“What is the emotional experience of a person who has suffered from Anorexia Nervosa?”

Jemma Meeson

A thesis submitted for the degree of Professional Doctorate in Systemic Psychotherapy

Department: Tavistock & Portman NHS Trust

University of Essex

Date of submission for examination September 2024

Acknowledgements

I am so lucky to be surrounded by many amazing people, but there are some that need a special mention here, without whom I would not have got through this process, which has felt endless for everyone involved.

Jasmine, Felix and Iris: Thank you for allowing me to do this whilst also being your mum, I hope you will understand why I did it one day and be proud of me.

Dad: Thank you for being my biggest supporter and inspiring me every day.

Britt, Juliet, Corrine and Zara: thank you for the help and guidance, dealing with endless questions and tears and believing in me when I didn’t.

Lara and everyone at FTS: thank you for tolerating my absence and working so hard to develop a service we can be immensely proud of.

Wendy Whitaker, the most inspirational social worker and human, and Janet Treasure, who both taught me so much about thoughtfulness, compassion and the importance of continuing to learn and adapt our ideas in psychiatric treatment.

Charles who held everything together always and enabled me to engage in another one of my far-fetched ideas and aspirations.

Most importantly- Thank you Rich, who literally saved my thesis.

Abstract

Manualised family therapy approaches are often used in treatment for those with Anorexia Nervosa (AN). Despite evidence of its efficacy, there is a lack of focus on targeting emotional management difficulties and addressing individualised goals for recovery. This study aims to understand the lived experience of those with AN, and their views on emotions and recovery, to better inform practice.

Methods

Participants with a formal diagnosis of AN who deemed themselves to be in ‘recovery’ were eligible for this study. Five semi structured interviews were conducted, and recordings were transcribed verbatim. Data was analysed using reflexive thematic analysis in MAXQDA software.

Results

Five White British women participated, and five main themes were generated to describe their emotional experience in relation to AN and recovery. These were; (1) My emotional experience in my family of origin, (2) This feels intolerable, (3) How my body got involved, (4) Modulating and suppressing emotions, and feeling in control, and (5) The journey to recovery.

Conclusions

More effort should be undertaken to understand the personal experience of those who seek treatment for AN, particularly in relation to emotional efficacy and management. Additionally, a collaborative approach by clinicians, addressing clearly identified and individualised goals for recovery identified by those they are treating, may be of benefit.

Contents

1. Introduction

According to the Diagnostic and Statistical Manual Fifth Edition (DSM V), Anorexia Nervosa (AN) is an Eating Disorder (ED) characterised by the following: (1) The restriction of energy intake relative to requirements which leads to significantly low body weight in the context of age, sex, developmental trajectory, and physical health; (2) An intense fear of gaining weight or becoming fat, even though underweight, and (3) Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the current body weight (American Psychiatric Association, 2013, pp. 338-345)

The UK charity for eating disorders (EDs), Beat, estimates that 1.25 million people in the UK have an ED (Beat, 2023). It is not possible to separate the different types of EDs in the research and, thus, we do not have an accurate picture of how many people experience AN specifically. The overall incidence rate of EDs has remained stable over the past decade; however, there has been an increase in the rate of ED’s among 15–19-year-old girls. This could be a result of earlier detection or the average age of onset becoming earlier (Smink et al., 2012). Evidence shows that up to 97% of those with AN have a comorbid diagnosis, meaning that they have also been diagnosed with another mental health disorder. Most commonly these are mood disorders, anxiety disorders and substance use disorders (Blinder et al., 2006).

Despite our increased understanding, questions remain about the pertinent factors related to development, treatment, and recovery in EDs (Treasure et al., 2020). EDs are important health concerns due to their longstanding psychological and physical effects. Due to physical complications, AN has one of the highest mortality rates of any psychiatric illness (Auger et al., 2021). It is notoriously challenging to treat, with many sufferers being resistant to change, specifically, gaining the necessary weight, given that weight gain is strongly associated with fear (Borgers et al., 2021). Research into factors that both contribute to and maintain the course of the illness is important, because of the impact of AN and complexities with treatment. In particular, further understanding of the emotional experience of individuals with AN appears to be an important focus, as understanding the meaning of AN to those who experience it indicates a positive effect on both treatment adherence, and outcome (Darcy et al., 2010; Federici & Kaplan, 2008).

As a family therapist working in the field of EDs, and specifically AN, I have noticed an overwhelming quantitative focus on the clinical and physical aspects of the illness, and outcomes of manualised family therapy treatments, with a distinct lack of research aiming to understand the perspectives of those who experience it. When speaking to those who are unwell, and their families, they describe that their needs are not being met when it comes to supporting them to manage their emotions.

Therefore, this research aims to present the voices of those who have recovered from AN regarding their emotional experience across the lifespan. This includes the way emotions were expressed in their families of origin, during the course of their illness, and in recovery. It seeks to understand the nuanced emotional landscapes experienced during the journey through AN and provide qualitative knowledge that can contribute to an understanding of what is required to overcome it.

Understanding the emotional experience of AN enables clinicians to offer more holistic support that can be adapted to the needs of those that they are treating. By validating the emotional experience of sufferers of AN, and including these experiences in treatment, it may also empower individuals in the recovery process. This goal of this study is to contribute to the field by highlighting the importance of including emotional experience in our work with those seeking help.

This research is grounded in a social constructionist epistemological position, recognising that meanings and the experiences of emotions and recovery are constructed through interactions and cultural narratives. By adopting this approach as a researcher, I seek to capture the subjective and contextualised nature of the emotional experience of those with AN, moving beyond reductionist or pathologising views of the illness and recovery process.

1.1 Research objectives and methodological approach

The research question is:

“What is the emotional experience of a person who has suffered from anorexia nervosa?”

with the following sub-questions:

- What is the experience of AN sufferers of their emotions?
- How do sufferers of AN report the emotional context of their family of origin?
- Do they see a link between their AN and the management of emotions?

This study uses a thematic analysis approach to capture the depth and complexity of the qualitative data. In-depth semi-structured interviews were conducted with five participants who self-identified as being in recovery from AN following a formal diagnosis according to the DSM-V criteria.

1.2 Structure of this thesis

The thesis is structured as follows.

Background

An introduction to the wider literature on AN, emotions, and emotional experiences, including the aetiology and treatment approaches.

Literature Review

This chapter comprises an overview of qualitative research exploring perspectives of those with AN concerning their emotional experiences, followed by a review of the literature and research related to family therapy and AN.

Methods

A detailed account of the research design, including the rationale for thematic analysis, data collection and interview process, and ethical considerations.

Findings

The presentation of the key themes and patterns identified in the data, with illustrative quotes from the participants.

Discussion

An interpretation of the findings in relation to existing literature, theory, and clinical practice, as well as reflexivity concerning me as a researcher.

Conclusion

This section is a summary of the research findings and their implications for clinical practice, as well as suggestions for future research. I consider the distinctive contribution of this study and include my final reflections and my learning from this research process.

2. Background

2.1 Introduction

I have worked in the field of EDs for over 10 years, first as a social worker on an adult inpatient unit, and then as a family therapist on a child and adolescent inpatient unit. I am currently the clinic director of a private outpatient mental health service in London. During this time, I have been trained in the Collaborative Care Model (Treasure et al., 2015), Family-Based Therapy (new Maudsley approach) (Lock & Le Grange, 2015), and the FT-AN approaches (Eisler et al., 2000). I have also trained in and delivered emotionally focused family therapy for EDs (Dolhanty & Greenberg, 2007), and Multifamily groups (Eisler et al., 2016).

Despite these manualised models being prevalent as the treatment focus in family therapy in the treatment of EDs, I have also been lucky enough to have a degree of flexibility in my work and to deliver more ‘general’ family therapy approaches using systemic ideas from the structural (Minuchin et al., 1978), narrative (Dallos, 2003), and attachment (Byng-Hall, 1995) approaches, amongst others. Working in an inpatient setting, in a medical model, has led me to become much influenced by the ‘evidence base’ when it comes to the treatment of AN. Although these approaches have been extremely effective in treating many, I have also witnessed individuals not experiencing the same benefits. This led me to be curious about how existing models could be tailored to consider individual’s unique experience, and to include their views about what needs to be addressed in treatment to support their recovery journey. Given this background, and my own clinical experience, it was important to adopt a more social constructionist position and to remain curious about the meaning of AN to those with lived experience.

I am going to begin by outlining the evidence base that has formed my understanding of AN and treatment whilst reflecting on my position. I will first describe AN, the treatment course, epidemiology, and risk/maintenance factors. Following this, I will review the literature related to emotions, paying particular attention to the social constructionist model of emotions, and the role of emotions in the development and maintenance of AN. I will also provide a brief overview of family therapy approaches used in treatment, and touch on perspectives of recovery.

2.2 Risk and maintenance factors and models

Those who have developed AN appear to have an increased level of individual vulnerability traits such as perfectionism, anxiety, and obsessionality (Karwautz et al., 2001). There is also evidence that sensitivity to perceived external threats, internalising of feelings, and underlying anxiety is present before the onset of ED (Adambegan et al., 2012). Social anxiety and loneliness often pre-dates the development of AN (Swinbourne et al., 2012), with sufferers reporting difficulties making friends and having poor social networks (Fairburn et al., 1999). Those with AN are more likely to compare themselves to others, and judge themselves based on external standards (Hambrook et al., 2011; Troop et al., 2003). They are also more likely to engage in submissive behaviour such as being passive, and be overly willing to give way to others in a social and family context (Troop et al., 2003). This is further discussed later in this chapter.

Moreover, those with AN are likely to have experienced bullying about their weight or shape (Menzel et al., 2010) and to have an idealisation of thinness, resulting in weight concerns (Keel & Forney, 2013). Tozzi et al. (2003) asked people with AN in referral interviews to an ED service which factors they believed contributed to the development of their ED. The participants responded with notions of perceived pressure, weight loss and dieting, stressful experiences, and dysfunctional parenting, implying the likelihood of various factors interacting to create a “perfect storm”.

There is also a prevalence of coexisting mental health difficulties. In a large cohort, Swinbourne et al. (2012) found that 65% of those presenting with an ED had a comorbid anxiety disorder (the most prevalent being social anxiety), with 69% of them reporting this existed prior to the ED. A disposition to heightened anxiety has also been documented by Kaye et al. (2004), as well as an increased sensitivity to punishment and reward (Jappe et al., 2011), and social threat (Schmidt & Treasure, 2006a).

Traits have been identified in those who develop EDs that make them more susceptible to social rules (Schmidt & Treasure, 2006a). For example, extreme social compliance has been demonstrated to exist before the development of AN (Fairburn et al., 1999; Karwautz et al., 2001). These individuals also have an increased vulnerability to be intensely detail-focused (Lopez et al., 2008) meaning that there may be a higher sensitivity to expectations on their appearance and the socio-cultural norms around the way one looks (Schmidt & Treasure, 2006a).

Treasure and Schmidt (2006a) present a cognitive-interpersonal maintenance model in which these underlying traits indicate that when dieting is triggered, it is “undertaken meticulously and the rules and rituals become embedded as rigid habits” (Schmidt & Treasure, 2006a, p. 3). This ensures success, leading to impaired brain functioning through starvation, which further enhances adherence to the diet as the ability to derive meaning from detail is reduced (Harrison et al., 2012), creating a self-reinforcing cycle which is very difficult to break out of. This biopsychosocial model is the one which I am most familiar with from my work in ED inpatient treatment.

Lester (2019), an anthropologist, social worker and researcher with lived experience of an ED, presents a model which proposes the relational nature of AN and describes it’s various functions. In her model, she categorises these as follows: 1) Ambivalent anaesthesia: numbing and intensifying, 2) Cultivating emotional states, 3) Suppressing emotional states, 4) Modulating emotional states by managing sensation and affect, 5) Ethical commitments: being “good” or conforming, and 6) Using the ED to ‘present’ and ‘conceal’. This resonates with me in my experience of those with AN, and highlights elements that often appeared overlooked in medical approaches to treatment which have a focus on weight gain.

Gulliksen et al. (2017) also propose a multistate model, referring to both internal and external experiences contributing to the development and maintenance of AN. Their social constructionist research collected data through interviews with a sample of 36 women aged 18-51 years. She and her colleagues outline precursors (conditions reported before the developments of the AN), triggers: “distinctive events that were linked in the participants’ narratives to the onset of the eating disorder” (p. 850), and self-determination: “the degree of which participants were aware of how external or internal reinforcers motivated their anorectic behaviour” (p. 851). They posit that these factors combine to contribute to the development of AN, which is maintained by ‘reinforcers’ that are external (e.g. positive comments about weight loss) or internal (e.g. feeling comforted). The research also outlines four distinct sub-types of AN sufferer which are recognisable to me from my experience: “avoidant,” “achiever,” “transformer” and “punisher.”

The avoidant subtype has strong precursors related to eating such as pickiness, shyness, loneliness, and a preoccupation with negative opinions about themselves. This group makes only modest references to ‘triggers’ and describes how they have lived with their problems ‘as long as they can remember’. In addition, they have low awareness of self-determination, e.g., they “accidentally discovered that starving themselves reduced feelings.”

The Achiever subtype refers to a distinct point of onset of the AN and one or two distinct ‘triggers’. They describe precipitating events, but these are not typically linked to diet; more commonly, they cite perfectionism or low self-esteem. For this subtype, the development and maintenance of AN was entered into voluntarily with a high awareness of self-determination.

The Transformer subtype describes an experience before the development of AN as being ‘unsuccessful’, for example, individuals feeling unhappy with their weight or struggling to make friends. Those in this category only have modest references to distinct events as ‘triggers’. The development and maintenance of ED is viewed as voluntary, with a high degree of self-determination and awareness, and they experience a sense of mastery of the illness.

The Punisher subtype describes pre-existing factors such as intense self-hatred from an early age, which can be further triggered in puberty. They appear to slowly discover how AN can be a means to punish or distinguish themselves and tend to refer to the emergence of the illness as a gradual process in interviews.

The idea of the role of AN as ‘punishment’ is supported in research by Harrison et al. (2011), indicating an enhanced sensitivity to it in those with EDs, and specifically, a reduced response to reward in those with AN. This trait was also present in those who had recovered, indicating that it may be an underlying personality trait associated with a vulnerability to the development of an ED. Among all of these presentations, Gulliksen (2017) describes a ‘sense of mastery’ as common, whereby participants describe their AN behaviours as helping them to overcome challenges. The author suggests that a sense of mastery is a central theoretical concept that could be present in all AN development.

Along with individual psychological factors, various biological markers have been identified. However, this is beyond the scope of this research and the aims of the study. For a review of biological factors please see Treasure (2007).

2.3 Family factors

The role of context, particularly the family context, is central to our understanding and development of emotional experience (Bowlby, 1969; Powell et al., 2009). One cannot assume causation from individual recollections alone; indeed, families remain a core and critical resource for recovery (Magill et al., 2016; Treasure et al., 2003; Whitney et al., 2012). However, the way emotions have been experienced, modelled and soothed in the family provides an important template for one’s emotional world.

Those with AN have been shown to rate their families of origin less favourably than the general population (Holtom-Viesel & Allan, 2014; Woodside et al., 1996). However, the reasons for this are unclear. When family functioning is separated into individual categories to look at emotions, organisation, and communication, the findings vary considerably and can contradict each other (Mcdermott et al., 2002). Erriu et al. (2020) argue that the variation in these results itself demonstrates the complexity of family relationships for those EDs.

The concept of the “double bind” (Bateson et al., 1956) is also important to acknowledge in systemic formulations, due to its contribution to shifting the focus from individual pathologisation to relational processes. Originally proposed to understand familial interaction contributing to the development of Schizophrenia, Bateson and his colleagues describe a pattern where someone receives conflicting messages, with one that negates the other, creating a landscape where no response is adequate and the contradiction cannot be resolved. They argued that the presence of this leads to an impairment in one’s ability to interpret reality. I describe this concept here as it is referred to later in the thesis.

Research indicates the “anorexic family” have difficulties with interpersonal boundaries (Kog & Vandereycken, 1989), and a conflict-avoidant communication style (Minuchin et al., 1978). There is also a well-documented link between continuing symptoms and emotional expression/ critical comments by parents (LeGrange et al., 1992; Szmukler et al., 1985; Zabala et al., 2009). In a sample of individuals deemed recovered from eating concerns, Haslam (2012) found they linked the development of difficulties to recollections of a parental environment that did not validate feelings. They also found, in the same sample, reports of emotional expression being perceived by family members as a weakness. In the same vein, it has been shown that conflict resolution skills and open communication between fathers and daughters can act as protective factors against an ED (Botta & Dumlao, 2002).

The data is mixed on the impact of parent’s relationship with eating, weight, and shape and the development of ED’s. Senra et al. (2007) found links between AN and the importance placed on thinness within a family. A relationship has also been found between negative feelings between mothers and daughters and emotional eating as a coping strategy (Blissett & Meyer, 2006; Elfhag & Linne, 2005); however, this was not indicated for mothers and sons (Elfhag & Linne, 2005).

Although parental dieting was not indicated as a risk factor by Karwautz et al. (2001), their research suggested a vulnerability to the development of AN linked to poor childhood feeding, and restriction of food by parents was also identified as relevant in the research of Andrews and Brown (1999). Parental negative comments is also linked to weight dissatisfaction (Keel et al., 1997; Tremblay & Lariviere, 2009), and, in particular, from mothers (Tremblay & Lariviere, 2009).

As mentioned earlier, AN is often characterized by high levels of perfectionism both during the illness and after weight restoration (Bastiani et al., 1995; Nilsson et al., 2008; Stackpole et al., 2023). Those with AN appear to have parents with higher expectations of them (Karwautz et al., 2001), which could contribute to the development of the illness. In their cognitive-interpersonal model, Treasure and Schmidt (2006a) suggest that shared genetic traits in parents of those with eating disorders can lead to difficulty in managing ED behaviours, and create a “battle for control” (p 4) which further exacerbates the symptoms. It is acknowledged that caring for someone with an ED is extremely stressful, and the supervision and support that is often required from parents can be overwhelming (Whitaker & Macdonald, 2008). This can lead to high levels of distress and emotional expression, creating interpersonal strain between the parent and child (Kyriacou et al., 2008).

In this context, there is often a high level of “expressed emotion” which can negatively influence treatment outcomes (Butzlaff & Hooley, 1998; Dare & Eisler, 2000; Szmukler et al., 1985; Zabala et al., 2009). The accommodation and reorganisation of the family system around the ED can also prevent changes that are necessary to enable recovery (Eisler, 2005). In the context of stress and highly expressed emotion, parents can fall into invalidating communication patterns which may lead to sufferers to be less likely to seek emotional support (Linehan, 1993).

In much of the research summarised here, and the majority of other studies, parents are represented as a single entity, as researchers do not distinguish between them by gender. It is important to acknowledge that the roles of fathers and mothers are not identical, and differences need to be explored and considered. From a feminist perspective, mothers have also been the main focus of pathologisation, perpetuating ideas about caregiving being a female responsibility, and a societal expectation of “perfect” mothering that is impossible to achieve Fallon et al. (1994).

Despite little research isolating the role of fathers, there is some evidence of strong attachments between girls with EDs and their fathers (Ward et al., 2000) and a lack of support from fathers has been identified as a risk factor for developing disordered eating (McVey et al., 2002).

This limitation of existing research also applies to the gender of those experiencing AN. Although there is some research on gender difference in ED symptoms and prevalence (Striegel-Moore et al., 2009), the bulk of research has been conducted with those identifying as female. Although some researchers claim that in adolescents protective and risk factors do not differ significantly between young men and young women (Argyrides et al., 2020), many others would argue that there has been a lack of focus on males in ED research, and that they are overlooked in diagnosis and treatment (Nwuba, 2024). There is also very limited exploration of marginalised sexual identities in research. It has been indicated that lesbian women have linked the development of their ED to “coming out” (their words) in heteronormative contexts, and further research is important to understand differing experiences (Jones & Malson, 2013).

Attachment

Anxiety in attachment relationships has been linked to the development of an ED. Illing and colleagues (2010) found that higher anxiety over attachment with parents related to increased symptom severity and poorer treatment outcomes. Increased attachment anxiety has also been linked to difficulty in differentiating the self, and reduced self-concept (Demidenko et al., 2010) which, in turn, are also risk factors for the development of AN.

In their questionnaire study, Ward et al (2000) examined adult attachment relationships in a sample of those with AN receiving inpatient or outpatient ED treatment, and a control group. The authors found that there was no link between a particular attachment style and the development of an eating disorder. However, those with a diagnosis of AN scored more highly in "compulsive care seeking" and "compulsive self-reliance" categories. This indicated a "pull-push" dynamic in their attachment relationships, representing a dual intensity of closeness and then distance. Anxiety in attachment may also be reflected in tendencies towards overprotection; In their study of 108 mothers of those experiencing an ED, Amianto and colleagues (2013) found a higher number of "fragile, dependent" mothers of those with EDs than in the general population, and recommended that interventions should seek to understand the personality traits of parents.

The empathy of caregivers seems to stem from their early ability to tune in to the emotional states of both themselves and others' (Eisenberg et al., 1998; Eisenberg et al., 2001). Additionally, childhood emotional inhibition appears to play a role in mediating the connection between childhood emotional invalidation (Linehan, 1993), and later acute psychological distress in adulthood (Cozzarelli et al., 2003). The development of emotional awareness through caregiver interactions has been extensively explored in various classical theories, including psychodynamic perspectives; for example, Klein's (1952) modelling theories (Kugiumutzakis et al., 2005) and attachment theory (Bowlby, 1969).

2.4 Treatment of anorexia nervosa

AN can be difficult to treat and with poor outcomes, especially among those with a longer illness course. Hypothesis as to why treatment is difficult are numerous, and include the difficulty in building a strong therapeutic alliance with clinicians (Vitousek et al., 1998; Warren et al., 2009), patients being ambivalent to change (Williams & Reid, 2010), with underlying comorbidities and personality traits that reinforce the ED symptoms, such as perfectionism and obsessionality, creating difficulties in treatment (Schmidt & Treasure, 2006a). Symptoms also appear to serve important psychological functions and coping mechanisms for those experiencing an ED, making them feel important to hold on to, and difficult to lose (Cockell et al., 2002; Nordbø et al., 2008; Serpell et al., 1999).

There are several treatment approaches for AN and mixed evidence regarding a clear recommendation of any one modality (Bulik et al., 2007; Fairburn et al., 2005). Current guidance for the treatment of adults from the National Institute for Health and Care Excellence (NICE) recommends specialist cognitive behavioural therapy (CBT-ED), the Maudsley Anorexia Nervosa Treatment for Adults, and Specialist Supportive Clinical Management. For the treatment of children, FT-AN is the recommended treatment of choice. Of note, qualitative studies with those who have recovered from AN indicate that although therapy is cited as contributing favourably, there are other factors that they deem to be equally significant, e.g., supportive relationships (Federici & Kaplan, 2008; Tozzi et al., 2003), awareness and tolerance of negative emotion and self-validation, and the perceived value of treatment experience (Federici & Kaplan, 2008).

2.5 Review of systemic literature

As a systemic researcher, a review of the relevant literature about AN and an understanding of the systemic contribution to the field of Eds is important. The starting point for this is Minuchin's description of the "psychosomatic family'' (Minuchin et al., 1978). He described AN as a symptom of a family system that featured enmeshment, rigidity, overprotectiveness, and difficulty with resolving conflict. This led to presenting a model in which working with the whole family in therapy to produce change would remove the need for the AN. His research with 53 adolescent participants showed that after a follow-up between 2 to 3 years after treatment, 86% of those treated with family therapy were deemed to be 'recovered'. However, of his sample, over half were also admitted for inpatient treatment during their illness and, thus, it is difficult to isolate family therapy as the sole contributor to this high success rate.

Building on the work of Minuchin et al., the first controlled trial at the Maudsley Hospital was conducted by Russell et al. (1987). Their approach was based on structural ideas; however, it included the parents engaging in refeeding their child until their weight had been restored. In their quantitative research, family therapy was most effective in those who had a short history of AN and had developed it before the age of 19. For those who had a later onset, individual therapy was found to be more effective. At a five-year follow-up, significant improvements were found across the whole participant group, which the authors attributed to a natural outcome (Eisler et al., 1997). There was also evidence, however, that the two groups described above still had significant benefits that could be attributed to their treatment. The findings that those with an adult- onset of ED appeared to do better in individual therapy, led to Eisler and team examining therapeutic alliance and the engagement of families (Eisler, 2014), and The wider family therapy field was also moving away from the pathologising of families in this period, influenced by ideas such as Hoffman's in regards to power and control, and "lenses" (Hoffman, 1990).

Extensive research at the Maudsley has led to the development of manualised interventions which are currently the NICE guidelines treatment of choice, and delivered in many services. There is also an idea that these can be delivered by those who are not trained in family therapy, however Eisler is clear that one should not "assume the manual is the treatment," or "assume that the only way to do the treatment is to do it exactly as described in the manual" (Eisler, 2014, p. 28). This means that both the alliance between clinician and family is vital, as is clinician experience and the knowledge and skills required to be flexible in it's delivery.

Eisler et al. (2005) argues that studying family functioning is difficult due to a limitation in study design. Factors that are exhibited in families in which someone has AN, such as conflict avoidance, may be due to the illness itself and do not demonstrate a causal relationship. They argue that there is a danger in focusing on factors that have led to the development of the eating disorder. Instead they suggest, as also recommended by Schmidt and Treasure (2006a), that clinicians should consider what is maintaining the illness and focus treatment there, and treat those with ED's in specialist services that integrate different treatments (Eisler, 2014).

It is important to acknowledge the critique that the focus on family dynamics in family therapy can result in ignoring broader systemic issues, particularly from the feminist perspective (Fallon et al., 1994; Maine, 2008). Feminist approaches emphasise the importance of considering societal pressures such as patriarchal control over women’s bodies, beauty standards and the thin ideal (Bordo, 2023; Orbach, 1993; Rasch & Wolfe, 2000). These factors can also be overlooked in treatment by an intense focus on refeeding in manualised treatments and medical models (Lester, 1997).

Caregiver burden

There appear to be several commonalities in how families are reorganised when AN is present, and the way they report it affects their family. Several quantitative studies have reviewed caregiver burden, such as that by Kyriacou et al. (2008), who assessed strain associated with caregiving and psychological distress using self-report measures in 151 parents of children with AN. They found carers scored above the clinical threshold for depression and anxiety and suggesting this may affect the outcome of treatment.

However, more recent research does not support this; Matthews et al. (2023) used quantitative measures to assess caregiver burden in 114 primary caregivers during their adolescent child being treated with family-based therapy in the United States. Although their sample also met the threshold for anxiety and depression, they propose that the caregiver burden was not associated with weight gain in their child with AN at 3 or 6 months. These contradictory findings could support that the “third” factor of engagement with clinicians, as posited by Eisler (2014) is the “difference that makes a difference.”(Bateson, 1972, p. 459)

Eating disorder family therapy

There are several evidence-based manualised approaches for family therapy in EDs. The general principle for the approach is a focus on working with the family to improve self-efficacy. In Maudsley family therapy models (Eisler et al., 2016), the family-based treatment model (Lock & Le Grange, 2015) and the Collaborative Care Model (Treasure et al., 2015), the initial focus of treatment is on eating and weight restoration, with a structural approach to the parents ‘taking control’, and aspects of family functioning considered once there is an improvement of physical health. The emotion-focused family therapy model (Lafrance et al., 2014) works solely with parents to support them to validate their child’s emotional experience, and undertake relationship repair to allow the sufferer to ‘let go’ of the eating disorder as a coping mechanism.

Family-based therapy (FBT)

FBT was developed into a manualised approach by Lock and Le Grange (2001) in order to conduct research and replicate the work across treatment settings. It is based on five key tenets (Rienecke & Le Grange, 2022):

(1) The therapist holds an agnostic view of the cause of the illness.
(2) The therapist takes a non-authoritarian stance in treatment.
(3) Parents are empowered to bring about the recovery of their child.
(4) The eating disorder is separated from the patient and externalised.
(5) FBT utilises a pragmatic approach to treatment, with a focus on the here and now.

Treatment is undertaken in three phases. Parents take control of food and meals in phase one. Following this, in phase two, responsibility is given back in an age-appropriate way. Finally, in phase three, there is a review of other factors that may need addressing such as family functioning.

A quantitative randomised clinical trial (RCT) undertaken by Lock et al. (2010) compared FBT to adolescent-focused individual therapy in 121 participants aged 12-

18 years old who received 24 hours of outpatient treatment over 12 months. They were assessed at the end of treatment, and six and 12 months post-treatment. Outcome was measured by remission rates, defined as maintaining normal weight and Eating Disorder Examination (EDE) questionnaire scores. At treatment end, there was no difference between the two cohorts in remission. However, FBT was superior at six and 12 month follow up. Conversely, the EDE score showed greater changes in those given FBT at the end of treatment, however, this was not significant at six and 12 months.

Datta et al. (2023) undertook a large quantitative study of 724 participants across six clinical trials in Canada and the USA to compare parents of children with AN receiving FBT to other treatments. They proposed that assumptions were made about whether FBT was appropriate based on how families were presented by referrers and, as such, access to treatment was restricted. They assessed several family and demographic factors and found that socioeconomic, demographic and clinical variables in parents do not predict treatment outcomes. The only significant affecting variable was whether families had previous FBT treatment, which appeared to lead to poorer outcomes. The authors posited that this indicates that FBT can be useful in a variety of different family presentations.

The evidence base for the approach is mixed. Contrary to Eisler’s assertions that the manual should be a basis for working, others argue that clinicians not adhering to the manual is responsible for poorer outcomes (Rienecke & Le Grange, 2022). In a study of 117 clinicians who used FBT in treatment, a third of them reported deviating from the approach, specifically offering individual therapy, mindfulness techniques and different uses of the set tasks (Kosmerly et al., 2015).

This is in line with my experience of the views of clinicians who have expressed that they want to offer a more tailored approach, and “more” than the manual.

Multifamily groups (MFT)

The multifamily group model has been used in the treatment of EDs since the 1980s to improve parental self-efficacy and family relationships (Slagerman & Yager, 1989). Further models have been developed by Dare and Eisler (2000), using the principles of ED family therapy. Manualised versions of AN (MFT-AN) for adolescents (Simic et al., 2021) and adults (Tantillo et al., 2021) have been adapted and used in settings across the world, with varying models regarding participant numbers, and workshops duration. There is, however, a commonality in focus on group activities withpatients, their parents and siblings, both separated and together, and the inclusion of shared meals supervised by clinicians. This variability in treatment, and its delivery alongside other treatments such as inpatient or outpatient interventions, means that it is understudied, and findings are hard to generalise. However, the evidence base points to the best outcomes being with adolescents in outpatient settings (Baudinet et al., 2021).

The largest study of MFT was undertaken by Eisler et al (2016) with 167 participants aged 12 to 20 years old across multiple settings. They were randomised into two groups, one receiving outpatient family therapy for AN and the other receiving this plus 10 days of MFT. Quantitative measures of weight, eating disorder psychopathology and mood, as well as caregiver burden, were recorded. Although those who received the MFT had better outcomes at the end of the treatment, this was not statistically significant at the six-month follow-up. However, those who had attended MFT did maintain a higher BMI.

Tantillo et al. (2019) also quantitatively examined the multifamily approach in adults with 10 participants and 14 family members in outpatient treatment. They used the EDE measure as well as weight (BMI) and the Difficulties in Emotion Regulation Scale. The EDE and emotional regulation scales showed significant improvement in both the end-of-treatment and six-month follow-up results. However, weight gain at both stages did not improve.

A systematic review of qualitative studies by Baudinet et al. (2021) examined 10 studies which included data from individual and group interviews with those experiencing AN and their family members. The results highlighted that parents felt they had gained new perspectives, learnt new skills and increased in confidence, as well as had a space to share their experiences. There was not, however, any mention of increased skills or understanding in supporting a loved one with AN with emotions across the studies.

Collaborative care

The Collaborative Care Model of treatment of adults with AN developed by Treasure et al. (2015), is considered to be instrumental in the inclusion of parents and loved ones of adult patients. A group workshop intervention is offered which includes psychoeducation about the ED and practical skills to support those who are caregiving to address behaviours associated with AN. By offering this resource, it is hoped that carer distress and burden, as well as ‘expressed emotion’ is reduced, contributing to a more conducive environment in which to work towards recovery.

A qualitative study of the workshops with 35 carers from 30 families was undertaken by Sepulveda et al. (2008). They attended six workshops in twelve weeks and measures were taken at the end, and three months post treatment. Results showed a reduction in carer distress and burden, as well as in ED symptoms, that were maintained at the three-month follow-up. However, feedback was that workshops did not address how to support loved ones with emotion and emotion regulation, and this was later included using ideas from emotion focused family therapy whilst I was on the ward, starting my interest in this area.

Emotion-focused family therapy for eating disorders

With a growing understanding in the field of Family Therapy, there has been a general rise in emotion- focused approaches. The emotion-focused approach to ED's recognises the importance of weight restoration and, as such, phase one of the treatment is focused on symptom interruption in line with FBT (Robinson et al., 2015). Parents are viewed as the 'expert' on their child, with clinicians on hand to offer advice as a 'consultant' due to their specialist knowledge of AN. Alongside this, parents are given specific training on supporting their loved ones with their emotions by being their 'emotion coach'. The parent is supported to validate the emotional experiences of the child and help them to gain efficacy over tolerating difficult feelings, with the goal of the person with AN learning to regulate and soothe themselves, reducing the need for AN behaviours.

There is also a component of healing unresolved trauma and 'wounds' by working with parents to understand where potential ruptures may have occurred (in a non-blaming way) and giving them a framework to repair the relationship with their child. This is often delivered through a manualised two-day group workshop to parents and loved ones delivered by a qualified clinician trained in the approach.

Research on emotion-focused family therapy is limited. However, a quantitative study was undertaken on the workshops by Dolhanty et al. (2014) with 24 mothers and nine fathers whose children (aged 13 to 31 years with a mean age of 18 years) engaged in a specialist ED programme. The areas examined were parental self-efficacy (parent vs anorexia scale), parental beliefs about children's emotions (questionnaire), parent "traps" (PTS) and parents' vulnerability to fears that may interfere with supporting their child. Following the workshops there was a significant improvement in parental self-efficacy, indicating that parents felt more able to support their child in recovery. There was also an improvement in carers understanding their role in supporting their child to manage emotions. Of the sample, 85% also reported an 'intention to change' concerning supporting their child with weight restoration and 92.9% 'intention to change' in supporting their child with their emotions.

This approach is one that I have both trained in and delivered extensively and that I most closely align myself with, due to its acknowledgement of emotional experience and the empowerment of parents. It is important to acknowledge that in my experience, families find this work confronting, and difficult, as there is no avoidance in reflecting on themselves, leading to feelings of shame. This may be particularly difficult for those from cultural contexts where emotions are not expressed. I have occasionally struggled to explain the ideas of parents "sharing responsibility" for development of the ED, and acknowledging ruptures in the context of non pathologising, and a therapeutic alliance with those we are working with is vital to enable that work to happen. This is built up extensive validation of the parent's experience, and reinforcement that they were trying their best with the tools they had available to them.

Summary of systemic approaches and research

Fisher et al. (2019) reviewed randomised controlled trials of family therapy approaches, comparing it to standard treatment for AN using a random effects meta-analytic approach. They suggested that evidence supporting family therapy is low quality with potential bias, and that further research is required to understand the efficacy of differing approaches used. Very few trials have been conducted with adults and they make a further recommendation that the impact of age is separated in future research.

Family therapy in the treatment of adults with AN is not mentioned in the NICE guidelines, despite many in treatment experiencing that recovery requires parental support, and living at home. The recommendation for adolescents is family therapy, using a manualised approach as a first line of treatment, with 18 to 20 sessions over one year (NICE, 2004). This is often delivered by clinicians who are not trained family therapists, such as nurses or other allied health professionals.

Manualised family therapy approaches are strongly aligned with structural ideas, and other useful interventions, such as those from the Milan method (Selvini-Palazzoli & Viaro, 1988), attachment therapy (Dallos, 2004) and narrative therapy (White, 1989) appear to have been left behind. In particular, the ideas of Dallos (2004) relating to difficulties with emotional expression in those with AN and feminist perspectives as described earlier, appear to be particularly pertinent and overlooked.

It seems there has been a loss of understanding of the distinct contribution of family therapy to AN treatment, and the benefits of delivery of family-based treatments by those trained in the systemic approach, who hold knowledge of the variety of ideas that inform therapy and can tailor work with families accordingly. As mentioned, many individuals don’t recover following a course of NICE- concordant treatment, leaving the question of how we can better attend to their treatment needs and factors maintaining the ED.

With this in mind, it is important to integrate evidence-based models with the views of those who are being treated, to develop a collaborative relationship and a treatment approach that targets their unique needs. Given the significant role of emotions in both the development and maintenance of AN, as I will go on to describe, this could be an important factor to prioritise in treatment.

2.6 The social constructionist view of emotions

Exploration of emotional experience has been in literature for centuries, but took a significant turn post-Descartes, who postulated the separation of body and mind (Thibaut, 2018), and further developed by Darwin in his theories of primitive states (Darwin, 1859). Within family therapy models, a systemic formulation was present early on in Bateson's presentation of the '*naven*' ritual (Bateson, 1958). This comprised his understanding of the function and importance of culture, values, and experience of emotions.

In the English language, the words *feelings* and *emotions* tend to be used interchangeably to refer to bodily experiences of emotional states. These are considered to be outside the control of the person experiencing them and separate from cognitive processes (Krause, 1995). In other words, they refer to the Cartesian split between psyche or 'mind' and soma, 'body'. However, constructionists consider that "emotions are appraisals and judgements based on cultural beliefs and values" (Krause, 2004). There are differing opinions on whether having a bodily experience of emotions is an integral part of, or separate from, understanding their meaning. Of note, this dualism is also not present cross-culturally; in many societies, a split between psyche and soma is not considered to be the way people experience emotion (Krause, 1989).

Krause (2004) suggests that emotions are connected to various factors, including feelings, affect, motivation, thinking, and bodily experiences. The very display of emotions allows others to understand their presence. She discusses how feelings in themselves will not solely inform the emotion, but that these need to be considered and interpreted in the context of the person experiencing them and their values. Krause (2004) also proposes that emotions are not merely operating inside of us, but are socially constructed and related to how we appraise a situation.

This, she argues, is why emotions should be considered as both social and biological. Similarly, Fredman (2004) considers the role of culture and suggests there is no 'universal' description of emotions that is accepted across cultures. One's response to emotion is impacted by different discourses of emotions, entailing both what the emotion means and the implications of how to act in response to it. In addition, Krause (2010) highlights both a "performative" and "indexical" expression of emotions and the idea that there may be a separation between what is expressed and what is experienced.

These social constructivist ideas, whilst building on the work of Bateson (1988 New Ed 2002) Ingold (1986) and Obeyesekere (1981) move away from the traditionally dualist approach of the mind and body 'split' that does not address the intentions, motivations, and meaning of human beings. This, Krause argues, is well illustrated in the treatment of AN through the focus on addressing familial relationships in therapy resulting in an improvement in symptoms (Minuchin et al., 1978; Palazzoli et al., 1978). Although there are various cultural discourses of emotions representing a more integrated and less dualistic perspective, this study will focus on the Western 'understanding' of emotions due to the focus in published research being situated within this context.

2.7 Emotions in anorexia nervosa

The role of emotions in EDs has been neglected by researchers for some time. Some argue that this has been due to the focus on the biological and behavioural factors, or, perhaps, that it mirrors the avoidance that is characteristic of those who experience them (Treasure, 2012a). This section is an overview of the limited research that has been conducted to understand AN regarding emotions, emotion regulation, and alexithymia.

Emotions and emotion regulation

Avoidance of emotion has been linked to AN from a theoretical (Fox & Power, 2009), empirical (Brockmeyer et al., 2016; Corstorphine et al., 2007a; Wildes et al., 2010), and patient perspective (E. M. Espeset et al., 2012; Nordbø et al., 2008). This emotional suppression can lead to a difficult cycle whereby beliefs about emotional expression link to avoidance and this, in turn, contributes to the maintenance of the ED (Schmidt & Treasure, 2006a; Wildes & Marcus, 2011). A study by Wildes et al. (2010) found that AN patients score more highly in emotional avoidance than patients with other mental illnesses, and demonstrate high levels of control over emotional inhibition (Claes et al., 2001; Davies, Swan, et al., 2011). Maladaptive personality traits that inhibit emotional expression have also been linked to restricted eating and the maintenance of AN by Arecelus et al (2013).

Emotional experiences have been demonstrated as connected to ED behaviours (Treasure, 2012a) and high levels of dysfunction in emotional toleration and suppression have been shown in those with AN (Oldershaw et al., 2012). Those with AN struggle with poorer emotional awareness, and less clarity (Monell et al., 2018). They use fewer words in emotional descriptions and have fewer positive affective words (Davies, Swan, et al., 2011) and commonly, unwanted emotions and physical feelings are often labelled as feeling “fat” (F. Skårderud, 2007).

Emotional avoidance has been identified as an endophenotype for AN (Treasure, 2007) and this has been supported in further research (Kaye et al., 2004). This avoidance is both linked to interpersonal factors and internal negative beliefs. Interpersonally those with AN tend to feel the emotions of others should be given priority above their own (Arcelus et al., 2013), and appear to be socially compliant even when their inner feelings are incongruous with this (Hambrook et al., 2011).

Strong internal negative beliefs about both their experiences of emotions, and the effect revealing their emotional expression might have (Geller et al., 2000; Hambrook et al., 2011) fits with increased levels of 'rejection sensitivity' that have been observed (Selby et al., 2010). Despite those with AN reporting intense emotional reactions, these are not displayed outwardly and this dissonance contributes to difficulties in effectively communicating their feelings (Davies, Schmidt, et al., 2011), in particular anger and sadness being the most difficult (E. M. Espeset et al., 2012). This leads to those with EDs presenting as shy, internalising their problems (Adambegan et al., 2012), and reporting feeling alone and inferior to others (Swinbourne et al., 2012).

Patients with AN report greater emotional dysregulation and are less able to manage distress tolerance (Hambrook et al., 2011), linked this to high levels of control by Treasure (2012b). Corstophine (2007) suggests that AN behaviours themselves, such as restriction and purging, are also used to avoid emotions. This, in turn, makes those who engage in these less used to tolerating them, creating a vicious cycle. Gulliksen et al. (2017), however, suggest that use of dietary restriction to avoid negative emotions might be established more or less 'by accident' and that patients might have low awareness about the effects of this behaviour, as they 'slide' into AN.

It has been demonstrated that a focus on emotional regulation during treatment can produce effective change (Abbate-Daga et al., 2012); however, there is still a lack of understanding of the complex dimensions of dysregulations in AN (Monell et al., 2018).

Alexithymia

Alexithymia is defined as “an impaired ability to be aware of, explicitly identify, and describe one’s feelings” (Nemiah et al., 1976). It has been studied extensively in the field of EDs, and high levels found in both those that have AN (Schmidt et al., 1993; Speranza et al., 2007) and their family members, indicating that it may have a genetic component (Rozenstein et al., 2011).

Overall, those with AN find it difficult to recognise facial expressions of emotion (Oldershaw et al., 2011) and are more attuned to facial expressions associated with negative emotions, such as criticism (Cardi et al., 2013) and anger (Harrison, Tchanturia, et al., 2010) and less able to identify those with positive associations such as compassion (Cardi et al., 2013) and happiness (Cserjési et al., 2011). Happiness was also reported as being experienced less by those with AN than in the general population (Joos et al., 2012). Interestingly, those with AN also appear to often misinterpret anger as disgust (Joos et al., 2012).

2.8 Recovery

It is important to briefly touch on the differing discourses around experiences of recovery as this a criteria for the participants in my study and a key area of enquiry. The definition of recovery is difficult, and is affected by “competing and complex meanings of bodies, food, health, illness, recovery and relapse” (Musolino et al., 2018, p. 547). Formal outcome studies in adolescents indicate that even for those with early intervention and evidence-based treatment, ‘good outcomes’ are reported as lower than 60% (Lock et al., 2010). There is still no agreement on a clear definition of what AN “recovery” means.

Recovery can be shaped by social worlds that one is engaged with, such as Instagram, where representation reinforces normative standards about the gender and ethnicity of both those who develop and those who recover from EDs. As such, there can appear to be “little space for those who do not fit the stereotypes to be recognised as legitimately suffering and able to perform recovery” (LaMarre & Rice, 2017, p. 11). It is also important to recognise, however, that many also find social media to be a safe space where they find a sense of community and motivation (Wellman et al., 2000).

Recovery, for those that experience AN, can often feel unimaginable (Malson et al., 2011), and something about which they are ambivalent (Darcy et al., 2010). Across the literature, those who have “recovered” describe it as an ongoing process (Federici & Kaplan, 2008) that is “transformative but non-linear” (Kenny et al., 2020). Lester (2019) argues that we need to move away from the idea of ‘success’ and recognise that many people in treatment will never ‘recover.’

Qualitative studies indicate a differentiation in accounts of recovery between clinicians and clients (Jarman & Walsh, 1999) and how complex the journey can be, in particular, the ‘inching out’ of it (Lamoureux & Bottorff, 2005). Participants have discussed the difficulty of changing mindsets and reclaiming the self as ‘good enough’ (Lamoureux & Bottorff, 2005). Recovery is also described as being strongly linked with “supportive relationships, hope, identity, meaning and purpose, empowerment, and self-compassion” (Wetzler et al., 2020, p. 1200).

Research indicates that when recovered, those who have experienced AN have the same ability to both tolerate and suppress emotions as the general population (Oldershaw et al., 2012). However, higher levels of judgement of themselves and comparison with others appears to remain (Connan et al., 2007; Oldershaw et al., 2012). Those who have recovered also report that they rely less on avoidance of emotions as a coping strategy and are observed to have healthy levels of emotion regulation (Harrison, Genders, et al., 2010).

Research into this area indicates that difficulties in social-emotional functioning both predates the ED and continues outside of it (Treasure, 2012a), perhaps indicating that treatment must incorporate learning skills in this area to succeed.

Having outlined the current landscape of the ED sphere, there is a clear need to integrate research into recovery into clinical approaches (Jarman & Walsh, 1999), enabling acknowledgement of its complexity and differences in meaning between individuals. In particular, for those with lived experience of AN, they report recovery represents more to them than weight restoration, or the ability to manage symptoms (Kenny et al., 2020). Although all ED clinicians will emphasise the paramount importance of weight restoration with those they are treating because of physical risk, consideration of the complexity of the ED experience, treatment and understanding of recovery outlined in this chapter may help improve the experience of treatment for those who access it.

3. Literature Review

As outlined in the previous chapter, the recovery journey for those with AN is complex, and considering emotional experience appears to be important, thus the focus of my research. This chapter reviews the relevant qualitative literature and research that aims to understand the emotional experience of those with AN.

3.1 Search strategy

To review the literature relevant to the research question, “What is the emotional experience of a person who has suffered from anorexia nervosa,” a systematic literature review was conducted. Different databases were searched between February and April 2024. The databases include APA PsycInfo, APA PsycArticles, APA PsycBooks, APA PsycExtra, Psychology and Behavioural Sciences Collection, PEP Archive, Education Source, ERIC, SocINDEX with Full Text, MEDLINE and Google Scholar.

Search Terms

Searches were conducted using the following terms:

Emotions in eating disorders = 6606 results
Anorexia + Emotions after 2014 = 1714 results
Anorexia + Emotion + Qualitative = 135 results

In addition to formal searches, when further research emerged in literature I used a traditional approach, searching manually through relevant journals and reviewing those I found.

The literature selected for review seeks to understand the emotional experience in those diagnosed with AN from their perspective. I include studies carried out within Europe due to the scarcity of research conducted in the United Kingdom, whilst holding in mind that this may be a different context than that experienced by my participants (White British women). Because of the small amount of data, I also consider both adults that were in treatment and deemed to be ‘in recovery,’ although it is recognised that stage of treatment may affect both their experience and recollection, which is discussed further later in this review. The variety of presentations in EDs is very broad and thus it was important to set a parameter based on diagnosis. Accordingly, studies where AN had not been formally diagnosed were excluded in order to make a comparison of findings, e.g. Kinnear et al. (2023).

In total, four relevant studies are reviewed. Two of the studies examine the perspectives of clinicians alongside participants with lived experience. When considering these studies, I have only included the findings related to the experience of those who have been diagnosed with AN, as this was separated in the results and the part pertinent to my area of research.

The selected articles are presented in a table with a brief description of the methods and samples used in Appendix 1.

Research Design

Espeset et al. (2012) and Fox et al. (2009) analysed material from qualitative interviews to explore the link between negative emotions and ED behaviour, and the perception of emotions of those with AN respectively. Fox et al. (2009) interviewed 11 participants engaged in both inpatient (n=5) and outpatient (n=6) treatment, with an age range from 5 to 19 to understand the perceptions of emotions from the perspective of those diagnosed with AN. Espeset et al. (2012) also used semi-structured interviews in a Norwegian ED service with 14 women aged 19 to 39 years diagnosed with AN. The authors were more descriptive than Fox (2009) about their participant group, distinguishing between those that had a restrictive (n=6) and binge/purge (n=8) subtype. They had a cohort of eight inpatients and six outpatients.

A grounded theory perspective was used for both studies and Fox et al (2009) and Espeset and colleagues (2012) discuss choosing a descriptive use to understand perceptions, viewing the patient (participant) as the expert in their own experience. Unfortunately, neither of these studies separate out findings between the inpatient and outpatient participants, which would have enabled an understanding as to whether perspectives may change over the course of treatment, and if so, how.

Rance et al. (2017) also undertook semi-structured interviews, however, their study used thematic analysis to understand the lived experience of those with AN. A purposive sampling method was used, and 12 women were included, of which 11 had a diagnosis of AN, and one had a long behavioural history of dietary restriction and had received treatment for this. This study is the only one where participants all saw themselves as having recovered, or in recovery, from AN.

The final study reviewed is a thematic analysis of focus groups and questionnaires seeking to understand the views of patients, parents and clinicians on emotions in AN by Kyriacou et al. (2009). The participants were six inpatients, four of the patients were diagnosed with restrictive AN and two with binge/purge AN. Detailed information about the sample group is provided, including a mean age of

26.8 and an average illness duration of 10.7 years. In this review, I have only included the results relating to the patients as those relating to the clinicians and parents are not relevant to this specific research.

Reflexivity on the position of the researchers and their own role is scarce across the research. Fox et al (2009) clarifies the position of the researchers most clearly of all studies considered in this review. They discuss their social constructionist approach and role in the data collection, in particular how they paid attention to and interpreted emotions. Rance et al (2017) acknowledged the importance of reflexivity in methods, and some information was given about the researchers. It was disclosed that all the authors had lived experience of an ED, however detailed consideration of how this may have affected data collection or other factors was not provided. The researchers declared a post-positivist stance and stated that the participants were offered transcripts and drafts for feedback, although it is not clear if this influenced the results.

All the studies I have chosen to review were conducted with a cohort that only included women. It is not specified whether this was due to research design or recruitment difficulties, except by Fox et al. (2009), where they stated a participant was excluded "due to being male" (p. 280). None of the studies identified or discussed the race or culture of their participants.

3.2 Findings

Experience in a family of origin

Fox (2009) was the only study to explore the experience of participants in their family of origin. They describe that a complicated developmental history appears to have elicited emotional difficulties in those they interviewed. Participants described their family context as an environment that left them feeling that “emotion seemed dangerous and almost toxic to them and people around them, and it was to be avoided at all costs” (Fox, 2009, p. 15). The authors posited this was due to an environment in which there was a lack of modelling of emotion management, along with active suppression of feelings, due to great difficulty in discussing emotions. This was largely described as a denial of emotions, and by parents denying the presence of both their own emotions and those around them. This left their children experiencing both confusion surrounding their experience of emotions and feeling ill-equipped to manage them.

All participants described how their fathers found it particularly difficult to discuss anything emotional, and they felt this as significant in their narratives of development. Three participants also stated that their mothers found emotional expression equally difficult. Moreover, in this study, participants attributed their difficulty in understanding appropriate emotional expression to the unpredictable nature of conversations regarding feelings in their family. They described that often someone would get angry quickly and unexpectedly in discussions, which they found difficult and prevented them from speaking about their experiences.

Although Fox (2009) was the only researcher to specifically look at the sufferers experience in families of origin, Kyriacou et al. (2009) provided views of parents who were asked to comment on their observations of their child. Those with AN were viewed as intellectually high functioning by parents, but described as showing significant difficulties in identifying and expressing emotions as outlined by Fox (2009). Parents also felt that their children with AN did not have empathy and were unable to consider the perspectives of others (O Kyriacou et al., 2009), which was not a trait those experiencing AN identified in themselves. However, it could be argued that these are difficult traits to both identify and disclose in relation to oneself.

Emotional experience before the development of AN

In addition to isolating families of origin, Kyriacou et al. (2009) and Fox (2009) enquired about emotional experience prior to the development of AN. Fox (2009) described how participants linked their experience in their family of origin to the development of two categories regarding their emotions: (1) “experiencing anger as overwhelming”, and (2) “too much emotion” (Fox, 2009, p. 283). They also described a sense of being “sad and alone” (Fox 2009 p 286) linked to disclosures of bullying, and feelings of anger, fear and disgust. These findings align with those of Kyriacou et al. (2009), who describe participants talking about feeling overly perceptive and sensitive to the emotions of others, and experiencing negative reactions of those around them as being attributed to themselves.

Alexithymia and expression and management of difficult emotions

Alexithymia

Across all four studies participants talked about confusion identifying their emotions (Fox, 2009), an inability to recognize, identify and label emotions (O Kyriacou et al., 2009), and difficulty in trusting themselves with what they felt, leading to a sense of helplessness and confusion (Rance et al., 2017). Participants that were fully recovered expressed how they experienced this as related to their AN in the study by Rance and colleagues (2017). When experiencing their AN 'in' phase, individuals found that thoughts, feelings, and actions were beyond their control, and felt compelled to engage in behaviours they could not resist. Conversely, during their 'out' phase, they demonstrated the capacity for an outsider's perspective and displayed signs of metacognition. Consequently, these women occasionally recognised that the thoughts, feelings, and behaviours they underwent whilst 'in' their AN were not in line with what they perceived as 'normal' when they had recovered. (Rance et al., 2017). This indicates that emotions, and how they are acted on, may relate to the stage of treatment one is in, and illness severity.

How emotions are managed

Across the research, there was a common theme that participants found emotional expression very difficult and it would be avoided wherever possible (E. M. Espeset et al., 2012; Fox, 2009; O Kyriacou et al., 2009). Fox (2009) described participants feeling alone with their emotions, and that there was no one to whom emotions could be safely expressed, leading them to mask them. Kyriacou et al. (2009) described participant’s uncertainty as to how to express emotions, and the feeling that expressing emotions would be a weakness that may lead to exploitation by others or being viewed as vulnerable. The worry about exploitation and vulnerability may also be in part due to the research interview setting of an AN inpatient unit, with its complicated dynamics of envy, competition, and associated distress (Rankin et al., 2023). Those unwell at the time of the interviews also described a feeling of confusion in the unpredictable nature of fluctuation between opposing emotions, resulting in feeling guilt and shame (O Kyriacou et al., 2009). The following emotions were isolated in the findings: anger, sadness/low mood, disgust, fear, and shame, and specific descriptions of these are outlined below.

Anger

Fox (2009) noted that he was surprised by the commonality of interviewee's description of the role of anger in their family of origin. Anger had been witnessed, coupled with violence, by a significant number of participants. They felt this led them to avoid all conflict and inhibit anger so as not to negatively affect relationships. Espeset et al. (2012) also found anger to be an emotion that some described as "unpredictable, uncontrollable and terrifying" (p. 455) and therefore very difficult to tolerate. These participants also described that they worried about expressing anger in interpersonal relationships generally; however, whilst unwell, they had outbursts directed at close family members, which they could see as symptomatic of their AN (E. M. Espeset et al., 2012). Furthermore, they discussed the anger they felt towards themselves, and how they lived. It is not clear if this was a description of living with AN or anger more generally. Others interviewed by Espeset et al. (2012) stated that anger was an emotion that they never experienced. Agarwal (2022), in her book about emotional expression, proposes that girls are encouraged to regulate their emotions from babies, in particular anger, resulting in them internalising it and expressing it as sadness, which tends to be seen more kindly by those around them. This also results in a feeling of wanting to be a 'good person' and to fit in.

Sadness and low mood

Sadness, low mood, and loneliness experienced across the lifespan was described by all participants in the study conducted by Fox (2009) and 'most of the time' by participants interviewed by Espeset et al. (2012, Pg 455). Sadness was described as an overwhelming emotion, but similarly to anger, expression of sadness was associated with appearing weak thus leading to feelings of shame, preventing them from discussing this emotion with others. In addition, they were not able to express sadness due to a fear of being a burden to others, which led them to describe it as “inexpressible” (E. M. Espeset et al., 2012, p. 455). Sadness was also linked with exacerbating difficult feelings about the body of those with AN, such as feeling “fat, disgusting or awful” (E. M. S. Espeset et al., 2012, p. 455) Conversely, others said that they never experienced sadness, nor had they ever cried. They attributed this to their AN ‘stifling’ the feeling and that they were not able to recognise it when it occurred.

Disgust

The feeling of disgust was characterised as disgust towards themselves, their behaviours, and their bodies by those with AN interviewed by Fox (2009) and Espeset (2012) during inpatient admission. The feeling was experienced strongly and pervasively, often accompanied by a feeling of nausea (E. M. Espeset et al., 2012). They also described how disgust was associated with the “feeling of fatness” (E. M. Espeset et al., 2012) and that eating, and the feeling of being full, triggered feelings of disgust in connection with their appearance; for example, when looking in a mirror. It is important to acknowledge that those interviewed in this sample were in an acute phase of their AN in hospital, and in this context it may be that their description of emotional experience differs both due to the stage of treatment and the intensity of focus on their illness.

Fear

In a similar vein to disgust, Espeset (2012) described how participants also experienced the emotions of fear and anxiety as being strong and overwhelming. Experiences of fear were linked to weight gain, changes in their body, and having to eat despite feeling a sense of loss of control and ‘feelings of fatness’. Fears of food and bodily changes were also found by Fox (2009), whose participants described this developing during their AN, rather than predating it.

Shame

Rance et al. (2017) note that in their sample there was a pervasive and overwhelming sense among participants of shame and hatred towards themselves. This general sense of unworthiness was also found by Espeset et al. (2012) in their sample. In addition, shame was strongly associated with AN thoughts, feelings, and behaviours which participants linked to their AN controlling them. These emotions were described as feeling ‘out of control’, and shame linked to an awareness of their irrationality; for example, feeling ‘fat’ when they were severely underweight (Rance et al., 2017). They also experienced shame at not being good enough at AN, and Rance et al. (2017) noticed that comparison was to others who were unwell, rather than the healthy population. These comparisons led to feelings of failure which, they believed, led to a guilt–shame cycle (Finn Skårderud, 2007) that reinforced the illness (Goss & Allan, 2009). Research indicates that shame is not disclosed in therapy by up to 42% of those who are unwell (Swan & Andrews, 2003), leading to this not being addressed by treatment.

Social difficulties and loneliness

In studies conducted by Kyriacou (2009), Espeset (2012) and Rance (2017), participants described loneliness and difficulty in social situations. Interviewees told Kyriacou et al. (2012) that emotional difficulties were linked to problematic experiences in their relationships. They felt overpowered by living with AN in terms of managing their thoughts, feelings and urges, and the consequences of doing so.

Social situations were associated with fear, stress and anxiety and could result in feelings of failure or ‘fatness’. These feelings, alongside a feeling of disgust, were also triggered when they experienced the judgements of others or felt that the feedback from their environment was negative (E. M. Espeset et al., 2012). This led to them avoiding opportunities to overcome their feeling of isolation and thus it being further perpetuated and difficult to escape from (O Kyriacou et al., 2009).

Isolation and avoidance of social situations contributed to a pervasive sense of loneliness, which was further exacerbated by differences they noticed between themselves and the ‘healthy’ general population in terms of how they behaved, particularly relating to dietary restriction and weight loss (Rance et al., 2017). Those who had recovered described that when they were unwell, they felt loneliness, due to a lack of understanding of their experience of AN and described feeling trapped in a world that could not be fully communicated to those around them (Rance et al., 2017, p. 5).

These findings are supported by Levine (2012) and Stewart (2004), who describe pervasive loneliness in EDs and its contribution to the maintenance of symptoms through the use of AN behaviours to manage difficult feelings.

The link between Emotions and their AN

Participants across all reviewed studies described using AN to manage their difficult feelings. AN behaviours were described as a way to “cope with their emotions”, “distance themselves from their emotions” or “suppress emotions” (E. M. Espeset et al., 2012). Fox (2009) also identified the use of AN behaviour to “release” difficult emotions, and of avoiding expression by using behaviours to manage and tolerate them. Rance et al. (2017) described that this functional aspect of the AN made a confusing and difficult choice for those working towards recovery, who found themselves in a “double bind” in which refraining from AN behaviours and working towards weight restoration entailed simultaneously experiencing intense negative emotions without a coping strategy.

I will now present findings from the reviewed studies describing differing functions that AN serves in relation to emotions. It is important to acknowledge that what participants express about their emotions may not reflect what they feel, or felt, and that there is no clear method to access and understand the emotions of others (Krause, 1995).

Avoidance

Using AN to avoid emotions was specifically identified by Fox (2009), Espeset (2012) and Kyriacou (2009). Espeset (2012) stated that participants identified using AN behaviours and a focus on eating, weight and shape to avoid anger towards themselves and others, sadness, and interpersonal relationships which caused anxiety.

Specifically, bingeing and purging were identified as avoidance strategies for disgust, anger (specifically in relation to having to eat), irritation and sadness. Participants described that focusing on these behaviours meant they did not have to acknowledge or tolerate difficult feelings (E. M. Espeset et al., 2012). Restriction and purging were also used to manage overwhelming emotion by those interviewed by Fox et al (2009). Their interviewees felt that engaging these strategies was not a conscious process, and described only realising that the emotion had been experienced once the AN behaviour had been employed. They also felt that if they did relate to their feelings, it would result in them feeling depressed. This poses a problem in recognising and management of emotions that could be difficult in recovery.

Kyriacou et al. (2009) note that participants were able to understand the difficult relationship between the illness and their emotional coping. This was a cause-and-effect relationship in which AN was used to avoid emotions, and numb overwhelming feelings and was experienced directly. They also described how this inability to connect with emotional states led to a loss of identity; however, this was not explored further by the researchers.

Suppression

The use of AN behaviour to suppress emotions by blocking reactions and modulating intensity was described by Espeset et al. (2012), Kyriacou et al. (2009) and Fox (2009).

In the research by Kyriacou et al. (2009), interviewees described AN behaviours as having the function of gaining numbness to emotions described as “painful and uncomfortable” (p. 848). Participants specifically name using restriction and purging to suppress overwhelming emotion, and experiencing this as bringing them “comfort” (E. M. Espeset et al., 2012). Both these strategies served different functions in that they would use the former to avoid emotion and the latter to ‘remove’ emotion (Fox, 2009).

They also disclose the use of physical activity to inhibit anger, and the feeling of hunger itself suppressing fear and anxiety (E. M. Espeset et al., 2012). These functions of the AN behaviour are perceived as useful, and again this illustrates the difficulty of letting go of these coping mechanisms in recovery and learning to tolerate the experience of difficult emotions.

AN as a “salvation” or to cope

This theme encompasses the descriptions of AN as a helpful presence in the participants’ lives, aside from the avoidance and suppression of emotions, and maintaining factors are important to acknowledge to understand the perpetuation of AN behaviours. Rance et al. (2017) describe that their participants in recovery discussed how AN was a source of feeling positive, and that this could feel strong enough to counteract the loneliness they experienced. They felt that as well as keeping difficult feelings under control, it also offered them a coping mechanism for life. They reflected on the dominant discourse in white Western society regarding a ‘thin ideal’ and that their efforts to adhere to this in extremity were valued, which alleviated shame. This is supported in wider research. Silverstein et al. (1986) found that those who are less curvaceous are perceived as more intelligent and competent than curvaceous women, and that standards expected of women regarding their weight have increased over time (Silverstein et al., 1986). Rodin et al. (1984) proposed that the ‘thin ideal’ expected of women is an unrealistically low weight, leading to a preoccupation with appearance that has psychological consequences, such as distorted body image and reduced self-esteem.

Espeset et al. (2012) studied participants who were currently in treatment, who described using their AN behaviour, in particular exercising, to ”release” emotions. This releasing of emotions was also described as self-hatred, which was in turn managed by self-control. When they felt frightened or anxious, they used purging to feel calmer. The participants also talked about fear of gaining weight, which they managed by body-checking numerous times daily. Although they described using restriction in their eating and purging to regulate their emotions, they also talked about the positive emotions that they experienced through restriction including "happiness, mastery and control" (E. M. Espeset et al., 2012, p. 455).

AN as a communication

There was very little in the reviewed literature regarding AN as a means of communication. However, those who were unwell, interviewed by Espeset et al. (2012), described using AN behaviours to communicate anger to those around them. They also stated that food refusal served a useful function in punishing others. The sample of those in recovery discussed how they felt that their illness had become part of how others viewed them and their identity, and described that they "elicited welcome attention". (Rance et al., 2017, p. 7).

3.3 Critique and Generalisability of the above studies

The studies described provide valuable insights into the emotional experience of those who have experienced AN. However, to my mind, there were several limitations.

First, it is important to consider the methodology. Fox (2009) and Espeset et al. (2012) used a grounded theory approach. This is generally considered to be from an inherently positivist epistemological position, despite it being qualitative (Bryant & Charmaz, 2010). This was reflected in the lack of reflexivity from researchers as to their own potential bias and difficulties, such as the power dynamics present in those in treatment being researched by professionals. The process relies heavily on interpretation and, thus, without understanding the position of the researcher, it is difficult to determine which data they deem as significant for inclusion. Generally, it is also considered that a large amount of data is required to reach saturation and the number of participants included in these studies was quite small.

The studies conducted by Kyriacou (2009) and Rance (2017) used thematic analysis which is an appropriate approach with small data sets that can provide a rich understanding of individual experiences. However, this approach can lead to a superficial understanding of data if nuances and complexities are not explored. It is also important for the researcher to be aware of potential bias and to be reflexive about their positions and power dynamics to mitigate this.

Across all the studies, there was a lack of reflexivity on the part of the researchers. The lack of awareness of personal biases and how this may affect data interpretation could have influenced research findings. It would be helpful to gain an understanding of their position, particularly regarding power. For example, three of the studies (E. M. S. Espeset et al., 2012; Fox, 2009; O. Kyriacou et al., 2009) involved participants in an inpatient context, and the researchers may be perceived as holding a role that may affect how experiences are reported.

All three researchers recruited individuals from a single site, which introduces the potential for bias in the sample. Drawing participants from one location allows for a rich context- specific understanding and data collected may be better quality than multiple sites if there was a strong rapport with participants. However, one must acknowledge that the studies will not capture the full diversity of experiences and perspectives among individuals with AN. Different geographic regions, cultural backgrounds, and healthcare settings can influence how individuals perceive and express their emotions, thus limiting the generalisability of the findings.

It is well documented that emotions and their perception can be influenced by cultural norms, values, and socio-economic factors (Engelmann & Pogosyan, 2013; Krause, 2007; Krause, 1995). None of the studies included considered the ethnic background and socio-economic status of the participants, and failing to account for diversity within the sample may overlook important variations in emotional experiences among individuals with AN. There is also, likely, a normative understanding of how emotions ‘should’ be expressed across the participant groups if there is no diversity in race or background. The lack of research cross culturally in eating disorders is attributed to a number of factors including; a western centric focus in the diagnosis and funding, stigma around mental health leading to a difficulty in recruiting, and a lack of cross- cultural expertise (Becker et al., 2009).

Another limitation of the samples is the exclusive inclusion of female participants across all studies. AN affects individuals of all genders, yet these studies only focus on experiences of women with the disorder. By excluding male and non-binary individuals, the studies ignore potential differences in the perceptions and emotional expressions. Strother et al (2012) describe how men are “under-diagnosed, undertreated, and misunderstood” (pg. 346) by clinicians, and thus have been overlooked in research and treatment. They also argue that approaches should be adapted in order to capture their unique experience, and focus should be on the differences between men and women with ED’s, which is not the realms of this research.

Only one of the studies (Fox, 2009) considered the experience in the family of origin of the person who had AN. As the NICE guidelines are clear in recommending family therapy in the treatment of AN (NICE, 2004), this appears to be a significant gap in the research to gain an understanding of context and how best to support families to help their loved ones in recovery.

Participants across the research were at different stages of treatment and recovery and the results were grouped together, which prevented an understanding of how perspectives may differ across treatments, illness duration or presentation. For example, in studies conducted by Espeset (2012) and Fox (2009), a mixture of those in inpatient and outpatient treatment were interviewed, and a lack of differentiation between settings means results are not able to be separated.

Where all the participants were inpatients and in a more acute stage of treatment, such as in the research conducted by Kyriacou et al. (2009), they were potentially less able to reflect on their emotional experience. Additionally, bearing in mind what research shows us about ED inpatient dynamics (Rankin et al., 2023), the use of focus groups may have meant that participants felt they could not speak honestly and openly to the interviewers.

There is also no information across any study regarding comorbid diagnosis and, thus, symptoms could also be attributed to these, of which there is a very high concordance in AN, specifically concerning affective and anxiety disorders (Halmi et al., 1991).

4. Distinctive contribution of the current study

The review of the qualitative literature exploring the emotional experience of those who have experienced AN has highlighted a gap in research. This concerns the perspective of the person who suffers, i.e. an expert by experience perspective. In addition, there is little understanding of the emotional experience of the sufferers in the family context, despite this being important in informing systemic treatment and interventions. A better understanding is required among clinicians about variations in the reports of those with lived experience regarding their understanding of the development and maintenance of their ED and their different psychological dynamics (Gulliksen et al., 2017).

The focus on quantitative research in examining manualised approaches to family therapy in AN has resulted in a distinct lack of understanding of the perspectives of those with AN, and their parents. More information is required regarding how experience is reported of family-based treatments, and what they feel would be helpful to their personal recovery. By understanding the emotional experience of those with AN through qualitative research, it is hoped that this will enable a deeper understanding of areas useful to explore in family therapy.

It is proposed that thematic analysis is the most appropriate approach to this research due to it allowing the identification and interpretation of patterns within data, and effectiveness with small data sets. It also allows for data to be presented in a way that both highlights individual stories and collective patterns which is an aim of this study, i.e. to produce a rich understanding of experience. Although thematic analysis can be employed in a positivist way, it can also fit with my social constructionist epistemological position as it allows the exploration of how realities are constructed with a focus on meaning. It also allows for reflexive and critical analysis to challenge assumptions that may be taken for granted, which I believe has occurred in the field of AN in the medical model.

The research project I report on here aims to examine these circumstances with the research question: “What is the emotional experience of a person who has suffered from anorexia nervosa?”, with the following sub-questions: How do those with anorexia describe their experience of feeling different emotions? What do people with anorexia feel might be helpful or unhelpful in the way emotions were processed in their families of origin? Do they see a link between their AN and the management of emotions?

In the next chapter, methodology, I present and discuss the methodology used to research these questions and following that, I present the findings.

5. Methodology

This chapter describes the purpose and aim of the research and the underpinning philosophical position. It then goes on to the qualitative methodological approach and recruitment of participants. Following this, there is a description of the research design, and the thematic analysis method undertaken to analyse the data (Braun & Clarke, 2019). Finally, I consider my position as a researcher as well as ethical dilemmas I faced and how these were addressed.

5.1 Research aims and purpose

This study aimed to be a small exploratory piece of research investigating how those who have recovered from AN describe their emotional experiences across their lifespan. The following question was explored:

“What is the emotional experience of a person who has suffered anorexia nervosa?”

With the following sub-questions.

1. How do those with anorexia describe their experience of feeling different emotions?
2. What do people with anorexia feel might be helpful or unhelpful in the way emotions were processed in their families of origin?
3. Do they see a link between their AN and the management of emotions?

5.2 Philosophical position

Ontology and epistemology

Fox (2007) states that research questions and methodological approaches are influenced by the core assumptions of a researcher, informed by their ontological and epistemological position in their attempt to gain knowledge about ‘reality’. Thus, in this section, it is important to define my position. I find this difficult as I often experience being torn between different ontological viewpoints as I am affected by the context in which I find myself (Bateson, 1972).

Blaikie (2019) defines ontology as a “researcher’s view about what the nature of reality is” (pg. 8) or “What is there to know?”. The positivist position of one objective reality is present in many institutions, such as psychiatric inpatient units using medical models. When working in this setting, in which I completed my training, I was influenced by the Milan school’s observations- that those discharged following treatment often do not manage to continue with the improvements made (Boscolo et al., 1987). This, inspired by the work of Bateson (1972) and Maturana (1988), led to the development of questioning as an intervention to understand relationships within the family and how the system responds to change.

The systemic approach aligns itself with the social constructionist position, which argues that knowledge evolves through discourse. It asserts that the knowledge that exists in one person’s mind may not be the same as another’s and as such, interactions between people and their use of language are paramount. Therefore, the method of interventive interviewing highlights how questions can promote change and be an intervention in the system. Palazzoli (1978) and Karl Tomm’s seminal papers have given systemic therapists a practical guide to interventive questioning (1987a, 1987b, 1987c), for example “if you were to do something differently, how do you imagine it might turn out?”. When considering these ideas, alongside those of Burnham (2005) on relational reflexivity, I find myself challenging the positivist assumptions made about patients and becoming more curious about the function AN may serve both for themselves, and in the family. It also leads me to consider how we align with those seeking treatment and encourage them to believe that reaching their goals is a possibility, rather than “recovery” being something that is done ‘to’ them.

However, there are serious physical health implications to maintaining a low weight that are important to recognise, and a strong evidence base for the importance of weight gain in treatment. Processes, such as refeeding and meal plans, are significant to treatment and key to the success of recovery from an ED. With this in mind, I can see the disadvantage of the social constructionist position, which denies the concepts of realism and aetiology, both of which are inherent in the evidence base of treating EDs successfully. Therefore, I find myself holding differing positions during the course of treatment, according to how the patient and family present, and my clinical judgement at that time.

Consequently, I view myself as standing between the realist and constructionist paradigms in a critical realist position (Bhaskar, 1975). That is, there are multiple subjective versions of reality linked to context (Maxwell, 2012). There is the “possibility of specific, local, personal and community forms of truth” (Kvale, 1995) in the critical realist position, and an acknowledgement of different valid perspectives. This approach suits the study as I am aiming to understand the perspectives of those I interview. It also fits with my systemic training and practice in which multiple perspectives are considered within a formulation, and therapy sessions.

Epistemological positions describe how knowledge about reality can be acquired, and what is regarded as meaningful knowledge (Bryman, 2008; Willig, 2008). Positions range from the objective to the subjective: How and what can we know about reality? Although the complexity of epistemological approaches to research means that there is no clear cut between them (Willig, 2008), researchers need to discuss their position to communicate how research has been guided by underlying assumptions (Madill et al., 2000). My epistemological position has been shaped by training as a social worker and then family therapist, as well as through working in multiple ED settings which has given me experience of many people who have experienced AN across their lifespans. It has also changed significantly in my journey through training, and becoming a parent, particularly in being able to appreciate the multiple “realities” and there being no clear “right” answer, something I have found very difficult at times.

I have gained an ‘objective’ understanding of EDs through working in medical contexts with consultants and colleagues who are very highly respected in the field. Although I feel privileged to have worked alongside them, and in many areas have learnt so much, this ‘knowledge’ and expert position impacted my ability to consider the complexity of individual experience, the degree of which only became truly apparent to me during this research process . This has been a key theme in discussions with my supervisor, in order to explore the subjectivity in understanding. Objectivity made me feel safe in terms of my knowledge about a subject, and amongst colleagues and the parents I was working with who were desperate for an ”expert” to help them. However, I am now much more comfortable in the realms of subjectivity, in terms of an individual’s own relationship with their ED and what it means to them, their narrative of how it developed, and their personal vision of ‘recovery’. Within this research, I have truly allowed myself to be “changed by what I find” (Leppington, 2011), and it has been transformational to my practice.

Commonly, qualitative research uses post-positivist paradigms of social constructionist or critical realist ontology (Ponterotto, 2005). That is, a more nuanced understanding of the complexity of knowledge; although there is a retention of the idea of a ‘truth’ that can be considered objective, it is affected by our own experiences and values as a researcher.

This study considers how those who have recovered from AN describe their emotional experience across the lifespan, and their understanding of the role their eating disorder served. I believe that how reality is perceived, and experiences of the world, will differ between individuals, but common patterns of meaning can be created between accounts. To do this, we must undertake critical evaluation and understand the context. I, therefore, align myself with a critical realist stance in that reality is independent, but it is mediated through our perceptions and frameworks.

Reality is complex and there are both agency and structural factors that impact human behaviour (Given, 2008). It is important to acknowledge that personal experience impacts the way we perceive reality. Thus, by aiming to understand the participants’ descriptions through this research, it can shape a deeper understanding of the ‘real’ experiences those who have had AN described, whilst simultaneously accepting that these cannot be explained by a single ‘reality.’

Whilst conducting this research, I noticed there were obvious moments where I was displaying both a positivist and critical realist position. For example, my main goal was to present the perspectives of those who had experienced AN as they describe it, as I feel their voices have been missing from research. However, I also found myself in a positivist position; for example, having strong thoughts and feelings about whether participants were in ‘recovery’ according to the directions in manuals and aetiology. Throughout the research, my view changed and my understanding of the definition of ‘recovery’ became blurrier and more related to the individual. I began to question the concept, and word itself, and how it is used in our work, becoming comfortable in the critical realist epistemological position, accepting that there is an external reality, but that individuals differ in their distinct perceptions of it (Clark, 2009). This push and pull continues in my work and I believe it will always be present due to clinicians bridging the gap between “treatment” and the person trying to make sense of their experience, particularly in the realm of AN with the undeniable presence of serious physical health complications.

This study included a sample of five women who deemed themselves in recovery from AN. All of them were White British with similar social backgrounds. I do not feel comfortable assigning them a ‘class’ as this feels problematic and difficult (Savage et al., 2013). However, universally they had parents who worked in a professional capacity with a stable income and owned their own homes. Four of them lived in London and went to private schools, and one grew up in Sheffield.

This is not representative of those who experience AN across the world, so the aim was not to make generalisations. Instead, the researcher wished to understand how people who had recovered from AN describe their lived experiences to add to the literature on EDs. Therefore, it is important to acknowledge that interpretation was necessary, which is affected by the researcher’s position, and it cannot be perceived that these findings represent reality in its entirety (Willig, 2008).

Rationale for qualitative research methodology

Quantitative research tests causal relationships and considers how phenomena can be generalised in an objective external reality (Yardley, 2000). It is an approach used widely in ED research, with participants' experiences being scored with numbers and statistical tests being conducted.

I aimed to allow the participants to share their personal experiences of emotions using their language, making a qualitative approach appropriate to allow for a deeper understanding of an area difficult to measure (Alderfer & Sood, 2016; Barker et al., 2002). This approach is also recommended for exploratory studies (Creswell & Creswell, 2018) and it allowed me, as a researcher, to clarify how the participants made sense of their personal events and experiences related to their emotions (Willig, 2008). This fits with the goal of this study of informing further research and clinical practice through the voices of those being treated, by gaining further understanding of an area that is difficult to quantify (Barker et al., 2002).

Willig (2008) states that due to the smaller sample sizes, qualitative research can be criticised as findings cannot be generalised to a larger population. Adopting a critical realist position, however, one can argue that as each individual's experience of reality is unique, findings can be open to theoretical generalisation; that is to say, qualitative data may help us build better theories for thinking about the topic (Holloway et al., 2010). Therefore, the qualitative methodological approach was chosen in line with the purposes of the study and the critical realist stance of the researcher.

Data Collection Procedures

Data was collected from participants during one-to-one interviews which were conducted to provide a detailed first-person description of their emotional experience in line with the research aims (Willig, 2008). Interviews were semi-structured as this allowed me to be led by the participants and elicit further information to interesting responses, as well as consider areas that I did not foresee arising to obtain data that was relevant (Robson, 2011).

Sample and participants

To find suitable participants, a purposive criterion sampling method was used. Criteria for the study were identified to understand the emotional experience of those who have recovered from AN, and the inclusion and exclusion criteria were set as follows;

Inclusion criteria

- The participants have had a formal diagnosis of AN according to DSM-5 criteria (2013) but now deem themselves to be in ‘recovery’ by their definition and are no longer receiving treatment.
  This is due to the aim of understanding participants’ reflections on their emotional experience concerning having AN rather than their experiences while suffering from it.
- If there is a secondary diagnosis, this would need to be considered on a case-by-case basis.

Exclusion criteria

- The participant is not able to take part in a 1.5-hour semi-structured interview in a safe location or online.
- The participant is still undergoing treatment for an ED or other mental health difficulty.
- The participant does not provide informed consent.

Recruitment and sample

Recruitment was undertaken through word-of-mouth, social media and both passive (adverts) and active (direct approaches) recruitment methods (Gelinas et al., 2017). I utilised the network that I have developed over many years working in the ED field and contacted those that I know who are publicly in ‘recovery,’ such as ED campaigners, ambassadors for Beat, or those known to these acquaintances. Despite casting this wide network, it was difficult to find participants, and although I achieved my initial goal of five participants, I would have liked to have interviewed more. Although several factors could be attributed to the difficulty in recruiting, it is important to recognise that both emotional experience and reflecting on childhood in our families of origin can be difficult subjects to discuss. Further to this, those who have recovered from AN may wish to put their difficulties behind them and not ruminate on their experiences.

My participants were all White British women between the ages of 18 and 42. I would have welcomed more diversity in terms of race, ethnicity, background and gender. Four of the participants lived in Southwest London and one in Sheffield. It is acknowledged that there are several difficulties with diversity across EDs, including a lack of access to services, a lack of recognition of the importance of cultural differences and a lack of representation in clinicians (Nwuba, 2024) and, thus, it is disappointing that my research reinforced this. I attribute this to several factors that may include; the stigma that can be associated with mental health, including EDs, the lack of cross-cultural recognition in how EDs are perceived and experienced, the historical and ongoing context of discrimination of minority groups in medical settings that may have contributed to distrust in professionals, and my insufficient effort to engage with different communities. On reflection, I would like to have done more to engage a participant group that included cultural diversity and taken more time to understand how to do this, however during the course of this research I understood more about the nuances of gender separation in ED research, and that whilst there is acknowledgement of shared symptoms, and one does not want to maintain the historical bias of associating the difficulties with females (Breton et al., 2023) the importance of gender specific research is also clear (Culbert et al., 2021).

I had previous contact with all the participants in some way, which is important to acknowledge, as this could have biased data. Two of the participants had engaged in my service, and I had conducted their initial assessments. However, I had not treated them. One was an inpatient on a ward where I was a student 10 years ago, and two of them were loosely socially connected. My relationship with all of them was positive, and I believe this to be a reason they agreed to participate in the study and talk about sensitive and difficult topics.

Throughout this thesis, pseudonyms have been used to protect participant's identity. Of the five participants, two of them were recently 'recovered' and still living at home with their parents. The other three had been 'recovered' for a longer period and had lived away from their family home for over 10 years with a long-term partner, and two of this cohort were parents themselves.

A demographic table with the participants' pseudonyms, ages and the period they deemed themselves to be in recovery for, is below;

Name	Gender	Age	Period of recovery
India	Female	18	1 year
Gail	Female	19	1 year
Emily	Female	41	13 years

Rose	Female	42	4 years
Claire	Female	39	12 years

5.3 Materials

Consent Documents

All participants received an information sheet (Appendix 2) which was discussed with them prior to the interview, allowing them to ask questions or seek clarification. The participants also signed a formal consent form before their involvement (Appendix 3), and it was made clear that their contribution was voluntary, and they could withdraw from the study at any time. Both the information sheet and consent form were pre-approved by the university ethics committee and the realms of confidentiality was clearly outlined in these and verbally.

Interview schedule and procedure

The interview schedule was developed with the research supervisor and consisted of six open-ended questions (Appendix 4). This format offered the opportunity to prompt for further information and follow interesting lines of enquiry. The questions focused on understanding the participants’ relationships with their emotions, the context of their family of origin concerning this, and whether they linked the development or maintenance of their AN to their emotional experiences. It was important to try and capture their descriptions of experiences, so the questions were framed to invite this, and were emotion orientated, for example “can you tell me how emotions were managed in your family?”   These questions were also followed with reflective prompts and memory cues, such as helping them to reflect on physical sensations in the body. As the researcher, it was important for me to be sensitive to the topic, and that difficult feelings may arise. My role was to balance gathering data whilst not causing harm, and to ensure that they left feeling comfortable with the interview that had taken place. The questions were used only as a flexible guide. My experience with the participants was that they had many of their own ideas about the subject and needed little prompting, and supplementary questions were often not necessary to ask as the topic was covered organically. I had to ensure that I stayed focused on the research question as I found so much of what they shared interesting and found myself wanting to hear more and more. This reinforced to me the importance of hearing and trying to understand their experiences. This was also difficult in phase 4 of the analysis when I had to refine the data and delete codes.

Four of the five interviews were conducted in person in a clinic room in Southwest London, and one online. Following the meeting, participants were invited to add anything else they felt may be pertinent and to give feedback on their experience of taking part, as well as a general check on how they were left feeling.

5.4 Transcription

Interviews were video recorded with a backup audio recording made for transcription purposes, and to have further information regarding gestures and facial expressions. Interviews varied between the shortest at one hour to the longest at two hours. Each of the interviews was then transcribed by the researcher and comprised all the words that were spoken during the interview, including laughter and conversation fillers such as ‘umming’ and ‘ahhing’. For examples of the transcripts, please refer to Appendix 5, where only extracts have been provided to protect anonymity.

5.5 Data analysis

Thematic analysis

The rationale for choosing thematic analysis

Thematic analysis was chosen to explore the data, due to the function of description rather than interpretation, and because of its flexibility as a model. This approach allowed me to analyse the patterns and themes, and consider how they could be accounted for (McLeod, 2011; Willig, 2008). Thematic Analysis allows for epistemological flexibility (Braun & Clarke, 2019) in enabling compatibility between the stance of the critical realist and the reality of EDs as a distinguished concept (2013). Braun and Clarke (2019) explain that thematic analysis using a critical realist position recognises an individual's capacity to provide an understanding of their unique experience, whilst retaining reality and materialism and considering the impact of the context. After some exploration, this felt the most fitting for my research goal of wanting to explore patterns of meaning within my data.

In my original proposal, I had wanted to use narrative analyses as I felt wanted to portray the "stories" participants had relating to the development of their AN and emotional experience. However, as I undertook my research, I was very struck by the themes across the data sets and how pertinent the commonalities were between my research participants, for example; their experiences in their family of origin, ideas on 'recovery' and what this looked and felt like, and the functions of their AN. I felt that an understanding and representation of these would be more helpful in informing further research and practice, rather than simply the individual accounts or a chronological depiction.

I also found it very difficult to let go of my bias due to my experience in the field, and recognised my ‘expert’ position. Although I recognise that this also affected my interpretations in the thematic analysis, I felt uncomfortable about the level of subjectivity and interpretation required in a narrative method, and conscious of how easy it would be to mis portray a deeply personal and complex account, and how this may feel to participants. It is also important to acknowledge, that by using a narrative method, I may have gained a deeper understanding of the meaning for each individual, and their stories as a whole (McAllum et al., 2019), and that in a landscape that is lacking in the voices of participants this may have also contributed rich data to the field.

Thematic analysis has been criticised for lacking structure and guidance to ensure precision. There is also an inherent risk to the approach that in fragmenting of data to streamline it, the voice of the individual can be lost. To address this, a six-phase process was used, following the recommendations of Braun and Clarke (2018) closely, and referencing their table of standards as a validity framework (Braun & Clarke, 2021). The key features of these standards are; reflexivity, Coherence and rigour through rich, nuanced themes, transparency in decision making processes, the capturing of patterns of meaning, and flexible and iteratirve coding (Braun & Clarke, 2021). Consideration of adherence to these to promote validity are outlined throughout the thesis.

I chose to use the method identified as *reflexive* thematic analysis (Braun & Clarke, 2019) to embed my research in the qualitative paradigm and acknowledge my place and role in the coding of data. The data is presented with many verbatim quotes to try and present the direct perspectives.

Phase One: Familiarising the self with the data

Interview data was transcribed, read and listened to several times, with no specific transcription tool used. My focus was on immersing myself in one transcript at a time to become familiar with the content, and make brief notes on ideas about both the "data items and the data set as a whole" (Braun & Clarke, 2019). This was the stage in which I reflected on the narrative approach chosen, and in discussion with my supervisor decided that thematic analysis was more appropriate.

Phase two: Generating the initial codes

Transcripts were imported into MAXQDA software to begin coding the data systematically by identifying segments of interviews pertinent to the research question. Using the reflexive thematic analysis approach, I used both an inductive and deductive coding method to label the semantic (surface) and latent (implicit) descriptions and ideas.

Example.

Code: Modulation of emotion through AN behaviour

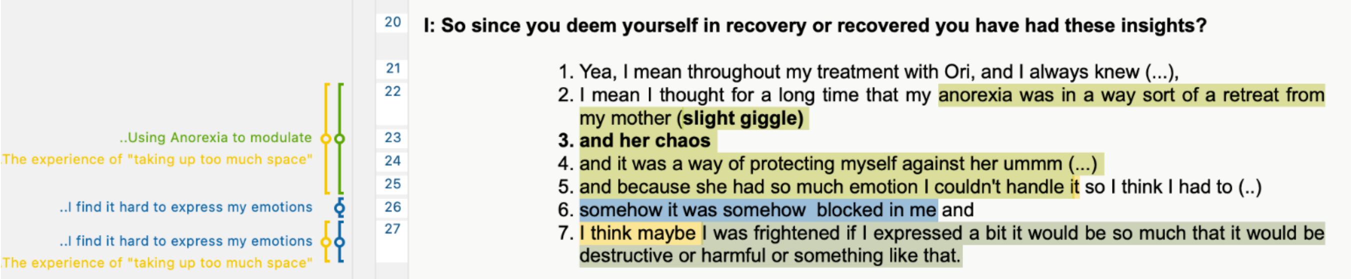
Semantic.

it was almost a method of stopping the homesickness and stopping the tears and stopping wanting to ring home at two o'clock in the morning (Emily Interview, Pos. 50)

Latent.

I can't remember bits it feels like kind of there is almost like, not like I have blotted it all out, there is a haze over it (Emily interview Pos. 20)

The whole of each transcription was coded systematically with thoughts and ideas, with little regard as to how these would later come together, and emerging concepts were identified alongside pre-defined ideas. Some sections of data were assigned more than one code. An example is given below.



I: So since you deem yourself in recovery or recovered you have had these insights?

1. Yea, I mean throughout my treatment with Ori, and I always knew (...),
2. I mean I thought for a long time that my anorexia was in a way sort of a retreat from my mother (**slight giggle)**
3. **and her chaos**
4. and it was a way of protecting myself against her ummm (...)
5. and because she had so much emotion I couldn't handle it so I think I had to (..)
6. somehow it was somehow blocked in me and
7. I think maybe I was frightened if I expressed a bit it would be so much that it would be destructive or harmful or something like that.

<u>Phase Three: Searching for themes</u>

Following all transcriptions being coded, I began to look for “shared pattern meaning across the dataset” (Braun & Clarke, 2019, p. 35). This part of the process was originally described as “searching for themes” (Braun & Clarke, 2006). However, it has now been acknowledged that themes are constructed by the researcher. It was important for me to notice at this stage how my experience, insights and research question informed how I was applying themes to form “candidate themes”. I did this by noticing key features and similarities across transcripts. For example, the map in Appendix 6 shows all the coded segments that were grouped to consider how emotions were experienced in families of origin, for example “a family script of not talking about emotions” and “parents not listening when emotions were expressed.”

<u>Phase Four: Reviewing the Themes</u>

Candidate themes were defined and refined by examining the content and context of coded segments. It was important to re-read coded sets of data to consider context and meaning, and whether this was representative of the code I had ascribed to it. I also began to group themes and delete codes when they did not have sufficient data to support them. This stage took a long time as it seemed important to represent the data in a way that felt authentic to the participants, and I felt it was difficult to ‘let go’ of authentic and meaningful disclosures that the participants had made when it was not justifiable to include them. I was also conscious of wanting to represent the participants’ experiences in their families of origin but to present these systemically without appearing to parent-blame or pass judgement.

Phase Five: Defining and naming the themes (and changing them all)

Once themes had been defined, they were discussed with my research supervisor. This led to them being regrouped and changed to reflect the personal experiences of participants and represent overarching themes more interestingly and comprehensively, rather than as a description applied to them by a researcher. For example, “experience in a family of origin” became “where is the space for my emotions?”.

Phase Six: Selecting extracts and producing the report

The final phase of data analysis was to write up findings thematically. I chose to use many direct quotations in order to represent the experience of my participants in their own words.

The outcome of this six-stage process was a set of themes that I believe retained the individual views and experiences of participants whilst recognising commonalities across accounts. The themes are; “my emotional experience in my family of origin,” “this feels intolerable,” “how my body got involved,” “modulating and suppressing emotions, and feeling in control” and “the journey to recovery.”

In presenting the data, it has been important to not be dictated by the number of participants who had discussed each theme and sub-theme, in line with a positivist position of accepting that their views represented some reality. Thus, themes identified were those that felt the most in keeping with the aims of the study and provided the focus for discussion and conclusions, as well as those that were interesting and surprising to me, for example, how participants described what life is like post recovery.

5.6 Assessment of quality in qualitative research

Credibility, transferability, and confirmability

Credibility

The move from quantitative methods in social research towards qualitative ones has prompted a discussion around validity and quality of findings (Yardley, 2000) and credibility is linked to the accurate representation of phenomenon, and the appropriateness of choices made in the research process. In this study, credibility was achieved by the collection of data in an *in-depth* way through qualitative interviews with five participants, and analysis through a reflexive thematic approach with a validity framework, which allowed for immersion in the data. Sensitivity to context has also been demonstrated by undertaking a thorough literature review on both relevant topics being explored and research using a similar methodology. I evaluate this in relation to the data later in the discussion chapter. I have also considered my position as a researcher and the balance of power in the process of the data collection interviews, as a professional in the field of EDs.

Throughout the research process, I have remained committed to representing the data most appropriately and accurately representing the participants' views. This was reinforced by offering them the opportunity to review the data after analysis stage and to engage in reflections together in a collaborative space, as recommended by Tracy (2010) and Braun and Clarke in their validity framework (Braun & Clarke, 2021). Only one participant took up this opportunity, and we reviewed an overview of the themes together. Her feedback was that the themes felt pertinent to her and reflected her experience.

Transferability

Braun and Clark (2022) tell us that it is *"hard to let go of the idea that value is ascertained by the ability of our research to speak more widely and more generally than the specifics of our dataset or 'sample'" (p. 143)* and explain that even the use of the word 'sample' leads us to indicate that we are looking at a subset of a bigger 'whole'. They argue that researchers are too focused on the idea that the purpose of research should be for empirical generalisability (Maxwell, 2012) and that this must not be perpetuated by 'apologising' for the lack of this in the writing up of qualitative research. Out of this, they have introduced the idea of *transferability* when thinking about which ideas can be taken from qualitative research and applied to a wider group.

It is important to acknowledge that context matters, and findings cannot be simply isolated. However, by describing the demographic aspects and the context of the data collection, we can allow scope for what Polit and Beck (2010) describe as "reasonable extrapolation" (pg. 1452). The accounts in this study are presented with a rich and detailed description using direct quotes to replicate the voices of those who participated, with the interview schedule provided and details given regarding the sample and context in this chapter.

Morrow (2005) also guides researchers to give enough information in the publication of research so that elements of the study may be repeated. I have aimed to do this, through description of the research design, clearly and transparently. I have included detail about participants, and the process and materials used for the data collection. It was important to me to use a clearly defined method of data analysis, hence my choice of reflexive thematic analyses, and this was a contributing factor to my choosing to change from the narrative approach. This method enables the analysis to be undertaken similarly by another researcher, and for the reader to understand how themes were generated, allowing for increased dependability and confirmability.

Confirmability

It is important to make known and acknowledge the role of the researcher as part of the data collection and analysis in qualitative studies (Ritchie et al., 2014). Reflexivity should make clear the implications of the involvement of the researcher (Bryman, 2008), and that methods of data collection and analyses have been adhered to. This allows for subjectivity to be embraced whilst sharing some of the objectivity of the quantitative approach (Morrow, 2005).

Willig (2008) advises that, as far as one is able, it is important as a researcher to recognise assumptions and personal beliefs and to separate oneself from them. One should also reflect on the actions taken during the research process and how this was influenced by personal experiences and perceptions. During the process of data collection, I kept a reflexive diary and made notes after each interview about my thoughts and feelings, and what I had observed arising in the “space between”

(Burnham, 2005) myself and the participant. I also discussed my thoughts, feelings, and analysis with my research supervisor to consider their responses and plausibility of the findings. For example, after my interview with ‘Rose’, I wrote in my reflective diary about the similarities between us in our upbringings and the loneliness I felt at boarding school, and generally growing up, which she also described. I wrote *“I connected to her expression that she found it very hard to be alone, at the same time as experiencing loneliness.”* A larger extract can be found in Appendix 7. I felt it important to think about what she had told me, and to try and separate my own experiences from hers, whilst also considering how it may affect my interpretation of her interview.

As mentioned previously, I invited participants to meet with me following the data analysis stage to reflect on findings with them and to clarify their understanding. The findings were also discussed at length with two supervisors and colleagues in the field during the analysis stage to consider how the themes were deduced and presented.

Transparency and reflexivity

> *The story collector (researcher) is a mushroom picker: he or she listens selectively, remembers fragmentarily, and re-counts in a way that suits his or her purpose. (Czarniawska, 2004, p. 45)*

It is vital to have reflexivity around one’s embedded values, norms and assumptions to undertake reflexive thematic analysis (Braun & Clarke, 2022). The starting point is to state one’s background and values as a researcher in a way to promote transparency (Thompson & Chambers, 2012) regarding how we see others in the light of our own cultures, power, position and history (Madden, 2010). I acknowledge that my training and lens have affected my choice of research, the questions I asked, how and who I recruited, how I heard and interpreted the data, what I was curious about, and my findings and presentation of the research. I will aim to explore this further in this section.

I am a 40-year-old White British female who lives in Southwest London. I am a mother of three children and a registered social worker and systemic family therapist. I currently work as the clinic director of a not-for-profit private mental health service in a prominent position on the high street in Wimbledon. All of the participants were aware of this, and it is important to consider how this influenced the responses that I was given during research, as my contact with a system, in itself, changes that system (Maturana, 1998).

I struggled with my own emotions, and appropriate emotional expression, during adolescence and am an only child of divorced parents. I did not feel understood or validated by my parents during my childhood and believe that this contributed to the difficulties I experienced. I have also been diagnosed with ADHD as an adult which has helped me have more compassion towards my younger self and counteract the narrative in my family that I was a “bad” child. Emotions and emotional experience were never discussed in my family of origin, and remains difficult, which has led to several ruptures in relationships. My systemic training helped me to understand multiple perspectives, process how I have been shaped by experience, and gave me skills and tools to enable to me to have these conversations. However, it is important to recognise that I am still affected by the past and have a personal relationship to emotional processing in families.

Consideration of this is vital in how this affected the stories I heard, and the themes that I was drawn to. I also recognise that what I would consider to be ‘usual’ for family relationships will not be the same for others who have had different experiences. I have also not experienced AN and cannot expect to understand how this feels, thus my ‘lens’ is that of a professional in the field without lived experience.

Whilst I was listening to the participants, there were certain examples and situations they discussed that resonated with me, and I was able to think about how they were like my own familial beliefs and context. Those that I was aware of, I could hold in mind. But it was important for me to understand that this could have happened in a way of which I was not aware, yet it would still influence how I responded to both the participants and the data (Josselson, 1996).

The motives behind this research are also important to acknowledge. I have 10 years of experience working in two different inpatient units. In one, families involvement in treatment were considered central to the work. They were a vital part of the system, and it was necessary to include them to support their loved ones in recovery, and provide support to them in their caring responsibilities. In the other inpatient unit, I found that the converse was the norm. There was a culture of looking for blame in the family context for the development of the AN, and I felt that the views of families and patients were not respected or included in treatment plans. I found myself, in this system, wanting to hear their voices and pushing their perspectives forward during meetings and reviews, as well as challenging assumptions made about them. It would be common that I would find myself saying “Is that what they said?” or “have you asked them?” This fed my desire to bring the voices of those who had experienced AN to the forefront of my research.

Factors that govern whether people ‘reveal’ or ‘conceal’ are embedded in social relationships (Caughlin & Vangelisti, 2009). As I had previous contact with the participants, their responses would have been affected by what I represented to them, and my actions and demeanour in our time together. They also may have viewed me as being in a position of power or as an ‘expert’, which would have influenced their answers to my questions.

The participants appeared to be open, in line with research that relational security promotes disclosure (Vangelisti, 1994). Although we did not discuss how our relationship may affect their interviews, I was conscious of trying to communicate a ‘safe space’ through my demeanour and warm approach before the interview started. By building rapport and adopting a non-judgmental tone I believe I was able to access richer material in relation to emotions in a more in depth way. With this in mind, it is also important to acknowledge that my efforts to present myself as a ‘supportive confidant’ (Greene et al., 2006) may have resulted in me emitting signals that inadvertently indicated preferred responses and influenced the data.

To counteract this, I used open-ended questions and provided the participants with minimal prompting to allow them to talk at length, recognising the importance of conversational ‘flow’ (Vangelisti, 1994). I was also clear about my motives and goals for the study, to promote the views of those who have recovered in AN research and treatment, and of my reasons for wanting to understand emotions and emotion processing. My participants appeared interested in the topic, and shared my view that literature and thinking around emotions appeared to be lacking, and this could have helped the participants to be more open to sharing, in order to help others (Vangelisti, 1994). I was conscious that many of the participants said they had never been asked about these topics, despite all of them going through ‘treatment,’ and they appeared to enjoy the opportunity to reflect on this, and stated they had valuable insights during the process.

Having a previous relationship also carries disadvantages in that sharing private information presents certain risks (Petronio, 2002), and participants may have been trying maintain our relationship, and keep me from forming negative evaluations (Vangelisti, 1994). I tried to mitigate this by assuring them of confidentiality and their ability to withdraw from the study, and by checking with them how they felt after the interview.

During the data analysis phase, I undertook several steps to mitigate the effect of my bias. I ensured that I discussed my thoughts, experiences and findings with colleagues and peers to deepen engagement and reflect on my ideas (Nadin & Cassell, 2006). I found this a very helpful process which gave me useful insights and alternative perspectives. I also ensured that I took time for the data collection and analysis to let ideas develop, to think, and to reflect on the process (Braun & Clarke, 2022).

I found it very helpful to review themes in supervision and appreciated being questioned and asked to explore the ‘essence’ and ‘intent’ of them (Braun & Clarke, 2022). My supervisor and I used a whole session to consider the theme names so that I could illustrate that I had interpreted what was meaningful in the data. As recommended by Nowell et al. (2017), I also kept a record of how themes developed and were merged, renamed and moved around to demonstrate quality. A list of themes before them being merged can be found in Appendix 8.

5.7 Ethical considerations

Ethical Approval

Ethical approval was sought and gained from the Tavistock Research and Ethics Committee (TREC) before the interview stage commenced (Appendix 9). This process involved making explicit any potentially problematic ethical difficulties and how I was going to mitigate them.

Informed Consent

All the participants who volunteering to take part in the study were sent an information sheet which they were given time to digest, with the opportunity to ask questions. Information provided included the purpose of the study and research question, how the research would be conducted, information on withdrawing and a description of the methods used to store and anonymise data. Before the interviews commenced, I reiterated the right to withdraw at any time and asked them to sign a consent form which included the recording of the interviews (Appendix 3).

Protection from harm

Ethical research

In thematic analysis, it is vital to consider representational ethics, that is the importance of striking a balance between meaning-making and *"telling a story that does not do harm" (Braun & Clarke, 2022, p. 214)*. The purpose is to tell a story through the interpretation of data and to find patterns of meaning. This can result in participants recognising some parts of the analysis as applicable to them and finding some parts unfamiliar. Although this is to be expected, it is important that the telling of these stories will not be harmful, either to the participants or to the population in general, and to recognise that those who experience mental health issues are a marginalised community.

To mitigate this, I ensured participants were thoroughly informed about the purposes of the research before they agreed to take part. I also brought my knowledge and experience in the field of EDs into the process so I could consider how discourses might be received (Chamberlain, 2011). I aimed to present the findings in a non-judgemental way, using a systemic lens without attributing parental blame, to try and not detrimentally affect family relationships and make parents of those with AN feel more blamed for their child's illness. This may have also contributed to reinforcing existing stereotypes about families who experience AN, which would be counter to the original goals of the research.

It is important to consider issues of power, and of representing the 'other'. Kitzinger and Wilkinson (1996) argue that it is important to consider the appropriateness of ourselves as a researcher representing a group to which we do not belong. To address this, I needed to be conscious of the questions that I was asking, to ensure that they were necessary to the research and that I was reflexive throughout the process about both my approach and role. For example, considering the setting, participants comfort, and naming our previous contact with them. It was also important to represent my participants in their language; hence, my use of many verbatim quotes.

The focus of the study was on finding patterns in the emotional experiences of those who had experienced AN. The use of an interview methodology has its ethical challenges as it involves participants sharing information that was highly personal, about both themselves and their families, and they could have been left feeling exposed after sharing such deep thoughts and feelings (Brinkmann & Kvale, 2005). It was also possible that participants could take the interview in a direction that I had not anticipated, and a risk that they could experience the interview as being akin to a therapeutic conversation (Willig, 2008). It was important to consider these and other possible risks throughout the interview and ethical approval stage (Bryman, 2008).

It was also necessary to have precautions in place to identify, protect from, and manage any distress caused. To do this, I had a conversation with every participant following the interview to debrief them and assess any negative effects. This also enabled me to share options for follow-up care and think, together with them, about self-care when they left the room. It was also vital to inform the participants of the realm of confidentiality and where this could be broken.

Confidentiality, anonymity and data protection

The findings of this research have been illustrated with rich and detailed descriptions and verbatim quotes to try and offer transparency in the research process, as recommended by Braun and Clarke (2022). The participants were informed that direct quotes would be included, but that there would be no information given that could identify them. Pseudonyms were used to refer to the participants, and all identifying features were removed, allowing the findings to be presented anonymously.

The data collected in this study has been treated and stored in line with data protection legislation. All the participant information, video recordings and transcripts have been stored in password-protected files.

5.8 Chapter summary

This chapter has provided a detailed description of the purpose and aims of the research. It has explored the critical realist philosophical position and the rationale behind this as well as the reasons for selecting a qualitative methodology. It has described the process of thematic analysis and the transparency, credibility, and confirmability of the research findings and given examples from the data. I have provided a section detailing my own reflections on myself as a researcher and how I may have affected the methodology, findings, and analysis. Finally, the ethical considerations have been outlined, along with the measures taken to protect the participants' data.

6. Findings

In this chapter, the data collected from the five participants is presented in excerpts that have been chosen to represent their voices. In selecting these extracts, I have excluded others that may have also been relevant to the theme; however, I have tried to cover all the participants and promote their perspectives.

The data is presented under five overarching themes to “provide a concise, coherent, logical, non-repetitive and interesting account of the story the data tells” (Braun and Clarke, 2006). As the research aims to highlight the voices and experiences of those who have experienced AN, direct quotes are used to illustrate the themes and give context to the data. To promote easier reading, some ‘filler’ words have been edited out and replaced with ellipses.

6.1 Themes generated

These data have been identified into five main themes, which are:

- My emotional experience in my family of origin
- This feels intolerable
- How my body got involved
- Modulating and suppressing emotions, and feeling in control
- The journey to recovery

During the interviews, I invited participants to explore their perceptions of how emotions were managed in their family of origin, their experience of these emotions, and their understanding of the emotions regarding AN. The participants were arranged into two groups. Group One (n=2) were 18 and 19 years old and still living at home with their parents. Their recovery had occurred within the previous year of the interview. Group 2 (n= 3) were in their 40s, had lived outside of the family home for a long time, and had been in recovery for a minimum period of over three years. Each theme is presented with extracts from the interviews included verbatim.

Theme 1: My emotional experience in my family of origin

“I didn't know that emotions were acceptable."

Rose, 12 - 12

This theme consists of participants’ descriptions of how emotions were experienced and processed in their families of origin, and how they described their emotional landscape both within themselves and in the context of their homes.

1.1 Sub-theme: My feelings are too intense for others around me

All participants described that they perceived themselves as being more emotionally sensitive than others, and that they experienced their own emotions as too big, too intense, and unmanageable for others around them.

Gail described how she felt emotions very strongly and had always been able to notice them easily. She discussed how she could ruminate on both her own emotions and what those around her were experiencing.

> *"I think ever since I was a child I was very (.) umm like aware of other people's emotions and I always thought I had this weird hypersensitive thing where I would immediately be aware of everything around me. Changes in emotions, changes in people's energy. I would always over-think emotion, my own, other people’s… emotions are a big thing for me basically. I always sense them."*
>
> *Gail, 3 – 3*

Claire also described perceiving her emotions as being intense, and that this felt for her like a point of difference between her and others around her.

> *"I always felt like very different to everybody else, I always felt like I had much bigger feelings."*
>
> *Claire, 57 – 57*

She described being stuck in a double bind of feeling that she was both exceeding her parents' expectations and disappointing them at the same time.

> *"It was a combination of being too much and also not enough all at the same time, which is very challenging for a teenager."*
>
> *Claire, 171 - 171*

Rose similarly described being preoccupied with her emotions but framed her emotional experience as being sensitive to hurting the feelings of those around her, rather than having overwhelming feelings. However, she did talk about intense emotions later.

> *"As a child, I was always worried about am I going to hurt this person, quite sort of sensitive."*
>
> *Rose, 147 - 147*

All three felt that these experiences had been present from birth, and thus appeared to have a narrative that they were born with the disposition to have intense feelings and emotional perception, rather than it being due to environmental factors.

> *"I do not think there is anything in the past that made me specifically like that. I think I was just born like that. I think I have always been like that and will always be like that."*
>
> *Gail, 37 - 37*

This was also the case for India, who felt that her emotional sensitivity allowed her to understand how others around her were feeling.

> *"My mum has always told me I am very much emotionally intelligent. So, I can, even if someone says I am fine if I know the person really well, I can connect and understand what they are going through."*

> *India, 49 – 49*

Emily, Claire and Gail expressed that this feeling of emotional sensitivity and strong emotional experience was not only present in their early lives but has continued following their recovery.

> *“In my head, I will start ticking over something that doesn't need thinking about."*
>
> *Emily, 26 – 26*
>
> *"I have a lot of emotions."*
>
> *Claire, 7 - 7*

Additionally, Claire, India and Gail also described a context in which they were not able to share their feelings. This was partly due to the emotional role modelling from their parents, which is discussed in the following theme, as well as the feeling that their emotions were so intense that they could not be managed by those around them. Claire shared that she felt that her emotions were overwhelming for her parents and that her expression of these was considered too ‘big’ and that her parents did not know how to help her process them.

> *"I: When you say about emotions being too much do you mean for you or for others around you?*
> *P: For others around me."*
>
> *Claire, 42 – 43*

When Claire tried to express her emotions, she had the experience of a script being replicated in terms of emotions being something that one should ideally not respond to, and that she was being oversensitive in her response to her feelings when her mother would tell her that she was overreacting.

> *"Don't be so silly….. Don't be so silly, don't be so ridiculous, don't be so sensitive."*

Claire, 271 - 271

India was more conscious about burdening her parents with her feelings, especially when comparing herself with her brothers.

> *“I feel like, especially from my part, I feel like I am worrying them the most compared to my siblings."*
>
> *India, 39 - 39*

Gail’s emotional experience and how this was received led to her feeling that she was frustrating her family with reassurance-seeking.

> *I’m always the one being quite annoying and pestering, always the one saying, ‘Are you sure, are you sure?’."*
>
> *Gail, 3 – 3*

This sub-theme illustrates the feeling of sadness running through the narratives of the participants: that they were ‘mismatched’ with their family of origin and viewed themselves as, in some way, defective in their intense experience of emotions. They recognised that they experienced emotions in a more intense way than others and that those around them were not able to understand this or know how to help them with it.

This relates to the social constructionist view of the relational aspect of emotions, and their display in order to allow others to understand them to be present. For these participants their experience of sharing their inner world resulted in an invalidating response, due to their parents discourses of emotions, leaving them unsure of how to act in relation to this overwhelming experience. This matches my experience in my family of origin, which I believe helped me to access this in my participants by allowing space for it to be expressed.

1.2 Sub-theme: Emotions should be hidden away

All participants described an emotional landscape in their home as one in which talking about emotions was difficult. There was a strong message that emotions should not be talked about, either through parental role modelling or being told so explicitly. There was also an experience that when emotions were expressed by their parents, it was done so in a way that felt frightening or overwhelming, further reinforcing the idea that “emotions should be hidden away”.

Gail, Claire and Rose all spoke explicitly about their family of origin in terms of a general emotional landscape in which feelings and difficult subjects were not discussed.

"We do not talk a lot about our emotions."

Gail, 71 - 71

"We don’t really talk about emotions as a family."

Claire, 97 - 97

"Yeah, we don't talk about anything difficult as a family."

Rose, 302 – 302

However, although India also experienced that emotions were not talked about, she hypothesised that her parents were discussing their feelings, just not in front of their children. Her hypothesis for this was that her mum would think that talking about difficult things would be too hard for them to cope with, but this meant there was no role modelling of how to talk about emotions.

> *"I feel like…. she wouldn't want to put on us. She would always, I think, keep it closed or tell my dad in a different room. When everyone is in bed, they were probably talking."*

India, 37 - 37

As the subject was explored further, it seemed that for Gail, Emily, Rose and Claire it was more nuanced than simply emotions not being expressed, and that there was also an experience of emotions ‘bubbling over’ when they became overwhelming and it being scary to witness them being discussed.

> *"We sometimes all bottle stuff up a little bit until it does come out and then when it does come out it is not off limits it's just (.) I think everyone kind of has their own stuff and then when it gets quite bad then it will come out."*
>
> *Gail, 73 – 73*

Gail described her dad as commonly “angry” and her mother as “upset and anxious” and that when her parents did express themselves with each other it was by arguing in front of them.

> *“When I was younger there was quite a lot of conflict between them. They used to argue quite a lot."*
>
> *Gail, 23 – 23*

Claire also talked about the struggle her mother had with expressing her emotions in a regulated way and attributed this to her upbringing.

> *"She could be quite shouty….my mum is incredibly tactile and says ‘I love you’ all the time, kisses and cuddles all the time, but very much can’t go beyond a surface level of emotions. How she's been brought up you know, and you don't go to her with feelings"*
>
> *Claire, 55 – 55*

Rose grew up in a family where there were also strong messages about how emotions should be repressed and not expressed.

> *" Don't complain, don’t express, don't want or don't want in public. If you have desires, you mustn't talk about them. Do your best, button up, chin up. Rise above it, don't succumb. Nothing…. it’s all, none of this matters. It's all*

> *irrelevant. So don't, …... you know, it's pathetic to be hurt, why would you feel hurt?"*
>
> *Rose, 224 – 224*

Rose was reflective about the effect it had on her of her mother sharing her thoughts and feelings in a way that felt overwhelming, and how this left her with a sense of being alone, with no space for her to have emotions and difficulties, which links to the overarching theme of this dataset.

This experience left Rose feeling scared about how much she chose to share, and this fear was illustrated in her description of her worries about even starting to tell others how she felt.

> *"So, she would come and sleep in my bed and tell me about her fears, and disasters in her life when I was home from school and I think (..), so I just sort (..)*
> *there wasn't really any room for anything else……*
>
> *And I think just all of that was just frightening to me*
> *and overwhelmed me…*
> *I knew I didn't want to be like that……*
>
> *I think maybe I was frightened if I expressed a bit, it would be so much that it would be destructive or harmful or something like that."*
>
> *Rose 39-47*

In a similar way to Claire, Rose reflected on her belief on why her mother struggled with appropriate emotional expression and put it down to both her experience in her own family of origin and disappointment in her adult life.

> *"I think her own personality had been stifled by all her problems which were a mixture of factors, social factors like her unhappy marriage, and er thwarted dreams and difficult family*
> *but also things inside herself and things that had happened in her own childhood."*
>
> *Rose, 64 - 65*

As well as this, Rose’s father used alcohol to manage his difficult feelings and Rose was clear in her thoughts about the role this played for him.

> *"My father, well, he manages shame by drinking, that is how he manages most things. I think that allows him to numb and express at different times depending on what's necessary."*
>
> *Rose, 182 – 182*

In summary, the participants described living in an emotional landscape of “not expressing,” or parental expression of emotions being overwhelming and uncontainable when it does happen. To them, the emotions felt very present, and tangible, but they were denied when they expressed experiencing them, so the relational aspect was lost. They also were unable to understand how their parents felt or to experience positive role modelling regarding appropriate emotional expression.

1.3 Sub-theme: Family context and impact of gender roles

All five participants told me that their fathers worked long hours outside of the home. This meant that they were not physically present, nor were they emotionally available.

> *"My dad wasn't around a huge amount he worked a lot, he wasn't somebody I would go to, he wasn't an emotional support."*
>
> *Claire, 55 – 55*
>
> *“I wouldn't go to Dad as that wasn't his area."*
>
> *Rose, 100 - 100*

Their mothers were stay-at-home mothers, except Emily’s mother who had a job as a social worker but was the parent that was consistently present and undertook the caring responsibilities. Emily is an only child, and she told me that she and her mother both loved horse riding; therefore, they spent a large amount of time together. She described their relationship as *“exceptionally close”*. However, she also explained that her mother could be very clear when Emily had done something to upset her, which then left Emily with an upsetting visceral feeling.

> *"I remember going to school at times and thinking ‘I've really pissed her off’, but I think it's important I probably felt that as well."*
>
> *Emily, 46 - 46*

She also experienced a dual experience concerning her parents by whom she felt both supported but also the most criticised.

> *"I generally felt, for both of them, they were my biggest fans but also my biggest critics."*
>
> *Emily, 46 - 46*

Claire experienced punishment from her mother when she had done something wrong, and this was in the form of non-communication, further emphasising the difficulty in talking about emotions or problems in the family, and them being resolved.

> *"If I’ve said things or done things they don't like, and my mum won't speak to me for about a week."*
>
> *Claire, 135 - 135*

Gail described a closeness with her mother; however, there was a sense that she was alluding to a feeling that their relationship was different to what she had observed in others around her.

> *"I was also quite attached to my mum as I kid, like my mum immediately knew any time I am feeling anything."*

Gail, 9 - 9

Rose also described a closeness, and, similarly to Gail, one that may be more unusual; however, instead of the connection leaving her with a feeling of being understood, it was that she was responsible for soothing her mother's feelings.

> *"I was her main confidant in her life… I think mum often, (....) she wanted me, I was responsible for her fear."*

Rose, 103 - 103

In addition to this, she was left in a confusing position in which there was a push-pull dynamic in their relationship with her feeling both wanted and rejected.

> *"I do remember that my mother just said, 'You are just poison, you are poisonous'."*

Rose, 81 – 81

These experiences with their mothers were confusing for the participants: on the one hand, they felt exceptionally close, and on the other quite rejected. There was a sense of never being quite sure what to expect, or where they stood, and a difficulty in understanding the boundaries of their relationships.

Gender was also discussed in the interviews. Four out of the five participants had one or more brothers (Gail, Claire, India, and Rose). None of them had sisters. All the participants who had a brother expressed that they felt they experienced and processed emotions differently from themselves. There were also differing expectations and stereotypical assumptions about how one should behave in their family based on gender. Both Gail and India said that their brothers found it difficult to express their feelings.

> *"My brother is the opposite of me. He doesn't show many emotions, and he is very reserved, and he will not talk about his emotions."*

Gail, 23 - 23

> *"My twin, he is very enclosed; he doesn't want to express his emotions, whatever he is going through."*

India, 35 – 37

Rose could not talk to her brother about emotions either but for a different reason. She described that her father had 'stereotypical' ideas of what a male 'should'" be, and he believed that her brother did not fit into these. Rose's brother had been labelled as too delicate to be able to manage any feelings, emotions or difficulties.

> *"You can't possibly tell your brother because he won't be able to handle it.' My brother always had to be protected."*

Rose, 113 – 113'

Claire also described, in the same way as Gail and India, how her brother found it difficult to express emotions. Additionally, she had a similar experience to Rose in that she was treated differently to her sibling due to the family's expectations of males. This made her feel alone and unable to share with him.

These stereotypical gender assumptions appeared to make participants feel even more 'distant' from their families, and further contributed to a sense of loneliness. There appeared to be a desire for the participants to be closer to their brothers, and a feeling of difference, that was exacerbated both in the way that they experienced their emotions and in the way they were treated in their family of origin.

1.4 Sub-theme: What I learnt about eating, weight and shape

Three out of the five participants stated that there were judgements about weight in their family of origin, or that one of their parents had eating disorder tendencies. Gail discussed how her dad was very preoccupied with sports and the body shapes of people around him. She described how he would *“hassle”* her mother about going to the gym and *“nag”* Gail about not going to training,

> *"My dad is very sport crazy, fitness crazy… he is very aware on people’s physics in a sense and would notice them and sometimes say unnecessary comments about them."*
>
> *Gail, 123 – 123*

India also described how she grew up in a house of brothers who were very sports-focused and thus her father valued fitness and eating the *“correct”* things. However, she was clear that she did not attribute body, weight, or shape concerns to the environment in her family of origin.

Claire also had the experience of body shape and weight being commented on; however, this was more personal as she would be told by her mother, who she described as *“really skinny”* and her father, that she needed to change the way she looked. This persisted, despite her having experienced an ED and being in recovery.

> *"She would tell me now I need to lose weight, often. My dad will say it, my mum will say it."*
>
> *Claire, 245 - 245*

Emily also described that her mother had a propensity to limit her food, in particular concerning stress, in a similar way to how she did.

> *"My mum would admit now she had tendencies, that she kind of probably restricted."*
>
> *Emily, 72 – 72*

These messages about eating weight and shape from parents suggested that one should be conscious of what you ate, and how you look, and that this was a value that was important in their families. This was also linked to their brothers being focused on sports and performance and them watching their fathers have a heavy involvement with this, and to their diet.

Summary

This theme encompasses the paradoxical nature of the intensity of feeling emotions that are intolerable, in an environment where they cannot be expressed. The inability to express them was linked to the messages they received from their families in terms of how emotions should be managed, as well as their relationships with their parents, and the expectations put on them based on their gender.

Theme 2: Being me feels intolerable

This theme encompasses the participants description of their experience of being in the context described in Theme 1. These involved a description of loneliness and sadness, and then the idea that they were a ‘bad person’. They also described an inability to express their emotions, and that they would ‘do anything’ to avoid them.

2.1 Sub-theme: I feel lonely and sad

The cohort of older participants who had been in recovery for longer (group 2) all stated they had experienced an intrinsic and overwhelming feeling of sadness during childhood. This was not linked to specific events but was just a pervasive feeling that was described as ever-present.

> *"I was so sad, very sad, I used to cry all the time. I would hide in the bathroom and cry; I was so sad. "*
>
> *Claire, 167 – 167*
>
> *“I think now I realise that I was very depressed.”*

Rose,78 - 78

Four of the participants also described strong experiences of loneliness across their lifespans. This was described as present before the development of AN, during their illness, and a feeling that could arise for them again in difficult times since their recovery.

> *"I think you know when I feel very alone when I feel lonely (...). It has just always been something with me."*

Rose, 310 – 310

“I probably felt a bit lonely."

Emily, 84 – 84

"I felt quite alone for a long time…I didn't really have anyone to turn to."

Claire, 57 – 57

Both Rose and Claire attributed this to their experience of not having their emotions validated in their families of origin or by others around them and that they did not feel that there would be anyone to listen to or support them.

“What would be the good of that, as there wasn't anyone to hear?"

Rose, 90 – 90

"I think there is people like me who just don't have support and don’t feel held."

Claire, 281 – 281

India described that she had a protective mechanism in which she would turn inwards and engage in self-harming behaviours (which she described as encompassing over-exercising and restricting) when she was struggling with her emotions or difficult situations, which then isolated her further.

> *“When those emotions got stronger, I would use a different coping mechanism, I would withdraw myself from everyone and to relieve that pain of emotion I used to do self-harm and I thought that would be a way to cleanse and detox that mindset whereas no, it feeds in more negativity, and it doesn't help you it does the opposite.”*
>
> *India 17-17*

For Rose, her experience of loneliness was so pervasive that eventually, it was a driver towards her recovery as for her, it was inextricably linked with her ED.

> *"So, I am either just going to have to be lonely which is fine, that will go on forever umm or I have to do something about it."*
>
> *Rose 310 – 310*

I felt a sense of sadness in the interviews when participants described their loneliness as children, and then later as adults. I was left with a sense of this being something that they also felt had been with them from the beginning, as if they had been born lonely through this experience of being mismatched in their families of origin. It was difficult to separate out my own feelings of loneliness as a child and over my lifespan, and to consider how reflection back to the past can result in different feelings to the experience in the moment. It was also aware of the isolating nature of the illness and how that may affects perceptions of being ‘alone.’

2.2 Sub-theme: I find it hard to know how I feel, and to express it

All the participants described that they found it hard to express to others how they were feeling. They discussed that they did want those around them to understand them, and to have their feelings validated and soothed, but they were not able to tell them, either because it just did not feel possible, that it was not acceptable to experience emotions, or because they worried about upsetting people.

> *"It is quite frustrating that you can't get the words out of how you are feeling but you want people to know."*
>
> *Gail, 35 – 35*
>
> *"I'm someone who never opens up…cause I'm afraid to, like, scare them or worry them."*
>
> *India, 37 – 37*
>
> *"I will hold stuff in which isn't necessarily always healthy either."*
>
> *Emily, 46 – 46*

Claire's description of the conditions that allow her to express herself more since recovery illustrates why she felt unable to do so before. She describes how her partner makes her feel that her emotions are valid which helps her to disclose them.

> *"Feeling like my emotions are too much so it's having actually having somebody … tell me that that it is acceptable, you know, that I am very needy…when it comes to that sort of thing cause I didn't get it, so I need to be told that it is ok to have emotions about things."*
>
> *Claire, 41 – 41*

Both Rose and Claire also talked about finding it difficult in the past to naturally express themselves to others in a way that was deemed "*acceptable*" and allowed them to be understood, but that this was something that Rose felt they had been able to do, with some effort, since recovery.

> *"It has come to me really clearly the past three years,*
> *as I've (.) tried to express myself in a healthy way. (..)*
> *I've recognised that this is something I have to make a conscious effort to do."*
>
> *Rose, 15 - 17*

Anger was a specific emotion highlighted as being very difficult to manage. Emily and Claire identified that this was the one that they found the most difficult to express towards others, and to process in themselves. Emily told me she is only able to display anger towards her mother. However, she stated that this made her feel very guilty and shameful afterwards. Anger was also described as being difficult to tolerate when there was a sense of it directed towards them.

> *“Someone being angry at me or being upset with me I just can't deal.”*
>
> *Gail, 11-11*

Rose talked a lot about anger and her difficult relationship with it. She linked it to being hurt by others and how this would sit with her for a long time, without her realising the reason for the feeling for some time.

> *"I start boiling over and I am bubbling away in anger for a couple of days and then I realise I am really furious because I am hurt about that thing."*
>
> *Rose, 226 - 226*

Anger was the most unpleasant emotion for Rose, and the most difficult to tolerate. She described how she got *“wound up really easily”* but, further to that, she got stuck in a difficult pattern with her anger, finding it a protecting guardian to her hurt and self-judgement about how she ‘should’ feel. This also interlinked with her feelings of shame about herself, which are discussed later in this theme.

> *"I think, when I do feel anger, I feel anger because being hurt would be what a pathetic person does so that would be shameful. But I also feel anger because (..) I think that my hurt is unjustified because look at me, I deserve to be hurt."*
>
> *Rose, 232 – 232*

Alexithymia

The participants described finding it hard to identify how they were feeling, and that, as described above in relation to anger and hurt, one feeling could be experienced as another. This made it harder for them to be able to communicate emotions to others around them in the moment as they would often become apparent to them after the event.

> *"(I'm) all over the place and I am always I just feel uneasy and then something happens and I'm like 'Oh my God, I really hurt or I'm embarrassed or I'm angry', any of those things. I always have a delay between an event and a reaction. It's usually about a day and a half or two. So, something happens, and I feel there is something going on, but I don't know what it is, so something strange and then about 36 hours later it will occur to me that I am upset because that person did that. It is really sad."*
>
> *Rose, 218 - 218*

Claire also identified that it was hard for her to use bodily sensations to identify how she was feeling; however, this had only come to light for her since recovery and trying to work on this in her therapy sessions.

> *"I am very bad at associating them (feelings) with my body. I am very disassociated from my body…if I am in a panic to think about my body where I am feeling it I can't do that, umm, I find that very difficult to do."*
>
> *Claire, 21 – 21*

This section summarises the difficulties that the participants describe in both identifying and expressing their feelings and emotions. Anger was most mentioned, both regarding their own experience of it, and how they feel when others are angry with them. This inability to express feelings to others around them meant that they were left with unprocessed emotions.

2.3 Sub-theme: I will do anything to avoid these awful feelings

As discussed above, the participants painted an emotional landscape of intense emotions, with difficulty both in identifying and expressing them to others. This left them having to manage their feelings alone, which felt difficult to tolerate.

> *"And I don't like being, like, in the moment when I am really upset."*

Gail, 35 - 35

Gail was able to see an improvement in this since she had been unwell, and in the sadness that she had experienced. She also explained that she had changed considerably through the process of recovery.

> *"I am much better at dealing with my emotions than I was this time last year when everything seemed so much worse… really sad and not really myself, just like a different person. I kind of see it as a ghost of a person."*

Gail, 11 – 11

Although India found it difficult to talk about her emotions, in relation to both her experience and how she processed them, she did share that she found the way in which her emotions changed during adolescence difficult, resulting in her desire to *"withdraw myself from everyone".*

Emily told me that she would *"do anything to avoid a confrontation"* and that she went into 'organisational mode' when she felt the *"need to escape"* to avoid feelings that she did not want to sit with, and that this affected the other people in her family as it was clear that she was worried.

> *"So, when I feel that anxiety, I then become very much like right give me a calendar, give me something to sort, give me something to organise and I know that this may impact on others as they would sense that tension."*

Emily,22 – 22

Claire was very clear about how difficult she found tolerating her feelings. The ones she named as the worst were being in trouble and anger, as they made her feel that she had lost control. She told me that she had a *"negative association with emotions"* and that she found silence very difficult. Her avoidance techniques included avoiding being alone, and having the TV on or headphones plugged in when she was going to sleep. She also described how she used self-harm to help to distract herself.

> *"I find it very difficult to sit on my feelings or my thoughts. Distraction is a huge thing that I do… I am very good at shutting things away, that is also a super skill …yeah, I mean techniques I have adopted over the years of how to sort of survive."*
>
> *Claire, 49 – 49*

Claire shared how she had discovered coping mechanisms at an early age when she would *"hold her breath until she passed out"* when feeling overwhelmed. Years of covering up her emotions resulted in her being successful in hiding how she felt, and this created a double bind for her as she was then unable to get the experience of it being validated as those around her did not know she was upset. However, this approach to managing also made her feel detached from overwhelming emotions which she experienced as helpful.

> *<u>Participant:</u> "I think probably years of of, errr, of, of covering that up has probably given me quite a good (.) buffer.*
> *<u>Interviewer:</u> So other people around you would not necessarily know? (how you are feeling)*
> *<u>Participant:</u> I think not unless they were very close to me."*
>
> *Claire, 15 - 17*

The tendency of the blocking and avoidance of feelings was also identified by Rose, who identified it had been a pattern over a long period during her AN.

> *"I felt like I had run away from loads of stuff for years."*
>
> *Rose, 188 – 18*

This section describes the difficulty that participants illustrated in sitting with their overwhelming emotions, and their desire to dissociate from them and undertake avoidance strategies to do so. This inability to be able to manage their difficult thoughts also contributed to a feeling that they were a ‘bad person’, as described below.

2.4 Sub-theme: I am a bad person

Four of the participants described that there was internal blame towards themselves for thoughts and feelings of sadness, loneliness, overwhelming emotions and being ‘too much’ in their families of origin. This resulted in them considering themselves as ‘bad’, and they had visceral self-hatred, which they shared with me.

"I hate myself."

Rose, 296 – 296

Rose, India and Claire specifically were very critical of themselves, both as people and how they managed their internal experiences and external situations.

"So, if I feel this I am a really bad person."

Rose, 139 - 139

"I know everyone copes with their emotions differently, they have their good coping mechanisms….and I sometimes wonder, ‘Why me? Why do I have that unhealthy coping mechanism?’"

India, 35 – 37

"I didn't have any security in myself at all of being worthy of anyone or anything."

Claire, 193 - 193

Rose and Claire also expressed a desire to be a ‘good’ person according to their moral values, and achieving this was very important to them, resulting in very difficult feelings towards themselves if they were unable to do so. Their high standards of themselves appeared to be unachievable, and there was no positive self-talk or description during the interviews.

> *"I will get fear that I haven't been helpful, I haven't done it right, and I've done it wrong."*
>
> *Claire, 305 - 305*
>
> *"I always strive to be a good person according to the values, so if I fall short of them I really hate myself."*
>
> *Rose, 145 - 145*

For Rose, this relationship between ‘good’ and ‘bad’ was heavily linked to emotional experience. There was an internalised message that emotions were ‘bad’, and this resulted in a desire to punish herself for experiencing them.

> *"I must punish myself as I feel I must be a bad person for feeling these things because emotions are bad things."*
>
> *Rose, 137 – 137*

These feelings were directly linked to her AN behaviours, which served the function of administering self-punishment. This was particularly linked to purging.

> *“Certainly, vomiting, as well, was certainly a punishment. I would be really aggressive about it, make myself really ill. And feel awful. I would be saying in my head, ‘You deserve it you absolute bitch’."*
>
> *Rose, 148 – 149*

Following purging Rose became stuck in a double bind in which her behaviour reinforced urges to engage in AN behaviours to manage feelings that arose as a result of her engaging in them. This became an impossible cycle to escape from.

> *"I could say to myself, look this is how you behave, you are this awful person. I was confirming to myself how I thought I was (..) by making myself even more worthless."*
>
> *Rose, 154 - 154*

Claire also related her relationship with food to reward and punishment. For her, restriction was being ‘good’, and the eating of food was used as a punishment.

"Food, that was probably more of a punishment."

Claire, 53 - 53

This internal world so vividly explained by the participants was striking. The pervasiveness of their feelings of loneliness, sadness and being ‘bad’ was intense, and the lack of skills with which to manage these feelings led to the development of coping strategies that were linked to food, as further discussed in the following theme. I was struck by how participants were able to talk about this deep shame so openly, which made me feel privileged and reinforced the desire to present their experience and widen understanding. I was able to tolerate and “stick with” their descriptions due to my own personal experience, enabling them to access and share deeply private refelctions.

Theme 3: How my body got involved

In this this theme the participants describe the emergence of AN thoughts, feelings and behaviours and their understanding of how they came about. They also describe how their AN served a function in communicating with others around them, and how a reinforcing cycle of guilt and shame kept them trapped in the illness.

3.1 Sub-Theme: How Anorexia came into my life

The participants gave two clear descriptions as to their perception of how AN came into their lives. The first group of younger participants spoke about acting on the desire to lose weight, which then became ‘addictive’. The second group of participants, who were older and who had been in recovery for a longer period, described using AN behaviours to manage difficult emotions and then experiencing the secondary gain of thinness.

India and Gail (the two younger participants) told me about when the desire to lose weight started, which was the beginning of their journey with AN.

> *"I looked at myself in the mirror and I was like, ‘I need to lose weight’, but I didn't know how."*
>
> *India, 23 - 23*
>
> *“I remember a day very clearly when we went to the river and all my friends and quite small, especially back then. I was always the tallest all my friends are shorter than me and all my friends were in bikinis, and I just remember feeling like just a little bit like off.”*
>
> *Gail 41*

The weight loss and behaviours associated with it then became addictive, and they found themselves in a cycle that they could not withdraw from.

> *"It just very quickly became like very obsessive and then it went I guess into a dark hole."*
>
> *Gail, 47 - 47*
>
> *"Nothing would break that cycle no matter how much, like no I shouldn't, it's addictive like you cannot stop, it would be like small little things and then it would creep and would be become further and further to the point it was very excessive."*
>
> *India, 23 – 23*

India also described how she felt that her weight loss made her mum happy, which was external validation that what she was doing was positive.

> *(talking about her mum) "I think she was happy that I wanted to be healthy."*
>
> *India, 97 - 97*

For the older participants, Claire, Emily and Rose, the restriction of eating was not conscious. Instead, they experienced AN behaviours as a helpful way to manage the difficult feelings they were experiencing. Claire was struggling at school and being bullied, and Rose and Emily were both intensely homesick at boarding school and university, respectively.

> *"If I think about the eating was very, I don't think this very often so forgive me if I am pausing (gestures to her head), but I think it came, it was very, very subconscious, my stopping eating."*
>
> *Claire 91 - 91*
>
> *"I don't think at the start it was ever about my body size or what I saw when I looked in the mirror. That definitely came significantly later. Umm, the start was definitely about suppressing this anxiety, this panic, this dread and homesickness."*
>
> *Emily, 50 – 50*
>
> *"It was a way of managing my emotions by myself without talking or without saying anything to anybody."*

Rose, 90 - 90

These coping mechanisms then resulted in weight loss, which drew external validation from those around them, reinforcing behaviours as acceptable, and even positive.

> *"Taking those comments, being with friends from London that I'd not been with for ages, 'Wow, you look good now!'"*
>
> *Emily, 50 - 50*

The weight loss itself then became addictive, and it also became an illustration to others of who they were and the difficulties they were experiencing.

> *"There was always something very, umm, addictive about being the thinnest person in the room. Or having something that people could see."*
>
> *Claire, 159 - 159*

The idea of the AN behaviours being 'addictive' was talked about by all five participants, as described above for Gail and India regarding weight loss. For Emily and Claire, it was the actual way AN made them feel, and its usefulness as a coping strategy, which were experienced as an addiction.

> *"I mean I think that came later, that desire (to be thin) comes I think after the addiction kicks in."*
>
> *Claire, 95 - 95*
>
> *"I feel better when I've barely put any food in my body. I feel better when I have been to the gym for two hours. Well, if I go a bit more I will feel even more better, and I will feel even more good about myself."*
>
> *Emily, 50 – 50*

Rose also explained that once the AN became part of who she was, and how people knew her, it was very difficult to escape from it, particularly as someone who had felt so ashamed of who she was before the development of the AN.

> *"It becomes, then, part of your identity, and it is very hard to break out of that."*
>
> *Rose, 294 - 294*

These descriptions of how the participants developed AN illustrate the interplay between using behaviours as a coping mechanism, weight loss and the external validation they received from others around them. This then became a cycle that felt impossible to escape from, both because it ‘worked’ in managing their emotions (as described later) and due to it becoming part of their identity. There is a striking difference in the development of the AN in the two distinct cohorts in relation to primary drivers and secondary gains that are directly opposite, and feelings of addiction are clearly described and relevant for them.

3.2 Sub-theme: I want to show you that I am sad

The cohort of three older participants with a longer recovery from their eating disorder talked openly about how they had been struggling in their lives before the development of the ED, and that they linked this to its development.

Claire talked about how she feels her AN was a way of asking for help when she was not able to manage how she felt and did not have the tools to do so. At the time, she was being bullied at school and felt that she “did not know who she was” and thus AN was a symptom of her difficulty coping with her emotional experience.

> *“It probably was a cry for help…probably seeking, trying to get help because I was so out, like felt completely …unequipped to deal with what was going on in my head."*
>
> *Claire, 149 – 149*

Rose was also miserable at school and described how this led to her trying to express pain, loneliness and despair through AN behaviours. She was trying to communicate her situation to others around her and was stuck in a double bind of wanting help but not wanting it concurrently, and not knowing how it was even possible.

> *"'Umm, I'm in pain. Somebody help me, but don't help me as I don't know what's wrong and I don't know how you can help me anyway'. I was saying those things. I would also say, 'I hate myself', umm (.) I was saying, 'I don't believe I have any future' and I was saying, 'I don't know what the hell life is about'. And I think I was saying, 'I feel unloved'. (...) All of those things."*
>
> *Rose, 296 - 296*

Rose told me that, *"dysfunctional behaviours for me have been ways of expressing things which I can't express in words"* and that she attributes this to both finding it hard to communicate and using them as an expression in themselves.

> *"I think communication is behind a lot of problems. Difficulties with communication or as a form of communication in itself."*
>
> *Rose, 292 - 292*

For both Rose and Claire, there was an experience of this 'working' for them, in terms of it being noticed. However, being taken to treatment was not a positive experience for Claire, whereas Rose was more successful in being taken out of the school that she hated.

> *"I suppose it got me what I wanted, eventually someone found out I had been making myself sick so they came to see the headmistress and they took me away to a different school."*
>
> *Rose, 88 – 88*

Rose was very clear regarding AN being a form of communication of sadness to those around her, invoking the function of emotion from a social constructionist viewpoint, by presenting as someone who was clearly struggling to cope, with her body being chronically underweight.

> *"I mean, it's a kind of passive-aggressive form of communication I think for a lot of people and it's an alternative and it’s, you can say a lot about yourself or who you think you are umm just by being in that state."*
>
> *Rose, 294 - 294*

However, Emily had a different experience. She was also in a difficult situation of being unhappy at university when her AN developed. However, she expressed she was desperate to keep her behaviours and sadness a secret to protect her parents and others and was never able to tell them. Her perceived communication to others was that she was coping well by losing weight and being told that she looked good. The AN served a dual purpose: to help her deal with her difficult emotions and to hide her inner feelings from those around her.

It is striking that this theme does not include any data from the two younger participants in the study. They did not link their AN to sadness specifically, or the communication of this, but more to coping with difficult feelings generally, which is discussed in the next theme. The description from the second cohort about wanting to be noticed and helped is striking, as is their use of AN as a symptom to express their difficulties in enacting others around them.

3.3 Sub-theme: The reinforcing cycle of guilt and shame

All five participants were aware of what they perceived to be a privileged position as middle-class White British women. This contributed to feelings of guilt and shame regarding their illness.

> *"I am very aware that I am very privileged, and I live a very, I have a very comfortable safe life and I always I just remember one person saying, ‘But your life is perfect why can't you know something like that?’."*
>
> *Gail, 91 – 91*

> *"The shame of almost, there was no recovery, no shame, why did I have anorexia? I have a good life, good family, good education and yet I felt invalid, shame because like (..), I shouldn't have had it, it's my fault, I had it."*
>
> *India, 85 - 85*
>
> *"What are you doing, get your shit together (smiles) because this is ridiculous, if you are doing this in this situation like this is crazy."*
>
> *Claire, 197 - 197*

They also talked about the guilt and shame of living with AN in terms of both acting on the desires and the effect it was having on their bodies. This was difficult to experience alongside external validation from those around them, which made the feeling of guilt more intense.

> *"Let’s be honest. So, I think some of the shame came around actually I’m getting validation in one sense but in the other, I’m doing this harm to my body, and I was very aware of that."*
>
> *Emily,84 – 84*

As well as feeling shameful about the effect they were having on themselves, they were also conscious of how their illness had affected those around them. This was expressed in terms of people worrying about them, how their behaviours affected others, and that it was shameful to have someone who had AN in the family.

> *"But I would say there is definitely shame with feeling from my parents in terms of the conversations they might have to have with some of their friends and in terms of the grandparents, those kind of conversions."*
>
> *Emily, 86 – 86*
>
> *"I would then feel ashamed as I was not the sort of person that no one wants around."*
>
> *Rose, 202 – 202*
>
> *“Shame about anorexia, about my family and putting them through that and, you know, feel pretty guilty about that.”*

Claire 199-199

For Rose, shame was an important topic, and she named many experiences of this, including the shame of her AN, shame of her past, shame of her family situation, and shame that she didn't *"speak up for herself".* Rose also expressed how her shame put her in a double bind of feeling that there was no point in achieving recovery, which left her stuck with her AN.

> *"I would always think, 'Well, what's the point of getting well because this is who I am now, I am this awful person."*

Rose, 204 – 204

Identifying the shame and allowing herself to think about it cognitively was also a key factor in Rose's recovery.

> *"I didn't really know about shame, even though I was feeling it the whole time (smiles) and identifying it was really helpful as I realised it was connected to this and this, so understanding something takes some of the pressure off the feeling. Ridding myself of my shame or my shame about my eating disorder has been really therapeutic for me, so I am not ashamed of that anymore."*

Rose, 168 - 168

A 'stuckness' regarding shame was also experienced by Emily. She expressed shame about her *"life not being sorted out"* in comparison to those around her, who she described as progressing their lives, for example, meeting partners or settling down. This led to the maintenance of her AN by using behaviours to cope with the difficult feelings, preventing her from progressing with her goals.

> *"There was no way that certain things would have come into my life, not while that was the main focus. So, I think there was a lot of shame around that. For a number of years, that was the main thing in my life."*

Emily 84-84

In summary, participants described guilt and shame and how these difficult emotions contributed to a reinforcing cycle in their AN that maintained their illness. Shame was described both as a psychological feeling and as a social-cultural emotion in terms of it being relational to others around them.

Theme 4: Modulating and suppressing my emotions, and a sense of being in control

> *"My experience or inability to experience or interpret my emotions directly contributed to my anorexia."*
>
> *Rose, 3 – 3*

All participants talked more openly than I had expected about the role of their AN in relation to emotional experience. These data were then organised into three sub-themes: the experience of feeling a sense of mastery or control, the modulation of their emotions, and using their AN behaviours to suppress feelings that they experienced.

4.1 Sub-theme: Using my AN to feel in control, contained and masterful

Control was a word used by all participants except India. They told me about their use of AN as a way of controlling what was going on in their lives in terms of experiencing a sense of mastery over emotions and experiences that they had not previously felt.

Gail described that for her, both purging and restriction had enabled her to feel that she had some control over her life in times when she felt stressed.

> *"Purging made me have like a sense of control…Umm and I guess so did the restricting as well. It was mostly just about control."*
>
> *Gail, 55 - 55*

Emily also linked her anorexia to control, in terms of how she managed both her own life, as well as the lives of others around her in terms of their relationships with her.

> *"You are going to control every aspect of your life and other people."*
>
> *Emily, 72 - 72*

She also used AN to control her responses to emotions when she was struggling with severe homesickness at university and did not want anyone to know. In particular, she did not want to share her sadness to maintain the idea that she was ‘coping’.

> *"In that period was also the, you know, crying was absolutely the last resort."*
>
> *Emily, 22 - 22*

Claire also described how, for her, the AN helped her to feel like she was able to cope when feeling out of control and unable to manage the intensity of her feelings.

> *“If I think about it, it was control obviously... probably seeking, trying to get help because I was so out, like felt completely …unequipped to deal with what was going on in my head."*
>
> *Claire, 149 - 149*

She also described how it was a ‘friend’ to her and that it gave her something for herself, a tool she could use to cope in difficult times.

> *"It kind of it gave me something that was mine."*
>
> *Claire, 159 - 159*

This sense of mastery was linked to a pervasive feeling of being vulnerable and ineffective when seeking to communicate what they needed from those around them.

"I don't think I ever felt like I had any power."

Rose, 178 - 178

Rose described a feeling of powerlessness in her life and that her way of coping with this was through AN behaviours which allowed her to *“put her fear away”* and dissociate by trying to *“stop myself before I even feel it”.* This linked back to using AN behaviours to control her internal world.

4.2 Sub-theme: Using Anorexia to suppress

Four out of five participants explicitly described a feeling of ’numbness’ during their period of active AN. This was about all emotions, both positive and negative, and was a function that helped them to avoid ‘feeling’.

“I would say in the time, yeah, I was numb."

Gail, 105 - 105

"I feel like when I had anorexia it blocks every emotion."

India, 73 – 73

"Especially, in the depth of kind the eating disorders, I would say I’m much improved now, but I think there was about three years where I didn’t cry."

Emily, 18 – 18

"I didn't really feel (..) extreme emotions. I felt just dead. So, I didn't feel."

Rose, 156 - 156

Of the five participants, Gail, Emily and Rose described that they considered purging as a way to expel difficult thoughts, feelings and emotions and that they found it a very effective way to do so.

> *"Yeah, I guess that is the way I would deal with that. You would get some sense of relief after doing that, thinking it was all gone."*
>
> *Gail, 93 – 93*
>
> *"It was almost a method of stopping the homesickness and stopping the tears and stopping wanting to ring home at 2 o'clock in the morning or jump on a bus and go to my boyfriend's house that kind of I need to escape."*
>
> *Emily, 50 - 50*
>
> *"Vomiting allows you to numb and express, depending on the circumstances. Maybe both at the same time."*
>
> *Rose, 182 - 182*

Further to this, Rose talked about how her AN protected her from anger, which she found so overwhelming.

> *"I do feel a lot of anger and when I was ill I was not sure I felt that anger and now I feel angry about all kinds of things, past and present. And I think that this protected me from that… I could just pretend certain things hadn't happened."*
>
> *Rose, 162 – 162*

She attributed both the numbness caused by low weight and the AN behaviours as causing distraction to help her manage emotions in different ways, and had a clear idea of the vicious cycle that she had found herself trapped in.

> *" So, the background low weight obviously numbed everything and then the daily behaviours were a distraction from anything else in life unpleasant and difficult and unmanageable that were replaced by something equally awful or of a different order."*
>
> *Rose, 164 – 164*

Emily also expressed that her AN helped her to avoid confronting emotions by suppressing, and giving her a way of processing them without having to confront them directly.

> *"Whereas when you had the eating disorder as a coping strategy, then you didn't feel things like that because it didn't make you confront the difficult feelings."*
>
> *Emily, 43 - 43*

This was how AN served its purpose for her when it first began in the period of homesickness at university, and purging was highly effective in 'getting rid' of the sadness.

> *"Feeling like I'm going to cry and the making myself sick, it would appear and then just go, so I think those traits were how it first began."*
>
> *Emily, 50 – 50*

This section illustrates the ability of AN to suppress difficult feelings in the participants, allowing them to avoid having to confront or manage them. The participants also described that AN served to modulate emotions, leading to the following sub theme.

4.3 Sub-theme: Using Anorexia to modulate

Gail, India, Emily and Rose were able to describe how AN behaviours helped modulate their emotional states and soothe difficult feelings. Claire talked about how self-harm "*has taken over from the using of food*", and discussed using coping mechanisms broadly, but was not specific about using AN thoughts, feelings or behaviours to modulate feelings. She did, however, talk about how she felt she experienced severe anxiety before the development of her ED and that the development of her AN was not something that happened consciously.

Gail described that a risky time for her acting on AN binge/purge urges was when she was finding things overwhelming, which in turn then led to her feeling the need to restrict.

> *"When I would get really stressed. And then maybe overeat and then purge, that was quite a big one…. like general anxiety about …like an event or something coming up or just something that was taking up a lot of my mind. I would just feel, like, this quite heavy feeling inside. It was a burden in my chest, and it sort of felt like a weird sense of relief, yeah, I would say that is probably and then I would say I would do my own restrictive phase."*
>
> *Gail, 17 - 17*

She described finding it comforting to *"know that I could do that"* to help her manage and that "i*t felt like a weird weight was off my shoulders".*

India also linked her restriction in AN to low mood and using it as a way of managing emotions. In particular, she experienced the urge to restrict when feeling anxious.

> *"I feel like, say, if I was like in a low mood the anorexia was a coping mechanism… restriction method of eating to cope with that emotion, and because it's helping the anxiety."*
>
> *India, 15 – 15*

She also described how for her the AN behaviours were linked to self-harming urges and described how she experienced the physical relief she felt after acting on them.

> *"In a way, it was different because it was more not mentally help my thoughts it was more physical; I feel like I did have self-harm urges but it changed into instead of cutting, it was more the restricted eating and the excessive running in a way it would damage my feet and knees so that was like self-harm, but it wasn't my original way of self-harming"*
>
> *India, 29 - 29*

Emily also expressed experiencing ‘relief’ after purging for the first time when feeling very sad and homesick at university.

> *"I made myself sick and I literally must of fallen asleep within a few seconds of it and it was like that relief (from the) homesickness feeling and the anxiety feeling, and I think then what started to happen was I then made myself feel better by some of my behaviours and some of the actions I was doing."*
>
> *Emily, 76 - 76*

She also described gaining a helpful relief from acting on urges linked to her AN by engaging in intensive exercise, and that she had a strong desire to do this particularly when experiencing stress. This was linked to a physical feeling in her body of being ‘“better’, which then became addictive.

> *"I feel better when I've barely put any food in my body. I feel better when I have been to the gym for two hours. Well, if I go a bit more I will feel even more better, and I will feel even more good about myself."*
>
> *Emily, 50 - 50*

Rose talked about how the AN helped her cope with day-to-day life by being so preoccupied with her thoughts, feelings and behaviours related to her illness that she did not have to deal with bigger stressors. The strength of how she experienced her illness was directly linked to the pressures that were on her at the time.

> *"I think I would get more ill when I started to think about how when I could see myself in the mirror and I would want to run away so I think I would know that I would be worse in certain situations, like when I had to do this or go and stay here or whatever."*
>
> *Rose, 274 - 274*

This theme illustrates the function that AN played to help participants manage intense and difficult feelings that they experienced, and how successful it was at doing so. This led to a cycle that they found impossible to escape from, in which the

AN caused them to experience difficult emotions but their only coping mechanisms were the behaviours associated with it, making recovery seem impossible.

Theme 5- Journey to recovery

The final theme outlines participants' descriptions of their journey to recovery. Three sub-themes appeared to stand out to me in their stories. The first was their own judgements of their AN journey, the second was their description of what helped them to recover, and the third was their relationship with their recovery and AN in the present day.

5.1 Sub-theme: I was never good at anorexia

Gail and Claire both talked about difficulty in recognising that they had AN and in not feeling like a 'good enough' anorexic. This contributed to unwanted emotions which they managed through further ED behaviours: a double bind.

> *"I didn't realise it was an eating disorder for a very long time."*
>
> *Gail, 47 – 47*
>
> *"They said 'You don't think you have got one?' (an eating disorder) and I said, 'No, no, no'. I was probably five and a half stone at that point."*
>
> *Claire, 99 – 99*

Emily also described how she found it difficult to acknowledge that she had an ED whilst unwell. She attributed this to a belief at the time that AN was something that happened to young girls and she was in her 20s. This led her to feel that she had to continue with the anorexic urges to 'justify' accessing treatment.

> *"I think there is also that thing of, well, I am not really ill like other people are, I don't really look like other people do so actually should I of make myself be more ill, should I make myself more skinny, you know, should I be making this sound worse than it is because you know you don't necessarily feel that you should be there?"*
>
> *Emily, 60 - 60*

India experienced preoccupation with her weight at the point of accessing help, and this presented itself in the form of shame that she had never completed her AN ‘goal’.

"Shame that I never completed the mission of getting to the weight I wanted."

India, 85 – 85

Rose talked about the relationship between acknowledging her AN and how it was affecting her, and then her choice to pretend that it was not happening whilst being unable to ignore it. This double bind made her feel constantly at war with herself.

> *"So, I think, in a way, I didn't want to be aware. I think I kind of knew but I didn't want to know because in knowing you then have to wonder is there another way? (...) So if you don't know why you are doing something and just blissfully go on in ignorance it is just a mystery (smiles). Or you can, it is easier to accept but once you see it and begin to question you think that is this what everyone does because, I mean, you know that everyone is not like this, so if this is what you are doing because of this why everyone isn’t else doing it. And then you realise there is something really weird about you and wrong. So, you have got to not know because then you are even more strange. So, it is a constant battle actually."*

Rose, 270 – 270

This section illustrates the difficulty participants experienced in acknowledging that they were experiencing AN, despite it being very clear to others around them, which was a huge barrier to accessing treatment in the beginning of their recovery journey.

5.2 Sub-Theme: How I recovered

The participants all had their own personal motivations to recover and moments they identified as the journey starting for them.

For Gail, it was when things got tough.

> *“You have to hit rock bottom to realise there is no point to go back there and that really pushed me to sort of recover, and I think time as well.”*
>
> *Gail 63-63*

And for Emily and Rose, it was when the idea of life outside of the AN got ‘bigger’.

> *“I think when I started to change was when I got a career I was really enjoying. I got a house that wasn’t mum and dad’s house, it was mine that I suddenly felt safe in, and I got a dog. All those kinds of things I go, ‘OK’, like I'm not just relying on this innate thing because deep down it wasn't a hobby it was a way of life.”*
>
> *Emily 68-68*
>
> *"What was a big motivator for me was the ability to feel joy, excitement, passion, desire, all these things which I hadn't felt for years."*
>
> *Rose Interview, 156 – 156*

For India and Claire, it was the influence of others, both in regards to wanting to stop having a negative impact on them, and the experience of feeling safe.

> *“I think it was the day I was coming back from school. I was in sports uniform and I would normally wear baggy clothes, but my sports uniform was not baggy and I remember walking my dad was in the kitchen and my dad was at the table and his face, the colour, completely changed and part of me was like, ‘Do I really want to carry on? I'm not just destroying myself; I’m destroying everyone who cares for me'.”*
>
> *India 79-79*
>
> *“I suppose with him, and it was feeling comfortable, and it would, you know, somebody loved me. Ummm (..) so it felt safe if that's the word.”*
>
> *Claire 219-219*

Those interviewed identified the importance of trusting the process and keeping going, holding goals for the future in mind, remembering the negative aspects of AN, and recognising progress as helpful to them in the recovery process. They also discussed the contribution of others. A significant helpful factor was the experience of not being blamed or pressured by parents or professionals.

> *“My mum came to all the sessions; she loves doing her research and stuff, so she researched a lot more and read a lot more and no blame.”*
>
> *Gail 69-69*
>
> *“They were not forcing what was going on, they were not pressuring me.”*
>
> *India 47-47*
>
> *“They didn't put a label on anything. It was, there are you know. And they also gave some brilliant support to my mum and dad as well.”* (about her clinician providing treatment*)*
>
> *Emily 72-72*

They also felt they were able to talk to people around them about their emotions, which helped them discover a new way of expressing difficult feelings.

> *“My mum was amazing about going to school, about me getting anxious before school. She wouldn't make me go in, we would go on a drive, we would sit by the river, and she would just chat to me, so I always knew that I could express anything.*
>
> *My dad would come in my room and see that I was upset. All he would say was, ‘You OK?’ I might burst into tears, but he would sit with me…. he would let me be upset.*
>
> *Gail 33-35*

Alongside empathy, and being able to talk to those around them, calm and kind boundaries from their loved ones were experienced as helpful with their AN behaviours.

> *“(They) let me kinda talk about it in my own ways. But also, she wouldn't let me have free rein if you are going to control every aspect of your life and other peoples’. But also, they both allowed me to find ways that would feel comfortable and kind of helped with that and didn't make a big deal.”*

> *Emily 72-72*
>
> *“Validation and its safety, those two things meant I felt safe in my own skin.*
>
> *There was no judgement there or any kind of, he never picked to ask more questions, it was as and when. It's always been if I go down a route of starting to talk about it he would always sit and listen, but I don't think he would ever ask me to ever kind of go over anything or ask anything about it. But, and he also, he doesn't pander but I can tell supports where he can see that I might be getting, you know, a bit tetchy about things.”*
>
> *Claire 225-227*

Although the participants differences in what precipitated their journey to recovery, the role loved ones had played in terms of enabling them to express their emotions and providing kind boundaries was clear.

5.3 Sub-theme: It could happen again at any time

Although all participants felt they could deem themselves as ‘recovered’ they still experienced similar thoughts, feelings and behaviours to those they had during their period of AN.

> *“I have stupid habits from it. Like, I definitely never finish a plate of food. Umm but yeah, I always have to leave something.”*
>
> *Claire 235-235*
>
> *“There are still like the odd thoughts and patterns that sometimes come to my head.”*
>
> *Gail 83-83*

This led to all of them believing that AN was not possible to ‘overcome’ but that recovery was not a linear process, and they had remain vigilant about its return for the rest of their lives.

> *“I've become more accepting of the fact that this is something that I probably will always have an edge of having to manage, still.”*

Emily 4-4

> *"It will be painful, the recovery, for years. It is not easy to recover from and it will not be linear; there is going to be ups and downs in recovery."*

India 95-96

For some, this was something that they had believed throughout their recovery journey.

> *"I was always under the impression that this is something that would be a problem for the rest of my life, I feel like this is even something that I was told."*

Claire 219-219

And for others, this discovery had been disappointing for them.

> *"I have thought, I am kind of a bit disappointed that that is the case but at least I can see it and I am aware, yeah."*

Rose 308-308

This experience of recovery was one that they shared universally: the idea that it was non-linear and that they would have to live with a 'hangover' from that period of being unwell, both in knowing that there were coping mechanisms that worked for them and fighting the urges to act on them.

6.2 Findings chapter summary

In summary, these findings describe an experience in childhood of participants both feeling emotions intensely and being sensitive to the emotions of others that was unmanageable for those around them. They understood that emotions were impossible to talk about in their families of origin and had difficulty with closeness and distance in their relationships with their parents. The communication function of emotion was difficult, with them feeling that their communications were unwelcome, and misinterpreted. This left them feeling lonely and sad and that they were a ‘bad person’, which could not be expressed. This led to the development of AN to help them to suppress and modulate difficult feelings, and for some, to continue to use it as a tool to communicate to others. Participants described being stuck in reinforcing cycles of guilt and shame and binds that served to maintain their illness and make it difficult to recognise, and, thus, recover. When they were able to work towards recovery, they experienced being able to share their emotions when they felt safe to do so. However, they have been left with a residual fear of the re-emergence of their symptoms.

7. Discussion

This research aimed to understand the emotional experience of those who have recovered from AN, and it also presented the opportunity to gain further understanding of ‘recovery’ journeys. I have aimed to present a small picture of the perspectives of those in recovery from AN concerning experiences in their family of origin, during their illness, and through recovery. In this chapter, I will discuss the findings of my study and consider links to previously reviewed literature, and outline suggestions and implications for practice that may arise from them.

Childhood emotional experiences and the context of families of origin

The descriptions participants gave of ‘intensely’ feeling emotions is a phenomenon that I have often heard described in my clinical work with sufferers of AN. Often, the focus can appear to be on the alexithymic tendencies that have been studied and discussed extensively in the field, both in those that experience AN (Schmidt et al., 1993; Speranza et al., 2007) and their family members (Rozenstein et al., 2011). The strong and overwhelming way that emotions were experienced, and the sensitivity to the way others around the participants were feeling at an early age is in line with findings in other qualitative literature (Davies, Swan, et al., 2011; Fox, 2009; O Kyriacou et al., 2009). I was struck by how open and honest the participants were, and the insights they felt they gained during our conversations, and that they did not feel these topics had been explored with them previously. I was left with an overwhelming feeling that as clinicians “we only had to ask- all this time!”

Participants spoke about an experience of feeling ‘different’ to others around them and they believed this had been present since birth, indicating a possible genetic component. This could also be linked to the elevated levels of anxiety and obsessive-compulsive traits that have been found to date back to childhood in those with EDs (Kaye et al., 2004). Alternatively, it could be attributed to possible early attachment difficulties and relational wounds from carers' limitations. This trait of emotional sensitivity was not always experienced as a disadvantage; for example, participants described how it allowed them to empathise with those around them and connect with others. It feels important in a paradigm of finding 'fault' to also acknowledge the benefits of certain sensitivities and how these could be nurtured and praised relationally to enhance self-esteem. As clinicians this could remind us to take more of a "neutral" view on experiences and allow space for pros and cons to be explored.

These findings add to the limited qualitative research into emotional experience in the family of origin. The context of denial of emotion in families of origin as identified by Fox (2009) was strongly present in these findings in a very explicit way;

> *"Don't complain, don't express, don't want or don't want in public. If you have desires, you mustn't talk about them. Do your best, button up, chin up. Rise above it, don't succumb."*
>
> *Rose 224-226*

The above quote illustrates a thick description of avoidance of conflict by minimising any emotion experienced by the participants as children, and an inability by their parents to validate it. This echoes research into the "anorexic family" conducted by Kog and Vandereycken (1989) and recollections of parental environments by those with AN by Haslam (2012). This relationship between childhood emotional invalidation and adult acute emotional distress is well documented (Linehan, 1993) and has been the foundation for the creation of emotion-focused family therapy workshops for parents in the field of EDs (Dolhanty

& Greenberg, 2007). Their findings indicate that teaching parents to validate their child's emotions could be helpful in both the prevention of and recovery from EDs as participants described that their feelings being heard was a key aspect to their recovery, as discussed later.

Fox (2009) states that an unpredictable familial environment can lead to a belief that "emotion seemed dangerous and almost toxic" to those with AN (Fox, p. 290). In this study, participants described how the consequence of an inability to talk about emotions meant that when they were expressed, this was felt as overwhelming and unpredictable. This left participants with insecurity in their relationships due to unpredictability and difficulty understanding how to express emotion appropriately.

> *"I think we are we sometimes all bottle stuff up a little bit until it does come out and then when it does come out it is not off limits it's just (.) I think everyone kind of has their own stuff and then when it gets quite bad then it will come out."*
>
> *Gail, 73 – 75*

Higher anxiety about parental attachment as described by three participants has been linked to increased symptom severity and poorer treatment outcomes (Illing et al., 2010). This was illustrated in the data by Emily's description of her parents being "*my biggest fans but also my biggest critic*". Those with AN appear to have parents with higher expectations of them (Karwautz et al., 2001), and this study highlighted that expectations of these participants differed based on gender roles in their families. Those who had brothers perceived more was expected of them by their parents, in comparison to their sibling. Although this was not something I discussed in my review of literature, it was interesting to me as a family therapist as I feel that sibling relationships have been somewhat neglected in treatment, despite research indicating they could be a key resource, particularly in family-based treatments (Dimitropoulos et al., 2009; Piekunka et al., 2023).

Gender was also relevant in considering the traditional roles played by parents in the study. Universally, fathers were described as absent, and mothers were the primary caregivers. This fits with research that indicates open communication between fathers and daughters is a protective factor in EDs (Botta & Dumlao, 2002) and that ‘emotionally absent’ fathers have been attributed as being highly significant in the development of AN (Fox, 2009).

Those with AN tend to rate their families less favourably than the general population (Holtom-Viesel & Allan, 2014; Woodside et al., 1996). The two distinct cohorts spoke about their families in very different ways. The ones who were younger, more recently in recovery, and still living with their families found it difficult to reflect on their experiences. However, the older cohort who had lived separately for a long time reflected a great deal on their families of origin. It may be that chronological distance from the illness and living apart from family makes it easier to reflect on experiences.

Of interest, two of the participants were mothers and had clear ideas about what they were trying to do differently in terms of not replicating family scripts (Byng-Hall, 1995), particularly in terms of validating their children’s emotions. This suggests that they themselves identify the importance of emotional experience as a potential protective factor from developing eating difficulties.

A pertinent finding for me was that participants did not consider ideas around eating, weight, and shape in their family to be significant in their development of AN. One would expect this to be the case. Despite some reports of unhelpful parental modelling and comments, only one participant felt that it had directly influenced them in their development of AN. Other studies have also shown there to be no increased risk factor for AN linked to dieting by parents (Karwautz et al., 2001) or weight-related criticism (Fairburn et al., 1999). Both India and Gail linked the development of their AN to a desire to lose weight and described how they had felt ‘overweight’. Again, neither of these participants described negative comments linked to weight dissatisfaction regarding their weight and shape coming from parents (Keel et al., 1997; Tremblay & Lariviere, 2009).

However, there does appear to be a higher sensitivity to appearance and the socio-cultural norms around the ‘thin ideal’ in those who develop AN (Schmidt & Treasure, 2006a). Gulliksen et al. (2017) and Senra et al. (2007) noted how cognitive precursors to the illness include an internalised thin ideal and so, possibly, one might not be aware of this despite it being present. In my experience parental comments and modelling are often focused on in treatment and formulations by professionals. To date, the contribution of unhelpful comments and modelling upon AN development remains inconclusive, however there is a need to remain curious about this, and to understand the personal experience of those we are working with.

As clinicians, these findings remind us that although we have moved away from pathologising families, it is important to consider context and experience. By taking a non-judgemental approach, building therapeutic alliance, and validating the difficulties of parenting we can access this important information about emotional experience that allows us to support those we work with to find appropriate ways to process difficulties,

Living with intense and intolerable feelings

The descriptions by participants of a pervasive feeling of sadness and loneliness throughout their childhoods were striking. These findings aligned with literature that reports this as present across the lifespan and pre-existing AN (E. M. Espeset et al., 2012; Fox, 2009; Swinbourne et al., 2012). Previous research has found that experiences of sadness and loneliness are linked to difficulty in social situations and poor social networks (Fairburn et al., 1999; Swinbourne et al., 2012). In this study the experience of loneliness seemed to be attributed to feeling in a double bind of being 'too much' and 'not enough' at the same time in their families, whiclst not being able to change. These inconsistent signals contributed to low self-esteem and their perceived lack of being heard and validated. The importance of this understanding was further apparent when participants reported that a lack of judgement and 'safety' to express themselves were key factors helpful in their recovery.

A predisposition to heightened anxiety as well as increased sensitivity to punishment and reward among those with Anorexia has been well documented (Jappe et al., 2011; Kaye et al., 2004; Swinbourne et al., 2012). Wildes et al. (2010) found that AN patients have higher scores on emotional avoidance than patients with other mental illnesses, and demonstrate high levels of control over emotional inhibition (Claes et al., 2001; Davies, Swan, et al., 2011). As described earlier, emotional avoidance may also be an inherited trait (Kaye et al., 2004; Treasure, 2007), indicating that it could be prevalent in parents of those who are unwell, and contribute to a context of not discussing feelings. This information Is important to hold in mind when building therapeutic alliance with parents in family therapy, in order to be able to explore the emotional context in the family without them feeling blamed for the AN.

I suggest that these predisposing factors, coupled with a family context in which emotions are not discussed and feelings are invalidated, have led to a pervasive feeling of sadness and loneliness in these individuals with AN. Sadness has been linked to exacerbating difficult feelings concerning the body, described as feeling “fat, disgusting or awful” in qualitative research (E. M. Espeset et al., 2012, p. 455). Loneliness has also been linked to the maintenance of symptoms by Levine (2012) and Stewart (2004). This has led to the participants being trapped in their experience of intolerable feelings and looking for a way to manage them.

This ‘bad combination’ of intense feelings and an invalidating environment may be further exacerbated by a difficulty in being able to identify and express emotions. In an environment where emotions are already difficult to talk about, the participants descriptions of themselves as people who ‘never open up’ and ‘can’t get the words out’ would have resulted in even more avoidance, which is further linked to the maintenance of AN (Schmidt & Treasure, 2006a; Wildes & Marcus, 2011). This is consistent with research carried out by others, which suggests confusion in identifying and communicating emotions (Fox, 2009), an inability to recognize, identify, and label emotions (O Kyriacou et al., 2009), and difficulty in trusting themselves regarding what they feel, leading to a sense of helplessness and confusion (Rance et al., 2017).

Although the description of their family of origin by participants is seen as their ‘truth’, it may also be relevant that research indicates those who develop AN find it difficult to recognise facial expressions of emotion (Oldershaw et al., 2011). They may also be more attuned to facial expressions associated with negative emotions such as criticism (Cardi et al., 2013) and anger (Harrison, Tchanturia, et al., 2010), and less able to identify those associated positively, such as compassion (Cardi et al., 2013) and happiness (Cserjési et al., 2011). This could lead to them experiencing their familial context with more difficulty than their siblings. Kyriacou et al. (2009)

reported that those with AN were described by their parents as showing significant emotional difficulties, perhaps indicating an environment where both parties were struggling to manage. Those with AN also have strong negative beliefs about both their experiences of emotions and the effect that revealing their emotional expression will have (Geller et al., 2000; Hambrook et al., 2011) which fits with the increased levels of ‘rejection sensitivity’ that have been observed (Selby et al., 2010).

The research described here supports previous findings that those diagnosed with AN use fewer words in emotional description and have fewer positive affect words (Davies, Swan, et al., 2011). It also suggests that they tend to put the needs of others before their own and to appear to be socially compliant, even when their inner feelings are incongruent with this (Hambrook et al., 2011). Once established, this reciprocal and relational experience between the parents and children could lead to a self-reinforcing cycle of an inability to express emotions, which is linked to avoidant behaviour (Oldershaw et al., 2012) and the development and maintenance of AN (Arcelus et al., 2013).

Difficult experiences in their family of origin appear to have contributed to an intrinsic belief held by participants that they were unworthy and a ‘bad person’. I was struck by the anger that they felt towards themselves and their descriptions of their inability to think of themselves as ‘good’. This adherence to a moral code was described by Lester (2019) as an intrinsic factor in the development of an ED, and feelings of shame, hatred and unworthiness are well documented by others (E. M. Espeset et al., 2012; Rance et al., 2017; Finn Skårderud, 2007) as being associated with those who experience AN and to feelings of ‘fatness’ (Fox, 2009).

The potential presence of feeling like a “bad person” would be helpful to name and be curious about during the treatment process as it could contribute to someone with AN struggling to feel deserving of treatment, or that recovery was impossible for them. Unpicking these binary views about ‘good’ and ‘bad’ people and allowing a more nuanced understanding of the context that they find themselves in may also be helpful and enable avenues for self-compassion, and in turn, positive change. This also links to ideas about identity, and the importance of exploring this, and reauthoring narratives they have of themselves.

How anorexia got involved and persisted

There were differences between the two cohorts in the way they talked about how AN developed. The first, younger cohort, who were more recently in recovery and still lived at home (n=2), described how they started losing weight consciously after being unhappy with their body, and it became addictive. They then experienced that dietary restriction, and purging helped them to manage emotions, for example, feelings of guilt and shame.

The second cohort of older participants who had been in recovery longer, and had moved out of the family home, described development of their AN as a method to cope with difficult emotions. They had all found themselves in a stressful environment when their AN arrived: Claire and Rose were both being bullied at school and Emily was struggling with severe homesickness at university. Claire and Rose also had the clearest descriptions of living with sadness and loneliness across the lifespan, and negative self-worth.

> *“I remember coming home from wherever we had been, not drunk but tipsy, absolutely sobbing my heart out, incredibly homesick and (.) I kind of felt that stomach-churning so I made myself sick and I literally must of fallen asleep within a few seconds of it and it was like that relief.”*
>
> *Emily 50-55*

AN as a means of communication was more relevant to the second cohort. Claire and Rose were clear that they were trying to communicate their sadness and misery, being unable to express it any other way. For Emily, it was about trying not to show her inner turmoil to her parents and to communicate that she was coping. This is also documented in Lester's anthropological writings on EDs, where she discusses what the ED serves to "present and conceal" (Lester, 2019).

The current focus in research, as well as in the diagnostic criteria and treatment, is on the central function of AN being related to weight and shape. However, although weight loss was initially the primary purpose for two participants, it was not for the others. This suggests that weight and shape concerns should be considered as only one possible motivation for the development of the disorder, and restricted eating and emotion regulation is another of equal value. This idea has been previously proposed by researchers such as Palmer (2003) and Schmidt and Treasure (2006b). Narratives and perspectives of those we are supporting should be considered in formulations and treatment, taking it away from a 'one size fits all' approach.

It could, of course, also be that as one has a greater period of recovery and reflection, views on how their AN developed may change. This was suggested by Rose at our follow up meeting to discuss study findings. She commented that having had a longer time to reflect on her ED the role of emotions felt more pertinent. Another reason for the differences between the two cohorts could be generational. Perhaps they all had the same predisposition of feeling emotions 'intensely' and experience of living in a family context where this could not be expressed. They then had different 'triggers' that led to the AN developing and being maintained as a mechanism to cope with this difficult experiences. This finding is one that presents as very interesting and could be developed and researched further in order to contribute to understanding of primary drivers and secondary gains, and whether there is a link with age of onset.

Anorexia and identity

Another aspect of the complicated relationship between participants and their AN was how it functioned as an identity. They reported an importance attached to the 'thinness' aspect that defines the AN to others, whether it was a relevant part of the initial development of the illness or not.

> *"There was always something very umm addictive about being the thinnest person in the room. Or having something that people could see."*
>
> *Claire, 159 - 159*

The 'thinness' and visual indication of their struggle, and the possession of a body shape that is celebrated in society was important to them. This echoes findings by Kinnear et al. (2023), where participants discussed the link between AN and being 'good' and keeping up with the standards expected of them due to the 'thin ideal' prevalent in society. Low weight is also a performative aspect of the illness due to it being the way that it is defined in the diagnostic criteria, as discussed earlier (Lavis, 2011).

Warin (2004) illustrates how AN can be reduced by the public to "the spectacle of thinness" (p 95), resulting in an objectification that reinforces and maintains the aspect of the illness that is visual. This then serves to ignore the other functions, such as "self-determination" (Gulliksen et al., 2017), management of emotions and sensations, and suffering. This is reinforced by the biomedical approach, which associates health with physical symptoms, making it very difficult to let go of the illness (Rich, 2006). Although the focus on low weight and refeeding is important in treatment, these findings indicate the importance of understanding their personal understanding and relationship to what the physical representation of AN means, and how it is important to those who we work with. We can do this by ensuring we acknowledge the attachment of those we are treating to their AN body, instead of considering resistance to weight gain simply as a ‘fear of fatness’. Clinicians need to separate out the AN from the thinness, because when weight is the definition of the illness, keeping this low may become important to maintain so that difficulties in other areas can be communicated to those around them. It is appreciated that these are not easy conversations to have, and we must also consider our own relationships to eating, weight and shape and how these may influence what we can and can’t access as clinicians.

Another maintaining factor or ‘reinforcer’ (Gulliksen et al., 2017) identified was the reinforcing cycle of guilt and shame, and the double bind this creates in which the participants became trapped. The shame described by the participants in this study was related to their development of AN, in particular, because of what they considered to be a privileged position as a white middle-class person. This, to me, illustrated the global view of AN which appears to be different to that of other mental difficulties. It is often considered to be voluntary, and controllable, rather than an illness. This was discussed by participants in inpatient treatment interviewed by Rich (2006), who talked about their experience of those around them expressing to them a belief that they had ‘chosen’ to be unwell. This view ignores the role that context plays, as explained by Doyal and Pennell (1979): *“It is always individuals who become sick, rather than the social, economic or environmental factors that cause them to do so”* (p. 35). By thinking about these factors, such as context in families of origin and the combination of this with the way participants in this study experienced emotions, it may help to reduce the guilt and shame that can cause those who are unwell to become trapped in their AN.

Skårderud (2007) describes a dual experience of shame experienced by those with AN, and this was also identified by participants in my study. In addition to feeling shame about developing an eating disorder in the first place, they also felt guilty about the effect their AN had on those around them. The shame was described both as a psychological feeling and as a social-cultural emotion in terms of it being relational to others. As described earlier, research indicates that shame is not disclosed in therapy by up to 42% of those who are unwell (Swan & Andrews, 2003). Therefore, it appears to be important that an opportunity to explore feelings of shame is offered in treatment, despite it being difficult to do so.

Exploring these complex subjects relies on courage by clinicians to raise inner feelings and experiences that are very difficult to talk about, and strong relationships, and extensive skills are required to do so. It is important to acknowledge that the current crisis in treatment services, and prescriptive nature of how those that access it should receive “treatment” can often prevent a context being created that can enable these difficult conversations to take place, and the building of a therapeutic alliance that makes it safe enough to do so.

The use of Anorexia to manage emotions and stay in control

Participants strongly linked their AN to the management of emotions in three ways; the experience of being ‘in control’, the modulation of emotion, and using AN behaviours to suppress difficult feelings. The description of how their AN helped them to feel ‘in control’ was linked to feeling able to manage their lives in a way that they had not previously experienced, as though they had felt previously powerless during their overwhelming experience of emotion. The idea of ‘control’ is well documented in eating disorder research, and fits under the umbrella of the "cultivating of emotional states" (Lester, 2019) and "sense of mastery" (Gulliksen et al., 2017) in the theories described earlier.

I find the language around the role AN played for the participants interesting. By using the word 'control' there was a framing of the development of this coping mechanism as an inner psychological ability, rather than contextual, such as their experience in their families of origin. This fitted with the description of difficulties in their family of origin being located within themselves as a "bad" person. These descriptions by participants of their AN being a way to give themselves power, avoid emotions and manage stress enable a deeper understanding of the functions of the illness. By engaging in this, we are moving away from the 'thin descriptions' that can situate pathologies in individuals as described by Geertz (1975) and understand them in a wider context, and relationally.

Fairburn (2008) categorises the sense of control experienced by those with AN as a maintaining factor which is also echoed by the findings here. This reinforces the rhetoric that AN develops in response to difficult life events and serves as a coping mechanism. The framing of 'control' as a negative was illustrated in research by Kyriacou et al. (2009), where it was described as "emotional blackmailing and manipulation' (p 848) by both clinicians on an inpatient unit and the parents of those with AN. This discourse contributes to the idea that there is something 'wrong' with sufferers, contributing to the shame experienced, which leaves them trapped. I propose that although this sense of mastery should be explored in treatment, it should be framed as a coping mechanism, and in a way that is sensitive to individual experience. This allows conceptualisations which move away from the AN being a key part of their identity, which can lead to feelings of hopelessness around recovery being an impossibility (Branley-Bell et al., 2023).

This study illustrates that the experience of ‘numbness’ participants describe during their illness needs to be acknowledged as something the AN brings and will have to be left behind to recover. Participants welcomed the loss of feeling and it functioned well to avoid emotions. In other research, this has been attributed to the overriding focus on food and eating, as well as a lack of functioning of the brain at low weight (Schmidt & Treasure, 2006a), and lower BMI associated with better emotion regulation (Saure et al., 2022). These findings echo what Lester (2019) calls “ambivalent anaesthesia” in which the AN serves to numbs and supress emotional states.

Gulliksen et al. (2017) suggest that the use of dietary restriction to avoid negative emotions might be established more or less ‘by accident’ and that patients might have low awareness about the effects of this behaviour, as they ‘slide’ into AN. Corstophine (2007) further presents a model whereby this numbing effect then results in those with AN becoming less experienced in managing emotions, creating a vicious cycle that is difficult to escape from as they have less self-efficacy over coping with the feelings. With this in mind, the function of AN to numb emotions is an important area to explore in treatment, as well as the readiness to experience intense emotions that may result from the loss of a coping mechanism.

Purging was identified by three participants as a way to ‘get rid’ of sadness, which has been indicated in research by Fox and Power (2009). Purging linked to Anger was also identified by Rose, who noted that her AN meant *“I could just pretend certain things hadn’t happened"* (162). This is also echoed in findings by Espeset et al. *(2012)* who outline anger and sadness as the primary emotions identified as desirable to avoid by those with AN, and suggestions by Schmidt and Treasure (2006a) that suppression of emotions in those that are unwell is through the distraction of AN behaviours.

There was a focus by participants on the use of AN to modulate feelings, in particular anxiety. They talked about the ‘relief’ they felt after engaging in behaviours such as purging and exercise, which helped them to cope with ‘big feelings’ they had experienced across the lifespan. Hambrook et al. (2011) showed that those with AN find it difficult to tolerate distress and this was echoed here, in addition to their experience of overwhelming emotions. Saure et al. (2022) found that a shorter illness duration was linked with decreased emotional regulation capability which is surprising, however they attributed this to those who have been more unwell experiencing longer treatment durations and thus learning increased emotional coping skills. This supports research by Haynos et al. (2014) and supported in this thesis, that a focus on emotional regulation strategies in treatment is linked to reductions in eating disorder psychopathology and improved outcomes.

My research, alongside many other studies (Cockell et al., 2002; Gulliksen et al., 2017; Lester, 2019; Nordbø et al., 2008; Serpell et al., 1999), indicates that symptoms appear to serve important psychological functions and coping mechanisms for those with AN, regarding feelings of mastery, emotional regulation and suppression. It appears vital that this is both acknowledged in treatment and that skills are taught to promote greater self-efficacy in coping with difficult emotions, this can be through an emotion-focused family therapy approach (Dolhanty & Greenberg, 2007) or in individual work.

These findings also serve as a further reminder to highlight the importance of recognising the ‘pros’ and ‘cons’ of having AN in our work with sufferers in order for them to feel accepted and validated, and to open up the opportunity to talk about shame and difficult feelings.

A deeper understanding of what “recovery” may mean.

Although it was not in the original aims of this research to understand the journey to recovery that participants undertook, it was something they all chose to discuss and appeared to be central to the description of their AN. Three key themes emerged: the process of recognising thoughts and feelings relating to their AN, what was helpful to them in enabling recovery, and their relationship with AN in the present day.

The first theme related to the women’s insight into their AN. There was both a difficulty in accepting a diagnosis, and a feeling of being ‘different’ to other “Anorexics.” This prevented them from accessing treatment, and enacted feelings of guilt and shame when they did, with experiences of intense intrusive thoughts as to whether they ‘deserved’ to recover.

> *"I think there is also that thing of, well, I am not really ill like other people are, I don't really look like other people do so actually should I of make myself be more ill, should I make myself more skinny, you know, should I be making this sound worse than it is because you know you don’t necessarily feel that you should be there."*
>
> *Emily, 60 - 64*

India disclosed the presence of *"Shame that I never completed the mission of getting to the weight I wanted”* (India, 85 ‐ 85). This disappointment illustrates the link between her AN and thinness, with weight indicating a measure of ‘success’, as discussed earlier in this chapter.

During discussions regarding recovery in interviews I was reminded of my work in drug treatment and the parallels I was hearing. Participants talked about the addictive elements of AN in relation to weight loss, identity, the communication it represented, and the management of difficult emotions. There was also a description of reaching ‘rock bottom’, which is often associated with the language of addiction.

The actual process of recovery also appeared to have similarities with theories I had learnt in my work in the addiction field. The cycle of change model in addictions proposed by Prochaska and Diclemente (1983), during which people progress through a period of pre-contemplation, contemplation, action, maintenance and then lapse/relapse, felt particularly pertinent. This model was in use to elicit change when I was a student social worker on Janet Treasure’s ward, who, together with my supervisor Wendy Whitaker, was instrumental in teaching me about the importance of work with families in AN treatment for adults, and the inclusion of an emotion focused approach.

A description of being in the ‘pre-contemplation stage’ to recovery was summarised by Rose.

> *“I kind of knew but I didn't want to know because in knowing you then have to wonder is there another way.”*
>
> *Rose 270*

This is echoed in the literature, which outlines that recovery for those who experience AN can often feel to be something they cannot imagine (Malson et al., 2011), and about which they feel ambivalent (Darcy et al., 2010). This research indicates that approaches which focus on the individual motives of the patient to recover may be more successful, as suggested by Nordbø et al. (2008), as well as techniques that promote motivation such as motivational interviewing, as recommended by Treasure and Price- Evans (2011), which studies indicate may increase treatment retention by up to 38% (Weiss et al., 2013).

Participants highlighted that what they found useful from those around them was not being blamed for their illness or pressured to change. This indicates that approaches viewing AN as being located more systemically rather than within the individual sufferer may be more useful, as discussed previously. Those interviewed also described that in recovery they needed to experience being able to express difficult feelings and have these validated. With this in mind, treatment that supports those around the sufferer to learn skills to talk about emotions, for example, emotion-focused family therapy (Dolhanty & Greenberg, 2007) appears to be relevant as previously mentioned.

I was further reminded of my work in addictions when all the participants reported that they felt their AN ‘could come back at any time’. For some, this was not the experience that they were expecting and, thus, it was disappointing. However, others felt that they had always known this would be the case. This fits with the 12-step model of addiction (AA, 2002), in which addiction is considered never to be able to overcome, and to live alongside. For them, and perhaps many in with mental health diagnoses, “recovery” is finding an acceptable state to be, that is fluid, and where difficulties are easier to tolerate, and urges more able to resist, rather than a final endpoint or “achievement.”

Research indicates that EDs and Substance Use Disorders (SUDs) often co-occur, although there is a large variability between rates of this in findings (Swinbourne et al., 2012). Dieting and ED behaviours have been shown to predict alcohol use in adolescents (Krahn et al., 1992), and increased rates of cigarette, alcohol and drug use in college aged women (Krahn et al., 1996). Research on the family context in co-occurring EDs and SUDs has focused on a genetic component of transmission (Kaye et al., 1996), however it has also indicated a family context in which there is anxiety, affective instability and substance abuse (Lilenfeld et al., 1997). The use of affect regulation measures in research indicates that both SUDs and ED's are used to regulate negative affect (Grilo et al., 1995) and it has been suggested that reward pathways in the central nervous system can be altered by food deprivation, thus increasing propensity for reinforcing substances e.g alcohol (Krahn, 1991). As identified earlier, reduced response to reward persists following recovery in those with AN (Hambrook et al., 2011), indicating a genetic vulnerability that could also be applicable to substance misuse. If AN is used as a coping mechanism to manage overwhelming emotions in a difficult context as previously suggested, then this is a commonality with SUDs and thus it would be reasonable to expect similar obstacles and experiences in recovery.

Those in recovery describe it as an ‘ongoing process’ (Federici & Kaplan, 2008) and a complex journey, in particular relating to its non-linear path (Lamoureux & Bottorff, 2005). My experience is that ideas concerning whether AN can or cannot be left behind are often not discussed with those we are treating, and this leaves me to question the very idea of working towards ‘recovery’ and when one can be deemed to be ‘recovered’. The literature tells us that definition of recovery is difficult and is affected by “competing and complex meanings of bodies, food, health, illness, recovery and relapse” (Musolino et al., 2018, p. 547). In addition to this and Jarman & Walsh (1999) indicate a differentiation in accounts of recovery between clinicians and clients suggesting that this is an area that could be further explored.

As a clinician, this leads me to reflect on the clinical work with those experiencing AN and the importance of making recovery, and what this may or may not mean, a key point of exploration. What do AN sufferers understand recovery to be? What are their personal goals for change? When will they know ‘recovery’ has happened for them? In my experience, this has not been made explicit, and it leads me to wonder how that leaves those in treatment feeling and to reflect on how it could feel impossible to achieve something that is not quantifiable. Further research on recovery “journeys” and the meanings of what “recovery” is from the perspectives of those with lived experience would add a valuable contribution to the field, and it is clear that as clinicians we need to be more clear, and collaborative about what “recovery” is with those we work with .

8. Conclusions

8.1 Strengths and limitations of the study

Strengths

This study adds to the voices of those with lived experience of AN, and their emotional experiences. The purpose of the research was to understand how adults in recovery from AN describe what stands out for them, and they feel to be important, and findings relating to the role of AN in their lives and identity are particularly important. The study highlights that it is essential to include emotions in treatment, which can often be focused on weight restoration and symptom management, and has already been identified as falling short by those with lived experience (Kenny et al., 2020)

The research contributes to the need to integrate research on recovery into clinical perspectives to understand the complex nature of its meaning for those who are working towards it. This reinforces the importance of clinicians taking a collaborative approach to understand the individual experience and formulation of the person who is seeking to recover. As a family therapist, I feel the contribution this study makes to considering the context of the family of origin and the environment it creates is important, both in addressing the needs of the family in treatment and supporting them to change. Family therapy can enhance manualised treatments by locating AN in a relational context, enabling the person diagnosed with AN to share their unique experience and goals for ‘recovery’ and bring awareness to the force of contextual factors, such as the thinness ideal and the role of shame.

Limitations

The study specified a stance on diagnosis in the inclusion criteria based on the DSM-5 criteria (2013). During the research and writing-up, I became aware of the difficulty of categorising AN according to thinness, as outlined previously in this chapter. This is one of the diagnostic criteria of the DSM- 5 and, thus, I may have missed collecting valuable data from those who did not get a formal diagnosis.

My sample consisted of White British women, and I would have preferred some diversity represented in it. It is acknowledged that there are several difficulties with diversity across EDs, including a lack of access to services, a lack of recognition of the importance of cultural differences, and a lack of representation among clinicians, as well as a large gap in the research literature (Halbeisen et al., 2022). It is disappointing to me that my research reinforces this. On reflection, I would like to engage different communities in my sample group and take more time to understand how to do this.

My sample of participants was very small, which was due to difficulties in recruiting. Braun and Clarke (2013) suggest that approximately 10 participants is appropriate when using TA to conduct a research project at doctoral level. This limitation could mean there was insufficient data to investigate the population and that there could have been alternative patterns identified if I had used a larger data set.

It is important to acknowledge my research position as an ‘expert’ and the prior familiarity with my participants and the likely impact on the answers given during their interviews.

This study collected the lived experiences of those in recovery and, thus, the experiences which we were discussing referred to the past. As retrospective data, it may have been affected by recall bias or several other factors that could affect the recollection of their past; for example, treatment, therapy, the passing of time, memory bias, their journey into parenthood, and their relationship with their AN at the time of the interview. This is particularly pertinent when considering that the participants described their AN as something ever-present and non-linear, however it could be equally argued that the way the women think about their AN contributes to them remaining relatively well in the present. There was a difference in recovery status in terms of the length of time that the five participants had been in recovery, the course of the illness that they had experienced, and the treatment that they had undertaken.

Overall, my conceptualisation of the themes is based on various experiences among a small sample of White British women with AN who deem themselves to be in recovery, and I acknowledge that additional discourses might have emerged in other contexts. Therefore, the generalisability of the study is limited due to the specific characteristics of the research participants.

8.2 Clinical implications

Participants named that calm and supportive boundaries concerning AN behaviours helped them to ‘recover’. This may be helpful for carers to hear as often this process can be difficult, with them having to fight the AN thoughts, feelings and behaviours in their loved one. It is important to note, however, that for those with AN, they believe it is important to first rebuild the relationship with parents or carers through the experience of being able to express difficult feelings. This is contradictory to the current manualised approaches, which enact the carer challenging the AN as the initial phase of treatment, and is a dilemma when held alongside the clear importance of refeeding and reduction of physical symptoms.

With the importance of supportive relationships in mind, this study supports family therapy approaches that are aimed at promoting efficacy in carers to manage their own emotions appropriately, and that teach them skills to validate and support their loved ones with theirs. This has been illustrated through the description of family context, the difficulty outlined by those with lived experience in emotional experience and expression, and the importance of this in supporting recovery. In order to do this, therapeutic alliance and a "safe space" is vital.

This research builds and contextualises the inclusion of an emotion focused approach, where clinicians are able to explore and understand the emotional context and experience in the system without pathologising, which can lead parents and carers to feel blamed and shamed, and be an obstacle to change (Brown, 2006). This can be supported in practice with families by clinicians discussing the huge number of factors that are shown to contribute to an eating disorder, and that one will never know the definitive "cause" of an individual's difficulties. But we can understand their experience, and work to repair wounds, and create a space for emotions to be explored and processed, with the aim of developing new coping strategies. By being open with parents and carers, and expressing that the experience of the sufferer, and the system in which they live, are the only factors that we can influence, they can understand the purpose in undertaking the very difficult work required of them, in an already extremely stressful time.

Although there has been some attention to emotions in the field previously, this approach to emotions is more existential and general not captured in a scale and can be viewed as a more inclusive and person centred approach.

There also appears to be an importance in remaining curious about both the development and maintaining factors of the ED, in particular the relationship with weight and shape, eating and emotional regulation. Resistance to weight restoration should be explored as perhaps being linked to identity, or a coping strategy for difficult feelings. In co-constructing understanding of the AN with the person being treated, that person's expertise is respected and privileged, giving them the experience of being validated and tailoring treatment to their experience, rather than relying on the discourses outlined by professionals and applied generically.

This may then, in turn, make treatment more meaningful and prevent what can be called 'pseudo-treatments' due to patients' ambivalence towards change (Vitousek et al., 1998). It is also important that qualitative research, where the views of those who have experienced AN are sought, is used to raise the awareness of clinicians to the broad differences in psychological dynamics between patients with similar presentations. This can then inform treatment by integrating patient's narratives about the development of the AN to improve both their experience and treatment effectiveness over a more generic approach (Vanderlinden, 2010).

By widening the context of understanding AN away from the individual, it can also serve to reduce the guilt and shame associated with it, and to move sufferers out of the traps they find themselves in, as well as give them hope for recovery. It is also important to understand their perspective on recovery, and what this will look like, as well as share some of the qualitative research regarding this and explore it together, as a life symptom-free may not be attainable or realistic, despite this being a prominent discourse.

These factors are important to consider and include when working with those experiencing AN, and this study makes a case for traditional family therapy in treatment that can be tailored to individual need and co constructed, rather than a manualised approach. It also highlights the importance of clinical skills and experiences by those with a specialist understanding of AN, and the space and time to create a strong therapeutic alliance.

8.3 Suggestions for future research and practice

There appears to be a gap in research on the emotional experience of those with AN in their families of origin. It would be helpful to understand this further to support family therapy approaches and widen the context in understanding the development of the ED. . Of particular interest, further research may add to the findings in this study relating to primary drivers and secondary gains in the development of AN . Further investigation into the discourses and experiences of recovery from those who have had AN would enable experiences to be shared with those we work with to discuss what change means to them. This would help promote an individualised, co constructed, targeted approach to treatment which is relevant to those seeking it.

Generally, an increase in qualitative approaches that collect the views of those with lived experience is needed, with a particular focus on underrepresented groups and how they can be recruited. Future research should aim to include a more diverse participant pool to better understand the intersectionality of AN and emotional experience.

8.4 Personal reflections

Using thematic analysis enabled me to gain an understanding of words used to describe experiences and underlying meaning rather than a chronological depiction of people's experiences. I was captivated by the links participants made between their emotional experience and AN, as well as the identity that it gave them. This highlighted how although there are many benefits to manualised treatments, there is also a case for tailored interventions which are co-constructed with those that access them. This study has provided the links between parents, children and AN, but not between parents and their parenting, or their self-efficacy in their parenting skills and tools. This would be a key line of enquiry in traditional family therapy and the need for this to remain an option for treatment appears to be clear.

In undertaking this research, I believe I have been able to represent the voices of a small number of those who have recovered from AN concerning their own emotional experiences and that these five rich descriptions of reality contribute to an under represented part of research.

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9. Appendix

9.1 Table of Appendices

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Appendix 1: Table of reviewed literature

Year	Author	Title	Design	Sample	Main Findings
2009	J Fox	A qualitative exploration of the perception of emotions in anorexia nervosa: a basic emotion and developmental perspective	Grounded theory methodology to gather and analyse interview data	11 women with a diagnosis of AN in inpatient (n=5) and outpatient (n=6) treatment aged 19- 51. Race/ culture of sample not indicated	The results highlighted two main overarching themes regarding the perception and management of emotions within anorexia nervosa: (1) development of poor meta-emotional skills; and (2) perception and management of emotion in anorexia nervosa
2009	O Kyriacou K Tchanturia A Easter	Comparing views of patients, parents, and clinicians on emotions in anorexia: a qualitative study	Focus groups and Questionnaires were reviewed using thematic analysis	6 female inpatients diagnosed with AN. Mean age of 26.8 (*SD* = 6.7); restricting AN (n=4) and binge/purge AN (n=2). Race/ culture of sample not indicated	Seven primary themes were identified showing congruence across groups: 'emotional awareness and understanding'; 'emotional intolerance'; 'emotional avoidance'; 'emotional expression and negative beliefs'; 'extreme emotional responses'; 'social interactions and relationships'; and 'lack of empathy'.
2012	E Espeset K Gulliksen R Nordbo F Skarderud A Holte	The link between negative emotions and eating disorder behaviour in patients with anorexia nervosa	Qualitative interviews analysed using grounded theory. Semi-structured interviews	14 women aged 19-39 years diagnosed with AN. Inpatient n= 8 Outpatient n=6. Study conducted in Norway. Race/ culture of sample not indicated.	Emotions were managed by specific eating disorder behaviours including restrictive eating and purging. Anorexia was also linked to self-control, self-harm and exercising
2016	N Rance V Clarke N Moller	The anorexia nervosa experience: Shame, Solitude and Salvation	Semi-structured interviews analysed using thematic analysis	A purposive sample of 12 women – Formal diagnosis of AN & NHS treatment (n=11) behavioural history of dietary restriction & private treatment (n=1)– who saw themselves as recovered, or in recovery Race/ culture of sample not indicated	Three themes identified – Shame, Solitude and Salvation. There was also a cyclical nature of sufferers' behaviours and feelings and the way in which anorexia nervosa is a form of distress that can make its sufferers feel better as well as worse.

Appendix 2: Information Sheet

TAVISTOCK & PORTMAN NHS FOUNDATION TRUST: Participant Information sheet

Study Title: "What is the emotional experience of a person who has suffered Anorexia Nervosa?"

Researcher: Jemma Meeson
c/o The Tavistock and Portman NHS Foundation Trust
The Tavistock Centre
120 Belsize Lane
London
NW3 5BA

You are invited to participate in a research study. Before you decide whether you would like to take part, it is important for you to understand why the research is being carried out and what it will involve.

Please read the following information carefully:

What is the purpose of the study?

This research is being conducted as part of a doctorate in Systemic Psychotherapy. Its purpose is to better understand the experience of those who have suffered from Anorexia Nervosa with the aim of supporting clinicians to be more helpful to people with Anorexia when they are working clinically.

Project Description

Despite emotions being included in more recent literature on systemic thinking, and guidance for working in this area with eating disorders, there does not appear to be any research on the role of emotions in relation to Anorexia. The research aim is to understand how persons who have experienced Anorexia Nervosa themselves think about their emotional experience. While persons diagnosed with Anorexia often have been studied quite intensely, they have seldom been involved directly in the studies so that their points of view often remain a missing piece in the understanding of the work.. The hope is that by understanding the emotional experience of participants better, the research will provide knowledge which will enable professionals to engage better with those who are currently experiencing strong anorexic conditions.

I am therefore seeking to interview 3-5 people who have had a diagnosis of Anorexia Nervosa over their lifetime and now consider themselves to be "recovered". This means that they will no longer be receiving treatment. Each person will be interviewed for approximately 1-2 hours and the conversation will be around how emotions were managed in your family growing up, how you feel you manage emotions now and any affect that Anorexia Nervosa had on your emotions.

Do I have to take part?

No, your participation is completely voluntary. If you decide to take part, I will give you a consent form to sign. If you decide to take part but find later that you change your mind, then you can stop taking part at any time prior to the data analysis stage You don't have to explain your reason for withdrawing. All information will be kept strictly confidential: there is a section that explains more about this further on.

<u>What will happen to me if I take part?</u>
I will arrange to meet you for an interview in which I will invite you to discuss your experiences with me. I would like to carry out the interview in a place that is as convenient as possible for you: you may decide that this is in your own home, or another location where we will be undisturbed. I will video tape this interview and then transcribe what you have said. I will offer you a copy of the interview and the analysis and will welcome any comments you may make. If you agree I would like to meet with you again to discuss this. I will also give you a copy of the final research study once it has been approved by the university.

<u>Confidentiality</u>
Any identifiable information will remain confidential to myself. In typing the transcript, your name and others referred to in the interview will be anonymised, so that they will not be identifiable to anyone else. In any written reports of this research, this confidentiality will be strictly upheld. All data will be kept securely in a locked cabinet or password protected file. The information you provide will be confidential subject to legal limitations. It is important to note, however, that there may be a limitation on confidentiality where there is disclosure of imminent harm to self/ and or others.
The video will be erased following the submission of my study to the university, which is anticipated to be in September 2023.

<u>What are the possible disadvantages of taking part?</u>
There is a risk that you may find it distressing to talk about the past and your Anorexia Nervosa. After the interview and if needed I will use my skills as a qualified clinician to debrief you and offer further support, should you find this helpful. I will also be suggesting other people you can contact if you feel you would like ongoing support. If you appear distressed during the interview you or I may end the interview early without any pressure to continue.

<u>What are the possible benefits of taking part?</u>
It is hoped that you will find the interview process interesting and perhaps useful in terms of reflecting back and processing your own experience. You may also feel that you are helping others who have experienced or are experiencing difficulties through your participation.

<u>What will happen to the results of the study?</u>
The results of the study will be written up in a research report as part of my doctorate at the Tavistock and Portman NHS Foundation Trust. Further it may be submitted to a journal for publication.
This project has been approved by the Tavistock and Portman Trust Research Ethics Committee (TREC)

If you have any concerns about the conduct of the investigator, researcher or any other aspect of the research project you should contact Simon Carrington, Head of Academic Governance and Quality Assurance (academicquality@tavi-port.nhs.uk)

Appendix 3: Consent form

Tavistock and Portman NHS Foundation Trust

Participant Consent form

Researcher: Jemma Meeson- jemmeeson@hotmail.com
Principal Investigator: Britt Krause

This study, which has received formal ethical approval from TREC, is investigating;:

"What is the emotional experience of a person who has suffered from Anorexia Nervosa?"

Involvement will require a video recorded interview which is likely to last between 1-2 hours. Following the transcription and analysis of this you will be invited to another further session to reflect on the interview together with the researcher. This is anticipated to take a further 1-2 hours.

All your data will be kept securely in a locked cabinet or password protected file.
The information you provide will be confidential subject to legal limitations. There may also a limitation on confidentiality where there is disclosure of imminent harm to self/ and or others.

Whilst all data will be anonymised and your information treated confidentially, the sample size is going to be between 4-6 participants, and thus this may have implications for confidentiality and anonymity, and you may be able to be identified.

Your participation in this research if voluntary and you are free to withdraw your consent at any time during the study, you are also able to withdraw and unprocessed data that was previously supplied.

If you have any concerns about the conduct of the investigator, researcher or any other aspect of the research project you should contact Simon Carrington, Head of Academic Governance and Quality Assurance (academicquality@tavi-port.nhs.uk)

Participant Name:		Researcher Name:	
Participant Signature:		Researcher Signature:	
Date:		Date:	

Appendix 4: Interview Schedule

Question Schedule

What is the emotional experience of a person who has suffered from Anorexia Nervosa?

1. When I say emotions to you what are your associations?

2. Can you tell me about how emotions were managed in your family?

   Prompt: Do you think other people in your family have the same associations as you to emotions?

4. Is there a difference in how you can "manage" the range of emotions?

   Prompt: Is this the case for all emotions or are some singled out?

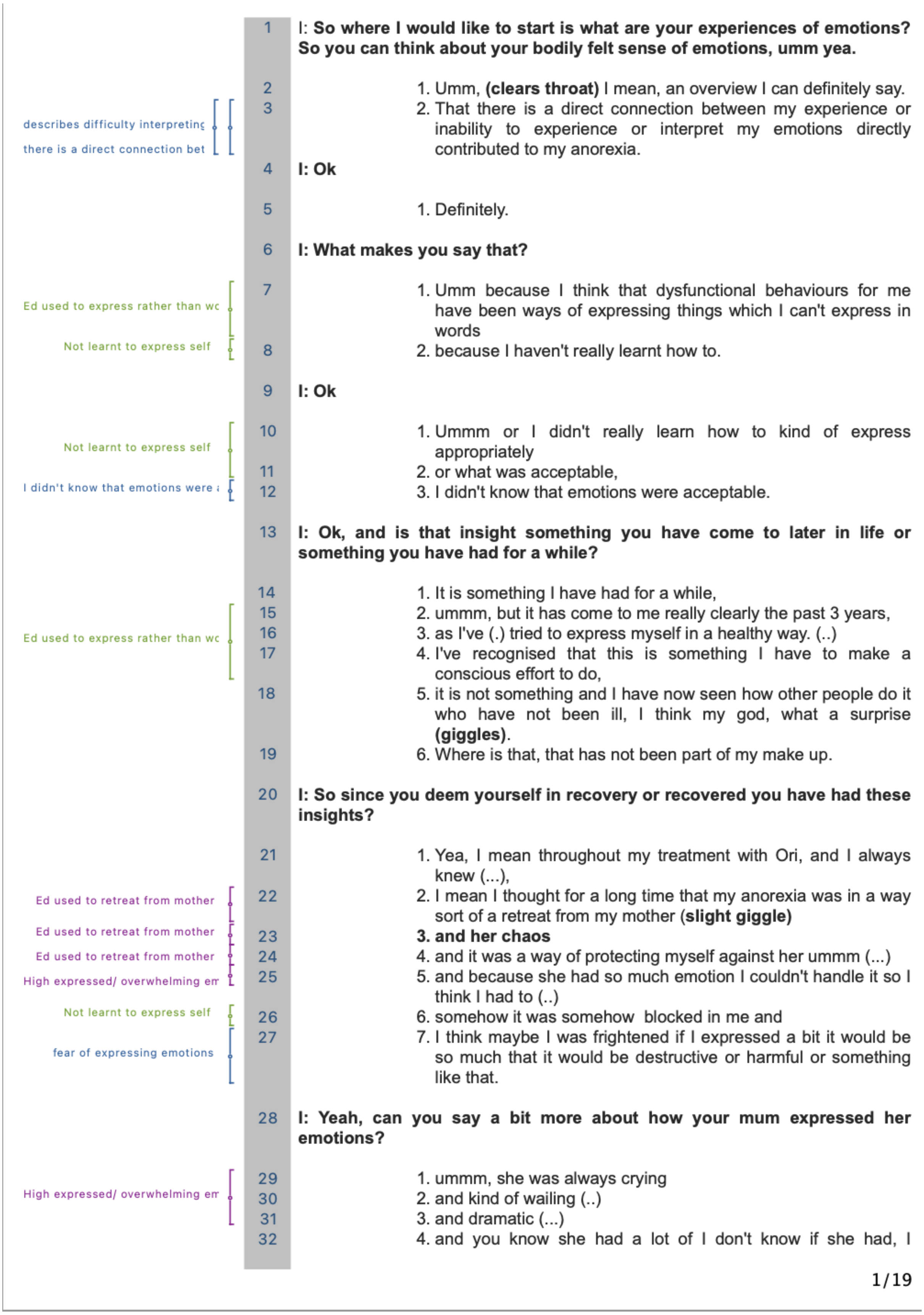
5. Can you tell me about how Anorexia came into your life?

6. Do you link Anorexia with emotions?

   If shame has not been covered then prompt.
   Prompt: How do you think about shame?

7. Can you tell me about your recovery?

Appendix 5: Extract of Transcript



I: So where I would like to start is what are your experiences of emotions? So you can think about your bodily felt sense of emotions, umm yea.

describes difficulty interpreting
there is a direct connection bet

1. Umm, **(clears throat)** I mean, an overview I can definitely say.
2. That there is a direct connection between my experience or inability to experience or interpret my emotions directly contributed to my anorexia.

I: Ok

1. Definitely.

I: What makes you say that?

Ed used to express rather than wc
Not learnt to express self

1. Umm because I think that dysfunctional behaviours for me have been ways of expressing things which I can't express in words
2. because I haven't really learnt how to.

I: Ok

Not learnt to express self
I didn't know that emotions were

1. Ummm or I didn't really learn how to kind of express appropriately
2. or what was acceptable,
3. I didn't know that emotions were acceptable.

I: Ok, and is that insight something you have come to later in life or something you have had for a while?

Ed used to express rather than wc

1. It is something I have had for a while,
2. ummm, but it has come to me really clearly the past 3 years,
3. as I've (.) tried to express myself in a healthy way. (..)
4. I've recognised that this is something I have to make a conscious effort to do,
5. it is not something and I have now seen how other people do it who have not been ill, I think my god, what a surprise **(giggles)**.
6. Where is that, that has not been part of my make up.

I: So since you deem yourself in recovery or recovered you have had these insights?

Ed used to retreat from mother
Ed used to retreat from mother
Ed used to retreat from mother
High expressed/ overwhelming em
Not learnt to express self
fear of expressing emotions

1. Yea, I mean throughout my treatment with Ori, and I always knew (...),
2. I mean I thought for a long time that my anorexia was in a way sort of a retreat from my mother **(slight giggle)**
3. **and her chaos**
4. and it was a way of protecting myself against her ummm (...)
5. and because she had so much emotion I couldn't handle it so I think I had to (..)
6. somehow it was somehow blocked in me and
7. I think maybe I was frightened if I expressed a bit it would be so much that it would be destructive or harmful or something like that.

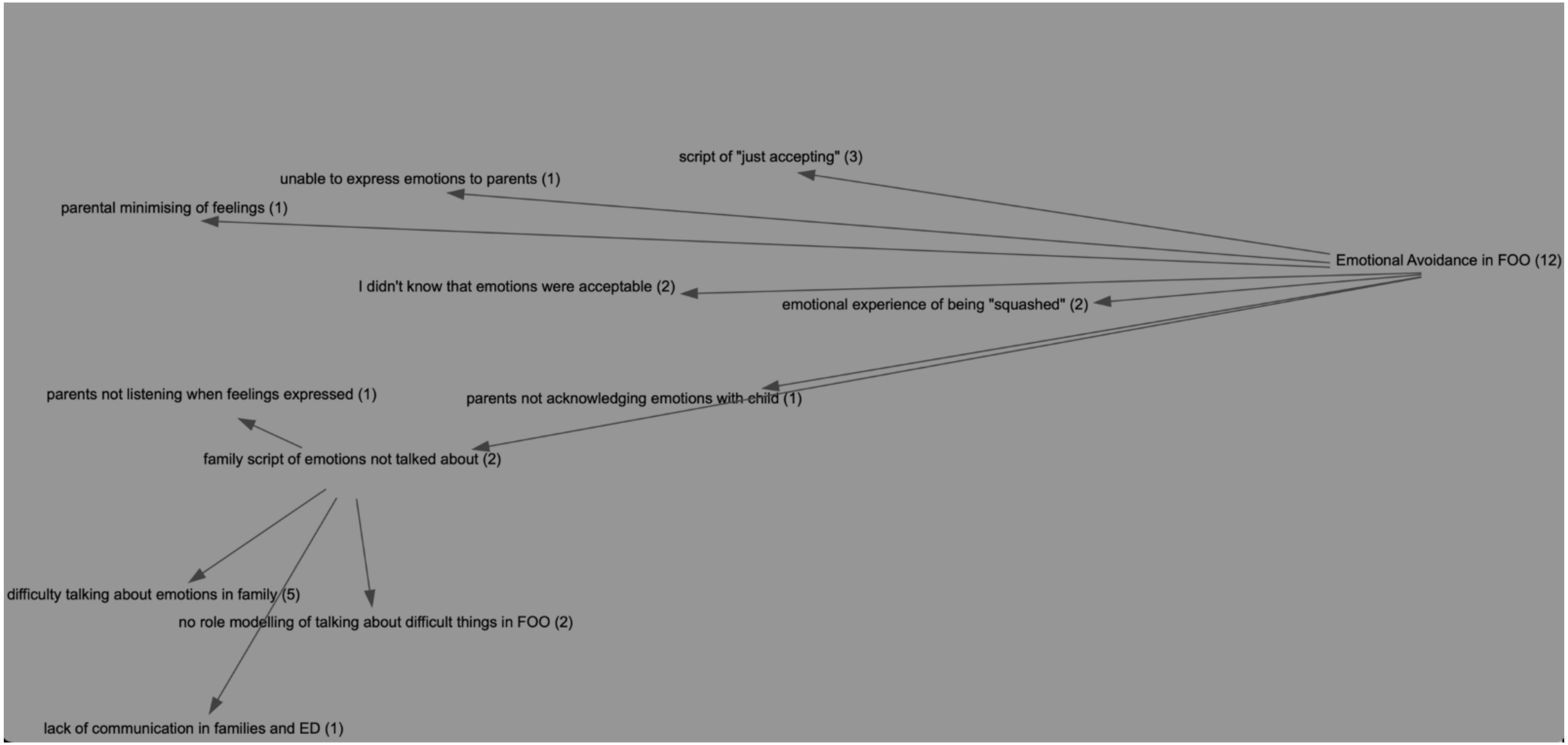
I: Yeah, can you say a bit more about how your mum expressed her emotions?

High expressed/ overwhelming em

1. ummm, she was always crying
2. and kind of wailing (..)
3. and dramatic (...)
4. and you know she had a lot of I don't know if she had, I

1/19

Appendix 6: Example map of coded segments



Appendix 7: Extract from reflective diary

Extract from reflective diary following my interview with R………

14th September 2022

When R got emotional about her experience at boarding school, I found myself being very preoccupied with my negative experience of boarding school, and overwhelming feeling of loneliness that I have been left with since. I also connected to her expression that she found it very hard to be alone, at the same time as experiencing loneliness. The experience I had, and of wanting to also numb this and forget about it felt important to acknowledge and to think about how to separate her feelings out from my own, and to make sure I spend extra time carefully transcribing this section and thinking about what I understand as the message she wanted to convey to me.
It is also important to consider the effect that I feel going to boarding school had on my relationship with my parents, and to hold that in mind when considering how R describes her relationship with her parents, which will be different. I also have to be careful to not over interpret what she tells me.

Appendix 8: Example list of initial themes that were merged into findings chapter

- ***1. WHERE IS THE SPACE FOR MY EMOTIONS?***
  - **1.1. Parental Relationship to eating/ Weight/ Shape**
  - **1.2. Taking up too much space**
  - **1.3. How emotions worked in their family**
  - **1.4. Mother's relationship to emotions/ role modelling**
  - **1.5. Father's relationship to emotions/ role modelling**
  - **1.6. Brother- emotional managment and relationship with Participant**
  - **1.7. Relational family dynamics.**
    - 1.7.1. Between Parents
    - 1.7.2. Between Participant and mother
    - 1.7.3. Between participant and father
- ***2. EMOTIONS AS A TRAP***
  - **2.1. Loneliness**
  - **2.2. Pre existing anxiety**
  - **2.3. Sadness**
  - **2.4. Control**
  - **2.5. Emotional Sensitivity**
  - **2.6. Bodily responses to emotions**
  - **2.7. Difficulty interpreting,tolerating or expressing emotions**
    - 2.7.1. Interpreting emotions
    - 2.7.2. Emotional expression
    - 2.7.3. Difficulty with emotion tolerance
- ***3. CONTROLLING, MODULATING SUPRESSING AND MANAGING EMOTIONS***
  - **3.1. Development of ED and relationship to it**
    - 3.1.1. thinness a secondary gain to ED
    - 3.1.2. ED thriving on oppurtunity
  - **3.2. Recovery and Relapse- this could be in control/ modulate etc - it could come back!**
    - 3.2.1. Motivation For Recovery
    - 3.2.2. Recovery- how others helped
    - 3.2.3. Recovery- worse before it got better
  - **3.3. ed addictive**
  - **3.4. ED started unintentionally/ subconsciously**
  - **3.5. ed and anxiety interlinked**
  - **3.6. ED/ SH To manage emotions**
    - 3.6.1. ED as control

Appendix 9: Ethical approval form

The Tavistock and Portman NHS
NHS Foundation Trust

Quality Assurance & Enhancement
Directorate of Education & Training
Tavistock Centre
120 Belsize Lane
London
NW3 5BA

Tel: 020 8938 2699
Fax: 020 7447 3837

Jemma Meeson

By Email

23 June 2022

Dear Jemma

Re: Trust Research Ethics Application

Title: What is the emotional experience of a person who has suffered from Anorexia Nervosa?

I am pleased to inform you that subject to formal ratification by the Trust Research Ethics Committee your application has been approved. This means you can proceed with your research.

Please note that any changes to the project design including changes to methodology/data collection etc, must be referred to TREC as failure to do so, may result in a report of academic and/or research misconduct.

If you have any further questions or require any clarification do not hesitate to contact me.

I am copying this communication to your supervisor.

May I take this opportunity of wishing you every success with your research.

Yours sincerely,

Paru Jeram
Secretary to the Trust Research Degrees Subcommittee
T: 020 938 2699
E: academicquality@tavi-port.nhs.uk

cc. Course Lead, Supervisor, Course Administrator