perceived as important, people experience preoccupations with their behaviours and the negative consequences causes feelings of ambivalence. People with anorexia need to be motivated to change and may experience episodes of relapse. Further research should explore the relationship between addictions and anorexia in more detail. For example, a study comparing the phenomenology of the roles that anorexia may play for the person with anorexia and the roles that alcoholism or drug use may play for the person with an addiction may determine the similarities and differences between the perceived functions of both behaviours. Another study may wish to ask those with co-morbid alcoholism or drug misuse and anorexia about the roles each may play in the life.

External Barriers to Recovery

External barriers to recovery included those areas outside of the person's control that were detrimental to the recovery. A small number of participants described how a lack of understanding about anorexia from family and friends might have affected the recovery process suggesting a role for the need for interventions that may increase these understandings in significant others. However, the main external barriers to recovery related to the understandings of healthcare professionals and service providers and focused on the treatment experience or the inaccessibility of services.

Unsuccessful and inadequate experiences of treatment can be damaging to the person with anorexia, exacerbating their anorexic thoughts and behaviours (see for example, Elkins, 2000). Research into general practitioners' experiences of caring for those with eating disorders in the UK has highlighted their lack of confidence and competence in recognising if a person has an eating disorder (Reid, Williams & Hammersley, under review). Reid et al. (under review) found that the lack of recognition is a result of both the professional's experience and the repudiation of a problem from the patient. The results of the current research expands this, suggesting that a lack of recognition from a family doctor is an international problem. In particular, one participant (Ruth) told how even when they reported severe weight loss, purging behaviours and feeling unable to stop exercising to the doctor this was not recognised as an eating disorder because she was still within a normal weight range. This is an unacceptable response and left Ruth feeling invalidated as a person.

Inadequate treatment experiences served to exacerbate anorexia. Sometimes the treatment experience may replicate the situation that triggers an anorexic response and this was evidenced throughout the three studies. A lack of validation and recognition from a healthcare professional can reinforce the person's negative view of themselves. An overly controlled, monitored and forceful environment could be humiliating for the person further lowering self-worth and feelings of lost control.

Treatments that focus too heavily on food and weight can reinforce the anorexic behaviours and may tap into fears of weight gain and lack of control.

Conversely, treatment experiences that were perceived positively could foster participants' self-esteem and support the recovery process. The most successful therapeutic relationships were experienced when a person believed their therapist genuinely cared for, and respected, them. Feeling validated and listened to was considered an essential part of the therapeutic relationship and encouraged self-acceptance, a key component of the recovery process. Treatments that were collaborative and focused on participants' own beliefs rather than imposing ideas onto them seemed most effective. It is also important, as participants consistently alluded to, that just as the onset of anorexia is individualised so too must be the recovery process. Treatment approaches that work with some will not work with all patients and each treatment plan should be tailored accordingly. However, all of this may be unimportant if a person cannot even access treatment services.

Participants in studies 2 and 3 described a number of issues relating to the accessibility of services including financial issues, the lack of appropriate services and long waiting lists. This was an international study interviewing people mainly from the USA, Canada, the UK and Australia. Participants from all four locations as well as the minority from other places (Spain, India and Romania) reported issues with accessing treatment services. Service provision for anorexia can thus be considered a global problem.

In the USA and Canada, financial issues arose because the health system requires that patients have to pay towards treatment and health insurers did not recognise all eating disorders as a health problem that they would pay towards treating. Financial issues in the UK arose when inefficient care had been provided by the National Health Service and thus participants had turned to private practice. Research looking at health services in the UK (Royal College of Psychiatrists, 2000, p.16) highlights "*spending on eating disorders is grossly inadequate*". The lack of funding for eating disorder services has knock-on effects on the staff training, staffing levels and the

referral processes of services, meaning patients do not receive the level of appropriate care that they need (Reid, Williams & Burr, under review). Patients can choose to use private care, which can offer a better quality of service but this is dependent on a patient's ability to self-fund. The results of this study suggest that funding issues are a major, global problem in the provision of eating disorders and highlight the need for health providers to be made aware of service needs.

Some participants described how a lack of inappropriate services in their area led to them having to move long distances that meant leaving a potential support network of friends and family that would otherwise have aided the recovery process. Participants in all locations also described having to wait for treatment, either because of long waiting lists or because they were waiting for the appropriate funding. The results above discussed the motivational issues in the acceptance of needing to recover from anorexia. Motivation for change can be fragile and sometimes interlinked with feelings of ambivalence. One participant, Jon, took part in an interview whilst on a waiting list for treatment and it was evident through his extracts that his motivation for change declined throughout this waiting process (see study 2). Jon also described how being on a waiting list led to a feeling of lost control over his situation and an increased need for anorexic behaviours, though he was trying to resist this by connecting with others through online support groups.

With these problems in accessing services for eating disorders, it is no surprise that people turn to the Internet for information and support. Chapter 3 has reviewed the literature on support and therapy resources online. Online support groups can provide users with much-needed social support and a form of coping (Malik & Coulson, 2008; Tanis, 2008). E-therapy has been considered of particular benefit when areas cannot provide the resources that sufferers need (Schmidt, 2003; Williams, 2003) and may serve as a first step when people are waiting for face-to-face treatment and can reach hidden populations who do not usually present for care (Schmidt, 2007). One important advantage of the use of online resources for support and therapy is the 24-hour, immediate nature (Alleman, 2003; Finfgeld, 2000). Online interventions therefore seem particularly appropriate for those with anorexia for a number of

reasons. First, the immediacy of access can be of benefit for those displaying ambivalence or low motivation to change. Second, it can offer some form of intervention for those who cannot afford traditional face-to-face therapy or who are on a waiting list. Third, the internet is not geographically restrictive and can offer those with limited appropriate services in the area access to some kind of service without having to leave their offline support network. Finally, for health providers, online interventions are cheaper to run (Williams, 2003) and thus by providing an online service they may be able to reach a greater proportion of those who need care.

Online interventions are being tested for those with bulimia and the family and friends of those with anorexia, with initial results appearing promising (Schmidt, 2007). However, as yet there seems to be no online interventions provided for those with anorexia. It is recognised that those with anorexia may be considered more of an “at-risk” group as they may reach dangerously low weights which may cause some to shy away from the idea of providing services virtually. However, given the reasons above and the fact that many with anorexia already utilise the internet for reasons of support it would be practical for future research to examine the efficacy of online interventions. Ideas to consider include investigating the efficacy of an online peer support system, self-help interventions based on CBT or a more interactive program between therapists and clients.

8.3. The Experience of Recovery

Researchers have questioned what constitutes a full recovery from anorexia (Bachner-Melman et al., 2006; Jarman & Walsh, 1999), however a more important question for the participants in this study was whether full recovery was even possible. One participant in study 3 even spontaneously posed this question to the rest of the group for discussion. Participants in the studies had different views on this issue with some believing that it was possible, as evidenced by their own experiences, others believing recovery is achievable but that they would always have to remain alert to situations and thoughts that may trigger a relapse. Others still, especially those who had experienced ‘twelve-step’ meetings (alcoholics anonymous, overeaters anonymous, eating disorders anonymous) or felt that they were addicted

to anorexia believed that they would always be anorexic in some way. Drawing analogy with alcohol research (Valliant, 2003) this belief was often based on the belief that a person may potentially relapse.

As yet, lapsing or relapsing is not readily discussed in the qualitative literature. Beliefs about lapses and relapses were important for a number of participants who believed that lapsing was an inevitable part of the recovery process. However, this should not be seen as problematic because if the person has the right attitudes and tools for dealing with the lapse this would not result in relapse. It is important for those with anorexia to recognise the potential for lapsing early on in the treatment to allow them to be prepared for this situation. Equally important is how the message about the inevitability of lapsing is conveyed. Clients must be clear that lapsing does not mean a failure (especially given their strong perfectionist tendencies) or a return back to anorexia but should be taught that a lapse is merely an indicator that other areas of their life (other than food or weight) needs to be worked and acted on. This has clear implications for the use of relapse prevention strategies in the treatment of anorexia. Treatment programmes such as CBT (Fairburn & Wilson, 1993) include sessions on relapse prevention near the end of a course of therapy. More useful, would be the exploration of client's attitudes towards recovery and relapse throughout the course. Participants in studies 2 and 3 described lapses as an inevitable part of the recovery process. However, the ability to see the lapse as a sign that something else in their life needed addressing (e.g. stressful emotions or a sense of lost control over an aspect of their life) was important in ensuring the lapse did not turn into relapse. This implies that clients need to be aware of the potential for lapse and be prepared to see it for what it is. In line with Jarman and Walsh's (1999) questions about what constitutes recovery, it would appear that having the ability to deal with lapses or situations that may trigger lapses is one sign of recovery.

The current research identified that a key component in the uptake of recovery and the motivation for changing behaviours was the acceptance that anorexia was problematic. This often came from a life or death situation where, faced with the idea of their own mortality because of anorexia, participants acknowledged the need to

change. Motivation was a key theme throughout the three studies. Participants often spoke of times when they did not feel ready to recover, did not want to or did not feel they were able to. There seemed to be, underlying the motivational issues, a sense of fear; whereby a fear of weight gain and fears of control being taken away led to a fear of recovery. Thus, sufferers understandably were not willing to give up their anorexia. These fears would need to be addressed if motivation were to increase. Furthermore, self-efficacy, or the belief in the ability to change behaviours was often linked with the length of time that a person had been experiencing anorexia, where over time behaviours became habitual and often seen as 'normal'. This lends support to suggestions that the earlier recovery is attempted the more successful it will be (NICE, 2004). Treatment for anorexia is often characterised by resistance and drop-out which can be interpreted as a culmination of low motivation to change and a lack of understanding (of clients' ambivalent and often positive views of anorexia) from healthcare professionals.

Clinical definitions of recovery range from reaching a physically stable weight to reaching cognitive and behavioural recovery and to date there is no clear definition of when recovery is reached (Bachner-Melman et al., 2006; Jarman & Walsh, 1999; Kordy et al., 2002). Not one of the participants in the study defined recovery in terms of weight. Many acknowledged the importance of physical health and nutritional stability but did not believe this contributed to recovery. Rather, this was something that needed to be dealt with before any significant recovery could be started. Participants often described how even if their weight improved they still experienced continuous cognitions regarding weight loss. Anorexia (and thus recovery) was therefore about cognitions and behaviours rather than physical weight, one participant even described weight loss as simply a "side-effect" of psychological problems. Thus, recovery needs to centre on rectifying maladaptive cognitions and behaviours. This is important to consider given the propensity for recovery to be measured by physical outcomes (APA, 2006; Jarman & Walsh, 1999). According to the current research, recovery comprised of four key factors:

1) The acceptance of self and others

This involves developing an adequate sense of self that is not determined by perfectionism, self-denial or the belief that a thinner body would lead to a better self. In relation to cognitive behavioural theories (Fairburn et al., 1999; Wolff & Serpell, 1998; Vitousek & Hollon, 1990), this may mean changing deeply set cognitions about the self (or negative self-schemata). This involves the recognition and gratification of needs, recognising that perfection is unattainable and acknowledging that a thinner body will not solve their problems. For some, as described above, their sense of self may be entwined with their identity as an anorexic and self-acceptance for them may involve the separation of their sense of self from anorexia. For these people, aspects of narrative therapy (Maisel et al., 2004) may be useful.

Acceptance of and from others will also aid in the acceptance of self in a reciprocal relationship. Unconditional love and acceptance of a true self from another will help the person adopt the same attitudes towards themselves whilst allowing others to see a true self suggests an element of acceptance for that self.

2) The development of healthy coping mechanisms

Developing healthy, alternative behaviours in place of maladaptive anorexic behaviours was considered essential. For many, anorexia and the sense of control it gave helped them to cope with life. In line with ideas of 'functional avoidance' (Cockell et al., 2002) anorexia enabled participants to avoid negative emotions, situations and relationships. The importance of developing healthy coping mechanisms is particularly evident in participants' descriptions of stress as a key relapse predictor (in particular, see study 2). Part of recovery also involved learning to explore and express emotions in healthy ways (e.g. through writing, art and communication with others).

3) The ability to dismiss or deal with residual anorexic cognitions.

Although some felt that a full recovery could be gained others described how they will always experience residual anorexic cognitions. Therefore, participants described how part of recovery was the ability to work on any residual anorexic cognitions and to see them as a sign that other areas in their life needed attention. This further lends support to the suggestion that a greater emphasis on relapse prevention is necessary. This also has implications for the definition of recovery which may not necessarily mean full cognitive recovery.

4) Living a 'normal' life

The three areas mentioned above, coupled with an acceptance of life means that an overall meaning of the recovery process is the ability to live a "normal" and fulfilling life.

With no accepted definition of recovery some researchers have recommended the use of client's own meanings of recovery to be utilised (Bachner-Melman et al., 2006; Garret, 1998; Jarman & Walsh, 1999). The meanings of recovery identified in this research are qualitatively different from clinical definitions of recovery which tend to relate to the diagnostic criteria. These findings are similar, and lend support, to the ideas presented by Garrett (1998) and D'Abundo and Chally (2004), confirming the need for recovery definitions to utilise clients' own meanings. In particular, participants' experiences of recovery highlighted supported D'Abundo and Chally's (2004) circle of acceptance whereby the three areas of accepting the problem, accepting others and accepting life contributed to the overall acceptance of the self. Further research should explore how these meanings can be integrated into clinical understandings.

8.4 Conclusion

Anorexia is a highly motivating disorder. The functional and egosyntonic roles that anorexia plays mean that initially it is perceived as a solution to sufferers' crises and problems. Thus, these pro-anorexic beliefs served to maintain the anorexic behaviours. Over time, anorexia becomes problematic but strong psychological and social factors result in further maintenance. Participants' experiences were characterised by overwhelming ambivalence about whether anorexia was a solution or a problem, a tool for control or something that controlled them, and whether it was something to maintain or recover from. This ambivalence suggests a role for motivational techniques, such as those used in CBT or motivational interviewing in the treatment of anorexia.

Anorexia can be experienced as addictive and this should be recognised by those involved in its management. In particular, anorexia shares aspects related to psychosocial theories of addiction where perceived positive functions, reinforcement of behaviours and low motivation to change and ambivalence ensures its maintenance.

One of the most striking findings of the study was participants' experiences of an 'anorexic voice'. This experience was interpreted as a cognitive mechanism of maintenance through the reinforcement of the person's existing negative self-schemata. This voice was a gross representation of the person's existing negative self-schemata (conceptualised as low self-esteem, need for perfection and self-denial). Participants experienced the voice as a barrage of persistent self-deprecating thoughts and demands reinforcing the need for continued weight loss. Every time a goal weight was achieved, the 'anorexic voice' demanded that they needed to do more. Participants across all three studies described experiencing this voice despite this being an uncommon theme in the eating disorder literature. This voice was seen as a way of externalising these self-schemata so that they were seen as belonging to a separate entity. Narrative therapy techniques may thus be useful for those who have experience of an anorexic voice as a method that taps into their own views and experiences.

Recovery from anorexia needs to focus on cognitive, behavioural and social aspects of anorexia rather than physical aspects. In line with cognitive-behavioural approaches, it is suggested that therapy needs to focus on maladaptive cognitions and behaviours. This includes: targeting sufferers' motivation to change behaviours; addressing maladaptive cognitions regarding anorexia (e.g. the idea that it is positive and the idea that it is an addiction) and the self (body image, self-denial, and perfection); promoting helping relationships outside of the treatment setting, enabling social recovery; developing alternative behaviours for expressing and dealing with emotions. Relapse prevention strategies, to enable the person to deal with residual cognitions, also need to be developed. Healthcare professionals need to remain aware of the views and experiences of their clients in order for an effective therapeutic relationship to be established as by validating the clients' experiences, therapists can foster self-acceptance; the key goal of recovery.

In conclusion, the experience of anorexia is highly motivating. This experience includes strong pro-anorexic beliefs and ambivalent attitudes (about anorexia, control and recovery). A person may also experience an anorexic voice (a cognitive mechanism based on existing negative self-schemata) and/or a feeling of addiction. All of these experiences serve to maintain the disorder.

Meaningful recovery from anorexia requires a psychosocial process and is characterised by acceptance. The principle aim of recovery is self-acceptance which is fostered by acceptance of and from other people, an acceptance of life and an acceptance of, and exploration of emotions.

9.1. Introduction

The purpose of this chapter is to provide a reflexive and reflective exploration of the three online studies. Therefore, as this chapter will be looking at my own experiences of conducting the research it makes sense for me to write this chapter in the first person. As I have discussed throughout the thesis, IPA is concerned with a meaning-making process co-created between a researcher and their participants through a double hermeneutic approach (Smith, 2004). Although, I have presented my own interpretations of participants' experiences in the preceding chapters I have purposely left much of my own subjectivity out of these discussions. This is because I have not wanted to deflect away from the experiences that participants have described, as it is their experiences, not mine, that we are interested in learning about. However, many qualitative researchers have identified the need to recognise the role of the researcher in the research process (Finlay, 2003, 2008; Smith, 2007; Willig, 2001).

Through this chapter, I will be bringing together my experiences of conducting research in the online environment with people who discussed, in often frank and detailed ways, their experiences of living with anorexia nervosa. This chapter explores my experience on a number of personal, practical and epistemological levels. I will be exploring how I have informed the research (and how the research has personally informed me). I will also be considering my practical experiences of actually conducting the research and my experience of moving the traditional phenomenological approach into the online environment and the epistemological implications that this may have.

Willig (2001, p.10) suggests that there are two types of reflexivity, a personal reflexivity and an epistemological reflexivity. Personal reflexivity involves exploring both how we have informed the research and how the research informs us “*by reflecting upon [...]our own values, experiences, interests, beliefs, political*

commitments, wider aims in life and social identities". In a similar vein, it is also important to recognise that the research process will also have an effect on the participants involved in the research (Nicolson, 2003) and this will also be examined. Epistemological reflexivity involves reflecting on how the ways we have conducted the research have influenced the findings, such epistemological questions posed by Willig include:

How has the research question defined and limited what can be 'found'?
How has the design of the study and the method of analysis 'constructed' the data and the findings? How could the research question have been investigated differently? To what extent would this have given rise to a different understanding of the phenomenon under investigation?

(Willig, 2001, p.10)

These forms of reflexivity will be drawn upon in this chapter. Furthermore, in this chapter I will also report on the practical implications of the 'online phenomenology' methodology. Thus, this chapter explores four areas, divided by subheadings: epistemological reflexivity, practical reflexivity, personal reflexivity and participant reflexivity. However, it would be impossible for me to discuss these separately as many of the issues interlink and some of the discussions fit within a number of subheadings.

9.2. Epistemological Reflexivity

Phenomenological research requires the researcher to 'bracket' off their pre-existing conceptions regarding the phenomenon under investigation to allow new interpretations to come from the participants' lived experiences whilst also acknowledging their own fore-understandings (Finlay, 2008; Smith, 2007). Smith (2007), drawing on his own research experiences and the hermeneutic ideas of Gadamer and Heidegger, acknowledges that often the researcher may not be aware of their preconceptions until they have been involved in analysis of participants' experiences. He also notes that although this encounter with participants makes clear the researchers' fore-understanding this is only "fleeting" as the researcher now begins to construct a new understanding with the new details provided by the participants (Smith, 2007). This was true in my experience of the current research.

Before the project, I had no particular stance on eating disorders. I understood from my previous research (Williams & Reid, 2007) that anorexia could be perceived as a functional and important aspect for some who experienced it and that although eating disorders were perceived by healthcare professionals as a disorder in need of treating these ideas were often not reiterated in those experiencing it firsthand. Yet, this was about as far as my understanding went. My understandings have certainly grown from the encounters I have had with my research participants. Although I had done the required reading before carrying out the data collection, it was not until I analysed the data that I could understand what previous authors were saying. I needed to go back to these texts and re-read them with new insights. I was able to better criticise other's interpretations once my own interpretations began to take shape.

I would certainly not consider IPA a linear, prescriptive process. Analysis of each group was different but followed the same general guidelines set out by Smith et al. (1999). For example, the steps taken in analysing study two were manifold, first looking at each individual transcript both from participants' meanings then with my own interpretations. Yet, when I came to write up these findings it appeared that my interpretations were lacking and constructed only as a re-writing of participants' own words. Whilst analysing the accounts I could tell that there were themes that I could not name or theorise but nonetheless I knew they had meaning. These themes (particularly the idea of an anorexic voice) were extremely limited in the existing literature, especially in the context in which participants used them. As such, I had no fore-understanding of this phenomenon, thus, by allowing the insights of my participants to be explored it allowed my own interpretations to be formed.

This experience may well be understood as a hermeneutic circle where as Smith (2007, p.5) explains, “[t]o understand the part, you look to the whole; to understand the whole, you look to the part”. The understanding of the researcher can be informed by the understanding of the participant; the understanding of the participant can be informed by the understandings of the researcher (Smith, 2007). The

participants' explanations of an anorexic voice caused me to begin gaining some (limited) understanding of the experience and then start asking questions of it (what is the anorexic voice?). Deeper analysis of the participants' meanings provoked even more questions (what is its function? Why and how does it manifest?) A break from analysis to survey the literature did not inform my understandings as well as hoped and left me with even more questions about the experience of the anorexic voice. For example, how can the voice be explained? Psychoanalytically as male/female traits (c.f. Woodman, 1982)? As a result of starvation and linked to gender (c.f. Bruch, 1978)? As an externalisation technique (c.f. Maisel et al., 2004)? As a metaphor for a battle between the body and mind? or as cognitive function due to addiction (c.f. Huebner, 1993)?) Even deeper analysis of the participants' meanings with some of the understandings gained through reading allowed me to form my own interpretation of participants' experience of the anorexic voice. This interpretation saw the voice as a cognitive function, not as a result of addiction, but as a way of reinforcing the person's negative self-schemata as a way of maintaining behaviours, which becomes externalised when the cognitions become so extreme as to no longer be recognised as their own.

Reading the literature the first time round provided some background to anorexia but it was not until I had heard from participants themselves that I could put meaning to these previous conceptualisations and begin to form my own. This is surely an example of reflexive co-research between the participants and myself and must have some importance on the participants' being experts and that qualitative research affords a deeper understanding than I may have first thought. If this research had used a quantitative approach such levels of interpretations would certainly not have been found.

Online research with its reduced power relationships allows for more of a co-research approach rather than a traditional interviewer/interviewee relationship allows (Fox et al., 2007). Furthermore, as described by Fox et al. (2007) the online approach allows for participants to feel more in control of the research process and this is obviously of benefit for those with control issues such as experienced by those

with anorexia. Watson et al. (2006) reported that participants in their online study often provided serendipitous data, for example references to a diary entry and a mini survey. Similarly, participants in this study also provided unexpected data: Kim sent a timeline done during therapy to me by international mail. Maggie posted extracts in the online focus group from an essay that she wrote during recovery. Helen sent me some articles of studies that had helped her with her recovery and provided stories and quotes from the Alcohol Anonymous Big Book. Ruth sent me links to some radio shows that she had recently participated in and invited me to ask questions. Again, this can be interpreted as co-research between participants and me. Undoubtedly, this unanticipated data informed the research and illustrated areas of experiences thought to be important by participants who wished to share this information with me. I wonder whether such opportune data would be gleaned from offline research or whether this would be possible in a synchronous, face-to-face environment without such materials to hand.

The study aimed to answer two overarching research questions (1) how do people with different attitudes and at different stages of experiencing anorexia understand anorexia and the recovery process? (2) How might these understandings affect pathways to and through treatment? A phenomenological approach was used to illicit individual meanings as this aims to get closer to participants' own experiences.

The use of a phenomenological approach has allowed for issues of importance to the participants to be explored at depth. By allowing the participants to tell their own stories of their experiences of anorexia, recovery and treatment new insights about these experiences have been formed. A quantitative approach would not have allowed important and complex issues such as overwhelming ambivalence, experiencing an anorexic voice and feeling addicted to anorexia to be identified. Furthermore, by using a phenomenological approach, participants' own definitions of what it means to have anorexia and then recover have been identified. These are qualitatively different to clinical understandings and would not have been found if measures based on clinical understandings were used. This suggests a role for qualitative research in informing both clinical understanding of what it *actually*

means to have anorexia and then recover from it and the role of qualitative research in the development of quantitative measures. Although this study is based on the individual experiences of only 43 participants, some of the results support previous qualitative findings and it may be feasible for future research to pilot measures based on these findings. In particular, I would suggest piloting a measure for identifying the levels of acceptance and motivation for recovery and a measure for testing levels of anorexic symptoms/recovery based on these participants' meanings.

The semi-structured topic schedules used in the study (see appendix 7) may have influenced the findings. A strength of the topic schedule is that the questions were developed from a review of qualitative studies on the experience of anorexia so were based on sufferer rather than clinical understandings. However, some of the questions may have been somewhat leading. For example, a question was asked about the roles anorexia played in the participants' lives and in studies 1 and 2 they were asked to describe whether these roles were positive or negative. This question could be leading for two reasons, first it assumes that anorexia does play a role for participants, and second it may impose the ideas of seeing anorexia as having both positive and negative attributes that may not have been previously considered by participants. Details of the roles of anorexia were also evident through participants' responses to other questions, alleviating concerns that results may have come from the question posed. However, a more open-ended approach may have provided quite different findings. For this reason, a future phenomenological study conducted online may wish to gather participants together in an online discussion and ask them simply to discuss their experiences of anorexia and recovery with one another with no formal topic schedule and then further questions can come from the participants' responses. Similarly, a non-participant, virtual ethnographic approach may be used where the researcher observes naturally occurring narrative. However, both of these approaches are not without their limitations as an approach that is too open-ended may lead to non-participation and virtual ethnography reduces the ability to collate any other information (e.g. gender, age etc) about participants.

The study was novel in that it used an online method to data collection and recruitment whilst using a traditional phenomenological epistemology. In chapter 4, I asked how phenomenological notions of embodiment, temporality, spatiality and sociality can be negotiated using an asynchronous, telepresent and written medium. For example, Finlay (2006) has expressed the importance of the researcher paying attention to the body of the participant during an interview as a way of getting further insight into their experience. In chapter 4, I questioned the ability for online interaction to be embodied. Through reviewing the literature, I argued that although online interaction is not embodied in a physical, corporeal sense it may be possible for emotional embodiment and a sense of presence to be achieved through the text conveyed between two people.

After experiencing firsthand the process of conducting online research, I would argue that the online environment allows the researcher to react to participants' experiences in emotionally and often embodied ways. Of course, this would depend on the language used by the participants and on the particular story that is being told. The example below is an account from my reflexive diary in response to reading Jane's detailed account of hospitalisation where, despite being placed on strict supervision for suicidal tendencies, the neglect of the nurses on duty meant that she was able to harm herself. I have also provided an extract from Jane's transcript for context. As can be seen from this example, Jane's language gave me strong embodied reactions. Although not indicated below, these embodied reactions allowed me to relate to Jane's feelings of resistance to the medical staff for allowing such events to happen.

I cut my wrists with a razor blade I found in te [sic] bathroom, I dug a builders nail that was left on the floor into my arm and managed to bite deeply through the skin on my wrists....I also poured boiling water over my arm - all this was when I was supposed to be under arm lenth [sic] supervision. (I had never slef [sic] harmed before I went into hospital and my parents and I believe it was down to the medication I was on.

(Extract from Jane's transcript)

It may be because I am slightly phobic about things touching my own wrists and have a fear of accidentally cutting them that this provided deeply embodied reactions. I cringed with disgust, my wrists ached and I found myself protecting and soothing my own wrists with my hands. The

deeply provocative language of “dug” and “bite deeply through” enable this reaction to occur [...] My pulse is raised and my wrists ache as a result of reading this extract. I wonder if writing it produced similar embodied reactions for [Jane].

(Extract from reflexive diary)

Although an online approach allows for emotionally embodied reactions that might aid in the interpretation of data it does not allow for physical embodiment. I would argue that this could actually be beneficial to the research process. Garrett (1998), a slim recovered anorexic, talks about the role of her body in her research with those with anorexia. Her participants often made comments on her body size and as Garret describes this had a direct impact on the way that they perceived her, she says “*the very bodies of researchers and participants always affect the communication which takes place in face to face interviews*” (Garrett, 1998, p.26). As someone who is of average weight (although possibly seen as overweight to the objective gaze of an anorexic), my body did not need to play a role in the research process. Just as, and perhaps more importantly, the bodies of my participants were not present. Participants unanimously agreed that low body weight was simply a side effect of their anorexia rather than an important aspect of their experience, thus by removing their body from the interaction and thus from the data analysis may have allowed me to focus only on the psychological and not on any physical aspects of their experience.

A lack of physical presence may actually be desired for participants with body image issues (Fox et al., 2007; Walstrom, 2000), as Debra describes the physical anonymity of not being able to see the bodies of other participants meant that she felt more open to share her experiences:

It was so much easier to be honest about things without worrying about what the "skinny" person across the room was thinking about me or what I had to say. [...] being able to hide behind closed doors while I "talk" about this. This feeds into my fears (social fears) a little, but like I said before, you are much more likely to get an honest answer out of me if I feel safely hidden (even baggy jeans and sweatshirts aren't enough to hide me if I'm face-to-face with someone).

As Turkle (1995) explains, people in an online environment can shape their online identities as they wish. This obviously has issues regarding validity but may also be advantageous. This study consisted of participants who may normally feel stigmatised presenting as their offline self in the offline environment. In particular, the males and older women in the study may have felt much more comfortable without presenting the physical, bodily reminder that they did not meet hegemonic ideas of a typical person with anorexia. Similarly, I, as a young researcher, did not have to worry about embodying the position of a 'typical' researcher or did not have to worry how physical reminders of my gender and age would affect the research.

Online communication has been criticised for the lack of non-verbal cues (for example, Chen & Hinton, 1999; Stewart & Williams, 2005) but as also asserted by Watson et al. (2006), I would argue that written communication should simply be considered different rather than inferior. Perhaps, with only the life story of a person in written form, free from the messy additions of physical presence, non-verbal cues and the body, and completely anonymous save for that written account which has been carefully constructed to tell the story that participants wanted to tell, it might be possible to get closer to that person's experience. The researcher may get closer to the text (and therefore the person) by visualising the person and learning from the text than if they had not met in person. The written form may also be of benefit for participants and this is considered further later in the chapter.

Phenomenology recognises the temporal nature of experience whereby experience and meanings may change over time (Langdridge, 2007). It can therefore be questioned as to how much the asynchronous nature of the research affected the results obtained. For example, ambivalence was a strong theme throughout the three studies and at one point I questioned whether this was a reflection on the asynchronous nature, whereby participants may feel one way one day and another way the next. However, one need only look to the rest of the thesis to recognise that ambivalence and conflict is a recurring theme throughout the eating disorder literature. Some researchers may feel that synchronous research provides a closer account of participants' actual lived experiences because of the immediacy and

spontaneity of responses (Oringderff, 2004). However, people's meanings of experience may change over time and it is argued that an answer a participant gives on one day may be different to the one they give the next. By conducting an asynchronous study, perhaps I have actually tapped into a closer representation of the fuller picture of the experiences of anorexia, recovery and treatment.

One advantage to the asynchronous nature of the research (for both researcher and participants) was the capacity in which participants could reflect on their answers before offering them to the researcher. Murray (2004, p.965) found in his study using both offline and e-mail interviews that those in the online study "*were more frank about their experiences, remained more focused on the research questions, and provided more reflectively dense accounts than their face-to-face counterparts*". The same candour and reflexivity can be said for the responses received in the current research. The double hermeneutic approach used in IPA requires the researcher to make sense of the participant making sense of the self (Smith, 2004) and with the time allowed for participant reflexivity it could be questioned as to what effect this has on the meaning-making process. Participants may have written, edited and changed their answer a number of times before responding and thus their experience may have already undergone a rigorous meaning-making process. For example, the following extracts from participants illustrate the multi-faceted way in which participants prepared their responses:

Helen: Just wanted to let you know that I'm working on my response to this question. It appeared simple until I started working on it. I have it saved "as a draft" in my e-mail so that I can work on it.

Kim: I am finishing the last question. I have it written on a piece of paper and just need to type it and send it to you.

Participant reflexivity was evidenced in their ability to think about answers before posting.

Debra: ...having time to think before answering - I didn't feel "on the spot" or pressured to answer. It sometimes takes me awhile to think through the mess that's in my head.

Natalie: Could think about answers and answer in one's own time... Could bounce off other peoples contributions. Could come back and

amend or edit or add.... Felt good to be able to give own perspectives and own experiences, without the structure so often imposed by more "traditional" research techniques.

One key advantage of the asynchronous and therefore reflexive approach is the depth at which questions can be explored. The interviewee can take their time answering the question and the interviewer can spend some time reading over the answer to ensure the next question is relevant and that any further questions that can be posed are done so. This all ensures more in-depth data. In this way, the researcher may also learn more about the participant and their experience before conducting any formal analysis. The researcher can even discuss initial emerging themes whilst the research is still progressing. The experiences can be explored in detail throughout the interview potentially reducing the propensity for a researcher or participant to leave the research situation without covering anything they wished to include. In a similar vein, the ability to spend time considering a question means that a person does not reveal something they wish they had not. Thus, asynchronous communication can allow a deeper level of reflexivity (on both parts) throughout the data collection phase.

9.3. Practical Reflexivity

One limitation of the research is that the sample was biased to those who had access to and already used the internet for aspects related to their anorexia. Participants were recruited through their participation in existing online resources so already had an interest in eating disorders. This may have affected the results obtained. This research recruited participants entirely from online sources whereas previous research has tended to recruit participants from treatment settings. Thus, the current study can be commended for its ability to access a novel and under-researched population. The online approach also allows access to a global sample, which can be advantageous given many journals' interest in the international scope of published research. Online research can only be conducted with those comfortable with and already familiar with the experience of online communication, otherwise, there is a danger that the phenomenon being investigated may be overshadowed by the

meaning-making of being online. This is an important consideration for future researchers considering using an online approach.

Another potential limitation of the online approach is the propensity for technical difficulties. Although a rare occasion, some technical difficulties were encountered. These included instances when the study site was down, albeit temporarily. Although some participants were aware of these problems and notified the researcher, this did not seem to have any impact on the data collection due to the asynchronous nature. If this had been a synchronous project where data needed to be collected at a set date and time then this would have created a much larger problem. It is important to remember that technical difficulties may also occur in a face-to-face interview whereby a tape recorder may run out of battery. Technical difficulties were also sometimes an issue in regards to the questionnaire stage of the research where some participants used different word processing applications and so could not open the questionnaires for the study. This frustration led to one potential participant losing interest and not proceeding with the study, however, on reflection this may have been avoided had the questionnaire information been included in the body of the e-mail.

Participants in studies two and three were asked about their experiences and opinions of the online focus groups. On a practical note, participants favoured the convenience of being able to log into the study at a time that was most suitable to them: *“Could come and go and do at own convenience... Didn't have to leave the house for it!”* (Natalie); and *“being able to log on whenever it was convenient - I work odd hours so this is very useful to me.”* (Debra). Moreover, Beth explained how as a result of her concentration difficulties the online approach was beneficial: *“For someone with serious concentration issues, online is the only way I could have done this!”*

With face-to-face research the interview takes place in the ‘here and now’ and takes between one to two hours. The interviewer and interviewee’s attention is drawn only on the interview for that time. With an online approach, there may be distractions in the participants’ offline life which may affect the interview (both at the time when replying and more general life events that may distract participants from logging in

to their e-mail account or the study site). With the asynchronous nature of the e-mail interview both have to re-familiarise themselves with the interview when a new question or answer is sent. For the researcher, (who may be conducting several interviews at the same time) it can take time to read over the answers that have been given, re-read previous answers and formulate an appropriate reply and an adequate question on the basis of these replies. This can be disadvantageous and advantageous at the same time as although it takes longer to conduct an e-mail interview than a face-to-face interview, this averages out when transcription time is taken into account.

The asynchronous, ongoing nature of the e-mail interviews can be beneficial for the researcher-participant relationship. A relationship may form between the researcher and participant that helps build rapport and increase the potential for the participant to share their personal perspective. This is helped by the ongoing nature of the method which means that the researcher gets a better insight into the person's lived experience. The researcher's questions and participants' responses are often punctuated by obligatory small talk (e.g. the weather, other things going on in each other's lives) and this helps establish rapport. One reported disadvantage of online research described by previous researchers is the potential difficulty in establishing rapport (Illingworth, 2001). I disagree with this view and believe that in many cases the lack of anonymity, coupled with the asynchronous nature, may actually aid the research relationship. From my own experience I found it easier communicating online than perhaps I would have done face-to-face and as the quotes from participants indicated some of them did too. I would therefore say that this comes down to the personal preferences of the researcher and participants. Participants recruited through online sources will already be adept and familiar to this form of communication and perhaps are using this medium because this is what they prefer.

9.4. Researcher reflexivity

Personal reflexivity involves exploring both how we have informed the research and how the research informs us (Willig, 2001). To help understand how I may have had an impact on the research it may be useful for me to introduce myself. I am a young

female in my mid-twenties who has lived solely in the UK. I am of normal weight with a BMI in the middle of normal range. I have never had any issues with food and weight that would be considered 'disordered', but I, like most women (and increasingly men), have had my fair share of anxieties regarding such issues as body shape, foods, relationships, identity and future goals. Although, these have not been to the same proportions as the participants in my study I feel that some of my own subjective experiences allow me some insight into their experiences. Growing up in westernised society, as most of my participants did, I am all too familiar with the societal ideals regarding eating, weight and gender. I have experienced contradictory societal messages of under and overweight, eating well and dieting, career success and family. As is natural in this society, I too am conflicted sometimes with ideas about food, career and who I am and who I want to be. This personal interest in meanings and behaviours around food and weight and previous research into pro-anorexic beliefs (Williams & Reid, 2007) precipitated my interest in the project.

Studying a degree in psychology gave me insight into the research process, although I understood the ideas of quantitative research, an optional module in qualitative research opened my eyes to the depth of experience that could be explored through such an approach. Qualitative research and the opportunity to explore experience through people's own words fitted my own personal philosophy of psychology about a need to focus on personal experiences.

Being reflexive may be aided by the use of a reflexive diary. Specific to my own experience a reflexive diary was useful for asking questions about my data. I would write out a question about the data and then debate all of the possibilities sometimes as a conversation with myself. The extract below illustrates how this process enabled me to work through a problem I was having with the data analysis at the time and illustrates the ways in which my thoughts influenced the interpretation of the data.

Doing the corpuses is taking a lot longer than it should and I think this is because I keep deliberating over which corpus quotes fit into and how some fit into 2 or 3 different ones. This could probably be resolved by broadening the corpuses, but to what? Should 'living/existing' (existential recovery) be amalgamated with 'personal recovery'? i.e. can

self-acceptance only occur once the person also accepts the world they live in (being-in-the-world)? Can someone feel 'alive' without accepting their identity? [...] Thinking reflexively, if I were feeling low self-esteem, feeling depressed and denying myself basic needs and pleasures then I would not feel like I was living a full life, yet if I was feeling good about myself I would want to engage more in the world and in life. Thus, on reflection, these two themes and their subthemes cannot be separated.

(Extract from reflexive diary)

Learning to be reflexive has taken time and has seemed to improve the more I do it. During study 1 I was not fully aware of the importance of reflexivity and the resultant data analysis probably shows this as it is less detailed than the subsequent studies. Being reflexive can be difficult, personally and can force a researcher to question a number of aspects about themselves. My research has forced me to think about my own attitudes towards my own identity, my relationship with my body and my relationship with food. The extract presented below illustrates some of the ways in which the research had an effect on me.

My research has also presented me with occasions where I have (momentarily) took on some of the attitudes of my participants (both negatively and positively). I have been on an emotional rollercoaster, reading experiences of sexual abuse, self-harm and suicide attempts one day and then joys of self-acceptance and recovery the next. I did not just read about my participants' experiences, I relived some of them (albeit not to the same level) but I felt some of their pain and some of their joy as if it were my own. Without experiencing sexual abuse, suicide attempts or an eating disorder, I was still able to gain some experience of how it was felt by participants through the openness and candour with which they wrote. Their frank and honest descriptions, perhaps as a result of the online, anonymous and written approach was sometimes surprising and hard for me to accept.

I reacted strongly to some of the data, physically upset when reading one account of a person who in the past had been so captured by her anorexic voice/mind she had attempted to hang herself. I felt disgust at the pit of my stomach reading one woman's account of being forced to wet herself for the sexual pleasure of her abuser. Panic, upset, disgust at some of my participants' experiences. Uncomfortable, reading an e-mail that candidly described horrific experiences yet also (shamefully) sometimes feeling humbled that they had chosen to share these experiences with me. Again, selfishly, excitement when people described how their experiences of taking part in the project had in some way helped them with their experience. Excitement because I may have

helped someone – the research had had a positive effect on the participant.

(Extract from reflexive diary)

The account above illustrates the emotional attachment felt during the research process. This assisted in the interpretation of participants' experiences. Reading accounts of negative treatment experiences, de-motivating experiences of long waiting lists and fights for insurance and then having my participants thank me for the opportunity to share their experiences or disclosing how the research experience helped them led to an increased desire to help people in this situation establishing my aim to work in the eating disorder field. On another note, reading participants' experiences of self-acceptance and recognition of their own needs has personally affected me through a more positive relationship with food and my own body.

9.5. Participant Reflexivity

Nicolson (2003) reflects on the interview process by drawing on her own research experience. She acknowledges how both the interviewer and participants can be reflexive during the research process. Nicolson (2003, p.136, emphasis authors own) demonstrates how "*the fact of being interviewed represent an **intervention** in the everyday life of the participant*" where many of her respondents found the interview "helpful" and "therapeutic", and this may be what they are expecting to get out of the interview process. Nicolson (2003) also identifies how the reflexive nature of the interview may also enable participants to "*construct a **meaning** around 'self'*" regarding the phenomenon being investigated. These two processes were also apparent in the current research. In a similar vein, Etherington (2003, p.34) describes the merits of writing about experience as a way of being able to understand and move past those experiences: "*We now know that putting stories of traumatic experience into words can itself become another step towards healing and transformation*". Through telling a story of a traumatic experience, a person can learn about their self and discover important meanings and elements of their experience (Etherington, 2003; Garrett, 1998). Participants in the studies found the research process beneficial:

Elizabeth: Thanks for the opportunity to participate in this study. I have found it to be very interesting to further explore my thoughts about this disease, and hope that my answers will be useful in helping treat others who suffer from anorexia.

Linda: I found this experience to be a reflective time regarding my ED and recovery experiences over the past 4 years. It was more emotionally stirring than I had anticipated. I came to realize how early my ED had its roots in my life, and also, how extreme my efforts were to attain social acceptance and inner control...which I felt were necessary for survival for many years of my life. I am relieved that I do not need my ED as I did before recovery.

Participants also described a personally reflexive experience, whereby being involved in the research project enabled them to subjectively think about their identity and their anorexic experiences. For example, Jon said *“I have to say that being involved in your project has really helped me to look at myself in a new way.”*

Whilst Lisa commented that:

Lisa: Actually, talking about it or emailing about it in your research study has been helpful to me as far as self-reflection and having to think about what is really going on inside me.

Adler and Zarchin (2002) found that their online focus group study with pregnant women on bed rest was considered “valuable and beneficial” by the participants who saw the experience as a form of peer support and a way of coping with their experience of bed rest. Another theme reiterated by participants:

Naomi: I found it a comfortable and relaxing environment. I felt safe posting here and even if I did not have something to say on all the topics I was interested to read the experiences of others.

Karen: I have enjoyed learning about others experiences.

An ongoing concern with the internet for both research and therapeutic reasons is how the lack of non-verbal communication can make it more difficult to recognise if a person is distressed. I often checked the mood of participants in the e-mail interviews, especially if their reply revealed an upsetting experience by saying something along the lines of “thank you for telling me about your experiences of X I hope you found it ok to talk about”. I also regularly reminded participants that they may refuse to answer any questions by saying something like “hope these questions

are ok for you, feel free to ask me to move onto the next one if you prefer”. Furthermore, details of support websites were provided throughout the study.

This chapter has already explored how negative affect could often be identified in participants’ responses through their use of language. During the research, Jon who was on a waiting list for treatment at the time of the study and Kim who was fighting for insurance discussed the highs and lows of their present situation. Far from this being distressing to talk about, it seemed that the ability to type out their feelings was actually cathartic. As Kim expressed, *“I enjoy answering your questions as it is like therapy for me since I am presently not in therapy. So keep the questions coming.”*

9.6. Chapter conclusion

Online communication is characterised by written language. Furthermore, asynchronous communication permits a greater level of reflexivity. Reflexive writing was perceived as a benefit by the participants in the research, allowing them to explore and learn about their experiences and their selves. A number of authors have recognised the therapeutic benefits of writing (Etherington, 2003; Garrett, 1998; Penn, 2001; Pennebaker, 1993; Smyth & Helm, 2003) and this may have implications for a number of activities explored in this thesis. First, it may suggest a therapeutic and reflexive element to the use of online discussion boards for health reasons. Chapter 3 highlighted the social support functions of narrating experiences to others who understand but not how the actual act of writing in these contexts may serve a therapeutic purpose. In a similar vein, this may have implications for the use of e-therapy that would rely only on written communication.

Second, much qualitative research utilises traditional face-to-face interviews for data collection. The current research has highlighted the benefits of using written methods for research. For the researcher, writing allows for greater reflexivity which may result in a greater depth of data and for the participant writing may assist in understanding their experience. The reflections presented above suggest an ability to

get closer to participants' lived experience as a result of the reflexive and physically anonymous nature of the approach.

Third, therapeutic writing exercises may also be utilised in face-to-face therapies as ways to assist eating disorder patients in emotional processing that may be difficult to verbalise or as a way of building motivation (Schmidt, Bone, Hems, Lessem & Treasure, 2002). For example, Pennebaker (1993) has reported on the health benefits of writing about personally upsetting experiences and Focussed Expressive Writing (FEW; Smyth & Helm, 2003) has been recommended as a self-help tool for managing stress and trauma. Similarly, narrative therapy works on the idea of re-storying the experience of anorexia through both verbal and written means. Future research should explore these potential benefits further.

To summarise the research experience, asynchronous online research retains a sense of emotional embodiment that allows for effective interpretation of results but hides the physical presence of the body, which, as argued above may interfere with the hermeneutic process. In particular, the lack of physical presence reduces the social and physical cues that may affect the research relationship and influence the interpretation of the participants' story. Although it is recognised that these social cues help make up the person's story, the lack of a physical reminder places these cues in the background allowing for the participants' story to be the principle focus. It is argued that future research, especially with those experiencing body image issues, should utilise an online phenomenological approach.

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