Recovery is a constant battle: Online exploration of sufferers' perspectives on anorexia and bulimia

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This work is original and has not been submitted in relation to any other degree or qualification.

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Abstract

Research into the problem of anorexia nervosa (AN) and bulimia nervosa (BN) has previously focused predominantly on perspectives of these eating disorders from an external point of view.

The subjective experiences of AN or BN sufferers, however, have not been sufficiently explored. Experiences, shared online, provide a rich source of data to provide a comprehensive understanding of eating disorders and their treatment. This study provides an insight into how individuals with AN/BN make sense of their eating disorder in the online world. Data were collected retrospectively from three online pro-recovery forums. Thematic Analysis revealed three inter-related themes: Paradox of control, Challenges, and Ambivalence, all of which describe the lives of individuals with eating disorder (ED), and demonstrate how they made sense of their eating disorder. Moreover, this study further shows differences between individuals with AN and BN that occurred within the key themes. Implications of the findings for clinical practice are discussed.
1 Introduction

1.1 Defining Anorexia Nervosa

Anorexia has long been recognized as an eating disorder, with the first systematic case studies describing individuals with this disorder published in 1874 by William Gull. Today, AN is classified as a psychological disorder and diagnosed on the basis of criteria stated in Diagnostic and Statistical Manual of Mental Disorders (DSM-V) last updated in 2013. This study utilises the DSM-V criteria for AN, which in the key criteria corresponds with the DSM-IV utilised by majority of the research introduced throughout this study.

There are three core criteria for AN according to DSM-V (2013). Firstly restriction of food intake that leads to weight loss or a failure to gain weight resulting in a significantly low body weight (in the context of what is expected for someone's age, sex, and height). Secondly an intense fear of gaining weight/becoming fat, or persistent behaviour that prevents weight gain. Thirdly distortion in the view of one's body weight and body shape. Instances of these distortions include a person thinking he or she is overweight despite being underweight, or a person believing they will gain weight from eating any meal (Waldman, Loomes, Mountford, & Tchanturia, 2013). DSM-V (2013) further allows differentiation of two subtypes of AN: Restricting Type, characterized by absence of binge-eating/purging behaviours, and Binge-Eating/Purging Type, associated with engaging in binge-eating/purging behaviours (i.e., self-induced vomiting, misuse of laxatives). Although Binge-Eating/Purging Type is similar to BN there is not weight-loss criterion for BN (DSM-V, 2013).

Currin (2005) reported that age- and sex adjusted incidence of AN in UK primary care services in the year 2000 was 4.7 per 100 000 population, with dramatic variations in rates according to age-gender groups. Despite some minor fluctuations across years, the
The incidence of AN has been stable (Micali, Hagberg, & Treasure, 2013). The ratio of female-male incidence rates are 12:1 with the highest incidence for females aged 10-19 years (Currin, 2005). The average age of AN onset is approximately 13 years (Hoek, 2006). Moreover, some studies suggested a continuous decrease in average age of AN onset (e.g., Favaro, Caregaro, Tenconi, Bosello, & Santonastaso, 2009). Unfortunately, the outcome of this serious illness is generally very poor (Arcelus, 2011). Furthermore, a meta-analysis revealed that mortality rates of AN are the highest amongst all mental disorders (Harris & Barraclough, 1998). In a more recent meta-analysis by Arcelus (2011) mortality rates of AN were 0.51% per 1000 individuals per year. On the other hand, there has been a decrease in mortality rates of AN during last two decades due to improvement of specialized care centres for individuals with AN (Smink, van Hoeken, & Hoek, 2012). Other negative consequences associated with poor nutritional habits typical of AN include hypoglycaemia, abnormal liver function, hypothermia, and osteoporosis (Gaudiani, Sabel, Mascolo, & Mehler, 2010). Depression and anxiety were also identified as psychological consequences of AN (Karatzias, 2010).

### 1.2 Subjective experiences with AN

Individuals frequently use AN in response to feeling out of control and they attempt to (re)gain it by exerting control over their eating and body (Bruch, 1974). Interestingly, individuals with AN often report an increased sense of control over themselves and their lives after they decrease their food intake (Rezek, & Leary, 1991). AN sufferers also view their ED as one of very few aspects of their lives that no one else can control (Young, 2000). When some AN sufferers talk about their ED, it appears to represent a certain lifestyle rather than a disorder (Espindola, & Blay, 2009). Other individuals with AN report using their ED as a way of coping with their negative emotions, or external events including family pressures.
and social pressure to be thin (Serpell, Treasure, Teasdale, & Sullivan, 1999; Chan, & Ma, 2003). Individuals who have recovered from AN reported they viewed their ED as a part of their identity and that recognising the need for treatment was problematic as it meant to lose a part of themselves (Tan, Hope, & Stewart, 2003; Tan, Hope, & Stewart, 2003).

Several studies were carried out to explore the self-concept of individuals with AN, that is, how they perceive themselves (Baumeister, 1999). These confirmed numerous findings including that individuals with AN often feel they have to deserve food, or worthless if they eat more than they are allowed which reflects low levels of self-esteem (Lamoureux, & Bottorff, 2005; Bachner-Melman, 2005). Also, AN sufferers perceive their body as large and consisting of fat which indicates their negative body image and it drives their desire to be thinner despite what other people say (Chan, & Ma, 2003).

When patients with AN were asked about the positive aspects of their ED, they often mentioned feelings of being safe in the sense of being looked after and protected by their AN (Serpell, Treasure, Teasdale, & Sullivan, 1999). Furthermore, the majority of them reported to feel strong and in control of themselves and their lives when they did not eat. AN sufferers further stated that thanks to their ED, they felt powerful, beautiful, and special, which were qualities they would otherwise not be able to gain (Serpell, Treasure, Teasdale, & Sullivan, 1999; Surgeon, Plumridge, & Horn, 2003). However, as an individuals’ AN progressed, they reported to be bothered by having to constantly think about food, their body and they felt trapped in their own obsessions (Thomsen, McCoy, & Williams, 2001). Sufferers also perceived more negative aspects of their AN including loneliness (Serpell, Treasure, Teasdale, & Sullivan, 1999), lack of control over their ED (Surgeon, Plumridge, & Horn, 2003), and negative impact of ED on many areas of their lives (D’Abundo, & Chally, 2004). These included worsened performance at school/work, disruptions in family and social relationships, and health problems (D’Abundo, & Chally, 2004).
1.3 Defining Bulimia Nervosa

It has only been 37 years since Gerals Russel (1979) published a paper with a first systematic description of Bulimia Nervosa (BN). He referred to BN as “an ominous variant of anorexia nervosa” that was defined by “the dread of overeating, various compensatory measures, and the morbid fear of gaining weight and getting fat” (as cited in Steinhausen & Weber, 2009, p.1331). Bulimia means “bull's appetite” or “ox hunger” which reflects the intensity with which individuals consume food during an episode (Sobel, 1996). Russel's (1979) term Bulimia Nervosa and criteria of its diagnoses were firstly introduced in the Diagnostic and Statistical manual of Mental Disorders, Third Edition, Revised (DSM-III-R) (1987) and were closely related to those of AN except for using laxatives, dieuretics, binging of food, and vomiting.

Today, the criteria for diagnosis of BN stated in DSM-V (2013) include behavioural as well as psychological symptoms of BN. Behavioural symptoms of BN refer to intermittent episodes of uncontrolled binge eating followed by inappropriate compensatory behaviours (both purging and non-purging) that prevent weight gain. Psychological symptoms include undue influence of body shape/weight on one's self-evaluation, and potentially occurring disturbance. Studies have shown a strong association between Major Depression Disorder (MDD) and BN (e.g., Kendler et al, 1991), however there is contradicting evidence on whether MDD precedes the onset of BN (Kendler et al, 1991; Brewerton et al, 1995) or vice versa (Bulik et al, 1996). Moreover, comorbidity of BN with anxiety disorders has been well documented (e.g., Kendler et al, 1991; Bulik et al, 1996) with few studies suggesting that anxiety disorders precede the onset of BN (e.g., Bulik et al, 1996).

Age- and sex adjusted incidence rates of BN were 6.6 per 100 000 population in 2000 (Currin, 2005) which is higher than those of AN. As in the case of AN, the ratio of female-male incidence rates was much higher for females than males (18:1) with the highest
incidence at ages of 10-19 years. A recent study by Micali, Hagberg, and Treasure (2013) found stability of the incidence of BN in the UK but also revealed that onset age of BN is higher (15-19 years and continues to be increased for those aged 20-29 years) in comparison with onset age of AN (Micali, Hagberg, & Treasure, 2013). Mortality rates of BN documented by Arceless (2011) were 0.17% per 1000 individuals per year, which is much lower than mortality rates of AN. On the other hand, BN shows the strongest association to suicide attempts than any other psychiatric disorder (Newman et al., 1996). Other negative health related consequences of BN include swollen salivary glands, stomach ruptures or dental enamel erosion (Southard, 2008).

It should be noted that individuals diagnosed with anorexia may restrict at times and have episodes of binging and purging at other times (Costin, 1999). Estimates indicate that between 30-50% cases of individuals with ED display both AN and BN symptoms (Yager et al, 2006). Diagnosis of BN is always secondary to AN, meaning that if an individual meets criteria for both AN and BN, they are diagnosed with AN, more specifically with anorexia binge eating/purging type, which is a combination of the two diagnoses (Berkman et al., 2006).

1.4 Subjective experiences with BN

Despite the fact that BN has been researched for more than 3 decades, little is known about how individuals with BN experience it. The following paragraphs summarize findings from studies that have looked into experiences of life with BN.

In a study by Welch et al (1997), individuals identified several critical events that precipitated the onset of BN including a major house move, a major illness of a close friend/relative/partner, pregnancy, change in family structure (e.g., marriage, divorce), sexual or physical abuse. Fairburn (1997) further found that individuals with BN reported more
adverse environmental events (teasing, bullying, sexual abuse, or physical abuse) and displayed greater level of personal vulnerability (i.e., psychiatric disorder, behavioural problems) as well as dietary vulnerability (dieting risk, obesity risk, parental eating disorder) in comparison with healthy controls. BN sufferers further report that binge eating episodes are also triggered by feelings of loneliness, powerlessness, shame, boredom, helplessness, or anger (Striegel-Moore, Smolak, 2001).

Sufferers of BN described their ED as a mood regulator, in which they comforted themselves with food during binge episodes followed by expression of their anger via purging (Costin, 2007). In a phenomenological study, Schachtel and Wilborn (1990) interviewed women with BN about their past, present, and future concerns. They revealed that the women generally used food to protect themselves from difficult feelings and relationships. Furthermore, the paradoxical nature of control was identified in that the control individuals sought via binging and purging at the onset of the illness became the controller as BN progressed (Schachtel and Wilborn, 1990).

Klein and Walsh (2004) found that individuals consume up to 10,000 calories during their binge episode and that they mostly binge on foods high in fat or sugars while other types of food are reserved for normal consumption during period of dietary restraint. Fairburn et al.'s (2003) revealed a cyclic nature of binge episodes arising from negative affect. They argued that binging episode reduces individual's self-efficacy related to their ability to control bulimic behaviour and leads to subsequent purging episode or food restriction that in turn increase a risk of potential binging episode (Fairburn et al., 2003). This corresponds with reported experience of BN sufferers. The majority of women with BN interviewed by Kalodner (2003) attributed their binging to negative affect rather than hunger. Interestingly, individuals with BN are often unable to recall the amount of food consumed or frequency of binge episodes due to negative affect, denial, and dissociation (Anderson &
Williamson, 2002). Some individuals even claim they feel as if it was someone else doing the eating during binge episode (Johnson, 1994). On the other hand, BN sufferers report to realise abnormality of their eating behaviour during an episode of binging and to experience an intense fear of losing control and not being able to stop eating voluntarily (Rowland, 1984). Lyons (1998) interviewed women suffering from BN and found that emotions following binge episode involved guilt, shame, disgust, rationalization, and blame. A common theme identified across all interviews was participants' struggle to maintain acceptable weight while gaining control over binge eating (Lyons, 1998).

1.5 Recovery from AN and BN

Characterization of recovery and its meaning varies depending on who is asking and interpreting, in what context, to what audience, and for what purposes (Jacobson, 2001). In the 1970s and 1980s, recovery from mental illness was predominantly related to elimination of physical symptoms such as restoration of weight (e.g., Morgan and Russell, 1975) and behavioural symptoms such as absence of binge-eating, compensatory behaviours, restricting behaviours (e.g., Bulik et al, 2000). With the progress of human sciences, elimination of psychological factors such as body image concerns or fear of gaining weight were incorporated as significant focuses during the recovery process (e.g., Couturier and Lock, 2006).

This study investigated how individuals with ED perceived and made sense of their ED in the pro-recovery forums. Therefore a definition of recovery based on subjective experiences of ED sufferers was deemed most appropriate, and will be used throughout the study. Recovery is defined as: “a deeply personal, unique process of changing one’s attitudes, values, feelings goals, skills, and/or roles. As a way of living a satisfying, hopeful and contributing life even with the limitations caused by illness. Recovery involves the
development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness” (Anthony, 1993, p.527). In this definition, recovery is seen as a continual task of individual, in which the aim is to rebuild a life beyond illness, but not necessarily eliminate the symptoms of illness. It further acknowledges recovery as a long lasting process with its inevitable periods of positive and negative events.

Since recovery is a deeply personal and individual process (Anthony, 1993), it is difficult to have one set of recovery enhancing “ingredients”. But we can gain a valuable insight into a recovery journey from: outcome studies, studies of factors associated with recovery, studies of subjective experiences of individuals in recovery and, internet-based studies of pro-recovery forums.

1.5.1. Outcome studies

Outcome studies bring valuable information about the quality of life of individuals after treatment (i.e., from ED), which in turn may subsequently improve decisions of other patients and their carers (Jefford, Stockler, & Tattersall, 2003). Traditionally, outcome in eating disorders is focused on quantitative aspects, such as behavioural/physical symptoms but there are also qualitative studies that provide insight into psychological aspects of post-treatment life that would be difficult to quantify.

Improvement in core symptoms of eating disorders is considered to be the central variable of treatment outcome (Bulik, Berkman, Brownley, Sedway, & Lohr, 2007). Many studies investigating long-term outcomes for eating disorders relied on the behavioural/physical level of the recovery concept that is weight gain, restoration of menstruation for AN (e.g., Bulik, Berkman, Brownley, Sedway & Lohr, 2007) and reduction or elimination of binge eating and purging for BN (e.g., Shapiro et al., 2007). Herzog et al. (1999) operationalized partial recovery as a reduction of eating disorder symptoms beneath
the level of full diagnostic criteria for a period of eight consecutive weeks. Full recovery was defined as an elimination of eating disorder symptoms for eight consecutive weeks (Herzog et al., 1999).

In their follow-up study, Herzog et al (1999) found that criteria for full recovery were met by 74% participants with BN and 33% participants with AN who sought and underwent treatment. 99% of individuals with BN and 83% with AN reached partial recovery according to Herzog's (1999) classification. Another follow-up study found that 7% individuals with AN and 18% with BN reached full recovery, and 55% individuals with AN and 60% with BN displayed partial recovery (Kordy et al, 2002). While it should be taken into account that Kordy et al (2002) utilized more strict criteria for partial/full recovery (e.g. time frame for remission of symptoms was 12 instead of 8 weeks), higher recovery rates for BN than AN were found by both Herzog et al (1999) and Kordy et al. (2002) as well as by many other studies (e.g., Herzog et al., 1999; Kordy et al. 2002; Von Holle et al., 2008; Van Son, Van Hoeken, Van Furth, Donker, & Hoek, 2010). This demonstrates discrepancies in recovery rates of individuals with AN and BN, indicating that treatment for BN has poorer outcomes than AN.

How long individuals should be absent of eating disorder behaviours to meet the criteria of recovery vary from eight consecutive weeks (e.g., Herzog et al., 1999) to one year (e.g., Strober et al., 1997). Moreover, studies have consistently found that behavioural/physical level of recovery precedes psychological recovery (e.g., Strober et al., 1997), therefore a shorter period for behavioural/physical recovery should be expected (Bardone-Cone et al., 2010). Indeed, Strober et al. (1997) found an average time of 57 months for partial recovery (elimination of behavioural/physical symptoms) and 79 month for full recovery (elimination of psychological symptoms). Interestingly, some studies supported a claim that duration of absence of eating disorder symptoms necessary for stable
recovery from AN is shorter as opposed to BN (e.g., Kordy et al., 2002). This might suggest more complex issues underlying BN that require more time to address, nonetheless previous research does not offer any specific explanation for this. Zipfel, Löwe, Reas, Deter and Herzog (2000) did a 21-year follow-up study for AN outcome and found a “good outcome” for 51% of participants and “intermediate outcome” for 21% of participants. Criteria for “good outcome” as well as for “intermediate outcome” correspond with criteria for “partial recovery” constituted by Herzog et al (1999) that are as follows: reduction of eating disorder symptoms beneath the level of full diagnostic criteria for a period of eight consecutive weeks. Such disparities in definitions of recovery and its criteria make it challenging to interpret findings across studies. Therefore, they should be considered only a source of information producing a general overview rather than specific and comprehensive knowledge of the problems of eating disorders. Such specificity can be gained from studies of subjective experiences of individuals with ED as is this one.

Approaching recovery only as an elimination of behavioural/physical symptoms is viewed as a “pseudorecovery”, and considered insufficient by some researchers (e.g., Keski-Rahkonen & Tozzi, 2005). This is because such individuals may display elimination of behavioural/physical symptoms of their ED but when asked about their internal state, they report to have unwanted eating disordered thought (Bardone-Cone et al., 2010). Therefore, it has been argued that when exploring recovery, psychological components of eating disorders (how individuals think about their bodies, food, and eating) should be included too (Bardone-Cone et al., 2010). Studies showed that only those individuals who have reached full recovery as classified by Herzog et al. (1999) on the level of behavioural/physical symptoms reported less concerns about weight, lower drive for thinness, and better social functioning comparable to healthy controls (Cogley and Keel, 2003; Bachner-Melman et al., 2006). Similarly, Noordenbos and Seubring (2006) found that participants who referred to
themselves as “recovered” did not obsess about their weight/body shape and reported accepting their appearance, and therefore they have reached psychological level of recovery. On the other hand, it has also been shown that if anorexic/bulimic attitudes and lingering preoccupation with weight and body shape are not altered, they often lead to relapse (Federici & Kaplan, 2008). According to Jarman and Walsh (1999), the definition of recovery is only complete when it includes behavioural/physical, psychological, as well as psychosocial functioning. Psychosocial functioning is typically assessed with measures of shame, social safeness, received social support, and self-compassion (Kelly & Carter, 2014). A strong link between a positive outcome of eating disorder and a good psychosocial adjustment has been documented by many studies (e.g., Fichter & Quadflieg, 1999). A 10-year follow up study by Herpertz-Dahlmann et al. (2001) even found no difference in psychosocial functioning, namely in social contacts, partnership, psychosexual functioning, occupational adjustment, etc., between long-term fully recovered individuals and healthy controls. This finding was supported by Cogley and Keel (2003) who focused on BN outcome and later by Bardone-Cone et al. (2010) who investigated outcome for eating disorders in general. Both studies also did not find any differences in anxiety/depression levels, body image and psychosocial functioning between fully recovered participants and healthy controls. Such findings indicate that if individuals have managed to overcome behavioural/physical and psychological aspects of their eating disorder, they have also adapted to a social life that was surrounding them (Herpertz-Dahlmann et al., 2001).

1.5.2. **Studies of factors associated with recovery**

Another approach to understanding recovery is to view it as a sum of components, or factors that may either enhance or hinder the recovery process (Fogarty, & Ramjan, 2016). The following paragraphs discuss concrete factors that long-term research has identified as
significant in predicting the recovery process, including those that sufferers' themselves consider important or challenging.

**Duration of eating disorder.** Zipfel et al. (2000) as well as Fichter, Quadflieg, and Hedlund (2006) observed that longer duration of eating disorder before the first treatment predicts poorer outcome. Moreover, some researchers suggest that recovery after 10-12 years of illness is rare (Wentz, Gillberg, Anckarsater, Gillberg, & Rastam, 2009). Conversely, studies have shown a better prognosis in cases of short duration of eating disorder (e.g., Steinhausen, 2002). Keski-Rahkonen et al. (2013) also found a strong association between duration of illness and unemployment, dissatisfaction with partner/spouse, and high perfectionism.

**Age of onset.** There are two typical peaks of AN onset found by Halmi, Casper, Eckert, Goldberg, and Davis (1979). The first around 14 years and the other around 18 years of age. However, onset of BN in adolescence is rare, instead typical age of BN onset is in young adulthood (Fairburn & Harrison, 2003). Furthermore, age of onset of both AN and BN has been found to be decreasing (Favaro, Caregaro, Tenconi, Bosello, & Santonastaso, 2009). Association between age of AN/BN onset and its outcome has been quite well mapped by research.

Studies indicate that later age of onset, meaning in later adolescence/young adulthood, is one of the most frequent predictors of negative outcome (Herzog et al, 1992; Steinhausen et al, 1991). When comparing outcome of early (adolescence) and later onset (adulthood), studies unambiguously show better outcome of those cases with early onset (Steinhausen, 2002; Lindberg, & Lindblad2006; Anckarsater, Gillber, & Rastam, 2009). However, the outcome of eating disorders which develop in childhood is variable. Despite this, research has revealed some specific patterns. A study by North et al. (1997) found that individuals whose early physical and psychosocial development was healthy made a full
recovery from their first pre-pubertal eating disorder episode. In these cases eating disorder is usually a response to a sudden negative event such as the death of a close person (North *et al.*, 1997). On the other hand, children with early onset of eating disorder and experiences with persisting social difficulties or abnormal personality development in childhood display worse outcomes (Gowers *et al.*, 1991).

**Comorbidity.** The majority of individuals diagnosed with eating disorder suffer from additional mental health diagnoses (Milos, Spindler, Buddeberg, & Crameri, 2003). There is a particularly strong association between eating disorders and anxiety disorders as well as mood disorders (Biederman *et al.*, 2007). Further evidence suggests that obsessive-compulsive personality disorder (OCD) is the most common personality disorder among individuals with restricting-type of AN (Kaye, Bulik, Thornton, Barbarich, & Masters, 2004). Milos, Spindler, Ruggiero, Klaghofer, & Schnyder (2002) noted that there are many similarities between AN and OCD such as obsessional character of psychological symptoms or ritualization of certain behaviours. For that reason, some researchers proposed seeing AN as a form of OCD (e.g., Holden, 1990). Generally researchers (e.g., Kaye, 1999; Jarry, Vaccarino, 1996) accept a view that these two disorder coexist as both seem to have a same neurobiological base, the serotonin system. In a similar manner, borderline personality disorder is the most common among individuals with BN (Sansone & Levitt, 2005). Research found lifetime comorbidity of at least one anxiety disorder in 71% of adult individuals with AN or BN (Godart *et al.*, 2003).

Comorbid disorders have been shown to hinder recovery process of AN and BN (Herzog, Nussbaum, & Marmor, 1996; Herpertz-Dahlmann *et al.*, 2001). This was demonstrated in a study by Wittchen, Essau and Krieg (1991). The study revealed lower level of psychosocial functioning (social relationships, school/work functioning) and less favourable long-term outcome of individuals with lifetime comorbidity of anxiety or
depression in comparison to those who had no comorbidity to their eating disorder. Moreover, longer recovery duration with worse outcomes have been found in individuals with BN and increased comorbidity (Thomson-Brenner & Westen, 2005). Therefore, both eating disorder and comorbidity should be considered when creating a recovery plan and frequently used as predictors of the course of eating disorder (Milos, Spindler, Schnyder, 2004).

Although these studies introduce findings that may provide information about the factors impacting on the outcome of eating disorders, they do not identify factors that contribute to the recovery process (Jarman & Walsh, 1999). This points to broader range of factors that are not exclusively related to treatment but yet they contribute to recovery (Jarman & Walsh, 1999). The factors include, for instance, sufferer's recognition of ED as a dangerous, and unwanted coping mechanism, commitment to change, increased tolerance of uncomfortable psychological sensations, adoption of coping mechanisms, learning to care for oneself, or promote feelings of self-esteem (Jarman & Walsh, 1999). Thus, sufferers' personal experiences with the recovery process should not be neglected.

1.5.3. Studies of subjective experiences of individuals in recovery

A need to investigate recovery from AN/BN from various complementary perspectives has been highlighted in previous paragraphs. Studies of subjective experiences of individuals in recovery provide a rather specific view of life in recovery from ED complementary to outcome studies, and thus they represent another valuable source of information about the problem of eating disorders. Such insight might inform nurses and other professionals and non-professionals who care for individuals in recovery from AN/BN about their ambivalent feelings from recovery, the ups and downs of recovery process, and the benefits of sufferers' active participation in treatment planning (Lindgren, Enmark,
Researchers have also noticed this gap in knowledge of the sufferers' perspective of recovery from anorexia or bulimia (Darcy et al., 2010). An increasing number of qualitative studies into this area have been conducted in last two decades (e.g., Pettersen & Rosenvinge, 2002; Tozzi et al., 2003; D’Abundo & Chally, 2004; Lamoureux & Bottorff, 2005; Federici & Kaplan, 2008; Lindgren, Enmark, Bohman, & Lundström, 2015; etc.). These studies identified the diverse experiences of individuals in recovery, some of them were unique (unconscious lying of individuals about being in recovery from ED to themselves and other people) others emerged across the majority of the studies (e.g., challenging thoughts related to eating disorder, ongoing inside struggle, and intimacy in relationships).

Pettersen and Rosenvinge (2002) investigated the subjective experiences of recovery from the perspectives of individuals who had previously sought treatment for their eating disorder. This study revealed that admitting that they suffer from eating disorder and accepting it was the first step towards recovery - increased self-acceptance, desire for a better life without food dominating it, and intimate relationships were identified by participants as motives contributing to recovery. The importance of acceptance in recovery was later supported by D’Abundo and Chally (2004) who gathered data from interviews of individuals who self-identified as being in recovery, focus groups, and observations of weekly support group. Similarly to Pettersen and Rosenvinge's (2002) study, accepting the disorder represented an imaginary “turning point”. According to participants, such acceptance was often incited by an event that made them acknowledge severity of the disorder (e.g., negative health consequences of ED, hospitalization, life-threatening situation, etc.). D’Abundo and Chally (2004) further identified desire and hope for life beyond eating as well as building and re-establishing supportive relationships with family member(s), friend(s), or a therapist as essential components of recovery. They argued that only those individuals who did well in all
three components, reached full recovery. Conversely, those who improved in only one or two components reported a persistant struggle for control, obtrusive eating-related thinking, and social withdrawal (D’Abundo, & Chally, 2004).

Both Pettersen and Rosenvinge's (2002) and D’Abundo and Chally's (2004) studies included participants based on self-assessment of recovery. Such recovery studies whose inclusion criteria rely on participants' self-identification as recovered/being in recovery suffer from potential inaccuracies of self-report (Bardone-Cone et al., 2010). These were demonstrated in a recovery study by Federici and Kaplan (2008), participants who relapsed in weight, denied the relapse and instead described themselves as being in the recovery process.

Tozzi et al (2003) explored views of patients on recovery 12 years after anorexia treatment. Recovered patients were identified by the absence of eating disorder symptoms. These patients also reported acceptance of anorexia as a difficulty, significant life changes, and positive life events were turning points often conditioned by maturity and supportive relationships. A study by Hsu et al. (1992) highlighted a variety of experiences that individuals who meet the same explicit criteria for recovery (score on Eating Disorder Inventory in the normal range, stable weight, return of menses for minimally a year prior the study) may have. In this study, many participants also mentioned specific turning points that led them to recovery, such as pregnancy or discovering a sense of spirituality. Weaver et al. (2005), and Jacobson and Greenley (2001) identified another example of a turning point - finding renewed sense of self. This was characterized by defining self apart from the disorder, more specifically the new self became an active participant in recovery process (Jacobson and Greenley, 2001). The view of recovery as a rediscovery and redefinition of self was also found in a study by Lamoureux and Bottorff (2005).
1.5.4 Internet-based studies of pro-recovery forums

A rapid spread of internet access gave rise to self-directed support groups for health-related problems such as eating disorders (Lieberman & Goldstein, 2005). Generally, online support groups provide a space for recognition as well as a social dimension for sharing experiences and knowledge, support, and importantly they create sense of belonging (Høyby, Johansen, & Tjørnhøj-Thomsen, 2005). Today, individuals with AN/BN have a possibility to receive these experiences in the online world as it represents a substantial part of young people's social life (Berriman & Thompson, 2015). It is also evident that online support groups can offer appropriate emotional support during recovery from AN/BN.

Winzelberg (1997) proposed that online support groups may be viewed as an intermediate step between individual coping and professional help. He found that support among individuals was often communicated through self-disclosure and played a major role in coping with weight gain during recovery, or external pressures from sufferers' families, friends, and society. Walstrom (2004) further suggested that self-disclosure is easier and more common on online forums as they are “bodiless” in their nature, and appearance-related judgements are therefore largely eliminated.

A more recent study by McCormack (2010) also revealed that encouragement and esteem support are the most common themes in online pro-recovery forums. The second most discussed theme was information support that seemed to fulfil an educational role. As in Winzelberg's (1997) study, here participants also reported to be misunderstood by family/partner and to have no one to talk to, and no support (McCormack, 2010). Thus, online forums represent a place where social support, possibly not received from families, is available at a convenient time, for as long a period of time as necessary, and from individuals who have had similar experiences (McCormack, 2010). Unlike in formal offline support
groups, members of online ones do not need to solve any practical problems related to the meetings, such as transport, timing etc. (McCormack, 2010). Furthermore, online support groups as opposed to those offline, create a relatively safe place for sharing sensitive experiences, opinions, and beliefs (Buchanan & Coulson, 2007). Feelings of shame related to eating disorder that may cause delays in treatment seeking (Martin, & Story, 2002), are eliminated during entering, exploring, and bonding in online support groups (Colon, 1997).

It is surprising that despite the fact that the benefits of online support groups were identified by Winzelberg in 1997, only a small number of studies have been conducted so far that would deeply explore phenomena occurring in those forums, or the role that online forums and support groups play in recovery from eating disorders. There is a corresponding gap in research literature with only few studies attempting to fill it (e.g., Winzelberg, 1997; Keski-Rahkonen & Tozzi, 2005; Stommel, 2007; Wesemann & Grunwald, 2008; Eichhorn, 2008; McCormack, 2010; Kendal, Kirk, Elvey, Catchpole, & Pryjmachuk, 2016).

Stommel (2007) analysed nicknames of individuals with eating disorder in a pro-recovery forum. His study demonstrated how nicknames can be viewed as identity displays and how they may be related to eating disorders. Smallness, weightlessness, childishness, negative self-evaluation, depression and self-confidence were identified attributes of nicknames that can all be linked to general characteristics of eating disorders. Another interesting online study was conducted by Wesemann & Grunwald (2008). They focused on a pro-recovery forum for individuals who suffer from BN and analysed threads to explore the character of participants' communication. Surprisingly, results showed that the postings that encouraging the members to fight eating disorders were more replied to, and viewed than postings, in which ED-related problems were discussed, indicating that the central function of the forum is social support. Moreover, postings that promoted eating disorders appeared to be very sensitive as they belonged to those most commented on and viewed.
Another internet-based study by Keski-Rahkonen and Tozzi (2005) explored what eating disorder sufferers meant when they referred to the word *recovery*. After analysing the context in which *recovery* was mentioned, they observed changes in participants' views of recovery according to the current stage of change. The meaning of recovery shifted through the stages from very abstract wishes (e.g., getting better) accompanied by ambivalent feelings to planning, implementing, and committing to concrete actions. Strong willpower and ceasing of identification with eating disorder were found to be helpful in recovery. Moreover, professional interventions were considered valuable only if the sufferer was ready to change.

Internet-based studies that analyse the content of pro-recovery sites and forums are, despite their benefits, quite rare. Those that exist usually investigate either the character of the communication between members (e.g. Winzelberg, 1997; Wesemann & Grunwald, 2008; Eichhorn, 2008; McCormack, 2010), or specific phenomena occurring in forums, such as users' nicknames (Stommel, 2007), or context in which word “recovery” is mentioned (Keski-Rahkonen and Tozzi, 2005). Nonetheless, there is paucity of research that explores subjective online shared experiences of individuals in recovery. Moreover, experiences with ED shared online of might slightly differ from those obtained by interviews. This is assumed because individuals feel more anonymous in online forums (Johnson, 2010), and self-consciousness typically accompanying sensitive face-to-face discussion, is largely decreased in comparison with face-to-face interviews (Darcy & Dooley, 2007).

The current study aims to examine how individuals with AN/BN make sense of their ED in the online pro-recovery forums. More specifically, I intend to investigate subjective experiences of individuals with ED, the role that the ED plays in individuals' lives, how they perceive it, and relate to it. I further aim to find out whether individuals' experiences with, and perceptions of AN are different from those of individuals' with BN.
2 Methodology

The current chapter provides important philosophical, practical, and ethical considerations of methods used within the study. Firstly, ontological and epistemological stances are provided that informed the choice of sampling strategy, data collection method as well as method of data analysis. An outline of, and justification for Thematic Analysis are also discussed. Moreover, criteria of sampling and sampling strategies are described. Finally, ethical issues related to the current research are considered.

2.1 Ontological and epistemological position

To begin, it is essential to establish ontological (what is the nature of reality?), and epistemological (how is the reality captured/known?) paradigms that will guide the study. According to Guba (1990), paradigms create a holistic view of how the researcher views the knowledge, how they relate to it, and what methodological strategies they use to uncover and explore the knowledge. The current study accepted relativist ontology that assumes existence of multiple realities, interpretations, from which none are more “true” than the others (Harré and Krausz, 1996). This further implies that the realities, or interpretations are culturally, historically, and conceptually informed (Krausz, 2010), and the truth of one individual is relative to the truth of other individual (Zimmerman, 2007). Moreover, it is necessary to ask what the truth is relative to. Denzin and Lincoln (2003) argued that humans construct multiple realities that are relative to their social as well as historical context. This relativity is for example apparent in constant (historically-, and socially-dependent) changes in human understanding of “normality”. In the context of the current study, what once was deemed “normal” eating habits may nowadays be viewed as “abnormal”, and vice versa.

Furthermore, it is argued that our perceptions and experiences are not a direct reflection of environmental conditions but should be understood as specific understandings
of these conditions (Willig, 2008). Such approach is referred to as social constructionism and
 corresponds with Hepworth's (1999) view of eating disorders being historically, culturally
 and linguistically determined. Therefore, social constructionism was adopted by this study as
 lens for exploration of eating disorder aspects that participants related to. The basic premises
 of social constructionism according to Burr (2003) involve: 1) a critical stance towards
 taken-for-granted knowledge, 2) historical and cultural underpinning of knowledge, and
 understandings, and 3) mediation of knowledge, and understandings by social processes.
 Social constructionism additionally posits that knowledge and truth are created by the
 interactions of individuals within society (Schwandt, 2003). Thus, social interactions, and
 particularly language are in the centre of social constructionists' attention.

 Historical and cultural determination of eating disorders is demonstrated by the fact
 that in various time periods in the past, disordered eating habits, such as ritual fasting or self-
 starvation, were more or less frequent, and their function was mostly spiritual (Miller &
 Pumariega, 2001). Moreover, cultural beliefs have been found to impact on a development of
 eating disorders (Miller & Pumariega, 2001). In Westernized cultures, a construction of thin
 ideal and its transmission by advertisements or by publicly known females presents a way for
 young females to achieve their goals (e.g., desirability, popularity) by maintaining skinny
 body via self-starvation (Bemporad, 1997). Therefore, inherent social and cultural aspects
 that construct beliefs, values, and perceptions impacted on the process of data analysis as
 well as on interpretation of the results.

 The aim of this study was to gain an insight into how people in recovery understand
 their eating disorder, and how they relate to it. Previous research into this area has well
 documented measurable outcomes of AN/BN but studies of the subjective experiences of
 AN/BN sufferers have only been published for a decade. The number of qualitative studies
 exploring eating disorders has been increasing and they contribute to our in-depth
understanding of eating disorders. For that reason, qualitative approach was deemed as most appropriate. The central concern of qualitative research is to understand what certain phenomenon mean in the human life (Turato, 2005), in this study how people make sense of their eating disorder in the pro-recovery forums. Furthermore, a qualitative research, unlike quantitative, is concerned with understanding human behaviour from their personal perspective (Minchiello et al., 1990). As such, qualitative investigation tends to be in-depth, and explores people's understandings of their actions (Maykut & Morehouse, 1994) and attempts to approach the phenomenon in its natural setting (Denzin & Lincoln, 1994).

Considering the exploratory nature of the two research questions and given a limited previous research into this area, an inductive approach was adopted (Elo & Kyngäs, 2008). An inductive approach, unlike deductive, data are examined at first, followed by construction of the larger categories and attempts to understand the relationship among them (Silverman, 2005).

2.2 Online observation

The aim of this study was to explore in-depth how people understand their eating disorder, and such insight into this phenomenon is of a great value when gained in the natural setting (Denzin & Lincoln, 1994).

Online forums represent a relatively safe place for sharing personal beliefs, opinions, and emotions due to their apparent anonymity (Bond, 2012). As such, online forums were considered a natural setting for sharing personal experiences related to eating disorders, and therefore they were employed as a source of data.

As a researcher I took on a role of complete observer of an online group, I looked at retrospective posts and was not involved in discussion with participants (Nørskov & Rask, 2011). This allowed for collection of data without observer effects typically mediated by
participant-researcher face-to-face interaction (Strickland & Suben, 2012). Additionally, covert online observation enables researcher to develop a holistic understanding of the phenomenon under study (DeWalt & DeWalt, 2002). Also, the researcher is not affected by participants' gender, sexuality, ethnicity or class during covert online observation as there is no direct contact between the researcher and participants (Kawulich, 2005).

2.3 Data analysis method

Thematic Analysis (TA) was chosen as the most appropriate method for this particular research because it allowed to identify broad themes (Braun & Clarke, 2006) that reflected participants' understanding of eating disorder in their life. Previous studies in this field that made use of TA (e.g., Rance, Moller & Clarke, 2015; Lindstedt, Neander, Kjellin, & Gustafsson, 2015) came up with unique themes that provided deep and original view of what eating disorders are about for people who suffer from them but want to recover. Rance, Moller, and Clarke's (2015) study found that sufferers of AN in recovery want to be seen as a “whole person” instead of just “person with anorexia”, while Lindstedt et al (2015) identified strong ambivalent feelings of anorexia sufferers towards treatment that were attenuated by building a trusting relationship with family.

Based on adoption of social constructionist paradigm, it was assumed that ways, in which participants related to the disorder were reflected in their posts, and were constructed through social and personal contexts such as gender, personal background, or social identity (Richardson, 1996). Furthermore, TA is very flexible method that allowed adherence to my epistemological and ontological stance in the exploration of this phenomena and further has a potential to provide rich, detailed, yet complex data descriptions (Braun & Clarke, 2006).

Although some of aims of the study concern meaning of personal experience, the overall aim was to explore the patterns. Also, as a researcher employing covert online observation, I was
unable to fully enter participants' offline world. For these reasons, IPA (interpretative phenomenological analysis), a tool that highlights the meaning of personal experience (Smith, Flowers, & Larkin, 2009), was not considered fully appropriate.

Grounded theory was not chosen as method of data analysis because the aim of this study is not to “develop a general, abstract theory of process, action, or interaction grounded in the views of participants” (Creswell, 2009, p.13 & 229), but instead to explore concrete subjective experiences of individuals with AN/BN. Moreover, it is typical to employ multiple stages of data collection and refine interrelationships of constructed categories in the process of developing grounded theory (Charmaz, 2006). Nonetheless, this would not be feasible in covert online observation as the researcher is not involved in the discussion with participants and can not observe the group multiple times. Thematic Analysis therefore seemed to be the most appropriate tool of data analysis in that it enabled to gain insight into participants' understanding of AN/BN from the data gathered during covert online observation.

2.3.1 Thematic Analysis

Thematic analysis (TA) is a method used to uncover patterns of meaning in participant's accounts of experience (McLeod, 2011). “Uncovering patterns of meaning” is claimed to be one of a few general skills across qualitative analysis (Holloway and Todres, 2003, p.347), therefore some researchers do not consider it a specific tool, but an element of various qualitative analyses (e.g., Boyatzis, 1998; Ryan & Bernard, 2000). Although this method is widely used, literature does not offer a consistent view on what TA is, and how it should be carried out. Thus, it is essential that the theoretical position of TA taken in this study is properly described.

The present study approached TA as a constructionist method that investigates ways in which events, realities, meanings, and experiences are the outcomes of variable discourses
functioning in the human society (Clarke & Braun, 2013). Constructionist approach to TA aimed to theorise the socio-cultural contexts that enabled participant accounts provided by the data (Clarke & Braun, 2013). Therefore, the “patterns of meaning” were viewed as socially produced rather than being created by individuals' minds regardless of the social surroundings (Burr, 1995). Furthermore, the identified patterns (themes) were deemed to have a strong link to the data (Patton, 1990), especially because they were collected specifically for the current research. For that reason, attempting to fit the data into a pre-existing coding frame, as is typical of deductive approach (Clarke & Braun, 2013), could lead to misunderstanding of the data themselves, or shield interpretations not previously explored. Instead, inductive or data-driven TA was conducted, in which patterns (themes) were developed bottom up, that is from individual codes of meaning identified within the data (Lodico et al., 2010).

A “theme” was considered a “pattern of meaning” that captured something important and relevant to the research question (Clarke & Braun, 2006). Moreover, Clarke and Braun (2006) argued that the importance of a theme is not determined by how frequently it occurs within the data, but rather by its “keyness” in relation to research question. Another important decision made concerned a level, at which themes were identified: semantic (explicit) or latent (interpretative) level (Boyatzis, 1998). This study aimed to present a constructionist accounts of participants' report of experience with, perception of, and relation to anorexia or bulimia. Thus, TA went beyond the semantic (explicit) content of the data, and focused on investigation and identification of the features (underlying ideas, assumptions, and conceptualisations), which shaped or informed the semantic content of the data (Clarke & Braun, 2013).
2.3.2 Process of thematic analysis

The process of analysis within this study followed the six stages outlined of TA established by Clarke and Braun (2006, 2013). In correspondence with Clarke and Braun (2006), the TA was conducted as a recursive process whereby researcher went back and forth in the process of analysis to ensure the codes (or later theme(s)) reflected what the data were saying. Following paragraphs are based on the phases of TA outlined by Braun and Clarke (2006).

Familiarisation with the data

This phase began after data collection via covert online observation was completed and data were properly anonymized. The first essential step was to gain the breadth and depth of the data content (Braun & Clarke, 2006). To achieve this, data were read multiple times and rigour initial notes, relevant to my research questions, also called “extracts” (Braun & Clarke, 2006), or “meaning units” (Meiner et al., 2006) were identified. The length of extracts varied from short phrases, single sentences to several sentences.

Generating initial codes

This phase followed a long list of initial notes along with extracts, and ideas about what was interesting in the data in relation to the research question. A “code” within this study referred to “the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon” (Boyatzis, 1998, p.63). Based on the outcome from the previous phase, I coded all meaning units that I identified and addressed my research question. This is in line with Braun and Clarke's (2006) recommendation to code for as many potential themes as possible. All data were coded manually, that is this study did not make use of any software, and codes were rated, and
discussed by two independent raters (me and my supervisor). This shows element of rigour or transparency that, according to Yardley (2008) improves quality of the research.

During further coding, data extracts were then organized into meaningful groups (Tuckett, 2005). In this phase, I went back to data to ensure the groups of meaning reflect it accurately. I took into account two of Cayne and Loewenthal's (2006) cornerstones of research exploring subjective experiences - description and horizontalization. These were crucial to my bottom up thematic analysis because I as a researcher, ascribed meanings to data extracts that are explicitly or implicitly located in data. Therefore, I focused on data description rather than data analysis from a particular theoretical position (description), and I treated each data information equally rather than immediately ascribing it certain a level of significance (horizontalization) (Cayne & Loewenthal, 2006). Further critical issues in dealing with prejudice and potential biases within self-awareness and self-reflection are discussed in Appendix A.

**Searching for themes**

After all codes with relevant extracts were collated, I started sorting the codes into potential themes, and putting together all relevant coded extracts within the identified theme(s) (Braun & Clarke, 2006). Where relevant, some codes also included a little of the surrounding text to maintain the context of the code (Bryman, 2001). The codes were subsequently analysed, and their combination to form a theme was considered and visualized via a mind-map. Braun and Clarke (2006) introduced visualization as an easy way to organize the codes. In correspondence with Braun and Clarke (2006), some data extracts were coded in more themes as long as they fit, and were relevant. Broader, and more abstract themes captured patterns of meaning between the groups of codes (Braun & Clarke, 2006).
**Reviewing themes**

This phase began when the list of potential themes was completed and refined (Braun & Clarke, 2006). This phase of analysis involved checking that themes “worked” in relation to coded extracts referred to as internal homogeneity, as well as to the full data-set referred to as external homogeneity (Patton, 1990). Two important conditions should be met here: 1) codes with data extracts within the theme should be meaningfully coherent, 2) there should be a clear distinction between individual themes (Braun & Clarke, 2006). To reach this coherence, two levels of reviewing and refining were conducted. Firstly, at the level of the codes with data extracts. Secondly, all themes were considered, reviewed, and refined in relation to the data set.

**Defining and naming themes**

This phase is about identifying the “essence” or telling a story of each theme as well as its story in relation to the other themes (Braun & Clarke, 2006, p.22). The “essence” was captured by going back to the data extracts collated for each theme, and putting them into a coherent and consistent narrative. The final step within this phase was to give the themes clear and concise names that will immediately give the reader a cue what they are about.

**Writing up**

Once the themes were fully worked out and named, the final task was to write up a complete data analysis story. This provided a concise, coherent and logical account of the data, and therefore it represents merit and validity of the analysis (Braun & Clarke, 2006). Moreover, data extracts were embedded into the narrative to illustrate the story.
2.4. Sample selection

Three online message boards that explicitly stated to be pro-recovery were included in the study. All of them were publicly accessible, that was no registration required, and were found by simply typing “eating disorders forums” or “anorexia and bulimia message boards” into the search engine. By sampling in this way, forums that are easily accessible to the majority of people were identified.

Exclusion criteria involved websites other than pro-recovery (e.g., “pro-anorexic” or “pro-bulimic”). Also, websites that explicitly disagreed with using their content for research purposes were excluded. For ethical reasons, only those websites were included, where no registration or password were required. Ethical issues were also taken into account when participants' age was considered. Since there was no way to obtain an informed consent from parents of participants younger than 18, they were excluded.

As the research questions aimed to explore how people relate to their disorder and not how they interact with each other, only first posts of the threads were collected. Moreover, posts only with question(s), were excluded, if they did not provide any information relevant the research questions. Also, crucial for answering the research questions was an assumption that people who visited and added posts on those message boards suffer(ed) from anorexia or bulimia. Therefore, if 1) a person did not classify themselves as anorexic or bulimic, or 2) report having anorexic/bulimic disordered eating patterns, or else 3) identified themselves with eating disorder other than anorexia/bulimia (e.g., binge eating disorder (BED), eating disorder not otherwise specified (EDNOS)), their posts were excluded. Lastly, as it is discussed in literature review, anorexia and bulimia often comorbid with other disorders (e.g., Herpertz-Dahlmann, 2009). Attempting to identify and exclude comorbidities would be difficult, therefore all posts that met inclusion criteria and
where comorbidity of AN or BN was mentioned, were included in the data set.

2.5 Ethical considerations

The study followed British Psychological Society's (BPS) for conducting an online research in order to ensure that ethical issues were considered throughout. This research received ethical approval from the Department of Psychology Ethics Committee on the 23rd February 2016, DOPEC code ESHH010316. The current research was retrospective, and the researcher did not make any contact with participants nor added any posts on the message boards, therefore, there was no risk of physical harm or any psychological distress to participants during, or post data collection (Rodham, & Gavin, 2006).

According to British Psychological Society, informed consent must be provided to participants wherever possible in order to inform them about the aims of the study and aspects that may impact willingness to participate. Rodham and Gavin (2006) argue that message boards not only represent a public domain, but also an environment, where replies or posts are deemed a deliberate and aimed act that is expected to be seen by others. In accordance with Rodham and Gavin (2006), there was no need to seek informed consent as long as the confidentiality was managed because no ethical boundaries were crossed.

None of the websites used by this study included age disclaimer that would guarantee users to be older than 18. For that reason, whenever suspicion arose that a post had been added by an individual younger than 18 (e.g., high school was discussed or age was mentioned), it was excluded. Confidentiality was ensured by keeping the data on a password protected computer. Firstly, data were collected on the university computer. Furthermore, data were anonymized throughout, that was names and other personal information such as names and nicknames were deleted.

The current study aims to examine how individuals with AN/BN make sense of their
eating disorder in the online pro-recovery forums. More specifically, I intend to investigate subjective experiences of individuals with ED, a role that the disorder plays in individuals' lives, how they perceive it, and relate to it. I further aim to find out whether individuals' experiences with, and perceptions of AN are different from those of individuals' with BN.
3 Results

A qualitative research investigation using Thematic Analysis (TA) was conducted to explore how individuals make sense of their eating disorder in pro-recovery forums. Two research questions were established as follows:

1) How do individuals with AN/BN relate to their ED?

2) Do individuals with AN relate to different aspects of their ED than those with BN?

The current chapter presents results of my TA and provides an account of what was captured in the data. The results provide descriptions of each theme in relation to the research question, that is “How do people relate to their eating disorder on pro-recovery forums?”.

Furthermore, last subsection of each theme is focused on differences/similarities in ways participants with AN and BN made sense of certain aspects of the theme.

Altogether, 76 posts were collected retrospectively on 3 different pro-recovery forums. Two posts were excluded because they did not meet inclusion criteria (one participant reported being younger than 18, the other promoted AN as a “normal lifestyle”). In 22 posts, participants identified themselves as anorexic, 19 participants identified themselves as bulimic, and 33 participants reported to suffer from eating disorder (ED) but did not specify whether AN or BN. Moreover, 9 out of 76 participants reported to be diagnosed with comorbid diagnose to their ED including General anxiety, Depression, Borderline personality disorder, Obsessive-compulsive disorder, and Posttraumatic stress disorder.

During the process of data analysis, three major themes were identified, two of which (“challenges” and “an issue of control”) were manifest – participants explicitly reported issues related to them. The third major theme (“ambivalence”) was latent in terms of not being openly reported on by participants but being implied by participants in their posts.
See Appendix B for a mind map illustrating interconnections of the identified themes along with their subthemes and codes. Descriptions of individual themes and subthemes will be presented in the following paragraphs along with sufficient supporting evidence, i.e., enough data extracts that demonstrate frequency and significance of the theme (Brown & Clarke, 2006).

3.1 Paradox of control

The theme “paradox of control” comprised of two following subthemes: “Struggling with ED” and “In control of ED”. The group of individuals referred to as “Struggling with ED” included participants who approached their ED in a passive way as well as individuals who took on more active approach to their ED and reported that the loss of control over ED was temporary. The other group - “In control of ED” included individuals who were either successfully maintaining their ED in remission or those who were using it as a tool.

Participants' subjective perceptions of control over their ED appeared to impact on ways in which they related to and made sense of their ED. The paradox of control lies in that the more participants wanted and tried to recover, the less control over their ED they perceived. Conversely, the more participants resisted recovery, the more control over their ED they perceived. Another paradox of control was demonstrated by participants who maintained their ED and reported to be in control of their ED behaviours, while at the same time they felt things in their lives are utterly out of control. In these cases, participants' perceptions of having their ED under control seemed to be an attempt to overcome cognitive dissonances that those individuals might have experienced.
The following data extract is an illustration of this:

“In mean not only do I feel happy mentally, but physically I feel healthy... and it's like a huge win for me to be doing this. Mentally I've told myself that I shouldn't ever stop doing it. I've convinced myself that there's nothing wrong with it, because I do feel healthier and happier when I do this.”

In other cases, ED was used as a tool to control emotional aspects of participants' lives or to achieve certain goals. These involved gaining attention and love of others, self-confidence, self-worth, and happiness. Several participants reported that despite being aware of negative consequences of their ED on health, social and family life, they felt helpless against their ED. A further exploration into this revealed that most of these participants suffered from comorbid disorder (Borderline personality disorder, Depression, Anxiety disorders, or Post-traumatic stress disorder), or they had unresolved issues with experiencing a traumatic situation such as being abused. These individuals often reported to lack control over their eating disordered behaviours in situations when their negative affect re-surfaces. In a general sense, all participants who perceived to have little or no control over their ED described it as a negative element which unfortunately became a part of them. This is evident from nicknames participants used to describe their ED: “awful disease”, “debilitating disorder”, “nightmare”, “affliction”, “demons”, “damage”, etc. In all of these descriptions of ED, participants put themselves into a passive position, in which ED made its entrance into their lives and negatively impacted on it:

“The illness has ruined my life, my family, my social life, literally everything”

“This awful disease is ripping my life apart.”

Other participants reported that their ED was unbearable and cost them a lot. Furthermore,
these participants seemed to believe there is something in their head that infuses ED-related thoughts into their minds that they are unable to control. Similarly, these participants desired to recover but their approach to elimination of ED-related behaviours appeared to be passive:

“I want to be free of this affliction”

“Bulimia rears its ugly head”

Such passivity combined with feelings of powerlessness and helplessness were even more obvious in cases where comorbidity to ED or other aggravating factors, such as unresolved emotional issues, were present.

3.1.1 In control of ED

There were different ways in which participants with ED, who perceived to control their disordered eating behaviours, made sense of their disorder. This was dependent on whether they were in recovery or used their ED as a tool. Recovering individuals often referred to ED as to something negative that can cause health problems. Appropriate support provided by therapist or other sufferers was perceived as important and helpful by recovering participants. On the other hand, individuals who used their ED as a tool referred to it as to something that increases their self-confidence, happiness, or self-worth. Figure 1 shows all codes and their organization in relation to a subtheme: In control of ED.

![Figure 1 Codes forming a subtheme In control of ED](image-url)
It is interesting that participants who felt in control of their ED could be split into two groups with contradictory goals. The first group involves individuals who expressed their desire to achieve happiness from love of their partner, or self-confidence and self-worth from getting a new job. From several participants' perspective, these were achievable only by losing weight, and maintaining a thin body. Following data extract is an illustration of this:

“I have to get rid of this weight to feel better about myself, and then hopefully other areas of my life will improve.”

As previously indicated, beliefs causing cognitive dissonance (such as that maintaining ED causes health problems, non-existent social life, disrupted family life, etc.) that might have interfered with participants' goals, were often eliminated.

The other group included participants who stated that they desired to recover and were taking actions towards recovery:

“I've managed to control my binge eating and purging.”

“I am now eating healthily and I've adopted a more healthy lifestyle.”

Many of these individuals expressed concerns about potential or real consequences of their ED-related behaviours on health, including permanent damage caused by a long-lasting period of purging or starvation and abuse of laxatives. Such conscious acknowledgement of ED as a health damaging element appeared to play a crucial role in remaining in recovery and challenging ED-related thoughts.

Another factor that seemed to enhance the participants' recovery process was support. It is not surprising that support represents an important element throughout the process of taking and sustaining control over ED-related thoughts and behaviours as it obviously is an extremely difficult task for participants. Altogether, participants reported that
therapists and other ED-sufferers help a lot in recovery as they understood them, and thus, participants did not feel judged.

3.1.2 Struggling with ED

This subtheme comprised of two groups of struggling participants: the first involved individuals who reported lacking control over ED for a long time and they could not see a way out of it, whereas the other group of participants indicated that their ED is in a temporary relapse. The two groups of struggling participants differed in that, the former, as opposed to the latter, displayed a greater passivity in approaching their ED. Moreover, several participants from the former group reported that eating disordered behaviours help them control negative affects. Both groups of struggling individuals perceived themselves as lacking support of others, which led to feelings of loneliness, hopelessness, and frustration. Figure 2 shows all codes and their organization in relation to a subtheme: Struggling with ED.

![Figure 2 Codes forming a subtheme Struggling with ED](image)

Figure 2 Codes forming a subtheme Struggling with ED
Participants' passive approach along with feelings of powerlessness and helplessness are well demonstrated in the following extract:

“Please, stop the world from turning and let me get off, I need somebody to stop it, pick me up, hold me tight and make everything go away”.

These individuals perceived gaining control over their ED as a sign of strength. On the contrary, long-term lack of control over ED was viewed as a source of participants' frustration and tiredness. The latter group includes posts in which participants approached their ED in a more active manner despite struggling with a relapse of their ED. Feelings of hopelessness were also present here but participants appeared to be aware of the fact that their actions are in their own hands. This group of struggling participants reported a desire to be supported by others. But at the same time they expressed concerns related to the first step they would have to take in order to obtain some support, that is to share their problem with others:

“I can't see a way out at the moment and I find it so hard to speak to people because I think it makes me feel weak and I'm so ashamed.”

Besides being seen as weak, further concerns included burdening family and friends, being misunderstood, and feelings of shame about all lies told by participants to conceal their ED. Such concerns along with feelings of embarrassment or weakness appeared to prevent participants from talking to somebody about their ED. Therefore, many participants felt they were trapped in a vicious cycle of needing support to take control over their ED, and facing challenges in seeking this support:

“I feel like I'm stuck. I daren't go to my GP in case he says I'm not skinny so I can't be bulimic”
Participants further described situations, in which they managed to tell their family, friends, or therapist about their ED-related thoughts or the whole story about their ED, but received reactions that were unhelpful or even made them feel worse. Negative reactions mostly included others lessening the seriousness of participants' ED, or pointing out the irrationality of ED thoughts. These reactions seemed to prevent participants from making further attempts to talk about their ED with other people, and thus contributed to participants' feelings of loneliness.

3.1.3 Differences and similarities in AN vs. BN sufferers

An issue of control appeared to play an important role for both sufferers of anorexia as well as bulimia. Nonetheless, only participants with BN reported experiences of being mocked by family, friends, or bullied by classmates for being chubby prior their ED. Self-induced vomiting was perceived by participants as a way to lose weight and thus to prevent others from insulting them:

“I was bullied about my weight and as a result I started to make myself sick because I thought if I was skinny people would like me and stop doing that”.

Conversely, only individuals with AN reported that certain behaviours that are typically a feature of AN (i.e., controlling tendencies, inflexibility, rigidity) appear in other areas of their lives, mostly social life and prevent them from making new friendships as well as romantic relationships.

Participants who indicated that their AN/BN is a way to control their negative affect often paradoxically indicated to feel out of control. Lack of control differed on behavioural level in participants with AN and BN - Participants with AN restricted and avoided certain foods, whereas participants with BN reported eating all food in the fridge and freezer,
searching the house for food, or to buying unhealthy food, eating all of it, and then vomiting. However, lack of control on an emotional and cognitive level appeared to be similar for participants with AN and BN. Both groups of sufferers who lacked control of their ED reported feelings of frustration and tiredness from a constant battle against their ED thoughts as well as a belief that restricting, binging, and purging are wrong and unhealthy.

Interestingly, only participants with AN seemed to have a separate “anorexic mind” that was a part of them and sometimes took control over their thoughts and behaviours. At the same time, participants reported that they are no longer in control:

“I see myself slipping and restricting, and I feel my hunger complex
starting to fade, but I feel helpless. I feel like I'm not in control anymore,
and that the label 'anorexic' fits the bill.”

It further appeared that “anorexic mind” determined participants' abnormal attitudes towards food and eating, for example, some individuals with AN considered food conditional or dirty rather than a life necessity. Such uncoupling of mind was observed only in participants with AN. Conversely, participants with bulimia who lost control over their eating reported it was because of a certain urge, pressure, or stress. According to these individuals, once they succumbed to binging, feelings of worthlessness, self-loath, and self-hatred resurfaced and purging was perceived as an attempt to re-gain control over their eating:

“I use food to deal with stress and depression. I seem to be stuck in the self
loathing cycle of I hate how I look so I eat to comfort myself; then I throw
up to make myself feel better. It doesn't make me feel better I just feel like a
pig, so then ill eat again.”
3.2 Challenges to ED

The second identified theme – challenges to ED involves two subthemes: “Challenges to maintain ED” and “Challenges to recover from ED”.

Participants reported various challenges they faced depending on whether they felt in control of their ED or struggling with their ED. The biggest challenge for those participants who perceived to have ED under control and used it as a tool (as described within the previous theme), were potential or real health problems:

“I noticed my health is getting worse but I don't want to eat, I will use any excuse not to eat.”

This extract further demonstrates signs of ambivalence between participants' disordered eating behaviours and negative consequences. Concerns about health were also present in participants who reported to have lost control and were struggling with their ED. Furthermore, these participants seemed to realise that their health may get worse, unless they leave their disordered eating habits:

“I feel guilty after every meal and worry it's going to make me fat but also know I'm making a step into the right direction, I just hope my body can function without laxatives and I haven't cased any permanent damage”.

Interference with family, social, and work life represented another challenge for participants whose ED was intentionally or unintentionally maintained. Interestingly, interference of ED with family life was reported least frequently. On the other hand, if reported, it had fatal consequences, such as loss of a partner or a family member. Many participants further reported that their feelings of shame and embarrassment disrupt their social life in that, they are unable to eat in front of other people. It appeared that health
concerns and unwanted interference of ED arose feelings of ambivalence towards maintaining the disorder in participants. Moreover, participants who struggled with their ED reported that talking to other people who were “in the same boat” helped them challenge ED thoughts. Similarly, various challenges and ambivalence arising from them could also be observed in lives of participants who either expressed a desire to (re)gain control and recover from ED or reported to be in recovery.

The greatest challenge for recovering participants was represented by their ED-related thoughts. These involved fear of losing control over eating, weight gain, negative self-image, urges to binge/purge, and tendencies to restrict or exercise excessively. During stressful times, participants reported little relapses as they succumbed to these thoughts and urges:

“I've had some work stress lately and it's all coming back, I am obsessing over my weight – I'm constantly weighing myself, exercising twice a day, obsessively counting calories and feeling anxious all the time.. but I don't want to go back to where I was few years ago.”

Furthermore, feelings of being misunderstood and lonely, as well as concerns about talking to somebody about having ED seemed to make participants' recovery process more difficult and contribute to relapses of ED.
### 3.2.1 Challenges to maintaining ED

A subtheme “Challenges to maintaining ED” included participants' health concerns that involved potential or real negative impact of ED on individuals' health, awareness that individuals' ED is negatively interfering with their social, family and professional lives, and other sufferers as a support. All these appeared to contribute to individuals' desire to overcome challenges of ED. Figure 3 shows all codes and their organization in relation to a subtheme: Challenges to maintain ED.

![Figure 3 Codes forming a subtheme Challenges to maintain ED](image)

Participants maintaining their ED mentioned dealing with challenges that elicit feelings of anger, frustration, helplessness, and ambivalence. Individuals who used disordered eating to control their negative emotions often reported to isolate themselves from the world:

“*I've been in a dark place. I've shut myself away from the world and found comfort in food which is very embarrassing.*”

Consequently, these participants perceived greater disruptions in their social lives including loss of friends and avoidance of lunch/dinner parties with friends, or dates with strangers. Such disruptions in social functioning included participants' perceptions of being constantly
judged and feeling anxious about losing control over eating (at other people's houses or restaurants). These ultimately led participants to challenge their beliefs in maintaining the disorder:

“My eating disorder seems to affect everything I do, like eating around people, how fast I'm supposed to eat if my lunch break is short, feeling like people will judge me, if I don't eat everything or opt for desert or think I'm fat if I do. I just want to be in control and freak out when I'm not. but I don't want all this. I want to recover”.

Participants' awareness of a close association between their ED and serious permanent health problems represented another challenge to maintaining disordered eating habits. Especially, when the health consequences of ED could interfere with family life, as in cases of women who wanted conceive a child, or were already pregnant:

“I want to have a baby but I know that bulimia will make this really difficult if not impossible. I need to be able to stop it”

Further disruptions in participants' family and professional lives caused by ED involved loss of concentration, erratic mood swings, low efficiency, and anxious feelings from not being able to cope. These resulted in failure to gain and sustain a job or postponement of university studies. Several participants also reported the negative impact of

“I find myself shouting at my daughter for the most stupid of things, why? Because of this horrible horrible illness. I have finally plucked up the courage to tell my mom and we are going to get some help”

ED on the relationship with their child/partner/parent that went beyond mere challenging ED to making the first step towards recovery:

Furthermore, other ED-sufferers were considered very helpful and supportive once
participants took action to take control over their ED.

### 3.2.2 Challenges to recover from ED

In a subtheme “challenges to recover from ED”, participants expressed a desire to (re)gain control over their ED, but they also reported having unwanted ED thoughts, being misunderstood by other people, and feelings of loneliness, all of which made the recovery process more difficult and often led to participants' relapse. Figure 4 shows all codes and their organization in relation to a subtheme: Challenges to recover from ED.

![Figure 4](image)

_Figure 4: Codes forming a subtheme Challenges to recover from ED_

Fear of gaining weight and becoming fat, self-hatred, and losing control were considered the greatest challenges that participants were dealing with, especially at the time of relapse. The following data extract illustrates participants' challenging ED thoughts:

“_I tried to push myself today and I ordered a burger with fries, I ate only half of it but feel really really queasy, I'm terrified that the horrible sick feeling I have is my body telling me that it is sucking up ALL the fat and that I'm going to bloat and balloon_”

Moreover, stress and excessive pressure at work, school etc. seemed to be contributing to participants' loss of control over ED and therefore further contribute to a relapse. Participants' perceived loss of control along with loss of hope, strength, and feelings of loneliness
appeared to be sustaining individuals' relapse, whereas support from other sufferers or a therapist seemed to reduce ED-related challenges (feelings of self-hatred, fear of gaining weight, obsession with food, etc.).

Participants who desired to recover from ED further faced challenging feelings of being misunderstood by others. These arose in situations, in which participants perceived that their partner/family member did not understand the extent of their problem or did not acknowledge a seriousness of their problem. Interestingly, several participants reported to have experienced these situations with a professional:

“I've started seeing a counsellor and finally opened up to her but she changed the topic to general anxiety and has told me that I did not have ED”.

These experiences seemed to deepen participants' feelings of loneliness, shame, and concerns about sharing their problem with others.

3.2.3 Differences and similarities in AN vs. BN sufferers

There appeared to be differences between the challenges that individuals with AN and BN were dealing with. Participants suffering from AN who maintained their disorder used more rationalisation to justify their eating disordered behaviours:

“I do feel a lot better when I'm not eating, because my diabetes is under such great control. I mean not only do I feel happy mentally, but physically I feel healthy.. and it's like a huge win for me to be doing this.”

Moreover, as was already mentioned in previous paragraphs, individuals who maintained and used their AN as a tool to achieve certain goals tended to focus only on positive aspects of their ED (loss of weight, higher self-confidence), while disregarding the negative ones.
including health problems. Similar tendencies were not present in individuals with BN who were maintaining their disorder. Individuals with BN who used their ED to cope with negative affect often reported intense worries about their health:

“Another thing is i’m sick... ALL THE TIME. I have stomach problems, chest problems and all around my emotion problems.”

Another difference between participants with AN and BN appeared to lie in their challenging of ED thoughts. Both reported to be preoccupied with their body and weight, but only individuals with BN expressed feelings of self-worthlessness, self-hatred, self-loath. No participant with AN reported similar feelings. On the other hand, only individuals with AN who desired to recover appeared to be challenged by ED thoughts including abnormal beliefs related to food and eating. These beliefs involved comparing the process of eating to defecating, or believing that food should be deserved.

Both participants with AN and BN perceived that they were misunderstood by others but the ways, in which they perceived themselves to be misunderstood differed. Individuals with AN and BN seemed to want other people to acknowledge what they were going through inside:

“They don't see how i see myself and in a way it frustrates me.”,

“My psychologist said my bulimia is mild, no big deal...but it is my eating disorder thoughts that hurt me more.”

However, only individuals with BN reported feelings of being “fake” and concerns that they “failed” because they were not underweight. These were even more emphasised when participants shared their worries of being bulimic with others (friend/partner/family member) who responded not to see any problem.
These concerns further appeared to make it difficult for participants to seek professional help because they believed they did not meet criteria for ED:

“I am not seeing any ED service, I would not fit the diagnostic criteria...

I binge and purge daily”

Conversely, individuals with AN reported feelings of loneliness and frustration from not being seen by others the same way they saw themselves. These also appeared to prevent participants from discussing their problem with others.

### 3.3 Ambivalence

The last theme – Ambivalence was not explicitly reported by participants, instead, it was latently involved participants' contradictory attitudes and feelings towards recovery from ED as well as maintaining ED. Participants' ambivalence was observed on multiple levels - behavioural, emotional, and cognitive. On a behavioural level participants' appeared to take contradictory actions such as eating healthily for 3 days but binged on unhealthy foods, purged and restricted on the 4th day. On an emotional level, participants' expressed contradictory feelings towards one thing, for instance losing control was deemed to be both “awesome as well as terrifying”. Ambivalence on a cognitive level referred to participants' contradictory beliefs and attitudes towards one thing, for example one participant believed that if she puts anything into her mouth and swallows it, she will choke and die, although she knew that this belief was irrational. The following paragraphs demonstrate various aspects of participants' lives, in which ambivalence towards recovery from ED/maintaining ED occurred.
3.3.1 Ambivalence towards recovery from ED

Participants who were in recovery or wanted to recover from ED often reported they realised that they were “making a step into the right direction” but they also expressed various concerns about it that elicited ambivalent feelings and attitudes towards recovery. The concerns about seeking and going into treatment involved feelings of embarrassment if other people (family/friend/professional) found out about their ED as well as fear from having to give up a career, or being temporarily separated from a child. The concerns and ambivalence that were elicited seemed to prevent participants with ED from seeking and commencing treatment. The greatest ambivalence was apparent in participants, who took actions towards recovery on a number of occasions but then failed. Such repeated failure appeared to invoke feelings of worthlessness and frustration related to recovery from ED. Figure 5 shows all codes and their organization in relation to a subtheme: Ambivalence towards recovery from ED.

Figure 5 Codes forming a subtheme Ambivalence towards recovery from ED

Discussing ED with others (family, friends or, professionals) seemed to be very difficult for participants as it invoked feelings of weakness and embarrassment for having ED. These also
appeared to contribute to their ambivalent attitudes towards going to treatment:

“I so don't want the whole world to know I am ill but I know for myself..but I'm going to see the doctors, I need to make this change.”

Going to treatment was further veiled by ambivalence because for some, it would have meant to be apart from their child or a loved one for some time. Participants reported that this was terrifying and anxiety provoking for them. One participant mentioned an interesting dilemma – whether to accept a job at an eating disorder treatment centre or not despite being an ED-sufferer herself. Although she reported to be in recovery for a few weeks and expressed her excitement about the job, she also stated that she was experiencing persisting emotional pain.

Participants' constant frustration from not being able to keep the unwanted ED thoughts under control seemed to ultimately result in participants' passive approach to ED, indicating their perceived low self-efficacy. The change from participants' active to passive approach is well illustrated in the following example:

“I've tried to deal with my ED through therapy, I've tried to ignore it, I've tried to go with it, I've tried to recover but I can't. I'm tired of this constant battle with myself, I can never escape from it.”

3.3.2 Ambivalence towards maintaining ED

A subtheme “ambivalence towards maintaining ED” included participants' contradictory feelings that arose either from participants' realisation of potential or real health problems related to ED. Then, positive aspects of ED that participants perceived, were challenged. Similarly, participants' perceived sense of control gained via disordered eating was challenged by disruptions in individuals' social/family/professional lives, which also
appeared to invoke ambivalence towards maintaining ED.

Figure 6 shows all codes and their organization in relation to a subtheme: Ambivalence towards maintaining ED.

Participants who intentionally or unintentionally maintained their ED reported to be aware that ED is “wrong”, “dangerous”, and “unhealthy”, but at the same time they stated various benefits that maintaining ED provides with them. These included weight loss, higher self-confidence, or less frequent occurrence of negative affect. Some participants further avoided addressing the negative consequences of their ED by emphasizing the positive ones:

“The corrupt part of my mind says this..problems? Yes, there are. But let me be miserable then, at least I’m thin. Problems aren’t so bad. No friends? Isolated? Oh well..I don’t need others, I don’t even need happiness or the feeling of being human. My body is my best friend, my happiness, self-lover, everything I can’t have.”

Others admitted to worrying about their health, but maintaining ED helped them maintain a sense of being in control, or to lose weight.
Ambivalence was further apparent in posts of participants who maintained their ED but perceived the negative effects of ED on their social/family and work life. These participants reported to maintain their ED as a tool to control themselves, or their negative affect. Interestingly, most of these individuals further stated to feel out of control:

“I can’t control it anymore, instead, it controls what I do...I’m frustrated that it owns me and some days it’s all I think about I can’t focus on anything.”

Moreover, few participants reported that the thought patterns typical of ED appear in other areas of their lives and cause great disruption in participants social lives including difficulty in dating, making new friends, etc.

### 3.3.3 Differences and similarities in AN vs. BN sufferers

Participants with AN and BN seemed to differ the least in their ambivalent feelings and attitudes. Although there were differences in the ways, in which participants with AN and BN perceived an element of control in relation to their ED and in the challenges they reported to be dealing with, participants appeared to experience similar ambivalence towards recovery from/maintaining ED. This makes sense as posts of participants with AN as well as BN were collected in pro-recovery forums where it is expected that the majority of individuals share their attitudes towards recovery.

Both groups of participants who desired to recover reported feelings of shame in relation to seeking help and talking to somebody about their ED:

Participant with BN “There is so much I want to talk about but I'm kind of scared that someone will know it's me writing this...I'm a bright and respected woman so why do I have this secret? It's so embarrassing.”
Participants with AN “Even writing this down fills me with shame and embarrassment, I feel like such a fraud and stupid that it prevents me from speaking to people.”

Participants with AN and BN further stated similar problems in relation to going to treatment (i.e., loss of career, leaving a child), and frustration from attempting to recover and failing. Similarly, participants who intentionally or unintentionally maintained their AN and BN expressed concerns about health as well as disruptions in social/family and professional lives caused by their ED.
4 Discussion

The present study aimed to explore how individuals make sense of their eating disorder in the pro-recovery forums. Two research questions were established as follows:

1) How do individuals with AN/BN relate to their ED?

2) Do individuals with AN relate to different aspects of their ED than those with BN?

The analysis revealed that themes “paradox of control” and “challenges” were the most distinctive themes in relation to how participants made sense of their ED. Moreover, ambivalent feelings and attitudes that were embedded in the posts represented another central theme that impacted on ways in which participants related to their ED. In a very general sense, participants could be split into two groups – those who maintained their ED “struggling”, and those who were in recovery “recovering”. The following paragraphs discuss the key findings identified within the themes in relation to both recovering and struggling individuals along with their impact on recovery process.

This study has confirmed that eating disorders play a significant role in lives of their sufferers as they not only impact on individuals' eating habits but also penetrate into other various aspects of their lives. Subjectively perceived extent of control was one of the central issues in participants' lives and appeared to determine how they related to their disorder. Some individuals who intentionally maintained their ED perceived to be completely in control of their eating disordered behaviours. According to previous literature (i.e., Orbach, 2005) these attempts to overly control own body may be associated with a limited control over other aspects of their lives (relationships, one's success, etc.). Brown (1990) suggested that women's preoccupation with weight and body reflects their need to gain a sense of control. Many participants in this study indeed reported that they perceived to have little
control over certain aspects of their lives (i.e., marriage, professional life). This may be explained by Williams, Chamove and Millar's (1990) study who found that individuals with ED display greater external locus of control as opposed to healthy individuals. External locus of control refers to individual's perception that their life is controlled by external forces rather than by themselves (Kalat, 1993). A link between low perceived control and eating pathology was further confirmed by Roth and Armstrong (1991).

Research has also revealed that eating disordered individuals with external locus of control show greater body-image distortions when they are supposed to do a task that they perceive as difficult in comparison with healthy controls. This was observed in participants who reported that their ED was in relapse as they experienced difficult or/and stressful period of life and felt helpless. Such perception of ED sufferers indicating individuals' low self-confidence were confirmed by previous research (i.e., Lamoureux, & Bottorff, 2005). Moreover, it is not surprising that these individuals often display learned helplessness in situations over which they perceive to have little control (Peterson, Maier, & Seligman, 1993).

The current study further found that some individuals intentionally maintained their ED to achieve certain qualities in life including happiness, attention and love of others, or self-confidence. Such phenomenon can be described by socio-cultural model of eating disorders. According to this model, cultural beliefs about what constitutes the ideal body image impact on how women' and men' bodies are constructed and perceived (Hesse-Biber, Leavy, Quinn, & Zoino, 2006). Many cultures including ours emphasise the image of a very thin women's body and present it in relation to success, health, happiness, love, and one's ability to control their lives (Hesse-Biber, Leavy, Quinn, & Zoino, 2006). Some individuals who are frequently exposed to such links internalize it, which in turn increases their body dissatisfaction and probability of developing and maintaining eating disorder (Stice and
Moreover, several participants in this study showed over-internalization of thin ideal (Stice and Shaw, 1994) in their belief that the only way to achieve all desired qualities in life is by maintaining a thin body. These participants often unconsciously used a psychological compensatory mechanism - avoidance of cognitive dissonance (Festinger, 1962) by focusing solely on positive aspects of their ED while ignoring negative ones. This prevented uncomfortable feelings from arising. Despite writing their experiences on pro-recovery forum, these participants maintained very strong beliefs about positive effects of ED which appeared to aggravate and postpone seeking help. This corresponds with findings by Tan, Hope, and Stewart (2003), in that individuals who intentionally maintain their ED and consider it a part of themselves find it difficult to recognize a need for treatment. Moreover, these individuals further reported feelings of sadness when they went to treatment because it meant losing a part of their selves (Tan, Hope, & Stewart, 2003).

Previous research into experiences of individuals who maintain their ED further showed that they often feel utterly out of control despite attempting to exert control over certain aspects of their lives via disordered eating (Brown, 1990). Such phenomenon - “control paradox”- proposed by Lawrence (1979) was observed in individuals with AN. Furthermore, these individuals perceived to have two separate parts of mind – an anorexic and non-anorexic. A typical characteristic of the anorexic mind was its controlling nature. Support for existence of separate anorexic entity in the form of mind or voice was provided by studies of subjective experiences with AN (i.e., Tierney, & Fox, 2010). These further confirmed that individuals with AN display high levels of control that are reflected in their AN-related behaviours including restricting food intake, excessive exercising, etc. (i.e, Jarman, Smith, & Walsh, 1997). As individuals in this study became more critical of their anorexic mind/voice and made attempts to recover, it started to question their actions, thus it often postponed help seeking and hindered engagement in treatment (Williams, & Leichner,
Existence of a separate mind/voice in individuals with BN was found neither by this study nor by previous literature into subjective experiences of BN.

Other participants in the present study maintained pathological eating to control their negative emotions or to control themselves. Such phenomenon were also documented by studies of subjective experiences of ED sufferers (i.e., Blay, 2009). These individuals also displayed greater cognitive dissonance in that they believed that eating disorders are wrong, unhealthy, and dangerous, but they also perceived themselves to be powerless against them. It should be noted, that many of these ED sufferers had another comorbid disorder and they used restricting or excessive eating as strategies to cope with their negative emotions that they were unable to control. Previous research found a link between individuals' low levels of control arising from lack of coping strategies and disordered eating patterns that follow social/emotional pressure (i.e., Osborn et al., 2013). This may explain why individuals who experienced overwhelming negative emotions or stress repeatedly resorted to restricting, or more often to binge eating/purging behaviours despite considering it wrong, dangerous, and unhealthy. Such inappropriate coping strategies were found to hinder a process of recovery and lead to poorer long-term outcome (Herpertz-Dahlmann et al., 2001). Considering the relatively high number of individuals who reported to be diagnosed with other comorbid disorder or to experience intense feelings of anxiety or depression in relation to their ED, professionals should conduct a comprehensive assessment of comorbidity before planning specific therapeutic strategies as a part of ED treatment (Milos, Spindler, Schnyder, 2004). Moreover, efficiency of ED treatment has been found to increase when it involves adopting skills to cope with difficult feelings such as anger, anxiety, or depression (Hinrichsen, Wright, Waller, & Meyer, 2003).

Another interesting finding is related to discrepancies between support that participants desired and received. Despite the fact that many participants reported to have
experience with talking about their ED with their family, friends, partner, professional, or other ED sufferers, the majority of them further stated to lack support. Moreover, only participants with BN reported adverse experiences with their family in relation to their ED, which is in line with previous research (i.e., Tiller et al., 1997). Nonetheless, Tiller et al. (1997) further noted that these individuals were likely to receive similar support from their families as did individuals with AN but the support was considered dissatisfying by BN sufferers. Participants' dissatisfaction with support was revealed by this study as well. However, it cannot be said whether only participants with BN, or also those with AN felt this way because the majority of participants who claimed to receive a dissatisfactory support only reported to suffer from ED (not specifically AN/BN).

What can certainly be stated though is that both AN and BN suffers perceived a lack of support in relation to their feelings of being misunderstood. BN sufferers are typically within the normal weight range or slightly under-/overweight (Habibzadeh & Daneshmandi, 2010). Individuals with BN who express their concerns related to having ED, are not recognized as having symptoms of the disorder and acknowledged by others (Gaillac, & Samuel-Lajeunesse, 1992). Such fallacy related to bulimia symptomatology was observed in the current study and surprisingly many participants themselves did not recognize they needed help because they thought they did not meet diagnostic criteria as they were normal/overweight. Individuals with AN are typically misunderstood in the opposite way, that is others perceive them as very skinny and recognize their problem while AN sufferers themselves do not (Rich, 2006). These individuals often seek support in other sufferers who have personal experiences with life with AN, and thus can understand them better (Rich, 2006).

As this study found, participants with ED considered a relationship supportive when it was understanding and non-judgemental, which was almost only managed by other ED
sufferers or participants' therapist. The importance of responsive, non-judgemental, and genuine relationship with a carer or therapist is an important prerequisite of effective treatment (Tierney, 2008). Furthermore, such relationship appeared to increase the participants' willingness to make little steps towards recovery. Fogarty and Ramjan (2016) found that when individuals make certain steps towards recovery from ED, they feel empowered by the changes they made and gain capacity to confront persisting aspects of their ED. This was observed in participants who reported to have taken some actions towards recovery and successfully managed to challenge their ED thoughts. Although the effects of online support of other sufferers have been less well studied in relation to recovery from eating disorders, they are showing to be beneficial. This was recently confirmed by Aardoom, Dingemans, Boogaard, and Van Furth (2014), who concluded that sharing experiences, finding recognition, and exchanging information with other ED sufferers in online pro-recovery forums are very important ingredients for successful recovery because they all contribute to individuals' empowerment.

The majority of participants in this study reported a desire to recover from ED, nonetheless they also expressed ambivalent feelings and attitudes towards the process of recovery. Previous research showed that these may hinder process of individuals' treatment, therefore they should not be neglected (Aubbate-Daga, Amianto, Delsedime, De-Bacco, & Fassino, 2014). Participants in the present study reported feelings of shame and embarrassment, concerns about their careers and children, or worries about losing control in relation to going to treatment. Furthermore, in line with previous research, several participants appeared to be ambivalent to change because of ego-syntonic nature of ED, that is they experienced symptoms of their ED as positive or comforting (Serpell, Treasure, Teasdale, & Sullivan, 1999). All these have been found to produce high drop-out rates (Wallier et al., 2009), relapse (van Son, van Hoeken, van Furth, Donker, & Hoek, 2010) as
well as poorer outcome (Fairburn, 2005). Therefore, Guarda and Heinberg suggested that individuals with ED must see their disorder as a problem rather than as a solution to other difficulties in their lives for the treatment to be successful (as cited in Thompson, 2004).

4.1 Implications

By providing insight into how individuals with AN/BN perceive and make sense of their eating disorder in the online pro-recovery forums, this study contributed to the current knowledge about issues individuals with ED are dealing with and perceive as difficult. These findings may help professionals who care for individuals with ED identify their patients' reasons for avoiding treatment, relapses, or poor outcomes of treatment. The clinical implications are as follow: firstly, the findings highlight an importance of conducting a comprehensive assessment of a patient with ED for comorbid disorders, along with a need to show the patient more appropriate coping strategies with difficult feelings they may be experiencing. Secondly, considering that the issue of control plays a central role in the life of an individual suffering from ED, it should be addressed and properly discussed during the process of treatment. Thirdly, individuals the experience of ambivalent feelings related to treatment and recovery from ED, these should be also addressed at the beginning of the treatment. And fourthly, based on findings of this study along with recent research into the effects of online support, professionals may inform their patients about existence and benefits of pro-recovery online forums where patients may receive adequate support from other ED sufferers. Furthermore, professionals should try to include those close to the patient such as family and friends within the process of treatment and enlighten them about appropriate ways of support.
4.2 Limitations

There are also methodological limitations to this study. The first one concerns the method of data collection and sits in line with previous research into similar phenomena with hard-to-reach populations. Although online observation was chosen as the most appropriate method for data collection, certain limitations of it should be pointed out. In correspondence with Ethical Guidelines for Good Research Practice (2007), due to using covert observation where there was no interaction with participants, I had no control of what experiences participants shared. Moreover, my position required filtering information about participants' experiences of ED through my interpretative frame, and did not allow for requesting further information about experiences that were relevant to the research questions (Schensul, Schensul, & LeCompte, 1999). The other limitation is related to inclusion criteria of sample selection. Although, inclusion criteria involved identification of oneself with AN/BN, I could not make sure that those individuals indeed met diagnostic criteria DSM-V (2013) for AN or BN. Furthermore, a considerable part of data were collected in eating disorder pro-recovery forums, where individuals did not specify whether they suffered from AN or BN, therefore I had limited data for exploring differences in lives of individuals with AN and BN.

Future research may benefit from employing interviews as a data collection method in order to overcome the limitations discussed arising from online covert observation. I suggest the research focuses on exploring differences between individuals' experiences with AN and BN. Considering the limited amount of up-to-date research into the subjective experiences of individuals suffering from BN, an emphasis of the follow-up study should be put on specificity of the life with BN and its comparison to previously relatively well-documented specifics of life with AN.
6 Conclusion

This study aimed to explore subjective experiences of individuals with AN/BN and how they make sense of their ED in the pro-recovery online forums. A conducted TA revealed that ED plays a central role in the life of AN/BN sufferers and impacts on many areas of their lives. An issue of control appeared to be an indicator of how individuals perceived and related to their ED. Furthermore, ways in which participants related to their ED impacted on challenges that they had to face. Their perceived extent of control then influenced the outcome of dealing with those challenges. The majority of decisions made by participants, that related to ED, appeared to be veiled by ambivalence which often made them question their decisions or reverse them. This may partially explain why so many individuals do not seek treatment for their ED, or postpone it.

All findings correspond with phenomenon related to ED that were documented by previous literature but the fact that they are provided from a perspective of ED sufferers brings a benefit of explaining their nature and function more authentically. These may be especially advantageous for strategies in clinical practice and the approach clinicians take with patients with ED. Despite methodological limitations regarding data collection method and sample selection, this study managed to upgrade the current research into the problem of eating disorders by confirming findings of previous literature and explaining them in a more authentic way contributing to a better understanding of the phenomenon of eating disorders.
References


http://dx.doi.org/10.1191/1478088706qp063oa


http://dx.doi.org/10.1002/eat.20367


http://www.qualitative-research.net/index.php/fqs/article/view/758/1644


http://eprints.uwe.ac.uk/21155/3/Teaching%20thematic%20analysis%20Research%20Repository%20version.pdf

http://dx.doi.org/10.1891/1559-4343.15.2.120

http://dx.doi.org/10.1001/archgenpsychiatry.2011.74

http://dx.doi.org/10.1192/bjp.186.2.132


http://dx.doi.org/10.1002/erv.775


DeWalt, K., & DeWalt, B. (2002). *Participant observation*. Walnut Creek, CA: AltaMira Press.


http://dx.doi.org/10.1111/j.1365-2648.2007.04569.x

http://dx.doi.org/10.1093/rsq/hdi0250


http://dx.doi.org/10.1002/eat.20112


http://dx.doi.org/10.1016/s0272-7358(98)00062-2


http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1188732/


http://orca.cf.ac.uk/60230/


http://dx.doi.org/10.1002/cpp.701


http://nbn-resolving.de/urn:nbn:de:0114-fqs0502430


http://dx.doi.org/10.1002/(sici)1099-0968(199906)7:3

Kendal, S., Kirk, S., Elvey, R., Catchpole, R., & Pryjmachuk, S. (2016). How a moderated online discussion forum facilitates support for young people with eating disorders. *Health Expectations, n/a-n/a.*


[http://dx.doi.org/10.1016/s0140-6736(13)60515-2](http://dx.doi.org/10.1016/s0140-6736(13)60515-2)


[http://dx.doi.org/10.1002/eat.10013](http://dx.doi.org/10.1002/eat.10013)

[http://dx.doi.org/10.1037/0022-006x.64.3.552](http://dx.doi.org/10.1037/0022-006x.64.3.552)


[http://www.qualitative-research.net/index.php/fqs/article/view/1567/3225#g34](http://www.qualitative-research.net/index.php/fqs/article/view/1567/3225#g34)


[http://dx.doi.org/10.1177/1359105315609088](http://dx.doi.org/10.1177/1359105315609088)


[http://dx.doi.org/10.1177/174701610600200303](http://dx.doi.org/10.1177/174701610600200303)

[http://dx.doi.org/10.1080/14733145.2010.486864](http://dx.doi.org/10.1080/14733145.2010.486864)


[http://dx.doi.org/10.1002/(sici)1098-108x(199903)25:2](http://dx.doi.org/10.1002/(sici)1098-108x(199903)25:2)


81


http://dx.doi.org/10.5172/conu.19.1-2.75

http://dx.doi.org/10.1186/2050-2974-1-17


http://dx.doi.org/10.1089/10949310050191755


Appendices

Appendix A – Research reflection

I have always found eating disorders interesting, especially because I think that beliefs, attitudes, and behaviours of individuals suffering from ED are contrary to a healthy human development. I believe, human thinking is closely related to a society, in which we grow up, its rules, traditions, and importantly to its values. These impact on ways, in which we perceive and make sense of the world around us. Therefore, I chose social constructionism as lens to explore how individuals with eating disorder perceive and make sense of their ED. Based on this epistemological position, participants perceptions were viewed as subjective and not necessarily true for all individuals suffering ED. Moreover, participants' social and cultural backgrounds were considered factors impacting on ways, in which these individuals perceived and related to their ED.

Stories of individuals with ED were familiar to me and I think, I was able to understand them deeply since I have an indirect experience with what life with ED feels like. Nonetheless, eating disordered thinking and behaviours have always been in contrast to my rational thinking and making sense of things around me. Thus, choosing to explore this topic from sufferers' perspectives was challenging but also valuable for me.

Prior to data collection, I thought that despite the limitations, online forums may provide different, more authentic experience of life with ED. At this point, I still think that the data might be slightly different from those collected by interviews. On the other hand, considering that online support forums are social environment similar to face-to-face data collection methods (i.e., interviews, focus groups), in that individuals make connections with others and openly discuss their problem, I do not consider reported experiences more authentic. Moreover, during process of analysing the data, I realised that I was interested in finding out more details about certain things mentioned by participants, which was precluded by employing covert online data collection.

All in all, if I were to conduct another qualitative research of subjective experiences of individuals suffering from ED, I would use a different data collection method that would enable to inquire details relevant to the subject of research.
Appendix B – Mind map of three identified themes, subthemes, and codes

How do people make sense of their ED in pro-recovery forums

- Desire to (re)gain Control over ED
  - Stress
    - Lost of hope
    - Lack of strength
  - Being misunderstood
    - Loneliness
    - Shame
    - Ambivalence towards recovery
    - To recover from ED
      - Concerns to share their problem
      - Ambivalence towards ED
        - ED-related thoughts
          - Weight gain
            - Fat
            - Control
            - Self-hatred
          - Ambivalence
            - To maintain ED
              - Health concerns
                - Work/School
                - Family/Partner
                - Social life
              - Interference of ED
                - Ambivalence towards ED
                  - Other sufferers
                  - ED thoughts vs. its consequences
                  - Lost/Little control Over ED
                    - Feel more or less in control of ED
                      - Burdening others
                        - Being misunderstood
                          - Guilt, remorse
                          - Control vs. “Lost” of control
                          - Eating: awesome and terrible
                          - No social life vs. ED thoughts
                          - Get help vs. leave a child
                          - Get help vs. being embarrassed