Beyond Measure: A Counselling Psychology approach to mental healthcare

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Introduction to The Portfolio

This portfolio is made up of three pieces of work, each representing a different aspect of my training. It begins with a doctoral research project that explores the experience of anorexia nervosa treatment from the perspective of those who dropout, and follows by presenting a clinical case study where cognitive analytic therapy (CAT) was provided to a client seeking help for anxiety within the National Health Service (NHS). With the aim of publishing the research findings, the thesis then concludes with a paper to be submitted to the journal, *European Eating Disorders Review*.

I have been inspired by many areas of my training over the last four years, yet nothing has impassioned and emboldened me as much as the research I present here on the treatment of anorexia nervosa (AN). I first came to the subject, not by way of clinical, but by way of personal experience, having myself suffered from anorexia in the past. When I embarked upon the course, I recall feeling conflicted about whether I wanted to pursue work with an eating disorder (ED) population. On the one hand, I felt naturally drawn to the field and, in many ways, it was my personal experience that first stoked my interest in psychology. But, on the other hand, I felt a strong need to expand my horizons and shape my professional identity in a way that was not tied to a sick identity I had fought to relinquish.

Thus, over the first few years of training, I took a ‘try-it-and-see’ approach, casting my net wide to gain a variety of experiences, none of which were related to eating disorders. I worked in a teaching hospital, offering CAT to clients with relational difficulties; in a redbrick university, offering short-term psychodynamic therapy to troubled students; in a bereavement service, offering existential therapy to the grief-stricken; and in an NHS clinic, offering long-term Cognitive Behavioural Therapy (CBT) to clients with complex mood disorders.

Then, midway through the course, and having gained clinical experience in a number of resolutely non-ED settings, I took a few years out from my studies to mother my first, and then my second, child. By the time I returned to complete my third year, I felt ready to renegotiate my relationship with the eating disorder topic. I knew that I was in an opportune position, to be recovered after so many years and, having not yet worked clinically with EDs, I saw the research project as an opportunity to draw on my combined personal and professional experience to contribute something to the field.

Over the course of this research, I have also come to realise that this is the area where I want to work professionally, not least because I believe it is one where the field of Counselling

Psychology can make a real and discernible difference. Eating disorders are unusual conditions for the fact that, while considered to be largely psychological in nature, they have very real medical consequences. This means that they have tended to be treated within medicalised contexts as 'patients' but, as my research project illustrates, there can be drawbacks to this. The participants described how they felt their subjective lived experiences often went unacknowledged, subsumed as they were by the standardised assessment and measurement of their more visible diagnostic symptoms. Counselling Psychology emerged as a critical reaction against the pathologisation of psychological distress and so we are perfectly placed to attend to these concerns. Indeed, at its core, Counselling Psychology privileges respect for personal, lived experience over and above notions of diagnosis, measurement and cure, and values it as a profound tool for learning about and supporting one another (Bury & Strauss, 2006).

This humanistic theoretical position has influenced my development as both a practitioner and a researcher. Accordingly, a common theme weaving through the fabric of each piece of work within this portfolio is the need to provide individualised care to those we treat, based on their own accounts of their lived experience, even as we work within more medicalised environments like the National Health Service. I chose to include the case study that I have because it illustrates a challenging situation where I had to adapt my formulation and standardised approach to meet the changing experiences and needs of my client throughout the therapy. Fortunately, with the aid of a relational approach and a flexible, progressive supervisor, I was able to make these adaptations in a way that was of great benefit to my client. The research project, meanwhile, highlights what is at stake when we fail to acknowledge and prioritise the lived experience of those we treat, with the participants describing how failures like these contributed to their decision to drop out.

As a profession, Counselling Psychology is *"currently at an interesting point in its journey"* (Strawbridge, 2016, p21), twenty-five years on from when it was first officially recognized by the British Psychological Society (Corrie & Callahan, 2000). While Counselling Psychology has its origins in the humanistic movement, increasingly we find ourselves working within mental health teams and other health care settings where notions of mental 'illness' prevail (Bury & Strauss, 2006). This brings both challenge and opportunity. Where do we position ourselves in relation to matters of diagnosis, psychological measurement and standardised approaches to treatment delivery? Perhaps we could seek to strengthen our scientist-practitioner position within these less familiar environments by adopting their 'illness' frame of reference. But this risks us sacrificing the reflexive, humanistic principles for which we also stand, something I believe would be of huge detriment, not only to those we treat within the NHS, but to society more generally. My view is that, in entering these more medicalised spaces, we have a unique opportunity to challenge pathological discourses from within and champion more person-centered approaches for the benefit of new client populations, such as those diagnosed with anorexia nervosa.

Over the course of compiling this portfolio, I have come to realise that, as a soon-to-be Counselling Psychologist, I have the opportunity to make a difference in a way that extends far beyond the therapy room. As a trainee, I have become experienced in helping my clients reflect on their experiences and exploring with them the ways in which they make sense of the world. I have witnessed how powerful this dialogical process can be in facilitating personal change. But, through my doctoral research, which I conducted with the same reflexive and explorative attitude, I now also recognise that I can potentially impact, not just those that sit opposite me in the therapy room, but also the individuals, services and societies that shape them.

Going forward, I intend to work clinically with eating disorders within the NHS, using what I have learnt from my participants' experiences of treatment to guide my practice. I hope to also continue researching eating disorder treatment, believing it to be an area that could benefit greatly from a more qualitative perspective. Having completed this portfolio of work, I see it to mark a defining moment in my professional training and career for, not only has it cemented my desire to work within the field of eating disorders, it has seen me grow into my role as a practitioner psychologist, integrating the reflexive therapist in me with that of the scientific researcher.

Sections of The Portfolio

PART A: Doctoral Research

This first section comprises the doctoral research, entitled: *'I had to get out…they were making me worse'*: A Qualitative Study of Anorexia Nervosa Treatment and Dropout. The research aimed to explore the perspectives of those who dropped out from anorexia nervosa treatment in order to enrichen current understandings of the treatment experience and to gain a better insight into the meaning of dropping out. Five semi-structured interviews were conducted with a sample of women, age 19-44, who had dropped out from AN treatment within the National Health Service. Their data was examined using Interpretative Phenomenological Analysis and four over-arching themes emerged. The findings are considered within the context of existing literature and theory. Finally, implications and suggestions for Counselling Psychology are presented.

PART B: Client Study

In this section, I present a study of clinical work I undertook with a client seeking help for anxiety, set within a Cognitive Analytic Therapy service at a London NHS hospital. While the client was not diagnosed with anorexia nervosa, I chose to present her case because I believe our therapeutic work demonstrates the value of individualised care – a central area of concern that arose from my research on anorexia treatment. As a single piece of work, this client study also demonstrates key aspects of my development as a Counselling Psychologist and illustrates my view of clients as nuanced individuals, seeking connection and understanding, rather than just an embodied collection of symptoms, requiring cure. Individualised care lies at the heart of Counselling Psychology and I hope this piece of work illustrate ways in which I cultivate it in my own practice by being collaborative, flexible and creative.

PART C: Publishable Paper

I present, in this final section, a publishable paper which explores the findings from my research project. My aim is to have it published in the peer-reviewed *European Eating Disorders Review (EEDR)*, and it has been formatted with this in mind (see Appendix A for EEDR's author guidelines). I decided upon this journal because of its global reputation in the field of eating disorders, and because it is the academic journal belonging to 'Beat', the eating disorder charity and organisation which helped me publicise my research study to potential participants. Their bi-monthly journal publishes *"articles, from all over the world, which review or report original research that has implications for the treatment and care of people with eating disorders and* *obesity, and articles which report innovations and experience in the clinical management of eating disorders"* (Wiley Online Library, 2019). Were my article to be published here, its findings would be read by professionals across a number of disciplines such as Dieticians, Social, Clinical, Health and Counselling Psychologists, and Psychiatrists, all of whom have a mutual interest in the field of disordered eating. The purpose of the article is to promote knowledge of how treatment factors could themselves contribute to dropout from AN treatment. I hope that the publication of these findings can provide those working within the field an understanding of how to tailor treatment to better meet individual needs, thereby increasing the chance of sufferers, not only remaining within the treatment process, but being helped by it too.

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PART A: Doctoral Research

'I had to get out…they were making me worse'

A qualitative study of anorexia nervosa treatment and dropout

Natasha Sutherland

Supervised by Dr Courtney Raspin

Abstract

This study sets out to explore the experience of anorexia nervosa (AN) treatment from the perspective of those who choose to dropout. Dropout rates are particularly high in the treatment of AN but the reasons for this remain unclear. There have been calls to facilitate patient-led explorations of the reasons behind dropout, believing it may further our understanding, as the focus of most research to date has been on trying to locate predictive patient characteristics, with little attention paid to patients' subjective experience. Adopting a critical realist epistemology, this study aims to explore the perspectives of those who dropped out from AN treatment in order to enrichen current understandings of the treatment experience and to gain a better insight into the meaning of dropping out. This study will describe participants' AN treatment experiences and the sense they made of their decision to dropout. Semi-structured interviews were carried out with five women, age 19-44, who had dropped out from AN treatment within the National Health Service. Their data was examined using Interpretative Phenomenological Analysis and four major, interconnected themes emerged. *Becoming 'The Anorexic': Identity and Belonging* describes their experience of having become increasingly focused on their 'anorexic' identity within treatment and on achieving acceptance and belonging through fulfilment of an 'anorexic' social role. *More Than Meets The Eye: The Unseen Subjective Experience* describes their perception that their subjective experience went unacknowledged, be that due to individual clinicians lacking psychological awareness or due to the standardised, symptom-focused approach of the program itself. *Disempowering Forces: Control and Chaos Within The System* describes participants' perceptions that the treatment environment was, variously, controlling and chaotic, both which created an experience of disempowerment and lost control. While these first three superordinate themes describe prominent aspects of participants' treatment experience, *Protest and Protection: Dropping Out from Getting 'Worse'* describes the meaning they gave to their eventual decision to dropout, framing it as a consequence of the harmful treatment experiences recorded within the preceding themes. The findings from this study provide Counselling Psychologists, as well as other clinicians working with eating disorders, a valuable insight into the meaning sufferers give to their decision to dropout from treatment, and identify opportunities to reduce clinical factors that might contribute while maximising those factors which protect against it.

Chapter 1. Introduction

Anorexia nervosa (AN), a condition hardly recognised before the 1980s (Brumberg, 1988), is now part of common parlance the world over. In the UK alone, more than 125,000 are thought to suffer at any one time (Beat, 2019) and it carries with it a bleak trajectory: less than half recover and one in five die within twenty years (Steinhausen, 2002).

Professional treatment is widely considered to offer sufferers their best hope for recovery (Dejong, Broadbent, & Schmidt, 2011). Nonetheless, treatment outcomes remain far from ideal and dropout rates as high as 50-73% have been cited for both outpatient and inpatient samples (Button, Marshall, Shinkwin, Black & Palmer, 1997; Sly, Morgan, Mountford, & Lacey, 2013; Fassino, Piero, Tomba & Abbate-Daga, 2009). Watson and Bulik (2013) have stated that dropout rates in AN treatment are *"inordinately high"* (p.2495) compared with most psychological conditions, including other eating disorders.

Dropout rates like these are thought to have wide reaching negative consequences, not only for the patients themselves but also for the professionals engaged to treat them and for the research efforts that inform how they do so. Reports suggest that those who withdraw from treatment prematurely are more likely to deteriorate further (Pike,1998; Beumont, Russell & Touyz; 1993), and professionals also admit to feeling demoralised when patients leave treatment without explanation (see Dejong et al., 2011). Dropout also poses problems for research because loss of participants within treatment trials can lead to underpowered statistical tests and imprecise estimations of effect size (Watson & Bulik, 2013). Halmi et al. (2005) even suggested that large treatment trials for AN should be abandoned altogether until the reasons for dropout are better understood and addressed.

I will now present my rationale for the current study, before going on discuss the contribution I hope to make to the field of Counselling Psychology. The chapter concludes with a brief clarification of some of the key terms I have used throughout the work.

1.1 Rationale for the Study

Having decided I wanted the broad focus of my research to be on eating disorders, I immersed myself in the literature. I found myself quickly drawn to the subject of ED treatment, perhaps because it was here that I was beginning to locate my clinical ambitions as a Counselling Psychologist. Perhaps too because of my own experience of treatment, which had been colourfully varied and yet uniformly ineffective.

As I read more around the topic, I learnt of how common it was for patients to withdraw from treatment early, particularly in the case of adult anorexia. It was intriguing to see leading academics in the field attribute this phenomenon to patients who were typically *"resistant"* (Vitousek, Watson & Wilson, 1998, p.391) or *"recalcitrant"* (Fairburn, Shafran & Cooper, 1999, p.2). I started to pay attention to how treatment retention was discussed and researched; how they tended to look for *factors within people* that made them *more or less able to complete treatment.* This trend seemed to betray an assumption that there existed an underlying cause for treatment withdrawal, that this cause was pathological and located within the individual and that, if only it could be identified, it could then be treated via a specific set of techniques. This did not sit entirely comfortably with me. After all, if the individual is treated as the locus of pathology, any who choose not to complete treatment are going to be framed as having failed treatment, neatly sidestepping any responsibility we might have to consider the role that the treatment environment or we, as treatment providers, might play.

I also noticed a significant lack of qualitative investigation into treatment outcomes within the literature. Indeed, when it came to discussions about dropout and why it might occur, the voices of patients were notable in their absence. I could only presume that this was because, within a context where dropout is attributed to *"'hostile', 'oppositional', 'uncooperative'" patients who are "'impervious to treatment'"* (Malson, Bailey & Clarke, 2011, p.26), the meanings they give to their own treatment decisions carry little weight. As one author puts it, the voice of the anorexic subject is simply discredited as being *"outside of the true"* (Saukko, 2008, p.6).

I realised that I wanted to question this stereotype, believing it to be based on assumptions grounded in an overly-rigid, pathological view of eating disorders. This is why I have chosen to explore individuals' own experiences of anorexia treatment and subsequent dropout, feeling that they might be able to offer an alternative account to those which currently dominate the research literature.

1.2 Contribution to Counselling Psychology

One of the key motivations for conducting research is the positive contribution one might make to their field. This study contributes to an area that is under-explored and yet highly applicable to all Counselling Psychologists who encounter eating distress within their clinical practice.

Specifically, exploring AN sufferers' experiences of treatment can contribute to our understanding of treatment practices, help address any research-practice gaps, and identify staff training needs. And, by exploring the way in which they make sense of their decision to dropout, we can learn more about how ‘treatment’ and ‘dropout’ are conceived and constructed by AN patients, and the impact this has on their ED.

The study also uniquely contributes to the clinical practice of Counselling Psychology. If the perceived value we bring to anorexia treatment is our specialist practice, it is important we understand how it may or may not contribute to a patient’s decision to drop out so that we might adapt our service to increase the likelihood of patients remaining within the treatment process and with motivation to recover. As we acquire a greater understanding of the subjective factors that motivate dropout we will also be better placed to challenge existing assumptions about the character of the ‘anorexic dropout’ and advocate for increased sensitivity towards, and better treatment of, those diagnosed with anorexia.

In this regard, it is important to consider how the discipline of Counselling Psychology emerged as a critical reaction to the positivistic medical model of understanding human distress (Milton, Craven & Coyle, 2010; see Chapter 2). The exploration of dropout within the AN treatment literature has almost exclusively been conducted within the confines of this model, putting it at odds with the value Counselling Psychology places on lived experience and its perception that we, as human beings, are intrinsically embedded within our environments. This study intends to rectify this by viewing the phenomenon of dropout through a more humanistic, Counselling Psychology friendly lens.

1.3 Clarification of Some Key Terms

There are many diverse readings of the term ‘anorexia nervosa’ within the literature, some which describe it as an over-pathologising, and thus stigmatising, label. Employing a critical realist position within this study, I use the term ‘anorexia nervosa’ (also ‘anorexia’ and ‘AN’) by presenting it as a ‘real’ object that can be viewed through various lenses, each which have their own constitutive effects.

I have also chosen to use the term ‘anorexic’ as a practical shorthand for ‘person with a diagnosis of anorexia nervosa’. All the women I interviewed had received an anorexia nervosa diagnosis and, while many of them questioned its clinical utility, they also admitted to having, at times, been invested in being seen as ‘anorexic’. Therefore, although ‘anorexic’ can be a stigmatising label when applied in certain contexts, it was not considered to be so here.

I also use the term ‘patient(s)’ throughout the study when referring to those in receipt of treatment for anorexia. I am aware that the term may be considered problematic since it implies traditional hierarchal relations of power between providers and recipients of healthcare services.

I considered alternative terms, such as ‘client’ or ‘service-user’ but felt that they implied an active and willing consumer-like choice to receive or engage with treatment. This was not the sort of treatment experience described by my participants, who more often underwent treatment involuntarily or engaged with it ambivalently. Therefore, I have chosen to retain the term ‘patient’ while also acknowledging the problem associated with its continued use.

I also questioned whether to use the term ‘dropout’ given that some authors have suggested that it may be beneficial to move away from this label, it perhaps implying that patients are to blame for ‘failing’ at treatment (Vandereycken & Devidt 2010). I had intended to use ‘early withdrawal’ to avoid any pejorative connotations but, when it came to writing up, the phrase felt awkward and clunky. Noticing that the participants themselves often used ‘dropout’ to describe their experience, I decided that I too could retain the use of ‘dropout’ for the purpose of the study while also agreeing with Vandereycken & Devidt (2010) that it is a term I would avoid using, or else would wish to deconstruct, within clinical practice.

Chapter 2. Literature Review

What follows within this chapter is a critical review of the literature and the empirical findings relevant to the topic of research. A brief overview of anorexia nervosa is offered, with particular attention paid to the ways in which our understandings and definitions of the condition have evolved. Recommendations for its treatment are then explored, and consideration given to the services currently provided to those diagnosed with AN within the UK. Discussion then turns to the issue of dropout itself, exploring how it has been conceptualised within the literature and identifying gaps in knowledge.

2.1 A Brief History of Anorexia Nervosa

While AN, as it is currently defined, may be a modern phenomenon, its primary characteristics are not. As Brumberg (1988) observes,

"…today's anorectic is one of a long line of women and girls who have used control of appetite, food and the body as the focus of their symbolic language. A historical perspective shows that anorexia nervosa existed long before there was a mass cultural preoccupation with dieting and a slim female body" (p.2-3).

Taken from the Latin, anorexia nervosa, translates to mean 'nervous loss of appetite'. However, this is now thought to be misleading – the self-starvation in AN being unrelated to appetite (Boughtwood, 2006).

The earliest recorded examples of self-imposed starvation occurred alongside the diffusion of Gnostic philosophy and Christianity, both which promoted a dualism between the 'sinful' material body and the 'holy' transcendent soul (Brumberg, 1988). Dating back to the first century, Christian Gnostics would engage in prolonged fasts in the hope of achieving ascetic transcendence (Bell, 1985).

For the Medieval Catholic Church, fasting constituted a 'miracle of existence without nourishment' and many clerical texts of the time promoted women's fasting as an honourable form of ascetisicm (Hepworth, 1999). Indeed, women who starved themselves were often held in the highest esteem, and even extolled as Saints for their efforts (Bell, 1985). One well-known example was Catherine of Siena (1347-80), who came to be regarded a Saint by the religious clergy. Unfortunately, as well as a Sainthood, her unusual aptitude for fasting also brought her an early death.

The clergy did not always interpret women's fasting to be saintly, however. They tended to grant only the upper-class aesthetes this privilege. For the others, less fortunate, their fasting was viewed with a great deal more suspicion and they were more likely cast a deceitful 'witch' than a holy 'saint' (Bell, 1985). The most extreme examples of this can be found in the sixteenth century, when the Catholic church, believing self-starving women to be demonically possessed, rooted them out and burnt them at the stake (Brumberg, 1988).

With the scientific revolution of the seventeenth and eighteenth centuries, self-starvation became increasingly associated with the material rather than the religious realm. The first case of what might now be labelled anorexia nervosa was reported in 1686 by physician Richard Morton. He described one twenty-year-old patient as *"a skeleton clad with skin"* (Silverman, 1988, p.83) and suggested she suffered from a nervous consumption brought on by sadness, anxiety and excessive study. Morton's work did not draw much attention at the time, however, as many of his contemporaries still invoked God to explain what, to them, appeared to be supernatural cases of starvation (Boughtwood, 2005; Brumberg, 1988).

The condition finally caught the attention of the wider medical establishment in 1873, when two renowned physicians published accounts of the illness (Boughtwood, 2006). Their reports differed in their emphasis, as Brumberg (1988) explains:

> *"Gull's report was primarily medical, focusing on how the physician came to conclude that the condition involved 'simple starvation,' and no organic cause. Lasegue's commentary was psychological, outlining the mental stages through which patient and family passed in the course of the disease"* (p. 119).

Both Gull and Lasegue identified adolescent girls as a group at risk of developing anorexia nervosa (Boughtwood, 2006). The widespread recognition of Gull and Lasegue's reports led to the anorexic being reconstructed in the public imagination. No longer a saint nor a witch; she was now a patient (Brumberg, 1988).

2.2 Contemporary Anorexia Nervosa and its Diagnosis

In the twenty-first century, anorexia nervosa continues to be viewed as an illness. Clinical research suggests it to be the third most common illness in adolescent girls (Touyz, 2005), and it carries a reported lifetime prevalence of 1.5% in women and 0.5% in men (Hudson, Hiripi, Pope & Kessler, 2007). Forthcoming longitudinal research will likely show an increase in these figures too, the diagnostic criteria for AN having recently been made less exclusive (DSM-5, APA, 2013)[1]. Indeed, Hay, Girosi & Mond (2015) have suggested that, within the general population, the lifetime prevalence of anorexia nervosa in women may be as high as five percent.

AN typically develops in mid-adolescence, with forty percent first diagnosed between the ages of fourteen and nineteen (Smink, van Hoeken & Hoek, 2013). It can, however, emerge at any life stage (Herpertz-Dahlmann, 2009). Additionally, while more females are thought to be affected, at a ratio of 1:8 (Steinhausen & Jensen, 2015), reports suggest men are increasingly at risk (e.g. Micali, Hagberg, Petersen & Treasure, 2013).

Anorexia is considered a chronic condition, with an average duration of five to seven years and the possibility of life-long struggle (Ben-Tovim et al., 2001). About a third of sufferers continue to meet the full diagnostic criteria five years and more after initial treatment, and only half show any significant improvement (Polivy & Herman, 2002). Longitudinal follow-up studies of over twenty years have suggested mortality rates of approximately one in five, the highest of any mental illness (Steinhausen, 2002).

The most influential sources of knowledge used internationally for understanding and diagnosing anorexia nervosa are the third and following editions of the Diagnostic and Statistical Manual of Mental Disorders. The latest edition of the Diagnostic Statistical Manual (DSM-5; APA, 2013) defines anorexia nervosa as a condition which compels individuals to restrict their intake of energy relative to requirements, resulting in significantly low bodyweight. It characterises the disorder through the following features: *"...persistent energy intake restriction; intense fear of gaining weight or becoming fat, or persistent behaviour that interferes with weight gain; and a disturbance in self-perceived weight or shape"*. (APA, 2013, p.339). For a full description of diagnostic criteria found in the DSM-5, please see Appendix 1.

While the DSM-5 attempted to improve on earlier descriptions of AN, such as by removing the pejorative *"refusal and denial"* of food (Hebebrand & Bulik, 2011, p.667) and adapting several diagnostic criteria, some authors question the utility of its checklist approach (Morgan, 2015). For example, the distinction between what is considered 'normal' and 'significantly low' weight seems arbitrary, with little guidance on how to distinguish individuals (Hebebrand & Bulik, 2011). Additionally, the categorical delineation between bulimia and AN fails to acknowledge that many individuals experience both (Fairburn, Cooper, Shafran & Wilson, 2008). These inflexible definitions have been criticised for being over-pathologising – thus laying claim to an objective

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[1] There is no longer a weight threshold that needs to be met for the diagnosis, and amenhorrea is also no longer a criterion.

and empirical truth and crucially reducing interest in the phenomenological and individual experience of the disorder (Giordano, 2009).

The diagnostic criteria can be seen to serve various purposes for various parties. For clinicians, they offer a way to categorise patients and, depending on their weight and frequency of behaviours, a justification for admitting them into hospital (Boughtwood, 2006). The anorexia diagnosis also has a number of wider socio-political implications for sufferers, such as whether they can secure a referral for ED services within the NHS, or whether they can secure funding from insurance companies for private treatment. An anorexia diagnosis can also hold considerable personal and social significance for the individual, defining a lifestyle for them, and an identity (Boughtwood, 2006; see also Rich, 2006; Osgood, 2014).

There are some writers that have queried anorexia's status as an illness altogether, pointing out that the clinical signs of anorexia have much in common with supposedly 'normal' dieting behaviours (e.g. Gordon, 2000). Anorexia is also sometimes presented as desirable within popular discourse with people commenting that they wish they could catch 'a bit' of it (Brumberg, 1988). As Lelwica (1999) observes, anorexia has a unique and peculiar status in this regard. Media productions have been accused of glamourising self-starvation and anorexia (Way, 1993) and play a central role in anorexia's popular profile, with a steady stream of memoirs, magazines, documentaries and talk shows on the subject, all which primarily target female audiences (Boughtwood, 2006). Within these media productions, the anorexia label does not appear to carry the same stigma as the one attributed to anorexia and other psychiatric categories within a medical context (Boughtwood, 2006).

2.3 Factors Contributing to Anorexia Nervosa

Most professionals working within the field of EDs believe AN to be linked to a complex interplay of biomedical, psychological, familial and sociocultural factors (e.g. Treasure, Claudino & Zucker, 2010; Bulik, Landt, van Furth & Sullivan, 2007). While some might make an individual vulnerable to developing the condition, others are thought to act as a catalyst or else keep the eating disorder going. There is also a widespread consensus that the precise influence of genes and environment vary for each individual. For some, genetics may be the most significant factor while, for others, the environment might play a more critical role in AN's development and/or maintenance. This variability likely influences the clinical presentation and course of the disorder and may help explain some of treatment's unpredictable, often disappointing, outcomes.

Space limitations preclude a thorough review of the, frankly vast, literature around AN's development and maintenance (for this, refer to meta-analyses and reviews by Keel & Forney, 2013; Striegel-Moore & Bulik, 2007; Jacobi, Hayward, de Zwaan, Kraemer & Agras, 2004) but the following section provides an overview of some of the more salient findings to date. For the sake of clarity, I have attempted to categorise possible factors as biological, psychological, environmental or sociocultural but the likelihood is that each of these interact and are, as such, inseparable.

2.3.1 Biological factors

Research on biological risk factors for anorexia has focused mainly on genetics and neurobiological disturbances (e.g. altered serotonin levels). Family studies have suggested that first-degree relatives have a lifetime risk of developing AN ten times greater than relatives of healthy controls (Bulik et al, 2007). They are also significantly more likely to suffer from generalised disordered eating. While family studies can show whether AN aggregates in families, twin studies can also show whether that aggregation is due to genetic factors, shared environment, or both. A growing body of twin studies confirm a link between genetic factors and EDs, with heritability for AN showing somewhere between 33-84% (Zerwas & Bulik, 2011).

Researchers have also sought to identify what it is precisely that, if inherited, confers risk for AN. Several groups have suggested that individuals who develop AN are more likely to carry a particular variant of the 5HT2A receptor gene (see Gorwood et al., 2002). This gene is thought to regulate serotonin, a neurotransmitter which influences satiety, mood, and impulse control. However, their findings, while promising, have not found support in follow-up studies. This lack of replication may mean the researchers are focusing on the wrong area, or it might just reflect inadequate sample sizes, and thus the statistical power to detect a genuine replication.

2.3.2 Psychological factors

While biological factors may have a role in predisposing a person to developing and maintaining AN, it is still largely seen to be an illness with a psychological basis. The two most prominent psychological theories for AN derive from the schools of psychoanalysis and cognitive-behaviourism.

Psychoanalytic theorists consider refusal to eat to relate to an ambivalent attachment to a controlling mother (Sours, 1974). Bruch (1978) expanded on this and argued that anorexia nervosa signified the resultant struggle for self-identity and autonomy.

The cognitive-behavioural view of AN highlights the role of thoughts and behaviours rather than family interactions or childhood experiences. Garfinkel and Garner (1982) described the potential sufferer as a sensitive, insular adolescent who reaches the conclusion that weight-loss will ameliorate their distress. The resultant dieting is then reinforced by their sense of achievement and the reaction – whether it be approval or concern – that they receive from others. Eventually, the negative reinforcement of food avoidance and weight-loss reaches a watershed point whereby the AN thoughts and behaviours become self-perpetuating.

Recent cognitive-behaviourally informed models also suggest that people who develop AN tend to experience emotions as uncontrollable and aversive. They argue that, when emotions are not validated in childhood, poor self-concept develops (Cooper, 2005), along with the belief that emotions are unacceptable and dangerous (Corstorphine, Mountford, Tomlinson, Waller, & Meyer, 2007). These maladaptive attitudes and beliefs are then thought to lead to an avoidance of emotional experience and anorexic behaviours get adopted as strategies to achieve this (Waller et al., 2003).

Both psychoanalytic and cognitive-behavioural models have received support from the many studies which have shown those with AN to describe their disorder as a means of obtaining identity, satisfying a need for control and/or avoiding painful emotions (Espindola & Blay, 2009).

Personality traits have also received a great deal of attention in models of AN (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). Personality traits refer to *“a set of psychological qualities that contribute to an individual’s enduring and distinctive patterns of feeling, thinking and behaviour”* (Cervone & Pervin, 2010, p.8) and are thought to be moderately inheritable and stable throughout life.

Research suggests individuals with obsessive-compulsive personality traits are at increased risk of developing AN (e.g Bulik et al., 2007). One study further identified a set of five obsessive-compulsive personality traits (inflexibility, perfectionism, rule driven, drive-for-order and symmetry, excessive cautiousness and doubt) and found those with AN to be significantly more likely to have displayed signs of these in childhood (Anderluh, Tchanturia, Rabe-Hesketh & Treasure, 2003).

Many studies have also found that people with AN often display traits of alexithymia - that is, difficulties identifying, expressing or describing their feelings (Schmidt, Jinawy, & Treasure, 1993; Taylor, Parker, Bagby, & Bourke, 1996). Sisters of AN individuals also have difficulties with alexithymia (Hason-Rozenstein, Latzer, Stein & Eviatar, 2011), suggesting it to be an inherited trait, or else a trait that developed out of a shared environment, rather than a temporary state brought on by the eating disorder.

How these traits might actually contribute to AN seems to be in the way they could influence how an individual perceives themselves and their environment, and how that individual interfaces with their environment as a result. For example, alexithymia, and obsessive-compulsive traits like perfectionism, probably predispose individuals to low self-esteem. Researchers have found low self-esteem to contribute to a variety of disorders, including AN (Striegel-Moore, 1997), and prospective research shows that girls with low self-esteem are significantly more likely to experience disordered eating over the following few years (Button, Sonuga-Barke, Davies & Thompson, 1996). Treasure & Schmidt (2013) specifically highlight how individuals exhibiting obsessive-compulsive traits will manifest low self-esteem by being more sensitive to social hierarchies and negative judgments from others, and to the desire to belong and be accepted by conforming to social norms (including thinness). Certain traits can also influence the likelihood of an individual choosing a peer environment with higher-than-normal pressure to be thin. For example, perfectionists may be drawn to one another, creating a social environment where concern about weight and shape and the importance of achieving a thin-ideal become magnified (Rayner, Schniering, Rapee, Taylor & Hutchinson, 2013).

Kaye and colleagues (Kaye, Wieringa, Bailer, Simmons & Bischoff-Grether, 2013) suggest that some childhood traits, such as anxiety, obsessions, and perfectionism might also reflect neurobiological risk factors for the specific development of AN. For example, they suggest that people vulnerable to developing AN may have increased serotonin receptor activity, contributing to high anxiety. Food restriction reduces levels of serotonin and thus would reduce anxiety in this group, potentially giving rise to a situation where the sufferer feels the need to eat less and less to maintain emotional equilibrium (see Kaye, Frank, Bailer & Henry, 2005). Other neurobiologically informed psychological models of AN have further emphasised the role of fear and stress (Guarda, Schreyer, Boersma, Tamashiro & Moran, 2015), the rewarding nature of anorexia nervosa symptoms (O'Hara, Campbell & Schmidt, 2015) and the subsequent shift to compulsive or habitual behaviours (Walsh, 2013; Godier & Park, 2014) as key factors in persistence of the illness.

2.3.3 Environmental Factors

Whereas genetic and neurobiological research has emerged with force over the last few decades, historically speaking, the vast majority of ED research has concentrated on environmental causal factors (Jacobi et al, 2004). Even now, with compelling data underscoring the contribution of genes to AN's aetiology, certain environmental factors remain strongly implicated for the impact they have on gene expression. For example, Klump and colleagues point out that dynamics within the family could interact with genetic risk to increase susceptibility for AN (Klump, Suisman, Burt, McGue & Iacono, 2009).

Indeed, family dynamics have received a lot of attention over the years. Research into family interactions has suggested ED families to be enmeshed, hostile, intrusive, and to be excessively concerned with parenting (Shoebridge & Gowers, 2000) or negating of the sufferer's emotional needs (Minuchin, Rosman & Baker, 1978). Mothers have received much of the blame; something which can be traced back to the 1970s and Hilde Bruch. She described the 'anorexic mother' as one who over-anticipated her daughter's needs, leading to dysfunctional feeding practices and the child's failure to develop appropriate awareness of her own hunger and satiation. The mother's hypervigilance was also seen to create a situation whereby self-worth and independence were unable to develop, presenting difficulties once the child entered adolescence (Bruch, 1970). Bruch identified three key areas of disturbance in her patients relating to these developmental failures: negative body image, perception and a sense of ineffectiveness, and she described how their quest for thinness became a kind of flawed solution for these difficulties.

There has been a lot of support for Bruch's hypotheses over the last half-century. For example, those with AN often describe a critical family environment and coercively-controlling parenting (Haworth-Hoeppner, 2000) and studies have also shown that both adults (Tasca & Balfour, 2014; Zachrisson & Skarderud, 2010) and adolescents (Jewell, Blessitt, Stewart, Simic & Eilser, 2016) with AN recall insecure patterns of attachment. Those family studies which show obsessive-compulsive personality traits and eating problems to run in families (Bulik et al, 2007) also support Bruch's hypothesis as these factors likely contribute to a more hyper-vigilant, over-controlling parenting style. Indeed, case studies show mothers' own eating restraint appears to influence the way they feed their children. In two studies of five-year-old girls, mothers' weight concerns and food restraint were positively associated with the level of restriction they imposed on their daughters' eating (Birch, 2000; Francis, Hofer & Birch, 2001). Research has also suggested that, in line with Bruch's early observations, this type of maternal control of a child's eating interferes with childhood development of self-regulation and sense of efficacy (Johnson & Birch, 1994).

Mazzeo and Bulik (2009) caution against conveying the message that parenting styles *cause* EDs, however, highlighting the multi-directional impact genetics and family environment have on an individual. Indeed, a child's genes will also shape how that child will respond to a particular parenting style. For example, those with the genetic constitution for developing anorexia might be much more sensitised to physical appearance than their more genetically robust sibling. The susceptible child may solicit feedback on how they look, for example, thereby generating more comments from their parents about their appearance than their sibling receives (Mazzeo & Bulik, 2009). These environmental experiences could then facilitate the expression of their pre-existing genetic predisposition for AN symptomology.

As can be seen, the interplay of genetics and environment can be complex, coming into play the moment an individual is exposed to their environment, one aspect of which is family life. Other environmental factors implicated in AN's development include non-specific difficult life events. Studies indicate that those with EDs are somewhat more likely than controls to have been neglected and/or abused in childhood, or to have been victimised as adolescents or adults (Briere & Scott, 2007). Teasing – particularly about body weight and shape - has been shown to confer elevated risk for AN relative to healthy controls (Machado, Goncalves, Martins, Hoek & Machado, 2014) and a history of relational trauma (e.g., abuse, assault) is prevalent among both men and women with EDs (Mitchell, Mazzeo, Schlesinger, Brewerton & Smith, 2012). Linehan's (1993) construct of the 'invalidating environment' may explain the link between relational abuse/neglect/victimisation and AN. She proposes that, when a child perceives others to disregard or minimise their emotional experience, it can result in developmental difficulties recognising, tolerating and expressing emotion. This mirrors the alexithymic traits often seen in those with AN (e.g. Schmidt, Jinawy, & Treasure, 1993; Taylor, Parker, Bagby & Bourke, 1996). Thus, perhaps a history of relational harm could confer a risk for AN through the route of alexithymia and its impact on self-esteem.

2.3.4 Sociocultural Factors

Interest in the way society and culture impacts on EDs has emerged from the overlapping fields of sociocultural and feminist approaches to eating and body distress (Holmes, Drake, Odgers & Wilson, 2017). Sociocultural perspectives typically emphasise contemporary cultural pressures on women to achieve an unrealistic level of thinness, believing these pressures to underlie the development and maintenance of eating disorders (see literature review by Keel & Forney, 2013). Specifically, problems are seen to arise when these social expectations and standards become internalised, generating body dissatisfaction and dieting behaviours in females and thus elevating the risk of AN development (Thompson & Stice, 2001).

Of all the perspectives on AN and its development, it is this one that has been most absorbed into the mainstream and into the mind of the layman. Perhaps it is due to the ease with which one can observe cultural manifestations of the thin ideal, be that in magazines, on social media or in advertising, and connect it to a condition that a) primarily affects young women and b) is characterised by a drive for thinness.

As well as casual observation, empirical research also confirms that being adolescent or female increases the risk of AN. Women are significantly more likely than men to develop the disorder, and adolescence represents a period of peak risk (Stice, Marti & Rohde, 2013). Of course, these patterns may not be due to cultural factors at all – biological factors will also affect sex and adolescent development – but they do invite questions about factors that differentially impact men and women and begin in adolescence. The sociocultural perspective proposes that culturally-based gender differences in thinness-idealisation account for these patterns because this ideal becomes relevant as girls mature and experience significant changes in their body shape (Stice et al., 2013)[2]. This hypothesis is supported by the finding that, as idealisation of thinness for women increased through the 20th century, so too did the incidence of AN (Keel & Klump, 2003; Hoek & Hoeken, 2003). Further, there was a linear increase from 1935 to 1989 in American females aged 15–24 years (Lucas, Crowson, O'Fallon & Melton, 1999), the group arguably most susceptible to cultural messages about the 'ideal body'. It is important to note, however, that comparisons over time are affected by changes in how AN has been conceptualised, defined, and assessed - all which influence case detection – making it difficult to determine whether AN has actually become more common or whether diagnostic methods have just become more sensitive.

It is also clear that, despite pervasive pressures to be thin, only a very small proportion actually develop AN. This indicates that there must be additional factors at play, leading some to fall prey to AN, while others are left unscathed. Perhaps the pressures of Western culture increase the proportion of females who *diet*, but only for those susceptible in some additional way does dieting trigger the biological and psychological sequelae necessary for AN. Klump and colleagues (2009) suggest that cultural pressures for thinness may increase risk for AN in genetically susceptible individuals via gene-environment interactions and that, while cultural factors are not themselves causes, *"in the absence of a culture that emphasizes thinness […] disordered eating may be diminished"* (p.804).

Feminist academics have also advanced the notion that the cultural promotion of a slender ideal is at the root of EDs (e.g. Bordo, 1993; Orbach, 1986). However, many have also been keen not to over-emphasise *"the inscriptive power of cultural images of thinness"* (Malson, 2009,

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[2] While boys can also be susceptible to cultural body ideals, they are more likely to have to contend with ones based on notions of hyper-muscled masculinity; ideals which may protect against disorders characterised by fear of weight gain.

p.124) believing that, by characterising EDs as merely problems of 'body image', there is risk of missing the symbolic meaning of eating/body distress as it plays out within wider gendered power inequalities (Holmes, 2017).

Perhaps more than any other area of ED research, politically feminist works have prioritised qualitative investigations – often interviewing girls/women about their experiences of disordered eating (Holmes, 2016; Malson, 2009; Burns, 2004; Saukko, 2008). Their findings have emphasised that disordered eating might not necessarily be motivated by the drive for thinness or any body image distortion, but rather by "*wider experiences of 'restricted agency'*" (Holmes, 2017, p.545).

Feminist research has also noted the variety of eating disordered experience and the multiple, often contradictory, meanings individuals give to 'anorexia' and 'bulimia' (Jones & Malson, 2013). Anorexia, for example, has been analysed as a means of securing an, otherwise lacking, identity; as a way of gaining control over one's life; and as both a hyper-conformity to, and a rejection of, femininity (Malson & Burns, 2009; Eckermann, 1997; Orbach, 1986). Jones & Malson (2013, p.63) observe that "*the thin body may signify the petite fragility, self-denial and child-like status of 'traditional' femininity as well as conforming, par excellence, to the cultural prescription of thinness as a central criterion of feminine beauty".* Conversely, with the erasure of breasts, hips and menstruation, it may also signify an attempt to escape the restrictions of traditional femininity through pursuit of a 'boyish' body (Bordo, 1993), which is instead associated with success and intelligence (Riley, 2012, cited by Jones & Malson, 2013).

Critical feminist studies propose, then, that eating/body distress should be constituted within the normative discursive contexts of contemporary western culture (Jones & Malson, 2013). This proposal stands in direct opposition to the medical construction of such problems as eating 'disorders'. Indeed, some feminist scholars prefer to avoid using terms like 'anorexia nervosa' and 'eating disorder' altogether, believing them too loaded and reflective of the social dominance of the medical discourse (e.g. Lelwica, 1999; Thompson, 1994). Instead they use the term 'eating problems' to avoid the biomedical connotations associated with the term 'disorder', believing that women's reasons for starvation may be a rational response to irrational circumstances (Boughtwood, 2006).

2.4 Treatment of Anorexia Nervosa

As can be seen, the reasons for the emergence and maintenance of 'anorexia nervosa' are far from clear, but it seems they are mediated by various factors across domains of biology, psychology and the wider environment. Treatment ideally needs to take account of all of these factors while also being flexible enough to tailor itself to the individual, addressing only those that are relevant to the ongoing maintenance of their specific disorder.

Like its conceptualisation, the treatment of anorexia nervosa has evolved in line with cultural change and scientific advancement. Until the 1970s, treatments were entirely medically based but growing awareness of AN as a psychological disorder saw treatment settings move from medical units to psychiatric hospitals, with a regime of behaviour modification, bed rest and high calorie supplements prescribed (Sesan, 1994). Bruch's seminal book on eating disorders (Bruch, 1978) then heralded a shift towards psychotherapeutic intervention. Within the book, based on her observation and treatment of eating disorders over several decades, she proposed that the therapeutic focus should be on exploring the meaning that food holds for the patient, and then helping them find alternative, healthier means of self-identification, expression and control.

The psychotherapeutic approaches that developed in the latter half of the 20th century orientated around a psychodynamic aetiological model like Bruch's, or else a family systems' or cognitive-behavioural approach (see O'shea, 2017; Zeeck, Zipfel & Friederich, 2015). In the 21st century, treatment approaches have continued to evolve, becoming more integrative and with increasing focus on empirical findings, such as the role of cognitive inflexibility in AN (Schmidt et al, 2015), rather than aetiological theory. The standard model of long-term psychiatric inpatient treatment has also been replaced by a model of community care (NICE 2004, 2017).

2.4.1 Evidence-Based Treatment

Within the UK, evidence-based eating disorder treatment guidelines are disseminated through The National Institute of Clinical Excellence. They updated their guidelines two years ago, for the first time in thirteen years, in an effort to bring it into line with current research. Their guidelines (NICE, 2017) state that the principal aims of treatment for anorexia nervosa are restoration of a healthy weight; the amelioration of extreme body weight and shape concerns; cessation of unhealthy eating behaviours; improvement in depression and other comorbidities; improvement in quality of life; and the identification, and ideally resolution, of contributing family and personal problems. To achieve these goals, they recommend a multi-disciplinary treatment be coordinated between services, including psychiatry, psychology, dietetics, social work, occupational therapy, and primary care. Medical care should be typically provided by general practitioners in primary care, and nutritional counselling by dieticians. Meanwhile, psychological therapy should be provided by psychologists and psychotherapists specialising in eating disorders. The guidelines emphasise that *"all professionals who assess and treat people with* *an eating disorder should be competent to do this for the age groups they care for"* (NICE, 2017, p.7).

Individualised outpatient therapy is considered the standard approach for anorexia treatment, with NICE (2017) recommending that admission to a medical inpatient service be reserved only for those whose physical health is severely compromised, and only when their medical stabilisation cannot be achieved within an outpatient setting. They stress that, in such instances, the decision should not be based on an absolute BMI or weight threshold; rather, rate of deterioration, and the extent of family support should also be taken into account.

A number of psychological therapies are recommended in the guidelines for older adolescents and adults with anorexia nervosa. These first line treatments consist of individual eating-disorder-focused Cognitive Behavioural Therapy (CBT-ED), Maudsley Anorexia Treatment for Adults (MANTRA) and specialist supportive clinical management (SSCM). If these prove unacceptable or contraindicated, then Focal Psychodynamic Therapy (FPT; Dare et al, 1995) is recommended as an alternative. For details of these treatments, please see Appendix 2.

Despite the clear treatment guidelines set out by NICE (2017), systematic evidence reviews of treatment have been none too encouraging: *"evidence…is weak"* (Bulik et al, 2007, p.10), *"we can draw no specific conclusions"* (Hay, Claudino, Touyz, & Abd-Elbaky 2015, p.3) and *"uniformly discouraging"* (Attia & Schroeder, 2005, p.62) typify their conclusions (Watson & Bulik, 2013). This has led one practitioner-researcher to enquire *"Is evidence-based treatment of anorexia nervosa possible?"* and to later retort, *"Barely"* (Fairburn, 2005). Indeed, the majority of NICE's treatment recommendations rely, not on evidence, but on the opinions and clinical experience of respected authorities in the field (Zipfel et al., 2014).

Over the last thirty years, there have been scores of randomised controlled trials (RCTs) conducted, each comparing different psychological treatments for adults with AN, but most have suffered from small sample sizes and poor methodological quality (Zeeck et al., 2018). This has made it impossible to draw firm conclusions about treatment effects. This last decade has brought a little more encouragement, with some well-designed and sufficiently powered treatment studies for adults with AN being published, many which report improvements in weight and other markers of health at the end of treatment and at follow-up (Touyz et al., 2013; Schmidt et al., 2015; Schmidt et al., 2012; Zipfel et al., 2014; Touyz & Hay, 2015; Bryne et al., 2017). Still, treatment response remains modest, especially once one takes into account the persistently high dropout rates; and there remains no clear evidence that any one psychological treatment is superior over another (Zeeck et al, 2018; Bulik, 2014).

Take, for example, a recent Cochrane meta-review (Hay et al., 2015a) which was unable to draw clear conclusions about the effects of particular psychological therapies for adults with AN. The authors included 10 RCTs of individual psychological therapy delivered in outpatient settings to adults and older adolescents with AN. They found *"a limited amount"* of *"very low-quality"* (p.2) evidence to suggest that individuals may do better when they receive Focal Psychodynamic Therapy than when they receive no treatment at all or else 'treatment as usual' (TAU)[3]. With regards to other specialised therapies, no significant differences between them were found, and all but one had equal acceptability (as reflected in non-completion rates) to TAU, the control group. Dietary advice was the one exception, which had a 100% non-completion rate in one trial (n=36).

It is also worth considering the largest RCT to date (n=242; Zipfel et al., 2014) – which compared FPT, CBT-ED and an optimised TAU - as it offers a good example of the mixed findings so often found within AN treatment research. Its weight outcomes appear promising across all three treatments (BMI increased by about 0·70 kg/m² in all three study groups after 10 months of treatment, and an additional 0·40 kg/m² by 12 months of follow-up). However, at the end of treatment and at 12-month follow-up, mean BMI across the three treatment groups remained in the underweight range. And, in terms of absolute outcomes, after 10 months of treatment, over a quarter of patients still had full-syndrome AN[4] (29% receiving FPT, 26% assigned CBT-E, and 27% optimised TAU) and, at 12-month follow-up, about a fifth had full-syndrome AN (21%, 22%, and 28%, respectively). It is encouraging that average BMI did not drop during the follow-up period (i.e. after treatment had finished) but the fact remains, a year on from treatment, average BMI across all groups remained clinically underweight and 31-41% of participants that completed treatment still had a BMI < 17.5.

The picture looks more sobering still when one accounts for the 30% of participants that were lost to follow-up, a year on. Bulik (2014) notes that the dropout rate was better than many AN treatment trials, but if one were to assume that those who dropped out and were not followed-up on also had BMIs <17.5, then the 31-41% suddenly jumps much higher, to over 50%. That is, more than half of those who started a 10-month, specialised first-line treatment still met the criteria for full-syndrome AN a year later. Admittedly, this is not an entirely fair assumption, partly because a minority of participants started treatment with a BMI of 17.5-18.5 (mean

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[3] TAU referred to a specific treatment where *"participants were actively treated for anorexia nervosa at a specialist psychiatric treatment centre where specific psychotherapies were not employed and therapy was not provided by a health professional experienced in treating eating disorders"* (Hay et al, 2015a, p10)

[4] As defined by the DSM-IV (1994)

baseline BMI was 16.7, SD 1.0), but it underscores the questionable benefits of even those treatments considered ‘evidence-based’ when it comes to treating adult anorexia.

2.4.2 Current Treatment Provision within the UK

NICE’s recommendations, evidence-based or otherwise, provide an expectation for best care of anorexia patients. The reality, however, is that treatment provision can vary greatly across the UK (Royal College of Psychiatrists, 2007) and the treatments recommended within the guidelines are frequently unavailable (NHS Wales, 2012). A large 2010 survey (Escobar-Koch et al, 2010) saw service users list their concerns about ED treatment within the UK. They highlighted a lack of availability and inequity in service provision and identified several barriers to accessing care. These included GPs acting as gate-keepers and long waiting lists for specialist services. Participants also expressed concern about GPs’ poor knowledge of EDs and failure to perform timely diagnoses, resulting in marked delays referring them to specialist services.

While the survey is now almost a decade out of date, the situation does not appear to have become any easier for sufferers seeking access to ED services within the NHS. Another survey of 14,878 people referred for ED treatment in the ten years to 2017 found that, on average, sufferers had to visit their GP three times over eleven weeks to secure a referral for a specialist assessment (Beat, 2017). Then, once the referral was made, they had to wait an average of eight weeks more for an assessment, and another eight weeks for the treatment to begin. This brings the average total waiting time to half a year. The researchers also discovered that it takes sufferers about two and a half years to first seek help. Bearing in mind that EDs becomes much more intractable after three years (Treasure & Russell, 2011), many are therefore reaching out for support at a time when they can still be helped, but fail to get any until later, when their chances of recovery are substantially reduced.

Of note, there has also been an upward trend in the number of people being diagnosed with AN and then immediately entering inpatient treatment in the UK. Research by Price Waterhouse Cooper (PWC, 2015) showed a 7% average rate of increase year on year between 2009 and 2015, and the latest data shows hospital admissions to have more than doubled over the past eight years - from 7,260 in 2010-11 to 16,023 in the year to April 2018 (The Guardian, 15 Feb, 2019). The rise has been attributed to waiting times for community-based services increasing, meaning more intensive treatments become needed, and also to inadequate outpatient treatments. These themselves are said to be the result of many years of government underfunding, resulting in lost services and staff, limited training, and NHS budgets and structural arrangements that deter the introduction of innovative services that could improve outcomes and treat people more efficiently (PWC, 2015).

Indeed, the situation is dismal enough to sell national newspapers. Some of the more sensational recent headlines have included:

Eating disorders: people 'wait up to 182 days for treatment' in England **The Guardian, 7 April 2016**
GPs are telling young girls with anorexia to come back when they are thinner, report warns **The Telegraph, 27 February 2017**
Long NHS delays can be 'devastating' for patients with eating disorders **The Guardian, 15 November 2017**
Patients with eating disorders told they are not 'thin enough' for treatment **The Independent, 17 October 2018**
I was anorexic and suicidal, but the NHS said I needed to be skinnier to get help **The Express, 20 January 2019**
Yorkshire eating disorder patient 'had to beg to be hospitalised' due to lack of NHS help **ITV News, 22 January 2019**

Table 1: National newspaper headlines about the state of ED treatment in the UK

One casualty of the treatment climate was nineteen-year-old, Averil Hart. She developed anorexia after her A-Levels and was admitted to hospital where she received specialist treatment for 10 months. She was then discharged from inpatient treatment in order that she could take up a place at university, with the expectation that the hospital trust would coordinate her continued outpatient care. Ten weeks into her first term, she was found collapsed in her flat. She was admitted to a general hospital but was not visited by a specialist for three days, during which time her condition deteriorated to the point of being fatal.

Last year, following a five-year-battle, her parents finally got the confirmation they sought, that *"avoidable"* failings in NHS care allowed their daughter to starve to death. This was the conclusion drawn by The Parliamentary and Health Service Ombudsman in their review, entitled 'Ignoring the alarms: How NHS eating disorder services are failing patients' (2017). Specifically, they determined her death would have been avoided *"if the NHS had cared for her* *appropriately"*, noting that several organisations missed opportunities to prevent the deterioration which led to her final admission to the hospital where she died. The review went on to warn the failures were *"not unique"*, rather they were *"symptomatic of wider health service failings in the treatment of people with eating disorders"* which demand *"urgent national attention"*.

Not surprisingly then, ED patients have been found to report low levels of satisfaction with treatment services (Rosenvinge & Klusmeier, 2000). These findings highlight the value of interviewing sufferers about their treatment experiences in an effort to better understand the problems they encounter and which of these may contribute to the, often poor, treatment outcomes.

2.4.3 Qualitative Investigations into Treatment Experiences

In recent years, there have been a number of studies exploring AN sufferers' experiences of treatment. These have been primarily focused on the treatment experiences of women and adolescent girls who have been admitted to inpatient ED wards (Eli, 2014). Some studies have explored particular elements of inpatient treatment, such as mealtimes (Long, Wallis, Leung & Meyer, 2012), while others have focused on the overall experience (e.g. Colton & Pistrang, 2004; Offord, Turner & Cooper, 2006; De la Rie, Noordenbos, Donker & van Furth, 2006; Smith et al., 2014; Tierney, 2008). This latter group have highlighted a number of common themes (Reid, Burr, Williams & Hammersley, 2008).

Firstly, supportive relationships are shown to be of central importance (Cockell, Zaitsoff & Geller, 2004; Bell, 2003; Pettersen & Rosenvinge, 2002). In particular, patients who were able to discuss their personal issues and feelings within a treatment relationship found it provided them with an alternative means of coping, thereby lessening their need for the eating disorder (Cockell et al., 2004). Empathy, trustworthiness, consistency, availability and a willingness to listen are all characteristics that, when displayed by staff, can facilitate this type of supportive relationship (Colton & Pistrang, 2004; Tierney, 2008; De la Rie et al., 2006). However, troublingly, treatment providers were often perceived by patients to be insensitive and ignorant about AN, and to convey a lack of belief in recovery (Colton & Pistrang, 2004; Offord et al, 2006; Fox & Diab, 2015).

Secondly, many studies have also shown that sufferers prefer interventions that address psychological issues over more medicalised treatments which address eating behaviour and weight (Bell, 2003; Smith et al., 2014; Westwood & Kendal, 2012). Westwood and Kendal (2012), for example, found a strong preference for treatment *"which considers their* *psychological and social needs, rather than a sole focus upon physical concerns"* (p.502). Meanwhile, Federici and Kaplan (2008, cited in Smith et al., 2014) found that patients who relapsed after an episode of treatment perceived there to have been few opportunities for them to learn psychological coping skills during their inpatient experience. This resulted in a perceived difficulty managing emotional distress after discharge, negatively impacting their eating disorder.

Thirdly, sufferers cite experiences outside of treatment as being major factors in their recovery (Bell, 2003; Cockell et al., 2004). Maine (1995) interviewed 25 former patients and found that half believed it was the empathic, validating relationships they had with extended family and friends that most helped them recover. Their assessment of the value of treatment varied, but many were unequivocal in their belief that they would have recovered without treatment.

Fourthly, given that many sufferers consider a perceived need for control to contribute to their ED (e.g. Malson, 1998), it follows that they would value being able to co-direct their treatment. Without any type of collaboration, treatment diminishes perceived control and so risks exacerbating the disorder (Bell, 2003; Eivors, Button, Warner & Turner, 2003).

Finally, an attitude of ambivalence has been shown to frustrate sufferers' experience of treatment, with them undecided on whether their ED is an 'enemy' or a 'friend' (Colton & Pistrang, 2004) and on whether it represents a problem requiring treatment (Malson, Finn, Treasure, Clarke & Anderson, 2004). This ambivalence extends to their relationships with others in treatment too (Tierney, 2008; Offord et al., 2006; Colton & Pistrang, 2004). For example, one investigation into adolescent experiences of hospital treatment identified that, while participants spoke of peer support and community on the ward, they also described a competitive element to their engagement, resulting in increased guilt and distress (Coltron & Pistrang, 2004). Further, while participants felt the treatment regime to have been helpful, they also experienced it as 'punishing' (Colton & Pistrang, 2004). Similarly, while Smith et al.'s (2014) adult participants said inpatient treatment felt 'safe', being free from the stressors of the outside world, they also voiced concern that the hospital environment constituted an abnormal space and did not adequately prepare them for recovery.

Only a handful of qualitative studies have extended their lens beyond inpatient treatment (Button & Warren, 2001; Eivors et al, 2003; Tierney, 2008; Reid et al., 2008; Rance, Moller & Clarke, 2015; Oyer, O'Halloran & Christoe-Frazier, 2015) but these suggest similar themes dominate accounts of outpatient treatment too. Button and Warren's (2001) study, which explored treatment as part of a larger investigation into the experience of living with AN, highlighted the importance sufferers placed on individual psychotherapy and the quality of relationship with their therapist. Tierney (2008) carried out semi-structured interviews with 10 adolescents who had experienced both inpatient and outpatient treatments for anorexia. Her participants emphasised a need for sensitivity and specialist knowledge from professionals and felt there to be too much focus on physical rather than psychological progress in both inpatient and outpatient treatment (Tierney, 2008).

2.5 Dropout

Dropout is another area of treatment still largely unexplored. This is a notable absence given that, while dropout is a common problem in the treatment of psychiatric disorders, generally falling within the range of 35–55% (Bados, Balaguer, & Saldana, 2007), it can be as high as 73% when treating AN (Fassino et al. 2009). Additionally, judging by the data we do have, rates seem to have increased in recent years. Campbell (2009) studied rates of dropout from psychological therapy for AN between 1991 and 2007 and observed that percentage rates of dropout more than doubled during this period (from 18% in 1991 to 38% in 2007). He also noted *"the majority of these data come from research trials in which great efforts are taken to retain patients. Data from standard clinical practice may paint an even more pessimistic picture"* (p.239-240). Given the impact of austerity measures on services, and the finding that long waiting times are associated with higher rates of subsequent dropout (Carter et al., 2012), it is unlikely the trend has reversed in intervening years.

This is concerning because it suggests treatment failure, or else unacceptability of treatment. And, at best, this equates to wasted time, resources and opportunity; at worst, wasted life. One study suggests that those who dropout of treatment are less likely to recover independently (Pike, 1998), while another suggests they are more likely to have a poor long-term outcome (Beumont, Russell & Touyz, 1993), at least in terms of BMI one year on (Dejong et al., 2011). Dropout can also undermine efforts to identify the best treatments through research trials as it results in biases of sampling, thereby impacting the validity, reliability and generalisability of findings (Mahon, 2000).

2.5.1 Defining Dropout

The literature has not ignored the issue of dropout entirely – many AN treatment trials record rates of dropout, after all – but, to date, not much of substance has been found to explain why it happens, what can be done about it or the impact it has on long-term AN prognosis. A major obstacle has been the inconsistent way in which the concept of dropout has been defined and documented (Wallier et al., 2009). On the occasions where it *has* been explicitly defined and documented, what it actually constitutes has varied substantially across studies, making it difficult to draw meaningful conclusions.

One important consideration when defining dropout is who initiates it and why (Dejong et al., 2011). In some studies, only patient-initiated treatment withdrawal is classified as dropout (e.g. Surgenor, Maguire & Beumont, 2004; Kahn & Pike, 2001) whereas, in others, any premature withdrawal from treatment is classified as such (e.g. Zeeck, Hartmann, Buchholz & Herzog, 2005; Sly, 2009). Dejong and colleagues (2011) think it prudent to distinguish between many types of withdrawal. They observe that a treatment team might, on occasion, withdraw a patient from a particular treatment, having decided that an alternative might be better suited. This type of team-initiated 'dropout' does not necessarily suggest treatment failure, or unacceptability of treatment; it might simply reflect a clinician's flexibility in tailoring treatment to the dynamic needs of their patient. Likewise, an early withdrawal from treatment for logistical reasons, such as going off to university, seems distinct from other kinds of early withdrawal. So too does an early withdrawal that is motivated by an unexpectedly speedy progress in recovery. With this in mind, Dejong et al (2011) have proposed making standard the distinction between patient-initiated, clinic-initiated, logistical, and progress withdrawal.

Another concern is the wide discrepancy in 'qualifying' criteria for dropout. Some researchers have used session counts, others duration of time in contact with the clinic, still others a simple categorisation of individuals into those who remain until treatment has been ended by mutual consent and those who do not. Some researchers fail to specify what criteria are being used at all (Mahon, 2000).

Another point of contention is the term 'dropout' itself. Mahon (2000) points out that it has traditionally conjured up an image of someone who is *"impulsive, unmotivated, not psychologically minded, socially isolated, hostile, defensive, and paranoid (Lorr et al., 1958; DuBrin and Zastowny, 1988)"* (p.204). Indeed, even when most neutrally defined, dropout means *"to abandon an attempt, activity, or chosen path"* (Merriam-webster.com, 2018). Other common definitions are *"to withdraw from established society, especially because of disillusion with conventional values"* and *"to give up in the face of defeat or when lacking hope"* (Vocabulary.com, 2018). Some researchers have suggested that such negative connotations imply patients are to blame for 'failing' at treatment, culminating in an over-emphasis in the literature on patient characteristics as predictors of dropout and a reluctance to consider a broader range of possible contributing factors (Dejong et al, 2011). There has even been suggestion we abandon the term 'dropout' altogether in the context of clinical work. Vandereycken & Devidt (2010), for example, proposed that we instead use the phrase ‘premature termination of treatment’ when the patient makes the decision unilaterally, and ‘premature discharge’ if the clinician or staff make the decision.

2.5.1.1 Dropout as ‘Resistance’ to Change

The AN research literature often frames dropout as analogous with ‘resistance’ to change (e.g Fassino & Abbate-Daga, 2013; Fassino et al., 2009). This assumption seems to be due to the notion that AN is ego-syntonic; that is, sufferers value its symptoms and believe it to be useful (Schmidt & Treasure, 2006). A number of qualitative studies support this view, suggesting anorexics believe AN helps them, variously, overcome a sense of ineffectiveness, feel safe, special and confident, communicate distress when feeling rejected or abandoned, and suppress negative emotions (Branch & Eurman, 1980; Serpell, Treasure & Teasdale, 1999; Nordbø, Espeset, Gulliksen, Skårderud & Holte 2006, 2008; Williams & Reid, 2009). Anorexia memoirs provide further support, often reading more like hubristic poems than accounts of suffering. Indeed, an article in The New Yorker criticises one *“patron saint”* of the genre for her *“laughably elliptical passages that read like demented ads for diamonds or bottled water: ‘I will be thin and pure like a glass cup. Empty. Pure as light. Music.’”* (The New Yorker, 11 December, 2013). Marya Hornbacher employed similarly bewitching language in her Pulitzer prize-nominated memoir, ‘Wasted’ (1998): *“We turn skeletons into goddesses and look to them as if they might teach us how not to need”* (p.28), she writes. And then, later: *“Maybe I would almost die, and balance just there, at the edge of the cliff, wavering while they gasped and clutched one another's arms, and win acclaim for my death-defying stunts”* (p.81).

The subjective, positive function AN holds for an individual provides an explanation for the ambivalence they so often have about recovery (Vitousek et al., 1998) and, in turn, the high rates of treatment avoidance (Nordbo et al, 2012) and dropout (Mahon, 2000), as well as relapse (Fichter, Quadflieg & Hedlund, 2006) and poor treatment outcome (Fairburn, 2005).

Given these associations, it is often assumed that dropout predicts future decline and must therefore be prevented wherever possible (Masson, Perlman, Ross & Gates, 2007). Indeed, some studies suggest that those who dropout are more likely to remain ill (Pike, 1998; Beumont, Russell & Touyz, 1993) and one review noted the consistently *‘‘unfavorable role that rejection or premature termination of treatment played for the long-term course of eating disorders”* (Steinhausen, 2009, in Dejong et al., 2011, p.643). However, is this always the case?

The reality is, we know very little about the long-term outcome of AN patients who dropout. Due to their lost contact, these individuals tend to be absent at follow-up and, often, outcome studies only report the data of those who finished treatment (Bjork et al., 2009). Reviewing the literature, it seems only two studies (Di Pietro, Valoroso, Fichele, Bruno & Sorge 2002; Björk, Björck, Clinton, Sohlberg, & Norring, 2009) have specifically addressed the subject of outcome among ED patients who dropped out.

Interestingly, when Di Pietro and colleagues (2002) analysed what happened to ED subjects who had dropped out of outpatient treatment 2-5 years earlier, they were surprised to discover that 71% had ‘improved’ (in terms of BMI, vomiting, amenorrhea) and that no deaths were recorded. Further, contrasting with the view that dropout necessarily reflects resistance to change, the researchers found an important motive for termination was what patients perceived to be their partial recovery.

Meanwhile, Björk and colleagues’ study (2009) found that their participants who had dropped out showed significant improvements at 3-year follow-up and were, in fact, clinically similar to those who had completed treatment. Specifically, 47% of those who dropped out and 52% of those who completed no longer met the criteria for any ED diagnosis as measured by DSM-IV criteria; and a further 20% of the former and 15% of the latter, while now diagnosable with EDNOS[5], showed improvements in terms of no presence of compensatory behaviour, amenorrhoea or BMI<18. Similarities at follow up also extended beyond diagnostic features to more general ED and psychiatric symptoms, self-image, occupational and marital status.

It is worth pointing out though that most of those who dropped out had received considerable treatment too before leaving (5.3 months on average) and they seemed to derive a benefit from it (i.e. significant positive changes from baseline). This suggests that, as with Di Pietro et al’s (2002) participants, dropout might have reflected a personal decision to terminate treatment after attaining personally meaningful improvement. In any case, the findings of both studies show that, contrary to popular opinion, dropout is not always indicative of treatment failure, and neither does it necessarily reflect a patient’s resistance to change.

2.5.2 Predictors of Dropout

It is likely that dropout is linked to several factors, including those of the patient, those of the treatment environment, and those of the interaction between the two (Vandereycken and Devidt,

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[5] Eating Disorder Not Otherwise Specified (EDNOS) was an eating disorder listed in earlier editions of the DSM (1987; 1994), referring to an eating disorder that does not meet the criteria for AN or BN. Those diagnosed with EDNOS usually displayed sub-threshold symptoms of AN or BN, mixed features of both disorders, or atypical eating behaviours that were not characterised by either the other established disorders (Fairburn & Bohn, 2005)

2010; Nordbo et al., 2012). The majority of existing research has focused only on the former, however. Vandereycken and Devidt (2010) suggest why this might be:

“Since dropout is commonly considered a sign of non-compliance, resistance or treatment failure, no wonder most studies have focused on individual patient characteristics associated with a greater likelihood of premature termination of treatment” (p.141).

I will now discuss the various patient factors that have dominated the literature on dropout, before moving on to consider the lesser studied contributing potential of the treatment environment and therapeutic relationship.

2.5.2.1 Patient Factors

Huas et al (2011) conducted a study between 1998 and 2004 and found the following to be predictive of dropout among anorexic inpatients: having one or more child; low desired BMI; low minimum BMI reached; high levels of paranoid-ideation; impulsive behaviours and lower levels of education. Other characteristics that have been highlighted include longer duration of illness (Vandereycken & Pierloot, 1983), more intense maturity fears (Woodside, Carter & Blackmore, 2004), a stronger drive for thinness (Fassino, Abbate-Daga, Piero, Leombruni & Rovera, 2003) and the binge/purge subtype of AN (Kahn & Pike, 2001; Woodside, Carter, & Blackmore, 2004). In other studies, borderline personality (Waller, 1997), impulsivity and anger problems (Fassino et al., 2003), depression, hopelessness and external locus of control (Steel et al, 2000) have all been related to dropout. Other researchers found that those who dropped out were more likely to have greater difficulty trusting and relating to others (Blouin et al., 1995). Meanwhile, Björck, Björk, Clinton, Sohlberg and Norring (2008) found that, contrary to their predictions, patients who dropped out had *less* negative self-image and *fewer* psychological problems at intake compared to those who completed treatment. This led them to conclude that dropout is *“not necessarily as pathological as often assumed*” (p.102). This obviously goes against the grain but, as Björck et al. (2008) point out, there have also been other studies that have suggested that dropout may be unrelated, or even inversely related, to symptom severity (e.g. Kahn & Pike, 2001; Palmer, 2000), social functioning (e.g. Mitchell et al., 2002) and factors associated with poor prognosis (e.g. Di Pietro et al., 2002). There has also been research suggesting there might actually be little difference between dropouts and completers in terms of personality characteristics, at least when defining dropouts as only those patients who themselves decided to withdraw from treatment (e.g. Masson et al., 2007).

As can be seen, predictive characteristics have been variable, and most findings have not been replicated. Fassino et al (2009) conducted a review of all the ED literature regarding predictors of treatment dropout. The only consistent predictors found were the diagnosis of the AN binge-purging subtype, the psychological traits of high maturity fear and impulsivity, and the two personality dimensions of low self-directedness and low cooperativeness. A further finding was that most of the quantitative studies were lacking in validity and reliability, having been plagued with methodological flaws and limited sample sizes. Often no distinction was made between treatment settings (inpatient, daypatient or outpatient) or type of dropout (administrative or patient initiated). Also, much of the research had been conducted using samples that failed to distinguish between anorexic and bulimic participants, even though treatment of the two disorders usually have key distinctions, such as the need for weight restoration and increased caloric intake versus the need to regulate chaotic eating patterns and cut out purging (Blechert, Ansorge, Beckmann, & Tuschen-Caffier, 2011).

Mahon (2000) has also observed that the patient characteristics included in studies tend to be based on information gathered at assessment for generic research or clinical purposes, and then examined a-theoretically. This means they may have little to do with patients' decision to remain in or leave treatment. Comparing dropouts and completers on an entire suite of assessment data often leads to a large number of comparisons on a small number of subjects; and, by chance, these studies are likely to find a few variables that differentiate dropouts from completers.

One patient factor that has been more specifically targeted in research is that of motivation to change. This is due to the perception that AN is ego-syntonic, as discussed, and the assumption that a resultant low motivation to 'recover' contributes to poor therapeutic engagement, including dropout. A number of studies have indicated that lower motivation for recovery predicts dropout from ED treatment (e.g. Vall & Wade, 2015; Sly et al., 2014) and various motivation models have subsequently been applied to treatment interventions in an effort to improve engagement. These include the transtheoretical model of readiness to change (Prochaska & Diclemente, 1982), motivational interviewing (Vitousek, Watson & Wilson, 1998) and the readiness and motivation interview (Geller, 2002), with each encouraging the patient to take an active role in therapy and promoting the idea that they have the power to change.

2.5.2.2 Treatment and Treatment-Patient Factors

There are only a few studies that have focused on how treatment factors, or the interaction between treatment and patient factors, might affect patients' dropout from services (Clinton, 1996; Morlino et al., 2007). Indeed, a review of the literature failed to find any that focused exclusively on this relationship. Such oversight seems counterintuitive given that clinicians are considerably more able to make adaptations to treatment factors and patient-therapist interactions than they are patient factors.

Clinton's (1996) study is one of few exceptions. He explored patient-therapist interactions and found dropout to be linked to a discrepancy between the therapists' and patients' expectations of what therapy would involve. This discrepancy likely resulted in conflicts around goal-setting and impacted overall satisfaction with treatment. Björk et al. (2009) found support for this in their study exploring outcome in ED patients following dropout. They found that patients who dropped out of treatment reported greater dissatisfaction with the suitability of the treatment offered them, and also with their therapists' ability to acknowledge and understand their point of view.

Morlino et al. (2007) also found a connection between treatment dropout and the patient-therapist system. They conducted a study exploring the extent to which a number of variables could predict dropout. These included age, sex, marriage status, education, employment status, comorbidity, disease duration, number of symptoms, diagnosis, global judgement of seriousness expressed by the therapist in the Clinical Global Impressions Scale (CGI)[6], 'perfectionism' subscale of EDI-II and Patient Perceived Weight (PPW)[7]. They found that none of the individual variables predicted dropout. However, they also developed a generalised linear model and found that CGI and PPW *collectively* predicted 65% of the dropout rate. Specifically, the probability of dropping out decreased from 53% to 28% when therapists considered their patients seriously sick and patient's PPW was altered, and it increased from 53% to 76% when the therapists considered their patients' condition as mild or marginal and patient's PPW was unaltered. These unexpected results forced the authors to consider the role patient-therapist interaction played in dropout and led to them suggesting that, when a patient perceives their weight inaccurately, the therapist considers it an index of disease severity and, out of concern for their condition, unconsciously makes greater effort to engage the patient.

Related to these findings, many studies have indicated, more generally, that therapeutic alliance is an important factor in ED treatment outcome. For example, Sly and colleagues (2013) found

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[6] The CGI is an oft used outcome measure of global functioning, consisting of a set of ratings made by a clinician in order to assess the overall severity of an individual's symptoms as well as changes in their functioning over time (Guy, 1976)

[7] This was defined by asking the patient how he/she considered himself/herself ("fat", "thin", or "normal" weight) and by comparing the answers with the body mass index (BMI). If the patient's perception was true, they considered the PPW "not altered", otherwise it was "altered".

that patients who reported a stronger alliance with their key-nurse at the start of treatment were more likely to remain in treatment to the end of the agreed program.

Treatment outcome studies have also shown patients prefer certain types of treatment and are less likely to dropout of some than they are others. In their systematic review, DeJong et al. (2011) draw attention to a pattern of highest dropout rates occurring in education-only interventions (e.g. nutritional advice), with intermediate rates in individual psychotherapy and the lowest rates in family therapy trials.

Of note, a few studies have shown that both clients and therapists rate collaborative treatment approaches more likely than directive treatment approaches to retain patients in treatment and encourage their adherence to the treatment plan (Geller, Brown, Zaitsoff, Goodrich & Hastings, 2003; Vandereycken & Vansteenkiste, 2009). This may provide an explanation for why educational-only interventions appear less popular than psychotherapy-based ones, the former being more directive than most psychotherapies.

When considering the rates of dropout between active psychotherapies, however, distinctions are less clear-cut. A large, recently-conducted, comparative psychotherapy trial reported a 22% dropout rate overall but with the highest rates being in their optimised treatment as usual arm (TAU, 35%) and the lowest in the enhanced cognitive behaviour therapy (CBT-E, 10%) arm (Zipfel et al., 2014). However, other recent studies have failed to find any significant differences in dropout rates between active psychotherapies (e.g., Schmidt et al., 2012).

2.5.3 Qualitative Investigations into Dropout Experiences

Many researchers have highlighted the importance of drawing on patient feedback to inform service development (Buston, 2002; Street & Svanberg, 2003), with some specifically calling for a patient-led, qualitative examination of dropout to help provide a comprehensive view of the issues surrounding it (Eivors et al., 2003; Mahon, 2000; Zeeck et al., 2005; Vandereycken & Vansteenkiste, 2009). However, to date, only two such studies (Eivors et al., 2003; Vandereckyen & Devidt, 2010) have been conducted.

Eivors et al. (2003) explored eight women's experiences of dropout from anorexia treatment through semi-structured interviews and written accounts. They analysed the data using a social constructionist revision of grounded theory (Charmaz, 2008). The women's main concerns centred on the lack of negotiation they experienced and treatment's excessive focus on eating and weight-related symptoms. They felt they were faced with a situation which recreated a condition of lost control, similar to that which inspired their AN in the first place. Therefore, for these women, dropout offered *“the opportunity to regain control and re-establish their position that their eating behaviour is functional”* (p.99).

It is worth noting that, while Eivors et al. (2003) set out to identify core issues surrounding dropout, because they spent a great deal of time eliciting the meaning and history of participants’ illness in their interviews, their focus on factors directly related to dropout was somewhat superficial and may have prohibited their ability to identify issues beyond the one of control.

Meanwhile, Vandereckyen and Devidt (2010) constructed a study that explored inpatients’ and staff’s perceptions of dropout from an ED inpatient facility. Each participant was given a self-reporting questionnaire. It consisted of 12 suggestions for dropout with a 4-point Likert scale and, following each suggestion, there was space to write a personal comment. If their reasons for ending treatment were not found among the 12 listed, participants could describe them at the end of the questionnaire. Both patients and staff reported the following as key contributing factors for dropout: treatment being too difficult, not enough freedom, and lack of trust. Patients tended to be more satisfied with their progress in treatment than staff, and thereby often did not anticipate further benefit in continuing. This highlights a situation where dropout *“can be a positive decision and not just a flight”* (Vandereycken & Devidt, 2010), at least from the perspective of sufferers’ own treatment expectations and goals. Of course, this perspective may be over-optimistic, and a treatment team may well be sceptical, but the issue now becomes one about differences in the interpretation and evaluation of treatment goals (Noordenbos & Seubring, 2006; De la Rie, Noordenbos, Donker & van Furth, 2008) rather than one about dropout signalling treatment failure or resistance.

Indeed, it seems that dropout can mean many things, dependent on context. It can *reflect* treatment failure, with patients withdrawing from a treatment they find unacceptable, and also *contribute* to treatment failure, potentially denying the patient ongoing support and undermining research that might otherwise be able to improve the quality of treatments available. Equally, there are instances where it appears to neither reflect nor contribute to treatment failure, representing instead a new stage in an idiosyncratic recovery process.

2.6 Summary of Debates and Implications for the Current Study

Happily, the self-starvers of today are no longer revered as saints, nor burnt at the stake. The theological explanations they inspired in the middle ages have today been replaced by earthbound explanations, incorporating knowledge from genetics, neurology, psychology, psychiatry, feminism and sociology. Yet, despite the now vast canon of literature dedicated to anorexia nervosa, treatment still often seems to fail and, certainly, rates of dropout continue to be unacceptably high.

The issue of dropout from eating disorder treatment has gained increasing attention over the last few decades, yet research has been almost exclusively focused on measuring rates of dropout and trying to identify patient characteristics that predict its occurrence. The findings have been underwhelming. Methodological inconsistencies have resulted in wildly varied reports of dropout and, to date, few significant clinical predictors have been found (Jordan et al., 2014).

Since it is commonly considered a sign of pathological 'non-compliance' or 'resistance', it follows that researchers have chosen to focus on identifying predictive individual characteristics (e.g., Björck et al., 2008). This, however, has meant that only limited questions are being asked, ones which fail to consider the wider context of the treatment system itself or the perspectives of those who have themselves dropped out. More recently, there have been calls to consider the role specific treatment variables play in treatment outcome, such as the quality of the therapeutic relationship and patient treatment preference (Jordan et al., 2014; Nordbo et al., 2012), heralding a subtle shift in focus whereby, rather than viewing sufferers as solely responsible for any apparent treatment failure, the treatment environment is now also considered.

There have also been calls for a patient-led, qualitative exploration of the reasons behind dropout, in order that it might provide a more comprehensive view of the issues involved (Eivors et al., 2003; Mahon, 2000; Zeeck et al., 2005; Vandereycken & Vansteenkiste, 2009). To date, however, only two such studies (Eivors et al., 2003; Vandereycken & Devidt, 2010) have been conducted. Both have made a valuable contribution to our understanding of the treatment experience, highlighting issues around control battles and treatment goals that differ between patients and health professionals, but they both have their limitations. Eivors and colleagues' study only identified one core theme common to all their participants' treatment experiences, appearing to have focused rather heavily on the meaning and history of their illnesses, whereas Vandereycken and Devidt's study only investigated the experiences of those who had been inpatient – thus representing only a small group of those who receive treatment.

Evidently, there remains a gap in the literature that, if filled, could help us better understand why dropout from AN treatment occurs at such an alarming rate. The implications for the present study then are to try and enrichen understandings of dropout from anorexia nervosa treatment, this time by exploring patients' experiences across a range of treatment settings, and with a particular emphasis on the meaning they give to their dropout. Given the risks associated with anorexia, we have an ethical imperative to do all we can to understand why patients may find it hard to remain in treatment in order that we can help minimise the factors which cause it and maximise the factors that protect against it.

Chapter 3. Methodology and Method

This chapter considers the methodological concerns of the study and the methods used. ‘Methodology’ and ‘Method’ are often treated as synonyms, yet they each reference different components of research practice (Finlay, 2006). Whereas the ‘method’ describes the specific research technique, the ‘methodology’ describes the underlying assumptions and principles guiding the development of the research question and the techniques chosen to answer it.

I begin by setting out the research aims and research question of the current study, before exploring the philosophical assumptions, perceptions and values that have guided me in their development. I then discuss the methodological approach I have chosen to answer the question, Interpretative Phenomenological Analysis, and why this seemed the best fit. Following this, I turn to more method-related matters, by describing how the participants were recruited and the procedures undertaken for data collection and analysis. I bring the chapter to a close by addressing how the credibility of the research might be evaluated, and describing the ethical considerations that have informed the work.

I recognise that my methodological approach to the research question will have inevitably coloured the context of what I am investigating and so I have sought to explore these influences throughout my discussions. There are also broader reflexive issues, however, and these I address at the end of the chapter.

3.1 Research Aims and Research Question

Overall research question: how do anorexia nervosa patients experience treatment and make sense of their decision to dropout?

Research aims:

1. To understand the treatment experiences of anorexia patients who dropped out of ED services.
2. To explore what dropout meant to them.

3.2 Locating the Philosophical Position of the Research

My focus on the way in which patients diagnosed with AN *experience* treatment and *make sense* of their decision to dropout contrasts with the traditional concerns of psychology, which have been more centered around locating the true ‘nature’ of anorexia and the best treatment to ‘cure’ it. Issues of experience and meaning have little relevance within this sort of framework because, here, AN is seen as an objective entity that exists ‘out there’, thus independent of its observers, diagnosticians, and those diagnosed.

This positivist view reflects psychology’s roots within the philosophy of science which developed out of the ‘Enlightenment’ in the mid-eighteenth century. The philosophy of science offered a framework for psychologists in their quest for knowledge (Willig, 2008) and included a number of assumptions about the nature of reality (i.e. ontology), the nature of knowledge (i.e. epistemology) and the appropriate process and procedures of research (i.e. methodology) (Denzin & Lincoln, 2000).

Central to the philosophy of science is the realist ontology that there is a singular, identifiable ‘reality’ and that it ‘exists’, independent of human awareness (Willig, 2008). Epistemologically, it takes the positivist view that phenomena and concepts can be defined through empirical categories, and that there is a direct relationship between these and people’s experience and understanding of them (Cacioppo, Semin & Berntson, 2004; Willig, 2008).

Positivism has been the dominant paradigm shaping psychology for one hundred and fifty years, explaining the preference in the field for quantitative, objective studies of behaviour, over qualitative, subjective studies of experience (Strawbridge & Woolfe, 2010). However, many have questioned whether it is appropriate to use the same methods to study the human world as those used to study the natural world, and have argued for an alternative to the traditional, empirical positivist model. It is these types of humanistic and phenomenological concerns that have led to the emergence of the field of Counselling Psychology and also to the increasing use of qualitative research (Willig, 2008).

Qualitative research, like quantitative research, can be rooted in a realist ontology, accepting the theory of ‘truth’ and viewing the world as, for the most part, knowable and objectively identifiable (Madill, Jordan & Shirley, 2000). This type of qualitative research would seek to generate knowledge about the ‘reality’ of what is going on (be that in a person’s life or mind) and so would employ a method that could develop an explanatory account of psychological and social processes (e.g. Grounded Theory; Glaser & Strauss, 1967).

Unlike quantitative research, qualitative research can also be rooted in a philosophy of anti-realist relativism. Relativism is incompatible with the positivist epistemology guiding traditional science as it rejects the realist notion of ‘truth’, instead taking the view that there are multiple constructed ‘realities’ (Madill et al., 2000; Willig, 2008). Relativists consider all experiences to be shaped and coloured by the social, historical, cultural and linguistic contexts in which they are embedded (Madill et al., 2000; Willig, 2008). Thus, language within social interaction is seen to be of central importance, as it determines a person's 'reality' rather than simply describes it (Burr, 2003). Relativist qualitative research would therefore be interested in investigating the way in which a particular experience is discursively communicated within a particular context rather than in investigating the experience itself (e.g. Discursive Psychology; Potter & Wetherell, 1987). There is also the more extreme relativist view of social constructionism, where the focus is on the 'discursive resources' culturally available to people when they talk of an issue and which govern what they can experience (Willig, 2008). Foucaldian Discourse Analysis is a research method based on this idea and explores the power relationships within society as expressed through discourse (Arribas-Ayllon & Walkerdine, 2008).

Qualitative research can also be rooted in philosophies situated somewhere between realism and relativism. Of particular interest to the current study is the philosophy of critical realism (Bhaskar, 1978). Critical realism shares the realist notion that there is a 'real' world in which stable and enduring features exist, independent of human thought. But it also distinguishes the 'real' world from the 'observable' world, contending that individuals experience real events and phenomena in quite different ways, dependent on the nature of their perceptions and beliefs (Bhaskar, 1978; Finlay, 2006). This means that the world as we know it is constructed through what is 'observable', not necessarily what is 'real' (Finlay, 2006).

While critical realism can be seen here to uphold a relativist epistemological position, it stops short of endorsing the more extreme relativist activities undertaken by social constructionists. That is, critical realist knowledge is produced using an element of deconstruction, but not to the extent that all data is methodologically reduced to this position alone (Pilgrim, 2013). Within a critical realist account, *"it is not reality which is deemed to be socially constructed…rather it is our theories of reality, and the methodological priorities we deploy to investigate it"* (Pilgrim & Bentall, 1999, p.262). Thus, while critical realists do not expect to achieve true objectivity, critical realism suggests they can, and should, attempt to investigate reality itself, with the proviso their developing theory is always subject to cautious and critical contextual analysis. Doing this, critical realists believe they can advance understanding of the real nature of things, replacing misleading or biased concepts with ones that are of more scientific and clinical utility.

3.2.1 A Qualitative Design

I chose a qualitative design for the kind of answers it would provide my research question. The primary goal of qualitative research is to locate meaning, drawn from participants' own accounts of their experience (Willig, 2008). It is therefore an inductive approach, exploring *"the quality and texture of experience"* rather than a deductive one, which would see it trying to identify relationships of cause and effect (Willig, 2008, p9). Its focus on subjective experience and meaning connects individual accounts to their particular context, which then also becomes part of the overall meaning. These contexts can provide a link between a person's experience, and the social, cultural and structural settings in which they are situated (Langdrige, 2007). This means the kinds of answers that qualitative research offers are contextual descriptions or interpretations, drawn from personal lived experience, and it was these sorts of answers that seemed best suited to the type of question asked by my research. As shown, existing research in the area is limited, and so I reasoned that a qualitative approach would allow me to produce knowledge that contained novel and unexpected insights into the individual, social and institutional aspects of anorexia treatment and dropout.

I was also attracted to qualitative approach for its emphasis on researcher reflexivity. Unlike quantitative research, qualitative approaches recognise rather than deny the way in which the researcher's characteristics influence the attention and perception they give to various aspects of their work (Willig, 2008). Given I was aware that my own experiences of anorexia inspired me to conduct research in this area, I felt a qualitative approach would allow me to consider these factors as they related to the study.

Finally, there was also a political component to my decision. As stated in the Introduction Chapter, I had noted how anorexia patients were often denied a voice within the literature, and how they were often described in terms such as 'incalcitrant', 'resistant, and 'difficult'. I therefore wanted to give them the opportunity to present their side. The inductive nature of a qualitative approach allowed me to do this.

3.2.2 Epistemological Framework and Research Paradigm

For a research design to be strong, it must be consistent with the researcher's understanding and belief about the nature of reality and the knowledge that can therefore be produced (Willig, 2008). With this in mind, I have given a great deal of thought to my own epistemological perspective, and how it should guide me in my research design.

Throughout my training as a Counselling Psychologist, my ambition has always been to help others explore the personal meanings they attach to their experiences, not to locate a singular 'truth' that somehow 'explains' their life to them. Indeed, while I maintain that there is such a thing as reality (distinguishing me from the bone fide social constructionists), I think it neither relevant nor possible for us to fully capture that reality, our experience of the world being so coloured by our beliefs and preconceptions. When I began considering my philosophical positioning within the research, I recalled an early memory of a story my primary school teacher once shared in assembly. It was an allegory about a group of blind sages who lived in a distant village many years ago. One day an elephant came to their village and, having never before met an elephant, they each ran their hands over the creature to get a sense for what it was like. Depending on which part they touched - the leg, the tail, the trunk - they each proclaimed that an elephant was like a pillar, a rope or a tree. Their variant conclusions led to a heated argument until a wise man approached and told them that they were each both correct and wrong at the same time. He observed that this was because they had only touched one part of the elephant, allowing them only a partial understanding of what an elephant truly was. Just like the elephant, the allegory itself can be interpreted in different ways to suit the story teller's agenda, but I understood it then, as I understand it now, to mean that we are all, in part, blinded by our preconceptions and limitations – allowing us to only ever be subjective interpreters of the (real) world we inhabit. Yet it is these subjective interpretations that I see to determine the quality of our lives and thus these that are of central concern to me as a Counselling Psychologist, far more so than the elusive 'reality' that preoccupies the hard science professions.

In terms of how this perspective has shaped my research question, as the Introductory Chapter suggests, I acknowledge that anorexia nervosa 'exists' in the sense that individuals can and do experience eating distress of a type that culminates in significant weight loss and attendant 'symptoms'. I also believe that we know more about the biological causes and consequences of self-starvation than we have at any point in the past, in no small part due to scientific enquiry. Nonetheless, I also believe we need to be sensitive to the different ways in which the supposedly singular 'reality' of anorexia might be experienced, bearing in mind the sociohistorical dynamics which govern its identification, observation and treatment. This is one of the key reasons why I am skeptical of the more positivistic claims made about anorexia treatment and dropout, and why the research question focuses on patients' own lived experience and understanding.

In acknowledging my own values and assumptions, I recognised critical realism (Bhaskar, 1990) as the paradigm best suited to my research, it supporting a philosophy of ontological realism and epistemological relativism that I could subscribe to. Critical realism has also been identified as a helpful approach in the study of mental health problems as it acknowledges empirical findings about the 'reality' of psychological distress and its multiple determinants yet *"does not collapse into the naive realism of medical naturalism"*[8] and simultaneously *"ensures proper caution about historical and cultural relativism, without degenerating into the unending relativism and nihilism attending social constructivism"* (Pilgrim & Bentall, 1999, p.271).

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[8] 'medical naturalism', a term coined by Hoff (1995), implies a straightforward medical approach: diagnose; speculate about aetiology and prognosis; treat and monitor (Pilgrim & Rogers, 2009)

In keeping with this attitude, while my aim is to gain a better understanding of what is 'really' going on for those who dropout of anorexia treatment, I am also aware that both my participants' accounts and my own research methods will be influenced by a number of social forces and interests, meaning the findings may not provide direct access to the reality I seek. (Willig, 2008).

3.3 An Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA; Smith 1996) was chosen as the qualitative methodology for the study, being thought to best complement its aims and critical realist positioning. I will provide a brief overview of IPA before examining in detail why it was the preferred choice, over and above alternative qualitative methodologies.

IPA is a qualitative method that examines the way in which people make sense of their lived experience. It aims to collect data that captures the rich quality of this experience. The IPA researcher typically encourages their participants to give accounts of an experience that is of great personal significance. These accounts are then recorded, transcribed and analysed by the researcher, and the findings are considered to be, not only rooted in the participants' interpretation of their experience, but to also involve inevitable interpretation from the researcher. This represents a two-fold aspect of meaning-making, or what Smith and Osborn (2003) have named the 'double hermeneutic'.

While IPA offers a modern approach to qualitative research, its intellectual origins can be found in phenomenology and hermeneutics (Smith, Flowers & Larkin, 2009), as I explore below.

3.3.1 Phenomenology

IPA draws from phenomenology its view of experience as being situated, embodied, reflexive and existential (Smith et al., 2009). Its authors acknowledge the particular influence of the philosopher, Husserl (1913/1982), who believed that science needed to ground itself, first and foremost, in lived experience. He proposed that it was only though a careful, systematic examination of human consciousness that science could develop second order concepts and theories. This phenomenological intention is captured in his rallying call to 'go back to the things themselves' (Smith et al., 2009).

Nonetheless, Husserl also recognised that access to experience is difficult because, in order to understand the things themselves, one must first be able 'strip away' bias and preconception and 'bracket' habitual ways of perceiving things. This requires a person to replace their 'natural attitude' with a 'phenomenological attitude' by way of a sequence of reductions that can shake off the prejudices routinely acquired through daily life and return them to the essence of the experience itself (Smith et al., 2009).

Eatough & Smith (2008) illustrate the ideal outcome of achieving Husserl's phenomenological attitude, using the example of a train journey. Here, it is not our experience of a train journey, seen from our own unique vantage point, rather the unique, consistent structure that all train journeys share; their essential *whatness* that distinguishes them from a journey taken by any other mode of transport. IPA has a similar intention but its interest is in how this process sheds light on experience as lived by an embodied, socio-historically situated being. Unlike Husserl, IPA does not seek to transcend the particular, rather it aims to grasp the texture of experience as it is lived by an experiencing individual (Eatough & Smith, 2008). The focus then is less on the structure of the phenomenon itself than it is on the person's experience of the phenomenon and the meaning they make of that experience.

IPA also owes a debt to the work of Heidegger (Smith et al., 2009). Heidegger puts forth the view that a human being is a Dasein, which translates to mean a 'Being-in-the-world' (Spinelli, 1989, p108). This reflects IPA's understanding of people and the world they live in as socially and historically contingent and contextual (Eatough & Smith, 2008). Heidegger's perspective offers a valuable alternative to the Cartesian dualism on which traditional science is based, which views individuals as mind/body and person/world. Through Dasein, we can see ourselves to be inextricably woven into the world, so that our "*our relatedness to and involvement in the world is mutually constitutive"* (Eatough & Smith, 2008, p.4).

Smith and his colleagues have also identified Merleu-Ponty as a leading influence in IPA's development. They suggest that Merleu-Ponty pushed *"the mutuality of Dasein"* (Eatough & Smith, 2008, p.4) even further through his ideas about the body being a body-subject which reveals the world to each of us in particular ways. This emphasises why the phenomenological interest is with the individually lived body rather than the generalised body of physiological mechanisms and chemical interactions. It also emphasises that our relationship to others must begin from a position of difference: We can never truly share an experience with another, because our experience is forever grounded in our unique, embodied position (Nelson, 2010).

Smith et al. (2009) also invoke Sartre for his notion that we are caught up in projects in the world. His oft-quoted expression *"existence comes before essence"* (1948, p.26) suggests that we are always becoming ourselves, and that the self is not something just there, waiting to be discovered, but rather an ongoing project to be developed. As Smith et al. (2009) point out, these projects inevitably bring us into contact with others, and with *their* projects. For Sartre, this is a tense, often ambivalent relationship. In his book 'Being and Nothingness'

(1948), he illustrates a situation in which a person becomes aware of himself becoming an object through the perception of another. Specifically, he describes a man looking through the keyhole at events in another room and then realising someone else is watching him watching. His self-consciousness becomes apparent only when he becomes aware of his own objectification, meaning his resultant shame only makes sense within its interpersonal context.

Heidegger's emphasis on the worldliness of our experience is significant for phenomenological psychology researchers, but Sartre develops it further by contextualising it within the realm of personal and social relationships, allowing a better understanding of the way in which our experiences are contingent on the presence of our relationships to other people (Smith et al., 2009).

3.3.2 Hermeneutics

The interpretative aspects of IPA are grounded in the philosophy of hermeneutics (Smith et al., 2009). Hermeneutics proposes that knowledge can only ever be accessed through interpretation (Heidegger, 1962), meaning that even phenomenology is itself interpretative. Smith et al (2009) have suggested how IPA can work with this apparent difficulty of interpretation. In accord with Gadamer (1990), they acknowledge the inevitability of bias and assumption when conducting research but propose that these preconceptions can be fruitfully acknowledged and engaged with for the purpose of developing understanding. Drawing on the notion of the hermeneutic circle, they suggest researchers take a questioning and dialectical stance toward their preconceptions and to the account they are investigating (Eatough & Smith, 2008). In this way, IPA can be seen to involve an iterative cycle of interpretation between the researcher and the account, and also between sections of data and the account as a whole. Fischer (2009) conveys this ongoing, iterative process well:

"The researcher repeatedly discovers what his or her assumptions and interpretive understandings were and re-examines them against emerging insights. Findings "regestalt," are again disrupted, and again "regestalt."" (cited in Eatough & Smith, 2008, p.6).

IPA also manages interpretation through the stance it takes toward the status of an account. Drawing on Ricoeur's (1970) ideas, its authors suggest that IPA occupies a middle ground between a 'hermeneutics of empathy' and a 'hermeneutics of suspicion'. Each of these are employed to encourage researchers to adopt a both/and perspective; on the one hand to take on an empathic view and imagine what it is like to be the participant; on the other, to critically analyse what *appears* to be the case, taking into account the nature of the experience-in-context being described. The former is committed to producing rich experiential understanding of the phenomenon, remaining close to the sense-making of the participant. The latter, meanwhile, involves the researcher putting to one side what they previously took at face value in order that they develop a multi-layered narrative of potential meanings (Eatough & Smith, 2008).

3.3.3 IPA Characteristics

Smith (2004) suggests that there are three main characteristics inherent to IPA. Firstly, it is *idiographic*, viewing individuals as unique and complex entities and valuing the in-depth, nuanced analysis of their contextually-dependent lived experience. IPA combines its focus on what is distinct for each participant with a concern for what is shared between them, resulting in a fine-grained and personally meaningful account from participants reflecting on a shared experience (Smith et al., 2009).

Secondly, IPA is *interrogative*, contributing to psychology through the way in which it illuminates existing literature. While IPA analyses a data-set in great detail, its findings are not intended to stand alone, rather they are positioned against the backdrop of existing literature on the subject (Smith et al., 2009).

Thirdly, IPA is *inductive*, using flexible techniques to encourage novel, often unexpected, themes to emerge during the analytic process. IPA research does not seek to prove or disprove specific hypotheses formed on the back of existing literature; rather it asks more far-reaching questions to give rise to expansive data (Smith et al., 2009).

3.3.4 Rationale for IPA

IPA was considered a suitable methodology for several reasons. Firstly, its phenomenological foundations appealed to me for the way they invited a thorough exploration of experience and meaning-making (Smith, 2010), and encouraged the researcher to develop an ‘insider’s perspective’ (Smith et al., 2009).

Additionally, its broadly critical realist stance married well with my own epistemological position. As Nelson (2010) observes, IPA endorses a level of construction on the part of the researcher and the participant while also maintaining the existence of an empirical world out there that accords respect. I consider this tension between phenomenology and interpretation particularly relevant to the subject of anorexia, and its value has already been demonstrated in previous research examining ED related issues (e.g. Fox & Diab, 2015).

I also liked IPA for its flexible method. It seemed to offer participants the freedom to choose how they wanted describe their experience, while also permitting the researcher to adapt their questions around this description. I thought that this would provide the best opportunity for participants to explore a range of meanings, while also enabling me to ask questions of them should I consider something of their experience to be missing or unclear (Smith & Osborn, 2003).

Another key factor, was the way in which IPA perceives the researcher. The method has been criticised for not clearly stating whether the researcher is a 'discoverer' or 'constructor' of reality (Willig, 2001). However, while some may levy this as a criticism, I appreciated it for this lack of distinction, my own understanding being that the researcher does both. Futhermore, I see this as a positive because it allows the researcher to make better sense of the subject under investigation. For example, the early stages of data collection and analysis saw me try to understand the participants' experience. This was mainly about discovery, but there was also a little construction involved due to the inevitable subjectivity of the researcher-participant relationship. Then, later, when I analysed and discussed my findings, I drew upon these 'discoveries' to construct links with more abstract or theoretical levels of interpretation (Finlay, 2008).

3.3.5 Why Alternative Qualitative Methodologies were Rejected

All qualitative approaches share in their aim to enrichen our understanding of the phenomena they investigate. However, as discussed, their philosophical positions, and so the methodological approaches they adopt, can be quite different. Within this section, I will explain my decision to choose IPA over three other qualitative approaches that I also considered: Grounded Theory, Discourse Analysis, and Narrative Analysis.

Grounded Theory (GT; Glaser & Strauss, 1967) was initially a strong contender, to the extent that I wrote my initial research proposal with it in mind. It seemed ideally suited to the critical realist sensibilities underpinning the research, given that GT encourages consideration of evidence and meaning, individual agency and social structure, and gradually moves the focus from data to abstraction to allow novel theory to emerge organically. The notion that I could use GT to develop a fully-fledged theory of dropout from AN treatment was also an attractive one. However, I was concerned the approach would prevent me from adequately capturing and honouring my participants' individual experience – the very purpose for which I was undertaking the research in the first place. Indeed, GT is most often regarded as a sociological approach (Willig, 2003), drawing on convergences within a relatively large sample to support wider conceptual explanations. What I wanted, however, was a psychological approach that could delve deep into each participant's experience, allowing me to offer a detailed, nuanced account of AN treatment and dropout (Smith et al, 2009).

My next consideration was Discourse Analysis (DA). This approach operates on the premise that all knowledge is discursively constructed, resulting in an analytical focus on the way in which people use language to construct and negotiate knowledge, meaning and identity (Potter & Weatherall, 1987). I considered this approach given that my research has been concerned with the many possible influences shaping participants' experience of treatment and their decision to dropout, and I recognised that the discursive construction of 'the anorexic' within the treatment environment could have a role to play. However, the main aim of my research has been to shed light on participants' overall experience of treatment and dropout, not just on the social interactions which contributed to them. My concern was that a discursive analysis might lead me to overlook important aspects of my participants' internal experience and, indeed, Smith and Eatough (2008) observe, *"what is missing from such (discursive) accounts are the private, psychologically forceful, rich and often indefinable aspects of emotional life"* (p.184).

Working as a therapist, I have heard a great many life stories and I believe people do more with their conversation than simply draw on a culturally available store of shared meaning. I like how Chodorow (1999) describes it when she says:

"That thoughts and feelings are entangled and that thoughts are thought in culturally specific languages – these ideas do not mean that there is no private feeling or that any particular thought has only a public cultural meaning. Culturally recognizable thoughts can also be entwined in a web of thought-infused feelings and feeling-infused thoughts experienced by an individual as she creates her own psychic life within a set of interpersonal and cultural relations." (cited in Eatough & Smith, 2008, p.22).

Thus, while my research has a certain synergy with DA, being concerned with the way in which discursive constructions might be implicated in participants' experiences of treatment and dropout, I rejected it as a methodology for the fact that it was participants' actual lived experience of these things that was my primary focus.

My final consideration was Narrative Analysis (NA) because of its central concern with meaning-making. NA is founded on the principle that the accounts we give of our lives are constructed as stories, and that the passing down of these stories over generations is what shapes the human experience (Cresswell, 1998). A key focus of the analysis is the way in which participants structure their narrative accounts and the approach employs a biographical type of interview. I eventually disregarded NA as a possibility because it only considers how people create and use stories to make meaning of their experience, not acknowledging other processes that might also be important, such as the use of discourse or symbolism.

3.3.6 Challenges and Limitations of IPA

Like all qualitative research methods, IPA does not have ‘stand-alone integrity’, meaning it is not, in itself, a guarantee of quality (Smith et al, 2009). The success of the approach therefore rests heavily on its application and, as Brocki and Wearden (2006) emphasise, researchers sometimes fail to address adequately the theoretical preconceptions they bring into the study or the intrinsic role they play in interpreting the data – both of which are key considerations within IPA. I have done my best to limit these concerns within the current study by reflecting on my preconceptions, values and motivations throughout the research process. Some of these have already been documented, but I consider my reflexivity more explicitly in sections 3.7 and 5.3.2.

Another potential limitation centres on the fact that IPA requires participants to adequately communicate the richness of their experience. If participants lack the necessary linguistic, cognitive or emotional skill to express themselves coherently, then the quality of the data will be negatively affected. I had some concerns about this given that my participants made up a clinical population often associated with emotional inexpression (Nowakowski, McFarlane & Cassin, 2013), particularly if still underweight. I therefore looked into techniques that could help me encourage them to open up and speak about their experiences. I made use of some of the suggestions I found in the literature, including speaking about emotionally difficult experiences in third person, and using humour and self-deprecation to make them more comfortable (Liamputtong, 2010).

Finally, proponents of IPA have sometimes received criticism for their small sample sizes; the reason being that large samples are needed to produce generalisable hypotheses. I support the view held by Smith et al. (2009), however, that the use of a small number of participants permits greater depth of analysis. I also believe the findings will pose broader questions about anorexia treatment than have previously been asked; questions that hopefully inspire a rereading of existing literature as well as opening up new areas for future research.

3.4 Method

3.4.1 Sample Selection, Size and Recruitment

The primary objective of IPA is to illuminate a particular experience. This calls for a relatively homogenous group to be selected for study, on the basis that it can provide access to this.

One of the most important decisions I had to make when deciding on my sample was whether to include those who had dropped out from treatment within *any* setting – inpatient, daypatient or outpatient - or whether to focus exclusively on one. Each option had its merits and drawbacks. If I did not distinguish between treatment settings, I presumed I might find more variation amongst the reasons given for dropout. This would allow for richer material but the lack of focus might impede the development of coherent themes and, ultimately, what could be said of the group as a whole. If I were to solely consider the treatment experiences of those who dropped out of an inpatient and/or daypatient setting, then I presumed I might hear more accounts of managing therapy alongside enforced food intake, weight gain and the experience of other relationships within the treatment setting. If I were to focus solely on treatment experiences within an outpatient setting, then these accounts might be less present, potentially limiting interesting areas of study. However, given that outpatient treatment is the preferred mode of treatment for most cases of anorexia (NICE, 2017) it seemed counterintuitive to exclude this treatment setting.

I decided then to focus solely on outpatient treatment. However, following preliminary phone conversations with prospective participants, I realised that, for many, treatment had been experienced as more of a blur across a number of settings, rather than neatly contained within one or another. Indeed, four of the five participants had experienced all three treatment settings; and the fifth, while having narrowly avoided a compulsory inpatient admission, had experience of both outpatient and daypatient. I therefore decided that I would not exclude participants on the basis of a particular treatment setting they had encountered and/or dropped out from.

IPA studies typically benefit from an in-depth focus on a small sample, the aim being to obtain a detailed account of individual experience. Formal guidelines for ideal sample numbers do not exist (Smith et al., 2009; Smith, 2010) but Brocki and Wearden (2006) note that, of the IPA studies they reviewed, participant numbers varied from one to thirty, with a preponderance using smaller numbers. I was keen to not lose sight of the particularities of my participants' individual experience, noting Smith et al's (2009) observation that it is more difficult to meet the commitments of IPA with a sample size that is too large than one that is too small. In general, for doctoral students, the authors recommend between 4 and 10 interviews to allow for in-depth analysis both within and across cases.

With the aforementioned guidance in mind, I set the criteria for this study to include adult female participants with a current or previous diagnosis of AN and personal experience of dropping out of an NHS treatment program for their eating disorder. The full inclusion and exclusion criteria are illustrated in Table 2.

Inclusion Criteria	Exclusion Criteria
Adult females	Male participants will be excluded
Individuals with a current or past diagnosis of anorexia nervosa	Participants who did not make the unilateral decision to dropout will be excluded
Individuals who dropped out from an ED treatment program where they were receiving treatment	Participants who were less than 18 years old at the time of dropping out will excluded
	Participants non-fluent in English will be excluded
	Medically unstable participants will be excluded

Table 2: Inclusion and exclusion criteria for sample

I decided to only include females given that 90% of anorexia patients are female (Strober, 2004). Additionally, as pointed out by Rance, Moller and Clarke (2015), both theory and research indicate that gender shapes the way in which those with AN understand themselves and are understood by others, thereby suggesting the treatment experiences of male patients might be quite different.

I also decided it was important that I only included those who had dropped out of treatment for, specifically, AN rather than any other ED. Much of the previous research into treatment has been conducted using samples that do not distinguish between anorexic and bulimic participants, presumably because there are many similarities between the disorders and individuals often move between the two diagnoses (Fairburn, Cooper, Shafran & Wilson, 2008). However, the experience of being treated for an AN diagnosis can be quite different to being treated for a BN diagnosis. For example, while for AN there is likely to be a primary focus on weight restoration and increased caloric intake, for BN the focus is more likely to be on regulating chaotic eating patterns and eliminating purging (Blechert et al., 2011). Therefore, in the interests of collecting a sample who could reflect on a specific type of ED treatment and dropout, it was decided that only those who had a diagnosis of AN at the time would be included.

Following a discussion with the research officer from Beat (the UK's eating disorder charity), I decided to also include those who may have been diagnosed with a-typical AN (i.e. EDNOS or

OSFED with anorexic features). This decision was informed by research showing there to be no significant difference in rates of dropout between the two (Jordan et al., 2014) and can also be seen to reflect the critical view I take toward ED diagnostic criteria. All the same, as it turned out, those who responded to the recruitment advert all described having received a clinical diagnosis of full-syndrome anorexia nervosa at the start of their treatment.

In terms of the medical health criterion, participants were only eligible if they could confirm that any significant health issues related to their AN were being monitored by a health professional. This stipulation was made to lessen risk to their safety should they feel a need to use ED behaviours to regulate any potential negative affect caused by the interview.

While the term ‘dropout’ can describe both the unilateral termination of treatment by a patient and the decision for administrative discharge made by a treatment team (Dejong et al, 2011), I decided to include only those who had experience of the former. This is because the current study is interested in the experiences that might contribute to patients making their own decision to leave treatment, not simply exploring the experience of leaving treatment early

Finally, it was also decided to only include those over the age of 18 due to the fact that those under 18 are treated within Child and Adolescent Mental Health Services (CAMHS) within the NHS, and treatment tends to differ from that found within adult services (e.g. family-based interventions are much more commonplace).

Participants were recruited via an advert (Appendix 3) placed on Beat’s website. The advert was formatted according to the stipulations of Beat’s research officer. My email details were included and potential participants invited to contact me.

The decision was made to advertise through Beat rather than an NHS ED service. This is because it was participants who had dropped out of NHS treatment that were being sought and so, as researcher, I did not want to be aligned with the same treatment provider as the one with which the participant had cut ties. Additionally, if many or all of the participants had been recruited through the same service, their experiences would only reflect experiences of treatment within that one particular program. This was the route taken by Vandereycken and Devidt (2010) and, while their findings were valuable, I was keen to expand the remit.

Potential participants were invited to contact me directly by email. I responded to each with a detailed information sheet (Appendix 4) and a consent form (Appendix 5), instructing them to read the former and confirm, by way of response, their informed consent to the points illustrated in the latter. Once I had their initial consent, I arranged a time to call them so I could confirm they met the criteria for the study and so that they could have me answer any questions they might have had. During our phone conversation I also gathered some basic demographic information so I could later describe my sample population (See Appendix 6 for the preliminary phone call screening guide; and Table 4 for participants' collected demographics). Having determined their eligibility, and still having their consent, I then confirmed a date and time for interview with them over email (see Appendix 7).

3.4.2 The Participants

In the end, there were five women that took part in the study. I interviewed seven but one became ineligible when it transpired that she had not so much 'dropped out' as been denied further treatment upon graduating from adolescent to adult services. For logistical reasons, the other needed to reschedule her face-to-face interview to one that took place over Skype and, because of a poor internet connection, the recording turned out to be of insufficiently good quality. Fortunately, upon finishing the interviews with the other five, I realised that there was already enough data for a rich analysis, meaning I did not need to recruit any further participants.

I collected demographic information about participants' age, location, and brief ED treatment history in terms of setting, diagnosis, dropout and current status. All five women resided in the southeast of England. Their age ranged from 19 to 44. They had each received at least two episodes of NHS treatment for clinically diagnosed anorexia nervosa and had dropped out of at least one of these. All but one had been treated as an inpatient as well as a daypatient and outpatient. I did not collect information on their body mass index (BMI) as it was not felt that such knowledge would make their experiences any more or less valid. It could also have been perceived as intrusive and triggering for participants were I to seek this information. Please refer to Table 3 for the information I collected from participants prior to interview.

Name	Age	Treatment History	Dropout Episode	Diagnosis at dropout	Current Treatment	Current ED Status
Caroline	27	NHS Inpatient x3, NHS Outpatient x1	Dropped out from NHS ED service 3 years ago in advance of return to inpatient treatment	Anorexia Nervosa	Outpatient therapy for the last 3 years	Weight restored for 3 years. Describes herself as 'in recovery'
Tali	44	NHS Inpatient x2, NHS Daypatient x2	Dropped out from ED services 3 months ago, having received treatment within a daypatient program for 8 months	Anorexia Nervosa	Recently started private ED outpatient treatment	Weight stable but not restored. Describes herself as 'in recovery'
Maggie	19	NHS Outpatient x1, NHS Daypatient x2	Dropped out from NHS ED service 2 months ago, having received treatment within their daypatient program for 1year	Anorexia Nervosa	Not returned to treatment	Weight partially restored. Describes herself as 'in recovery'
Suri	43	NHS Inpatient x1, NHS Daypatient x1, NHS Outpatient x1	Dropped out from NHS ED service 5 years ago, having received treatment within their daypatient program for 6 months	Anorexia Nervosa	Recently completed episode of NHS outpatient treatment	Weight restored. Describes herself as 'in recovery'
Taryn	28	NHS Inpatient x1, NHS Outpatient x1	Dropped out from NHS ED services, where she had been receiving long-term outpatient therapy, in advance of return to inpatient treatment	Anorexia Nervosa	Not returned to treatment	Weight stable but not fully restored. Describes herself as 'in recovery

Table 3: Profile characteristics of participants

3.4.3 Data Collection

Smith et al. (2009) recommend interviews and diaries as the best means of obtaining the rich subjective accounts required for IPA. I briefly explored the possibility of using diaries but opted for semi-structured interviews, deciding they could better assist me in answering my research question. Diaries would perhaps have been useful had I been exploring an experience that was unfolding in the current moment but, because I was asking participants to reflect on past experience, interviews seemed the more sensible option. My training as a Counselling Psychologist also made this a natural choice, as I already had experience in creating dialogue in order to encourage the exploration of personal meaning.

Interview Schedule

I followed Smith et al's (2009) recommendation to design a schedule to help guide the interview (please refer to Appendix 9). I found that drawing up an interview schedule in advance allowed me to predict possible difficulties, as well as how I might best handle them e.g. considering the most sensitive way to word a potentially provocative question. I also believe that, having thought ahead about the different ways the interview may proceed, I was more able to fully attend to participants' accounts as they told them during the interview.

The questions I asked in interview were built around the aims of the study and the gaps I had identified in the literature on my initial reading. Smith et al., (2009) proposed that interview questions be open-phrased and, typically, shift between those which call for participants to be descriptive and those which call for them to be more analytic. Accordingly, the interview schedule started with me asking participants to describe their treatment history in general terms. It was hoped that this relatively innocuous opener would help put them at ease, allowing us to begin to build a rapport that would later enable them to provide a more personal and analytic account of their treatment experience and subsequent dropout (Kvale & Brinkmann, 2009; Smith et al., 2009).

I kept in mind Mahon's (2000) observation that interviews can give rise to powerful demand effects. She noted, *"Many eating disorder patients will initially give an 'environmental' or practical reason for leaving treatment, such as claiming that transportation or childcare was too difficult to arrange"* (p.211). Quantitative studies suggest that there are no differences between those who dropout and those who complete treatment on these variables, implying that participants might be providing a polite excuse. Qualitative studies also indicate patients who drop out may have been negatively impacted by communication difficulties with their therapists, or otherwise felt unsafe with them (Mahon, 2000). Thus, there appears to be differences between treatment dropouts and completers which could be discovered if respondents felt comfortable enough to share their real reasons for dropping out.

I sought to encourage the participants to speak their mind openly by giving them as much control over their accounts as possible during the interview. This meant I often followed them down unexpected turns in conversation to see where it would take us. As Smith et al. (2009) contend, these unexpected turns can be particularly valuable as they tell us something we did not even anticipate needing to know that, due to arising unprompted, are likely to be of particular importance to the participant.

Pilot Interview

It can be helpful to use pilot interviews to test out the best open questions to include in an interview schedule (Kvale & Brinkmann, 2009; Smith et al., 2009). I conducted a pilot interview with a non-participating woman known to me who had a history of anorexia and experience of treatment for it within the NHS. Feedback from her, following the pilot interview, indicated that she felt comfortable with the questions asked and even said she enjoyed answering them. I did however notice that some of my questions appeared too complex/convoluted to elicit a satisfactory response so I adapted these to either be phrased in more colloquial terms or else broke them down into more than one question. I also constructed more explicit prompts within the interview schedule that could follow on from certain questions as needed.

Interview Procedure

The five participants were interviewed over a period of 4 weeks in July and August 2017. Interviews were carried out in a private therapy room at City University during work hours, when the university was staffed.

Before the interviews commenced, participants were provided with printed copies of the information sheet and the consent form, both of which they had previously received via email. I described again the purpose of the research and explained issues of confidentiality (see section 3.6). They were then asked if they had any questions, after which they signed the consent form.

The interview began with a broad question: ‘Could you give me a brief history of your eating disorder treatment?’ It later led into more specific questions about the type of treatment they had experienced, the circumstances surrounding their dropout and their understanding of why it occurred. Once the interview had finished, participants were offered a debrief and once again invited to share any questions or impressions they had about the study and their participation. They were then provided with a debriefing sheet that included a list of potential contacts for personal support (Appendix 8). Their bank details were also taken and £30 was transferred to them within 24 hours, to compensate them for their time and travel. The interviews lasted between 73 and 118 min, with an average interview lasting 95 minutes.

Post-Interview Notes

Following each interview, I spent about ten minutes making notes. These provided me with a contextual record of the interviews (please see Figure 1 for an example) and proved useful when starting to interpret the data. Within the notes, I gave brief physical descriptions of each participant, described the atmosphere I felt with them and gave some suggestions on why this may have been. I also identified anything that seemed to evoke a strong emotional response in the women and reflected on my interviewing technique. Finally, I recorded my emotional responses and any initial thoughts I had, bearing in mind how my own subjectivity would inform the analysis.

Wednesday, 20th July

Caroline was a petite brunette with a bubbly demeanour, who presented with what appeared a healthy weight. She was open and talkative, and we developed an easy rapport from the start.

Both the interview and her first email communicated how passionate she felt about the subject of AN treatment and she readily admitted she wanted to participate in the study because she thought the treatment available 'barbaric' and needed to change.

I found her passion and conviction drew me in to her narrative, making it easy to be empathic. I realise I have to be careful to not let this prevent me from also maintaining a more critical perspective when interpreting her account. For example, while she spoke convincingly of the unfairness of NG feeding being implemented as a 'punishment', on reflection I realise the NG feeding could have been justified on account of her extremely low BMI at the time. Nonetheless, the lack of support she described receiving, both during and immediately after its implementation, likely contributed to this sense of being 'punished.'

Self-acceptance and social acceptance were important themes running through her narrative, the quality of each having provided a catalyst, first for her illness, and then for her recovery.

Figure 1: Post-interview notes for Caroline

Transcribing the Interviews

I transcribed the interview recordings verbatim, in accord with Smith et al’s (2009) guidelines. Each transcript was page and line numbered so that extracts could be easily located. Information that could have identified the participant was also anonymised. The primary aim of IPA is to interpret the meaning content of an individual’s account, therefore detailed description of the prosodic aspects features within an interview, such as non-verbal utterances, are not required (Smith et al., 2009). However, I thought certain details would be necessary for me to to make an informed linguistic and psychological analysis. I therefore decided to include emotional expressions (such as laughter or crying) and significant pauses and emphases in intonation. I noted emphatic intonation by underlining the relevant text, and all other features were recorded within the transcripts with text in square brackets. Please see Figure 2 for an example.

Researcher	And what’s your thinking in terms of treatment in the future? Would you consider treatment again?
Participant	I think when I was away in xxxxxx the first month I was there, I was saying to myself, you know when I get home, I’m gonna go back in to treatment, I’m just gonna sort it out. But then as the placement progressed I was like I don’t think I need anything. I don’t feel like saying anything to anyone that would really make any kind of difference. And I feel like I would just fall straight back into that role of being, like that role that you play for therapists. So, if they weighed me I’d just feel really embarrassed if it went up cos I’d be like ‘oh well they don’t think I’m a very good anorexic if my weight’s gone up, that’s just really embarrassing’. Whereas if I just don’t weigh myself … at the moment, I don’t weigh myself and no one looks at my weight then … it’s not a problem. Whereas if someone weighed me and I knew what that number was and then I knew it had gone up the next week, then I’d be like, ‘oh, I’ve eaten too much’. I dunno, I just feel like it would trigger me a lot to go back in to treatment.
Researcher	You’ve described that caregiver role that they take up, that then promotes your, what you describe as a victim position…
Participant	Yeah.
Researcher	… and do you find that’s something that happens when you are in therapy?
Participant	Yeah. I think it does. But it’s like, I don’t *mean* to do it. I only noticed I was doing it when my therapist pointed it out. And at the time I got really upset and was like how dare you [laughs], *you’re so rude*! But then the more I thought about it, the more I’m like, yeah that does tend to happen. I dunno the more … I find with anyone, the more I’m like, oh, oh, oh, I’m really sad, I need help, the more that becomes true.

Figure 2: Extract from Maggie’s transcript (lines 447-457).

3.4.4 Data Analysis

While not intended as prescriptive, Smith et al. (2009) give guidelines on how to develop an IPA analysis which is ‘good enough’. These were referred to throughout the analytic process, which I will illustrate below.

Stage 1: Reading and re-reading

Much of the IPA literature emphasises the importance of ‘immersing’ oneself in the data (e.g. Smith et al, 2009; Kvale & Brinkman, 2009; Willig, 2001). Eatough and Smith (2006) suggest that, with each reading, the researcher becomes increasingly sensitive to what is said. With this in mind, I listened again to each interview whilst comparing it against my corresponding transcript. I then read through the transcript another time. I found that this approach helped me re-familiarise myself with the interview and consider the process issues that had been involved. I carried out the same routine for each of the interviews before analysing them individually.

Stage 2: Initial notations

I then began making initial annotations in the right-hand margin. I made an effort to maintain an open mind and record anything of interest. These initial notes included content summaries, script-wide connections and initial interpretations (Smith et al. 2009). I referred to my post-interview notes at this stage, cross-referencing the thoughts and issues I had recorded there with observations I was now making. As suggested by Smith et al., (2009) my commentary focused on the *descriptive*, the *linguistic* and the *conceptual* aspects of the text. The descriptive comments drew attention to the content of the participant’s account, highlighting the issues which seemed to matter most to them. My linguistic comments then paid attention to the various ways in which they presented their concerns (e.g through the use of long pauses, or by emphasising certain words). As recommended by Smith et al. (2009), my conceptual comments were of a more interrogative and analytical nature. I observed interesting connections between various parts of the text and noted down questions about possible meanings. These last comments drew more on my theoretical and experiential knowledge, using both to tentatively inform emerging understandings of the participant’s lived experience.

I made these notes by hand, finding it the most intimate way to engage with the text. I made the three types of notation in parallel but used a different colour pen to distinguish the descriptive, linguistic and conceptual commentary. I found that this helped maintain clarity and also ensured I was disciplined in my focus on each.

Stage 3: Emergent themes

For the next stage of analysis, the aim was to reduce the volume of my commentary without forfeiting its complexity and meaning. I therefore focused on discrete portions of my preliminary notes at a time, distilling them into something more concentrated while also trying to keep the whole transcript in mind (Smith et al., 2009). Admittedly, this felt quite disorientating at times, but the temporary fragmentation of the transcript was undertaken with the aim of then bringing it back together to form a "new whole", representing a manifestation of the hermeneutic circle (Smith et al., 2009).

As I worked my way through, I noted emergent themes in the left-hand margin. These intended to more succinctly capture the essence of my earlier commentary, and to express it using more psychological language. In this way, the emergent themes reflected, not only the participant's account of their experience, but also my interpretation of their account. Please refer to Appendix 10 to see an example of stages 2 and 3 of the analytic process.

Stage 4: Finding connections across emergent themes

Next, I typed up the individual transcript's emergent themes into a chronological list, printed them out and cut each into a paper strip. I laid these on a table and began to reorganise them into clusters (see Figure 3)

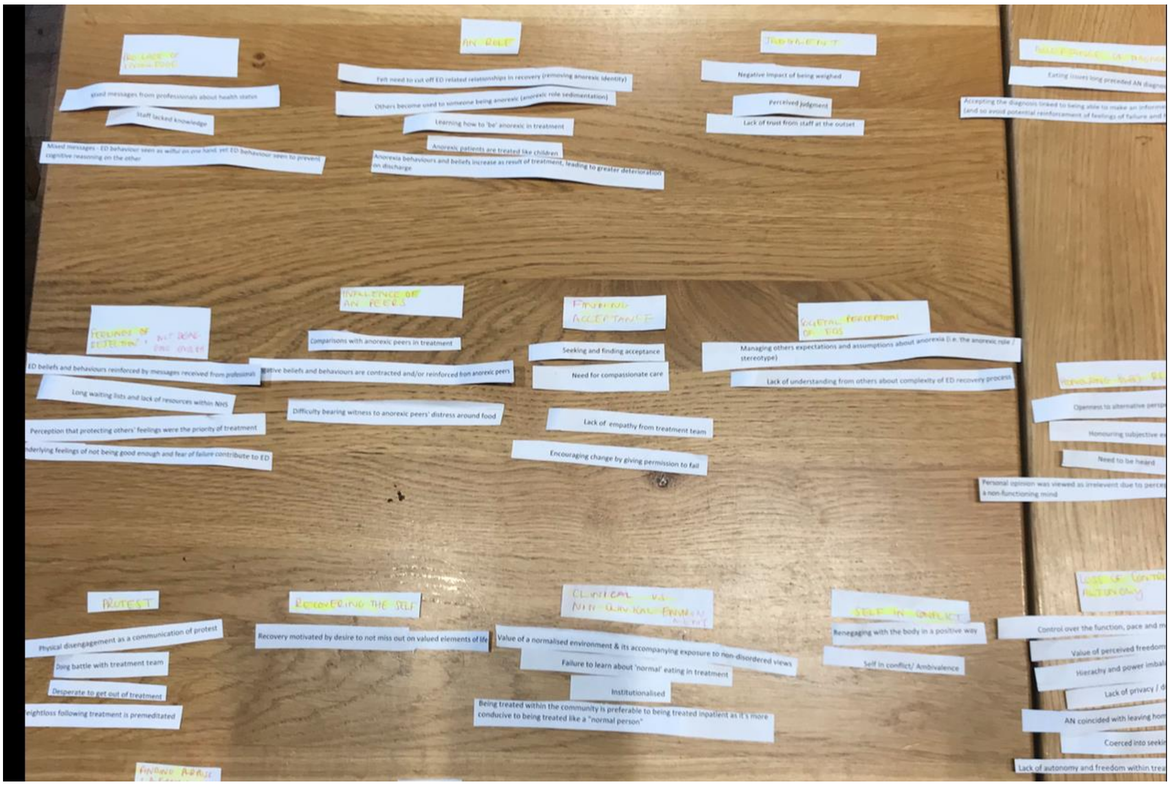


Figure 3: Process of finding connections across emergent themes

Smith et al. (2009) give recommendations on how to identify clusters through abstraction (by placing like-with-like); polarisation (seeking out oppositional relationships within the transcripts); subsumption (where an emergent theme draws in related emergent themes, morphing organically into a higher-order theme); contextualization (locating the contextual/narrative similarities of an analysis); numeration (how often a theme is supported) and function (how useful the themes are found to be).

I created names for the clusters and discussed these with my supervisor to ensure I was on the right track through the analytic process. In some instances, I revisited and relabelled emergent themes, allowing me to develop a more comprehensive clustering. The aim here was to produce over-arching themes that represented the individual lived experience of each participant while also representing higher-order theoretical ideas.

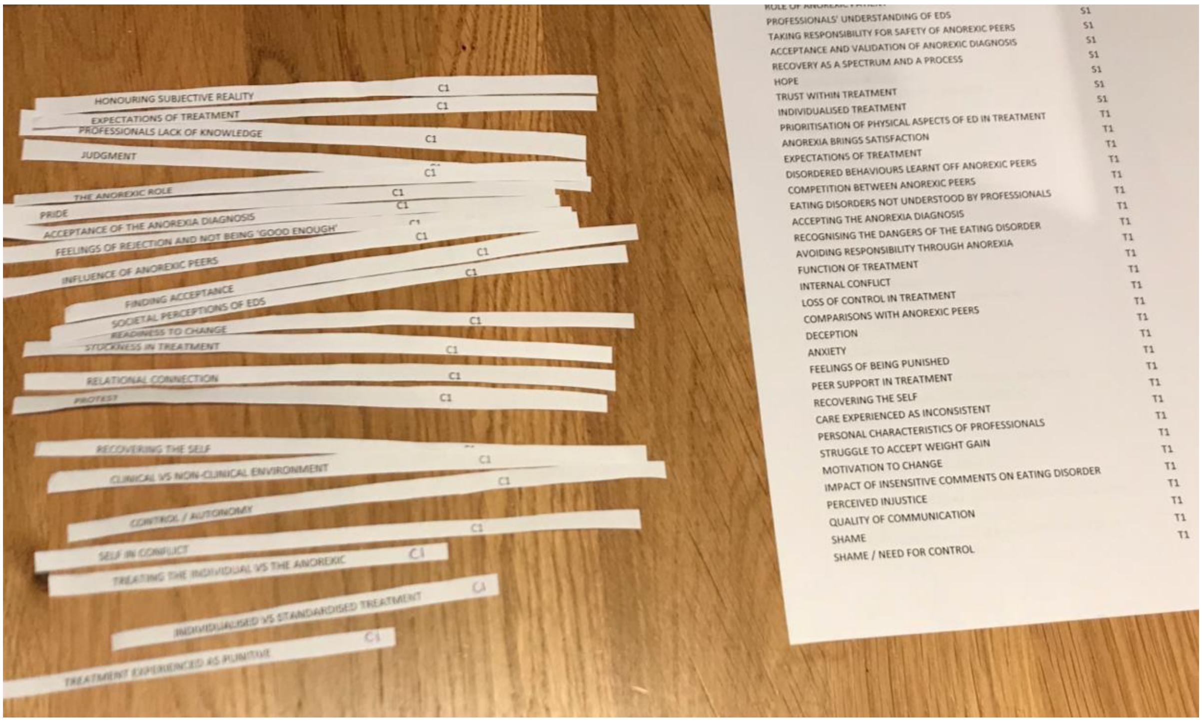
Throughout these stages, I used an iterative analytic method in that I continuously checked my interpretations against supporting data in the transcript, and also again the preconceptions I had recorded in my post-interview notes. As a last step in my analysis of the first account, I created a table for the participant's transcript which illustrated its cluster themes, alongside their associated emergent themes and relevant quotations (please refer to an example in Appendix 11). At this point, a few of the themes were deprioritised (by shading them grey), pending complementary evidence from the subsequent transcripts.

Stage 5: Moving to the next case

IPA is an idiographic approach, meaning the unique experience of the individual is honoured, and so I treated each transcript as an isolated piece of data throughout the first four steps of the analysis. I attempted to bracket any ideas or themes emerging from the analysis of previous transcripts by writing them down in my research notebook and then setting them aside. I know, however, that I would have not managed to do this with perfect objectivity and that I will have inevitably been influenced, to some degree, by information I had already found.

Stage 6: Across case analysis

During the next stage, the focus shifted to identifying the patterns shared across transcripts. In order to do this, I created a spreadsheet containing all the clustered themes that had emerged from the individual transcripts, along with a code (e.g. T1) identifying which participants' transcript they applied to. I printed the spreadsheet and cut out the individual rows of themes containing the transcript codes (see Figure 4).


HONOURING SUBJECTIVE REALITY C1
EXPECTATIONS OF TREATMENT C1
PROFESSIONALS LACK OF KNOWLEDGE C1
JUDGMENT C1
THE ANOREXIC ROLE C1
PRIDE C1
ACCEPTANCE OF THE ANOREXIA DIAGNOSIS C1
FEELINGS OF REJECTION AND NOT BEING 'GOOD ENOUGH' C1
INFLUENCE OF ANOREXIC PEERS C1
FINDING ACCEPTANCE C1
SOCIETAL PERCEPTIONS OF EDS
READINESS TO CHANGE C1
STUCKNESS IN TREATMENT C1
RELATIONAL CONNECTION C1
PROTEST C1
RECOVERING THE SELF C1
CLINICAL VS NON-CLINICAL ENVIRONMENT C1
CONTROL / AUTONOMY C1
SELF IN CONFLICT C1
TREATING THE INDIVIDUAL VS THE ANOREXIC C1
INDIVIDUALISED VS STANDARDISED TREATMENT C1
TREATMENT EXPERIENCED AS PUNITIVE C1

PROFESSIONALS' UNDERSTANDING OF EDS	S1
TAKING RESPONSIBILITY FOR SAFETY OF ANOREXIC PEERS	S1
ACCEPTANCE AND VALIDATION OF ANOREXIC DIAGNOSIS	S1
RECOVERY AS A SPECTRUM AND A PROCESS	S1
HOPE	S1
TRUST WITHIN TREATMENT	S1
INDIVIDUALISED TREATMENT	S1
PRIORITISATION OF PHYSICAL ASPECTS OF ED IN TREATMENT	T1
ANOREXIA BRINGS SATISFACTION	T1
EXPECTATIONS OF TREATMENT	T1
DISORDERED BEHAVIOURS LEARNT OFF ANOREXIC PEERS	T1
COMPETITION BETWEEN ANOREXIC PEERS	T1
EATING DISORDERS NOT UNDERSTOOD BY PROFESSIONALS	T1
ACCEPTING THE ANOREXIA DIAGNOSIS	T1
RECOGNISING THE DANGERS OF THE EATING DISORDER	T1
AVOIDING RESPONSIBILITY THROUGH ANOREXIA	T1
FUNCTION OF TREATMENT	T1
INTERNAL CONFLICT	T1
LOSS OF CONTROL IN TREATMENT	T1
COMPARISONS WITH ANOREXIC PEERS	T1
DECEPTION	T1
ANXIETY	T1
FEELINGS OF BEING PUNISHED	T1
PEER SUPPORT IN TREATMENT	T1
RECOVERING THE SELF	T1
CARE EXPERIENCED AS INCONSISTENT	T1
PERSONAL CHARACTERISTICS OF PROFESSIONALS	T1
STRUGGLE TO ACCEPT WEIGHT GAIN	T1
MOTIVATION TO CHANGE	T1
IMPACT OF INSENSITIVE COMMENTS ON EATING DISORDER	T1
PERCEIVED INJUSTICE	T1
QUALITY OF COMMUNICATION	T1
SHAME	T1
SHAME / NEED FOR CONTROL	

Figure 4: First step in identifying patterns across transcripts

I stuck them all on a large white wall with blue-tac and began the process of moving them around and re-clustering them in accordance with their shared higher order qualities (see Figure 5). I labelled newly emerging connections with brightly coloured post-it notes, which helped me identify the more salient and interesting themes. As suggested by Smith et al., (2009), I also took account of the level of recurrence across cases when grouping, naming and discarding superordinate themes.

Figure 5: Second step in identifying patterns across transcripts

Once this stage was completed, a final table was created illustrating the higher order themes for the group with exemplar quotes from each of the individual participants (Appendix 12).

The full analytic process was then written up.

3.5 Ethical Considerations

The proposal for my research was reviewed and approved by City University's Ethics Committee, and a Counselling Psychologist with a specialist interest in EDs supervised me through the process of carrying it out. This meant I always had an appropriate forum in which I could discuss my research and any concerns that arose.

The research was conducted in accordance with the British Psychological Society's (BPS, 2009) ethical guidelines and principles, which require researchers to act with respect, competence, responsibility and integrity to ensure the psychological wellbeing and dignity of participants. Some have suggested, however, that the BPS' list of ethical guidelines can come across a bit like a procedural shopping list to tick-off, downplaying the idea that ethical issues are actually embedded within every stage of the research process (Kvale & Brinkman, 2009). With this in mind, I have therefore chosen to take Nelson's (2010) lead and present the ethical considerations and decisions I have made in terms of, firstly, the conception, secondly, the design and implementation and, thirdly, the write-up of this study.

3.5.1 Conception of The Study

In line with my critical realist position, I do not consider the production of knowledge to be neutral. Indeed, having been influenced by the feminist writers I have read (e.g. Boughtwood & Halse, 2010; Holmes, 2016), who themselves will have been influenced by writers like Foucault, I see knowledge and power to be immutably connected. Power is based on knowledge but it also makes use of it. Further, power simultaneously reproduces knowledge by shaping it to fit its own agenda.

Thus, by deciding to focus on the experiences of individuals who dropped out from treatment for anorexia, my aim has been ensure that, not only did my participants benefit from the research process, but also that the knowledge produced could be used to benefit a broader group of others diagnosed with AN, such as through it being disseminated in the media and applied to clinical practice.

3.5.2 Design and Implementation of The Study

In order to ensure my participants benefitted from their involvement, I had to consider how the study's design might impact on them and, here, informed consent was perhaps the most important ethical consideration of all. I made sure participants had several opportunities to reconsider their involvement before taking part. My first email contact with them involved detailed description of the study procedure, as well as the possible risks and benefits involved (see Appendix 4). I then spoke with them over the telephone and, upon confirming their eligibility (see Appendix 6), talked them through the process again and answered any questions or concerns they may have had. After this, we communicated by email to finalise and confirm dates for interview. This staged process took a number of weeks, giving ample opportunity to ensure informed consent. It was also further enhanced by our discussing the research and signing an informed consent form (see Appendix 5) on the day we met, immediately prior to interview.

Another vital consideration was how to ensure participant anonymity. Smith (2010) suggests it inappropriate to assure participants of confidentiality, given how others will see their data in the write up of the research. Rather than confidentiality, it is their anonymity that must be ensured. I did this by allocating pseudonyms to individual participants and using these across all written documents. I also removed or modified any data that could potentially identify them (e.g. location of treatment setting, age, job description). Informed consent forms, printed transcripts and a master list of pseudonyms were kept in a locked filing cabinet. Meanwhile, my analysis was held, along with digital copies of the transcripts, on a password-protected laptop to which only I had access.

A final design-based consideration was my duty of care toward the participants, and also toward myself. My duty of care toward the women participating was especially important given they represented a vulnerable population and I was keenly aware that any psychological distress caused by their involvement could result in very real damage to their health. I felt that my experience as a trainee counselling psychologist gave me the skills I needed to conduct the research sensitively. I also hoped that the health risk screening and the thorough consent process meant that the potential for risk was minimal. Despite this I recognised that participation still had the potential to cause discomfort. There were a couple of ways in which I addressed this. Firstly, I encouraged the participants to take the lead in the interviews, giving them considerable room to share their accounts in the way they preferred. Secondly, on the one occasion where a participant did display signs of distress (i.e. crying as she recalled her hospital treatment experience), I took the time to re-confirm whether she was comfortable continuing the interview. Following each interview, I also provided participants with a debriefing. I checked whether they had experienced any unanticipated distress and let them know that they could contact me or my research supervisor should they have any concerns related to the research. They also received a debriefing sheet that included a list of relevant sources of personal support should they wish for it (Appendix 8).

Measures to ensure my own safety were also considered. Prior to each interview, the research officer was notified of the location and time of the interview, as well as the estimated finishing time. Once I had completed the interview, I then contacted the research officer to confirm all was well. In terms of my emotional resilience, many years had passed between my engaging in eating disordered behaviours and my carrying out the research interviews. However, as discussed below, I made active use of a reflective journal to ensure I was adequately considering my thoughts and feelings as they arose during the research process.

3.5.3 Write up of The Study

Finally, there were important ethical issues to address in terms of the write up of findings from my study. During the transcription process, I did my best to ensure the data remained as grounded as possible in the participants' original phenomenological accounts. Similarly, during the analytic process, I spent a great deal of time sifting through the data in an effort to locate its meaning, and also to select the excerpts that most clearly articulated the voices of my participants.

3.6 Quality Criteria in Qualitative Research

Over the last few decades, researchers have come to recognize the value of there being consistency between the epistemological positioning of research and the criteria used to evaluate it (Willig, 2008). Indeed, while validity and reliability are appropriate criteria for evaluating research that assumes a direct relationship between research and an external 'reality', they do not work so well within, for example, a critical realist paradigm. This is because, while critical realism considers research-based knowledge to reflect some 'truth' about the world, it also considers a large element of construction to be involved due to the inevitability of researcher-participant subjectivity.

These concerns over compatibility have resulted in a number of researchers creating guidelines that exclusively evaluate the quality of qualitative research. Smith et al., (2009) recommends Yardley's (2000) guidelines for being accessible and adaptive, and for being easy to apply across all types of qualitative research. Yardley (2000) offers four principles for assessing quality within qualitative research: *sensitivity to context*, *commitment and rigour*, *coherence and transparency*, and *impact and importance*. There are several ways in which I have aimed to fulfil each criterion, and I discuss these in detail within the Discussion Chapter (see 5.3.3).

3.7 Reflexivity

Finlay (2003) refers to reflexivity as *"the project of examining how the researcher and inter-subjective elements (between researcher and participant) impact on and transform research"* (p.4). She goes on to suggest that, for qualitative researchers to foster self-awareness of these inter-subjective dynamics, it is important that they adopt explicitly self-reflexive practices.

My understanding of reflexive practice has been informed by Eatough & Smith's proposed use of the 'hermeneutic circle' within IPA, and with Finlay's (2008) description of reflexive practice being like a *"dialectical dance"* (p.3). Some authors, influenced by Husserl's description of the 'phenomenological attitude', encourage researchers to reflexively restrain their preunderstandings in order to make sense of phenomena. Finlay (2008), however, points out that the researcher's understanding of their own experience can be positively exploited, enabling them to move into and reflect more intimately on the lived experience of others. Willig (2001) further suggests that the knowledge and assumptions the researcher brings into the analysis are 'necessary preconditions' for making sense of their participants' experience.

To this end, I have reflected on my being located within the study as, not only a researcher and trainee Counselling Psychologist, but also a former anorexic and patient. Indeed, having been diagnosed with anorexia at 15 and having subsequently run the gamut of treatments – from inpatient to outpatient, and with a variety of psychiatrists, psychologists, family therapists, dieticians and counsellors – I am very much *"embedded in the research process rather than a distant observer"* (Charmaz, 2008, p.166).

This of course suggests that my interest in the research topic, as well as the manner in which I carried out the research, will have been influenced by my own experiences of, and feelings about, treatment. It is worth noting then that I feel largely ambivalent about the time I spent in treatment for my eating disorder. I suppose that this is because, while many of those who treated me seemed highly skilled, treatment itself never drew from me a sustained motivation to recover. On the contrary, treatment more often motivated me to get worse rather than better: it offered witnesses to my self-destruction; something of which, at my worst, I was perversely proud.

When I became serious about recovery, I also decided to end treatment. For me, a treatment that exclusively addressed my eating disorder behaviour acted more as a trigger than a cure and, as such, I felt I needed to remove it from my life, along with everything else that anchored me to an anorexic identity. Of course, this isn't true for all – or even most – it's one experience of many. It did, however, influence my desire to understand why so many others also dropout, especially today, in a climate where demand for treatment is high and NHS waiting lists grow ever longer.

Within the literature, it is widely reported that dropout from anorexia treatment evidences lack of desire to recover and predicts future crisis. The onus also seems to be placed on character deficits in the sufferer: it is because of flawed characteristics that they are 'non-compliant' with treatment protocols, and it is because of flawed characteristics that they 'fail' to recover. My preconception, undoubtedly shaped by my own treatment experience, is that eating disorder sufferers are being misrepresented here. Thus, I have been curious to hand over the mouthpiece to them themselves, so that other questions about why and how and when drop out occurs could also be raised, and maybe even answered. It has been said that anorexics use their bodies to convey that which they could not say in words (Hornbacher, 1998). My hope was that here, perhaps, they could.

I kept a self-reflective journal (Morrow, 2005) throughout the research process to help me become more aware of my own preunderstandings and so that I could process any personal responses I had to the material I uncovered. I also explored reflexivity within the meetings I had with my supervisor, and she provided feedback on whether my interpretations seemed more prompted by the data itself or by my preunderstandings.

In terms of more functional elements, my position as a doctoral researcher will likely have had an effect on how participants responded to me, given its association with institutional power. Conversely, the shared gender experience I had with participants could have redressed the power differential to some extent. Tang (2002) suggests that when the interviewer shares the same gender as the interviewee, it can help build rapport and facilitate closeness.

My body shape will also have likely had an effect on the interview process. Research has highlighted ED patients' tendency to observe and make assumptions about their female therapist's body, drawing conclusions about her behaviour and character which then impact on the extent to which they are willing to open up and engage (Rance, Clarke and Moller, 2014). I expect a similar dynamic would occur in interviews with ED participants as, similar to therapy work, they are required to share of themselves and trust that their accounts of eating and weight distress will be received with compassion. Perhaps, had I been overweight or obese, participants would have assumed me to be less empathic about their anorexia experience, or accepting of their decision to dropout from treatment; and, had I been underweight, they may have worried that I was judging them for not appearing more ‘anorexic’. My sense though is that, by being neither of these, I appeared more trustworthy and less judgmental to the participants than I might have done otherwise (see Eisinga, Grotenhuis, Larsen, Pelzer & van Strie, 2011).

This finally brings me to a reflection on disciplinary issues (Wilkinson, 1988). I have already presented some of the major disciplinary factors that I believe to have shaped my research (i.e. my stance on the status of phenomena, and my position as researcher), but perhaps the most important consideration of all is the political purpose of the research. What have I wanted to achieve? From the start, I have seen the potential benefit that Counselling Psychology can bring to the treatment of eating disorders and other more ‘medicalised’ mental health conditions. My key political purpose within the research has been to highlight this potential. I believe the study fits with Counselling Psychology’s challenge to normative patterns of thinking, particularly its critique of the medical model that dominates mental healthcare (Bury & Strauss, 2006; Strawbridge & Woolfe, 2003). The medical model tends to ignore the lived experience, social context, and psychological impact of treatment. A key purpose of this study has been to redress this issue in some small way, with regard to the experiences of those diagnosed with anorexia nervosa.

3.8 Summary

This chapter reviewed the study’s methodology and method. IPA was chosen as it was considered to be the method best suited to meet the study’s aims and epistemological positioning. This section also discussed how the study was carried out and its data analysed, as well as issues of reflexivity, quality, and other ethical considerations.

Chapter 4. Analysis

This chapter explores the four superordinate themes that developed from the analysis. Taken together, they offer one possible account of how those diagnosed with AN experience treatment for their condition and make sense of their decision to dropout. The account seeks to highlight the various perceptions reflected across the dataset, including indicated similarities and differences. Due to the volume of data, it does not, however, attend to every issue raised nor every aspect of experience. Themes were developed in accordance with their perceived salience and relevance to the research topic. They are also those I considered most novel and, hopefully, interesting for the reader.

Relevant quotations[9] from participants are incorporated throughout my commentary in order to illustrate and ground the themes. As Smith et al. (2009) observe, integrating data with analysis aids transparency. Connections to existing theories and literature are not made at this point, instead these can be found in the Discussion Chapter that follows. The aim of this chapter is to reflect directly on participants' experience, allowing the reader a window on their world.

Considerable care has been taken to remain close to the data, with me having returned to participants' original accounts throughout the analysis. Nonetheless, what I present remains a subjective account, the analysis being a co-construction of meaning between participants' data and myself, as researcher. Indeed, another researcher may have drawn upon different themes and presented different extracts.

4.1 Overview of Themes

Superordinate Themes
Becoming 'The Anorexic': Identity and Belonging
More Than Meets The Eye: The Unseen Subjective Experience
Disempowering Forces: Control and Chaos Within The System
Protest and Protection: Dropping Out from Getting 'Worse'

Table 4: Overview of superordinate themes

The first superordinate theme describes participants' experience of becoming increasingly focused on their 'anorexic' identity and achieving acceptance and belonging through fulfilment

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[9] These are verbatim extracts, taken directly from participants' interview transcripts, with the participant's pseudonym and the transcript's line number referenced alongside e.g. (Maggie:200-204).

of an ‘anorexic’ role. The second superordinate theme describes participants’ experience of treatment failing to acknowledge their subjective experience, be that due to individual team members lacking psychological awareness or due to the standardised, symptom-focused approach of the program itself. The third superordinate theme centres on participants’ description of a treatment approach that was experienced to be excessively controlling and/or chaotic.

These first three superordinate themes represent prominent aspects of participants’ treatment experience. The final superordinate theme then explores the meaning given to their eventual decision to dropout, framing it as a consequence of the experiences described in the preceding themes.

The four superordinate themes also contain a number of subordinate themes (subthemes). From a phenomenological perspective, the nature of experience is indivisible, so any division I have made is not intended as literal. Rather, it is meant simply to facilitate the comprehensive presentation of participants’ experiences and reflects the process by which I have made meaning of them. Please refer to the table below for a summary of the superordinate themes, their subordinate themes and the participants whose accounts contributed to their development.

Superordinate Themes	Subordinate Themes	Contributors
Becoming ‘The Anorexic’: Identity and Belonging	Identity and The Anorexic Diagnosis *“That is what you do when you have an eating disorder… so I should do that too”*	All Participants
	Social Acceptance and Belonging *“There was a community…I felt like I belonged”*	All Participants
More than Meets the Eye: The Unseen Subjective Experience	Professionals Lack Psychological Awareness *“They were just absolutely clueless”*	All Participants
	Standardised Symptom-Focused Interventions *“They keep you ‘til you get to a magic weight”*	All Participants
Disempowering Forces: Control and Chaos within The System	The Controlled Patient *“It’s really hard, because you just feel like a prisoner”*	All Participants
	The Unsupported Patient *“You can either see the person who's never here, or you can join the end of the waiting list”*	All but Taryn
Protest and Protection: Dropping Out from Getting ‘Worse’ *“I had to get out, they were making me worse”*		All Participants

Table 5: Summary of all themes and their participant contributors.

In an effort to hold the tension between being sufficiently psychological and interpretative, whilst also maintaining connection with participants' lived experience, the titles of the themes marry the language of psychology with the words of the participants themselves.

While each theme addresses particular issues within participants' accounts, there are also intimate and intricate relationships between the themes. These are outlined in greater detail at the close of this chapter.

4.2 Becoming 'The Anorexic': Identity and Belonging

This first superordinate theme examines participants' accounts of their increased identification with, and seeking of acceptance through, anorexia while in treatment. While they did not attribute their dropout to this directly, in hindsight, their perception that treatment enabled an 'anorexic' identity had them conclude it was all the more warranted.

4.2.1 Identity and the Anorexic Diagnosis

"That is what you do when you have an eating disorder…so I should do that too"

Taryn, line 65

This subtheme considers the extent to which participants accepted their diagnosis and the impact it had on their identity and behaviour in treatment. All experienced concerns about not being 'sick enough' for treatment and used other patients as a barometer against which to compare their 'anorexic' status. They also felt an internal pressure to adopt the disordered behaviours they observed. This pressure seemed born of a need to maintain, or conform to, the perceived role of 'anorexic' to justify their place in treatment and gain acceptance from their peers and team.

Like all participants, Taryn doubted her diagnosis at the start of treatment and distinguished herself from other patients:

"I didn't think that I was ill and I didn't think that I was like all of the other people on the ward." (Taryn:54-57)

Notably, this perception of difference caused her concern:

"People were doing behaviours at the dinner table, and you are like: 'Oh…That is what you do when you have an eating disorder, maybe there is something wrong with me, because I am not doing that so I should do that too.'" (Taryn:65-69)

Her assessment that that is what you *do* when you have an eating disorder suggests treatment informed her belief that her diagnosis carried with it a social role and associated norms. She went on to describe feeling pressure to conform to these lest it appear she have something "wrong" with her. This pressure resulted in what she described as:

"[…] a <u>new version</u> of anorexia, where I was doing different things, I could hide it better and really just started losing weight again, and again, and again and again." (Taryn:70-72)

The 'new version' of anorexia she developed in treatment seemed worse than the version she had before – with her description of now being able to *"hide it better"*, suggesting increased isolation, and her repetition - *"again, and again, and again and again"* – suggesting her weight loss to have become unrelenting. Overall, it seems Taryn went through a process of doubting her diagnosis and then, due to perceived pressure to fit the 'anorexic' role ascribed her, adopting new behaviours that worsened her condition.

Like Taryn, Tali's perception she was less visibly 'eating disordered' than her peers gave rise to a conscious adoption of their behaviours. She was initially diagnosed with EDNOS ('Eating Disorder Not Otherwise Specified' in DSM-IV, 1994) and she described how, encountering other ED patients for the first time, she associated her diagnosis with failure:

"I think, to be honest, cos I'd never met anyone with an eating disorder before going into hospital and I think that actually made me worse because I was finding out other people's habits. I was becoming a little bit competitive especially as I had EDNOS as opposed to anorexia, so, I actually felt like I was a bit of a failure because of my weight and things like that." (Tali:17-21)

Because the main diagnostic distinction between AN and EDNOS was weight-dependent, it seems Tali viewed her diagnosis as evidence she had 'failed' to lose as much weight as those patients who had been diagnosed with AN. Understandably then, when EDNOS came to represent failure, AN came to represent success. She described how she increasingly restricted her food over this period, eventually leading her to also be diagnosed with AN. It seems this provided the social validation she was looking for:

"At that stage I was really pleased. The sense of satisfaction for me to have lost enough weight." (Tali:55-60)

So, as with Taryn, Tali's belief she did not fulfil the 'anorexic' role supposedly expected within treatment, elicited a motivation to do so to gain acceptance, and a resultant worsening of her disordered behaviour.

Suri described how her own difficulty identifying as ‘anorexic’ affected how she perceived her team to view her:

“[…] because it’s such a weird thing, not to be able to eat, you keep thinking you must be doing it deliberately. As you probably know, it’s always a continual thing that ‘I’m a fraud, I could probably eat if I really tried.’ So there is definitely a constant thing of feeling a fraud. And so I’m sure some of it is being projected from me onto them: ‘They think I’m a fraud. They think I shouldn’t be there, I’m too fat.’” (Suri:373-377)

Despite her concern others viewed her a fraudulent ‘anorexic’, she did not explicitly adopt other patients’ disordered behaviours in an effort to conform, as other participants did. However, it seemed to me that she too felt a pressure to conform, she was perhaps just less conscious of this than the others. She described how, when first admitted, she overheard patients telling staff they were going to ‘throw up’ their lunch and that, because no one stopped them:

“[…] it was like one of the only times I’ve ever tried to throw up food, because my mind just got like destroyed that first week and I didn’t know what I was doing” (Suri:287-288)

As can be seen, she *did* pick up new disordered behaviour from her peers, she was just less explicit about *why*, saying only that her mind had been temporarily “destroyed” and she therefore did not know what she was doing.

Caroline recognised that she had an eating disorder relatively early in her illness. However, her first encounter with ED services changed the way she perceived her condition and, as with the others, increased her desire to conform to perceived ‘anorexic’ social norms:

“I went to an eating disorders’ service […] and I saw someone there and they told me that until I was a BMI of about 13 that they wouldn’t take it seri… well not take it seriously, but that it wouldn’t be an issue […] At the time I was just going because I was encouraged to go there and I was ‘oh okay, I’ll go get help’. But it just gave me a goal...” (Caroline:10-20)

In an apparent effort to show that there was, indeed, an “issue” warranting recognition, she continued to lose weight. She was eventually forced to leave her studies and, upon returning to her hometown, entered treatment. Once there, she too distinguished herself from other patients, seeing them as more unwell:

“[…] to me it was just something like, I didn’t need to eat that. I wasn’t as poorly as these other people and I didn’t wanna do it.” (*Caroline:136*)

Furthermore, she described how comparisons with peers led to the worsening of her condition:

“I learnt to <u>be</u> anorexic the first time I went in. Because I’d learnt, I’d already known so many things, but suddenly all my fears got added to by nine other people’s fears. Which maybe were different to mine. So, I learnt even more things that were wrong and how to get away with stuff in the hospital. How to lower calories by like walking ‘round a room, so if when they do check, you’re like, ‘I’m just going to the bathroom’ and things. But it was really horrible.” (*Caroline:152-157*)

The way she describes how *“horrible”* it was to adopt other patients’ behaviours suggests an internal conflict, on one hand feeling compelled to act but, on the other, feeling dreadful doing so. It appears, like Taryn and Tali, she felt a pressure to meet the perceived ‘anorexic’ standard set by other patients, throwing into conflict her motivation to recover. It is interesting she says that she learnt to *“<u>be</u> anorexic”* in treatment as it seems to distinguish *having* anorexia from *being* anorexic. She already *had* anorexia when she began treatment – in the sense that it was AN for which she was being treated – but she felt herself to *become* an anorexic only later, signifying a moment during treatment when anorexia became more than just a diagnostic label, it became an identity.

She later refers more directly to this notion of anorexia as identity:

“[…] anorexia is so your identity that it's scary to lose that. Like people always…I've read so many things of people who are like, 'oh I'm terrified of losing it, cos who am I if I'm not an anorexic, if I'm not the anorexic girl, if I'm not the thinnest one in the room, who am I?'" (Caroline:1097-1101)

With this perspective, receiving treatment alongside numerous other ‘anorexics’ - who equally like to distinguish themselves by being the ‘thinnest one in the room’ - could present a particular challenge. Indeed, participants spoke of a competitive dimension to peer relationships in treatment. Maggie observed:

"When groups of anorexic people get together, we are a bunch of competitive bitches [laughs] (Maggie:1099-1104)

She gave the following description of her own competitive behaviour:

"[Over-exercising] definitely got worse being there. Because it's then other people started copying me. So, if I'd be standing up, okay, other people started standing up as well. And then it would just be this weird thing of, well I'm not sitting down, she's not sitting down [laughs]. So,

I used to... I think, I set off other people and then that set off me even more and then, yeah." (Maggie:351-356)"

Her laughter suggested she found her whole thought process incredulous now she was no longer subject to the social pressures of treatment. But she paints a clear picture of a mutually reinforcing spiral of disordered behaviour that occurred between her and her peers, and that seemed to develop from her perceived need to maintain an ‘anorexic’ identity and role within the group.

4.2.2 Social Acceptance and Belonging

> “There was a community…I felt like I belonged”
>
> Taryn, line 85

While participants initially felt distinct and separate from others within treatment, all but Suri gradually developed a sense of shared identity and, with that, acceptance and belonging. This was experienced positively, but there was also recognition it reinforced their ‘anorexic’ identity, undermining motivation to recover.

For Tali, she came to accept her diagnosis because of her peers, recognising in them similar patterns of thinking:

"[…] it wasn't until I was with other people that had really similar thought patterns that I thought this must be an illness because it's so... you have so much in common. (Tali:450-458)

It seems this developing identification allowed her to feel supported by her peers, something she credits to her continuing treatment, despite its perceived inadequacies:

“*The only reason I kept going for as long as I did was because I got such good strong peer support from the other patients" (Tali:275-276)*

Later in the interview she observed how hard it is for those without personal history of an ED to understand the experience:

"It is so difficult for people who do not suffer from an eating disorder to possibly know what goes on mentally for someone with an eating disorder" (Tali:438)

It is little wonder then that she developed an affinity with other patients, perhaps feeling uniquely understood by them. As she suggests later, this affinity might not be a productive reason to remain in treatment, however, particularly when the environment fails to challenge ‘anorexic’ status quo:

"I had nothing better to do anyway. Just go with the flow. And really, a lot of people do get kind of institutionalised and there's not the incentive cos it's quite… It becomes actually quite safe, especially if […] they don't really challenge you, foodwise and you know, you go see your friends and something to do. And you're not really getting a lot out of it" (Tali:903-909)

Her choice of phrase – *“just go with the flow”* – conveys a passive sleepwalking through treatment, at odds with the self-aware, active approach one might assume necessary for recovery-orientated change. Indeed, it seems that, combined with an unchallenging treatment environment, emotional dependency on her ED peers meant any *“incentive”* for change transmuted into its opposite: that is, an increased desire to maintain the safety of the familiar – the routine, the friendship, the institution and so, ultimately, her role of ‘anorexic patient’.

Taryn also developed a camaraderie with her peers in treatment. Indeed, when considering dropout, her greatest concern was for the loss of community:

"I had been there for a year and I had kind of created this community…well there was, I guess, there was a community of people who were really struggling with their eating disorders in the unit and that is where I felt like I belonged. So the thought of leaving was quite overwhelming" (Taryn:84-87)

Such was her dependence, it was one she maintained, even after her initial dropout:

"At that point I was completely avoiding doing anything social with anybody, mainly would not drink, would not go out for any dinners with friends, just would not do any of those things. And I had like a core group of friends that I had either met on eating disorder sites on the internet or from the hospital. And they were the people that I hung out with.” (Taryn:203-205)

Taryn highlighted the isolating nature of her disorder, having becoming increasingly avoidant of social situations for fear of being around food. Understandably, she did not enjoy her isolation and so she looked to others who shared her fears so that they might keep each other company. She acknowledged, however, that these relationships enabled her disordered behaviour:

“*We didn’t go out in the evenings, we sometimes stayed at each other’s houses and made ridiculous cocktails and not eating anything. And it was really just, probably not great health-wise." (Taryn:206-207)*

However, she also pointed out:

"I don't think it was helpful, but in other ways I think it was helpful, because I had people who understood things and I think if I didn't have anybody, I probably wouldn't have coped…" (Taryn:213-215)

Like Tali, Taryn stressed the importance of having understanding others to help her 'cope' with the isolating experience of anorexia. At this point, Taryn only felt understood by other eating disordered individuals and so she naturally gravitated toward them, thereby increasing her dependence on an 'anorexic' identity and further separating her from those who, had they been able to convey more empathy, might have been a healthier influence.

Maggie was the only one to describe a sense of belonging that developed through her relationship with her treatment team - who had become *"a bit like family" (Maggie:425)* - rather than with her peers. Their relationship seemed similarly enabling, however:

"The relationships that I'd build with each person that worked there depended on me being this small victim, the sad little anorexic girl that couldn't feed herself and they would be caregiver or whatever. And I didn't feel like I could ever change that, like I could ever be anything other than this small anorexic kind of role." (Maggie:630-635)

She highlights that the continuation of the relationships she'd built *"depended"* on her fulfilling the *"small victim"* role. That she described feeling she could not *"ever change"* shows how much she prioritised the continuation of those relationships – she could not change as she could not risk jeopardising the relationships she valued. Indeed, as she stated, her team had become like family, with the implication being that she was cared for; that she belonged.

Unlike the others, despite not making much progress within treatment, Maggie had not wanted to dropout in the weeks prior to doing so. This may have been due in part to the sense of belonging she had forged with her team. Indeed, it was only when she felt rejected by them that she withdrew. Having discovered she was continuing to over-exercise despite numerous interventions, her team issued an ultimatum: try and kerb the exercise or leave the program. Maggie interpreted it as a sign they did not like her after all and wanted her to leave, obliterating any sense of belonging she had previously felt. She relates this directly to her decision to dropout:

“I just figured that if they were telling me to go then, they don’t like me [laughs]. I know it wasn’t like that. I know they’re professionals. And like whatever. But it just felt like […] ‘You don’t like me anymore, I’ll leave.’” (Maggie:435-439)

She spoke of how it was only when she did leave that she was finally able to break free from the “small victim” role she had taken up in treatment:

“I stopped being that role. And I did everything I could to just push that away. And when I went [abroad], just in anyway when I recognised that kind of role, I would push against it. So, I would try and be as loud and outgoing as I possibly could and stand up for myself […] And I just feel like I created a different role. I was a different person. And so that made it easier to… like, it didn’t make the eating disorder go away. But it made it easier to not act like I had an eating disorder.” (Maggie:636-646)

Maggie makes explicit what the others merely implied – that is, that they felt an expectation to fulfil a particular ‘anorexic’ role while in treatment – one which Maggie describes as *“very small and quiet”* and passive, letting *“people walk all over me” (625)*. Maggie observed that, while taking on a more assertive role following discharge did not cure her, it did help her improve her behaviours. This suggests that the sense of belonging she secured within treatment directly enabled her eating disorder, dependent as it was on her fulfilment of an ‘anorexic’ social role. Indeed, she feels that she would revert to type if she returned, even now:

“[…] especially if it was the same staff that were there, I would just fall straight back in to playing that role. And I feel like I’m not the only one that gets stuck in that role. I’ve watched a lot of people do it… but I don’t think they’re aware of it. So, that’s why, I’m really not sure how much good eating disorder treatment does.” (Maggie:769-773)

4.2.3 Summary

As illustrated, all the participants disputed their diagnosis to one degree or another, impacting on their identity and behaviour within treatment. It seems, the more they doubted their diagnosis, the greater pressure they felt to conform to what they perceived to be ‘anorexic’ social norms. Most also spoke of a competitive dimension to their relationships with peers in treatment, which seemed to develop from a need to consolidate their ‘anorexic’ identity in an environment shared by others who identified in the same way. All but Suri eventually found a sense of belonging; however, it depended heavily on their continued fulfilment of an ‘anorexic’ role, endorsed by the treatment environment, thereby reinforcing disordered beliefs, behaviours and their ‘anorexic’ identity.

4.3 More Than Meets The Eye: The Unseen Subjective Experience

This superordinate theme explores participants' perceptions that their treatment failed to acknowledge their individual, lived experience. Specifically, it was felt many team members lacked psychological awareness, displaying insensitivity and indifference. They also considered the program itself to lack focus on their individual experience, with too heavy an emphasis on clinical symptom-management and too little focus on individual need. For many, the perceived disregard for their experience reinforced dysfunctional beliefs that perpetuated their disorder, such as the belief their needs were unimportant or that others judged their value by their weight.

4.3.1 Professionals Lack Psychological Awareness

"They were just absolutely clueless"

Tali, line 248

Participants' accounts of professionals lacking psychological awareness fit, broadly, within one of two categories. The first relates to their apparent ignorance for the psychological aspects of AN, evidenced by insensitive, ill-judged comments. The second relates more to perceived indifference toward participants' psychological state, evidenced by dismissing their opinions, and prioritising others.

Tali labelled healthcare workers within her daypatient treatment program *"absolutely clueless" (Tali:248)*. When pressed to elaborate she said:

"This is gonna sound awful. But they're not very intelligent. They're not very tactful. And they just have… they talked about diets in front of us. They talked about really inappropriate things." (Tali:379-381)

In referring to their tactlessness and apparent lack of intelligence, she indicated an ignorance for how their words and actions might be interpreted by someone with AN. Tali gave an example of an occasion a staff member's comment reinforced her desire to restrict:

"They used to say, cos there was an option for a jacket potato for lunch. I tell you what, no one picked the jacket potato. Cos, they would say "gosh you know, sometimes those jacket potatoes...", these are the staff, "they come so huge I can't even eat all of it." You know, well I'm never gonna order that." (Tali:244-248)

For Tali, the staff member's claim that they were unable to eat a whole portion of something that, conceivably, *she* could eat seemed to threaten her anorexic identity. The staff member was likely unaware that Tali interpreted her comment as a challenge to prove that, if the staff member struggled to eat something, then she, the 'anorexic', must struggle to eat it *even more*. Tali's experience suggests that naivety about this type of anorexic 'logic' can be dangerous amongst staff members, especially when they are the one in charge of overseeing meal times.

Maggie also described comments from her team that appeared to be naively insensitive. She gave the following example of one such occasion:

"[The dietician] was just <u>really</u> insensitive. She just didn't <u>get it</u> at all. So, she'd be like: 'oh you need more in your snacks, shall we add some biscuits?' And I'd be like: 'I don't like biscuits. I don't feel comfortable eating biscuits.' And she'd be like: 'why not?' Biscuits are a good source of fat and… whatever'. And I'd be like: 'I don't care, I don't want biscuits. I don't feel comfortable eating them. I wouldn't eat biscuits at home, I don't want biscuits.' And she'd be like: 'well, you need to have something, you don't want to <u>not</u> put on weight, do you?' And you'd be like: <u>'are you stupid</u>?!'" (Maggie:806-812)

Of course, central to the role of any dietician treating anorexia is their encouragement that the patient increase the variety and quantity of food in their diet; but it did not appear to be the recommendation that Maggie found insensitive, rather the manner in which it was provided. For Maggie, the dietician's comments betrayed a failure to recognise her subjective reality – one in which she was very ambivalent about gaining weight – wrongly assuming that *of course* she would want to gain weight in pursuit of recovery. Unlike the previous example with Tali, the dietician's comment did not appear to trigger Maggie, but it did alienate her, leading her to dismiss the dietician as *"stupid"*. This points to the challenge within ED treatment to balance behavioural intervention with psychologically-informed personalisation – something which is discussed in the next subtheme, and examined further within the Discussion Chapter.

Suri also described occasions where she found professionals to lack understanding of the psychological aspects of AN. When she first entered daypatient treatment, she had weekly sessions with a psychologist whom she described as *"very validating" (Suri:314)* of her experience. But the psychologist left after a few months, at which point Suri's therapy was passed to an occupational therapist. Suri felt that, in contrast with her predecessor, her new therapist lacked appropriate insight:

"I just kind of got the impression that she didn't actually get anorexia, and how it operated. (Suri:200)

As mentioned previously, Suri often doubted that she was ill and deserving of support. While her psychologist had successfully challenged her self-doubt, her new therapist often made comments that seemed to reinforce it. Suri described one such occasion:

"I said something about how things had been difficult, and she was like 'oh but you've obviously been eating well, you know, your weight's up', or something. Which…and I'm sure from her point of view, it was perhaps a misguided way of saying, 'oh look on the bright side, you know, don't be down, things are good in some aspects'. And I can see it, but it didn't feel even remotely like that at the time, it just felt like completely invalidating." (Suri:183-188)

Suri was quick to acknowledge that her therapist would not have knowingly invalidated her experience, describing her intervention as *"misguided"* rather than malevolent. However, it seems the therapist's poor understanding of the psychological aspects of AN meant that, even with good intent, she overvalued the relationship between Suri's weight and her wellbeing and lacked the insight into Suri's psychological state to anticipate how dismissive her intervention would appear.

Taryn also perceived members of her treatment team to dismiss her feelings and opinions, to the extent where she *"just completely lost trust that they were bothered about how I was" (Taryn:622-628).* Her comment about having *"lost trust"* indicates that her team's apparent indifference toward her subjective experience undermined any alliance they might have had, with her concluding they did not care about her wellbeing. She also indicates the effects it had on her self-perception – their apparent dismissal leaving her feeling like what she had to say did not matter. As with Suri, this conclusion mirrored pre-existing beliefs she had about herself. She describes these here:

"Even though there was part of me that felt like what I had to say was important, there was also a big part of me that didn't feel like any of me was important. So I think asserting myself, taking up space, all those things, was particularly difficult for me, especially when things were really bad. Because for me it was just all about: 'Well, you are not...you don't deserve any of those things. Your needs are the least important thing.'" (Taryn:631-638)

Taryn suggests that her eating disorder itself encouraged in her the belief that her needs were unimportant. She describes the internal conflict this created – while one "part" of her wanted, quite naturally, to assert herself to get her needs met, another "big part" believed she did not "deserve" to. She recognised this contributed to her difficulty asserting herself within treatment. However, rather than her team acknowledging this psychological dimension and creating an environment that encouraged assertion, they created one that appeared to unknowingly reinforce the belief she should remain passive. One can see how ED behaviours, like food restriction and over-exercise, could be fuelled by the belief that one's needs are unimportant, meaning any perception Taryn had of her team dismissing her experience could also have risked enabling her ED.

Some of the participants also felt staff displayed their lack of psychological awareness in their insensitive prioritisation of others' needs. Caroline, for example, described mealtime interactions with staff:

"We would be told […] they were disappointed in us if we couldn't do it. Or, if we got upset, it was like 'come on, you're upsetting everyone, think about the other people here […] think about all the stress you're putting on your family' [...and…] Because we were all in a dining room together, like 'you're making it really hard for all the other people'. And then you just feel like completely, like almost a small child would. But like, okay, I feel really bad." (Caroline:177-190)

Caroline portrays a situation where, not only was her mealtime distress dismissed by staff, they blamed her for negatively effecting others' experience. Their response – particularly their voicing *"disappointment"* - suggests they perceived her disorder to be one of wilful disobedience, displaying a lack of awareness for the, often conflict-ridden, psychological dimensions of anorexia. Caroline described how the dismissal and public admonishment left her feeling *"really bad"* like *"a small child would".* She reflected on how these negative feelings reinforced dysfunctional beliefs she already had and which undermined her recovery:

"Now that I've got more of an insight into my illness, I felt like a bad person anyway and that was, I was punishing myself anyway. So, being and having that sort of reaffirmed around food, just completely was like detrimental to any form of recovery cos I was just associating again, well I've got to eat because I'm a bad person." (Caroline:191-194)

Here, once again, a lack of apparent awareness from staff for the psychological aspects of anorexia seems to be associated with iatrogenic effects: reinforcing the negative beliefs that give fuel to anorexia.

4.3.2 Standardised Symptom-Focused Interventions

“They keep you ‘til you get to a magic weight”

Caroline, line 399

Participants’ also felt their individual experience to go unacknowledged in the face of a standardised treatment approach that reduced their condition to the ‘physical' dimensions of health and illness. Caroline described the meeting with the dietician that would follow any failure to gain the expected kilo/week in inpatient treatment:

“So you’d sit down and she’d go, we’re putting an increase in. And you’d be like, well I… you’d plead, you’d cry, you’d say you couldn’t do it. It’s too much. I can’t cope, I’m not coping. And she’d be like, ‘I need to put an increase in.’ She just wouldn’t, there was like nothing, she was very cold.” (Caroline:260-265)

Caroline’s description portrays a rigid treatment approach and suggests Caroline believed the dietician to be governed by a set of rules that took precedence over anything Caroline may have to say about her psychological state. The result was Caroline’s experience of her as *“cold”*, a word carrying connotations of being cold-blooded and unhuman.

Maggie similarly described her dietician’s efforts to implement a diet plan as *“pushy”* which meant she *“hated talking about meal plans and diets and like, stuff like that” (Maggie:1014).* Fortunately, she had a contrasting experience with her psychotherapist, who seemed able to adapt treatment in a way that benefitted her:

"He was very, very clever. And he used to do it more like, rather than treating me like a patient like everyone else, he would be like… he knew I was really interested in science. I found neuroscience really interesting and stuff. So, he'd present it more in that kind of way. Yeah, I guess he just treated me a bit more like a person than anyone else ever did." (Maggie: 847-852)

Her psychotherapist was able to mould his approach, allowing Maggie to feel recognised as a person rather than just a collection of symptoms. This helped them broker a more robust working alliance than the one had with the dietician:

“I used to do all of [my meal plans] with [my therapist]. And we would come to our own agreement about it. And then he'd tell the dietician." (Maggie:1015-1017)

Notably, Maggie and her psychotherapist came to their own agreement – developing shared goals and understandings rather than rigidly adhering to a symptom-focused protocol. Some participants however, criticised the fact that they had to contend with a much more rigid regime. When Taryn's care was transferred to a new ED therapist, she was unimpressed by the inflexibility shown:

"She was like: 'You need to do this, I can't work with people with a BMI under 16, you really have to gain it like right now or we don't work with you. And I was literally like: 'What do you want me to do?' So none of it was... I didn't experience it as therapeutic, it wasn't like... you know when I assess my clients, whether they have an eating disorder or not, it is like: 'Okay, what do we want from the therapy? What are we working towards?'... Like: 'What do you need?'" (Taryn:436-443)

Taryn had herself trained as a psychotherapist since leaving treatment, so she spoke from the perspective of both therapist and patient. She clearly distinguished between the approach she took with her own clients and the one she experienced from her therapist. Whereas she described using her clients' own description of their needs as the starting point for therapy, by contrast, she felt her own therapist demanded she meet the needs of the service. These needs appeared entirely focused on her fulfilment of standard weight criteria and did not make any room for the personal collaborative approach Taryn valued.

Caroline, meanwhile, spoke of how her team viewed the achievement of a particular weight to be the singular goal of treatment:

"They keep you 'til you get to a magic weight… They keep saying to you that once you get to this weight, you'll feel really happy and everything will change. Sorry, it's just really frustrating that that's the concept. Because you've lost weight for a reason in the first place. Yet they think when you get back to a weight, you're gonna feel great without any psychological input at all." (Caroline:399-407)

Her sarcastic tone – and reference to *"magic weight"* - emphasised her disagreement with the idea that weight restoration was a curative. She described how frustrating it felt to have this view upheld in treatment, particularly as it failed to consider the motivations of the sufferer, and the subjective function the ED had for them. Her own weightloss first came about as a means of managing her fear of *"not being good enough"* (*Caroline:75*) while at drama school. She also identified as someone with a pronounced *"fear of failure"* and compulsive tendencies *("I just spent my time, like rehearsing […] I could just go on and on and on in the same way that I would then go and restrict my food" (Caroline:76-79*). From her perspective, weight restoration alone would not have ‘magic-ed’ away the subjective function her ED had for her, it changing neither the beliefs nor traits that made her vulnerable.

Tali displayed similar frustration, having noted a pattern in the UK (having previously received ED treatment abroad) on treating only those with pronounced physical symptoms of anorexia:

"That's what annoys me so much, this emphasis on weight because you know it's a mental disease and just because you've got a healthy body weight, it's the torture mentally and physically that you're going through." (Tali:106-108)

Her suggestion is that eating disorders develop and persist as ‘mental’ conditions, and that an individual’s weight therefore provides poor indication of suffering. Indeed, she later stated her belief that the weight-restored ‘anorexic’, while often regarded an example of treatment success, may suffer as much as ever:

“… a lot of people that reach normal weight, are deemed not anorexic anymore. Even though they might still have to go through the same thing...” (Tali:471-472)

Tali’s comments suggest that, within an environment where weight represents the standard measure of sickness/wellness, weight gain can lead to a person feeling their suffering is being ignored. Tali’s own experience showed this to be a difficult evolution:

“See it's difficult because when I was looking really unwell, that was kind of helpful because people would look at me and see that I was ill. Now, even though I still know that I look thin, I don't know really that I look... ill thin." (Tali:463-465)

She makes a clear distinction between *“thin”* and *“ill thin”*, the latter sending a *“helpful”* communication to others about her being unwell. She was not explicit about *why* it was helpful to have others know she was suffering. Perhaps she was able to elicit more caring behaviour when visibly unwell, or perhaps others more readily excused her for struggling with aspects of life they might typically expect her to manage. In any case, Tali’s account suggests weight restoration might be all the more difficult within a treatment environment where the anorexic body is perceived to be the only medium through which suffering can be recognised.

One might suppose psychotherapy offered one place in treatment where participants felt they *could* communicate distress with their voice rather than their body. However, even when therapy was offered, as with Suri, Taryn and Maggie, there was unanimous criticism of its focus on physical symptoms over individual experience. Taryn became very close to her first therapist, who she started seeing while inpatient and continued seeing, on and off, for another three years.

Despite their close relationship, however, Taryn now believes her therapist's focus on symptoms obscured underlying psychological issues:

"I think back to that time and I think that was years of therapy that, I think in some ways clouded the real issues because it was like: 'Okay, what are you eating? What do you weigh?'" (Taryn:300-302)

Taryn had experienced domestic violence as a young child and was only now able to acknowledge its impact on her self-esteem and the part it played in her developing anorexia. She described having never discussed these experiences in therapy, partly because she had not had the language to do so but also, seemingly, because the therapeutic focus had been largely elsewhere – on what she ate that week, or on what she weighed. She believed her therapist's exclusive focus on physical and behavioural symptoms enabled her ongoing avoidance of psychological issues that contributed to her eating disorder, denying her the opportunity to explore and adapt unhelpful beliefs she held about food, need and the self.

She admitted her therapist's focus on her weight also led to conflict, affecting their therapeutic relationship:

"Like all of those things, which I just, were not therapeutic at all, there were certain points where I just refused to be weighed and I was like: 'You are not weighing me!' (Taryn:298-304)

It reinforced her disorder more directly as well:

"I was so terrified of what I weighed and so terrified of, like, anyone knowing that in case it had gone up […] I was that person that who even if my therapy appointment was at 5pm, I wouldn't eat or drink all day, because I was terrified that my weight would go up like ten pounds, because I have had that one drink before I went and was weighed." (Taryn:311-313)

She described the terror of having another person witness her weight gain and attempted to protect against this eventuality by starving herself on days she knew she would be weighed. It suggests she associated weight gain with feelings of shame and being weighed as a form of public judgment. Suri addressed this directly:

"Weighing is judging; to me it's judging. It's not, they say it's maybe like keeping medical care and whatever, but I see it as a massive amount of judgment in it. That then you're not allowed, like my therapist, you're not allowed to have a problem if you've eaten and there's nothing wrong." (Suri:392-395)

Suri believed her weight was read as a quantifiable measure of how deserving she was of support. Understandably then, she described how freeing it was when, after withdrawing from ED treatment, she found a therapist who did not weigh her or otherwise focus on symptoms:

“The situation outside of eating disorders is just so much freeing, ‘cause they’re not weighing you, and making judgments about you […] So if you’re seeing a therapist that’s got nothing to do with any… like you don’t have to prove there’s something wrong by being underweight, so you can eat what you want. And just deal with what’s wrong.” (Suri:389-398)

Like Taryn, Suri described a need to restrict her intake before being weighed, explicitly linking it to having to prove there was “something wrong”. Interestingly, she said she was not usually concerned by her weight, and that it only became an issue when weighed by someone else:

“It’s not actually something I’m hugely concerned about unless someone weighs me. It’s not something that I would kind of necessarily go around doing.” (Suri:492-494)

Again, as with Tali and Taryn, Suri’s preoccupation with weight seemed largely based on concern for other’s reading of it. For each, having others exclusively focus on their weight risked reinforcing the belief they could only communicate their need for support through the public display of an ‘anorexic’ body. This also echoes the perceived social pressure participants had to fulfil the role of ‘anorexic’, raised earlier. Maggie made a link between being weighed and the perception she needed to fulfil certain role expectations:

"I feel like I would just fall straight back into that role of being [‘this sad little anorexic girl’], like that role you play for therapists. So if they weighed me I'd just feel really embarrassed if it went up cos I'd be like: 'oh well they don't think I'm a very good anorexic if my weight's gone up, that's just really embarrassing.' Whereas if I just don’t weigh myself…. at the moment, I don’t weigh myself and no one looks at my weight then… it’s not a problem. Whereas if someone weighed me and I knew what that number was and then I knew it had gone up the next week, then I’d be like, oh, I’ve eaten too much. I dunno, I just feel like it would trigger me a lot to go back into treatment." (Maggie: 729-739)

Like Suri, Maggie was not overly concerned with weighing herself in private. However, once her weight becomes a matter of public interest, as in treatment, it morphs into a perceived measure of her social acceptability. This appears fuelled by the belief she needs to fulfil a particular role – what she called the “good anorexic” – in treatment. As we saw earlier, this role fulfilment brought her a sense of belonging and being cared for. However, as seen here, should she believe she had fallen short, such as on an occasion her therapist noted her weight to have increased, she would feel embarrassed, giving rise to pro-anorexic thoughts about eating too much and triggering disordered behaviour.

4.3.3 Summary

Participants all experienced an approach to treatment that failed to acknowledge their individual, subjective experience; instead prioritising physical need over psychological need, and symptoms over suffering. This experience left participants feeling misunderstood and dismissed by their treatment team, and reinforced dysfunctional beliefs that enabled them in their continued efforts to focus their life around food as a means of coping, and the use of their body as the medium through which to communicate distress.

4.4 Disempowering Forces: Control and Chaos Within The System

This superordinate theme explores two extremes of treatment approach – at one end, coercive-control, at the other, chaotic-neglect. Both extremes impacted powerfully on participants; often quite similarly. Coercive-control had many damaging effects, leaving participants feeling disempowered and punished, and often reinforcing pro-anorexic beliefs, such as the notion they were ‘bad’ and deserving of punishment or that anorexia offered a means of regaining control. When coercion was used as a motivational tactic in place of collaboration it also alienated participants, leading them to withdraw from treatment altogether or else resort to deception to get their needs met.

Most participants also perceived their treatment to be chaotic, particularly in relation to the emotional and psychological support received. Poor planning, communication and frequent cancellations all contributed to participants feeling, similarly, disempowered and unsupported. And, once again, in some instances, a chaotic approach reinforced participants’ pro-anorexic beliefs, such as the notion they were undeserving of care, or that anorexia offered a means of restoring control. The lack of guidance and information participants received within chaotic treatment environments also resulted in them feeling ill-equipped to take charge of their recovery.

4.4.1 The Controlled Patient

> “It’s really hard, because you just feel like a prisoner”
> Caroline, line 384

All participants described their treatment team using coercion as a means of control. Participants felt disempowered and punished by these tactics, undermining treatment motivation and often reinforcing beliefs that contributed to their eating disorder.

Participants found coercive-control a significant feature within inpatient treatment. Caroline and Tali compared their hospital experience to prison (Tali:966; Caroline:378), and emphasised staff’s use of coercive strategies, such as graded restriction on freedoms and ‘punishment’ for bad behaviour. Caroline described one coercive tactic which seemed to capitalise on patients’ fear of being fed through a nasogastric tube:

“They use food as punishment quite a lot. You’d be, if you didn’t finish, like literally scrape your plate clean, they’d nasogastic feed you.” (Caroline:235-237)

This practice is recommended as a last resort to facilitate medical stabilisation in severely malnourished patients (NICE, 2004; NICE 2017). However, from Caroline’s perspective, staff also used it as a means of punishment for minor eating infractions. She described her own experience:

“So they'd hold you down and like feed you, like put it in, put it down your throat and then… and then they'd just leave the room. And you'd just be there feeling guilty and disgusting and hating yourself. And there was no support. There was nobody to talk to. There was nobody who wanted to sit and talk with you." (Caroline:242-245)

She noted the experience stirred up feelings of guilt and self-disgust. It also seems the subsequent lack of support both prevented her from managing these feelings and gave her reason to conclude nobody “wanted” to spend time with her, thereby likely creating a reinforcing cycle of negative feelings and thoughts. She believed that the experience also reinforced negative pre-existing beliefs that contributed to her eating disorder:

“I felt like a bad person anyway and that was, I was punishing myself anyway. So, being and having that sort of reaffirmed around food, just completely was like detrimental to any form of recovery cos I was just associating again, well I’ve got to eat because I’m a bad person.” (Caroline:191-194)

She saw her anorexia to function as a means of self-punishment for being a *“bad person”*. Punitive treatment therefore seemed to reinforce the very beliefs that justified her anorexic behaviour: she is bad and so deserves to be punished.

Tali, who struck me as quite dominant during the interview, became visibly withdrawn and tearful when reflecting on how she too had felt punished while an inpatient:

“I was locked in for the first two weeks, I couldn’t leave the ward and then I got a ten-minute benchmark. It sucks the like... Sorry, I get quite upset about it. And you know I was just in hysterics. I was so unhappy there [tearful]. I really… I don’t want anyone to have to go through that. It was like we had done something wrong and we were being punished.” (Tali:969-971)

For Tali, the most intolerable aspect of treatment seemed her team’s control of her freedoms – with her experiencing being *“locked in”* as an unjust punishment. Like Caroline, she also found the controlling environment counterintuitive:

“There was no control. And also, it was a waste of time. A waste of time for me physically as well, because I just came out and the first thing I did was go ‘they don’t control me anymore.’ So, I really do think that I would not have spiralled the way I did, physically, had I not gone in.” (Tali:973-976)

The loss of control she experienced seemed to create a rebound effect on discharge – giving her the impetus to claw back all the more control to make up for the lack. She had previously spoken about a relationship between her anorexia and the need she had for control (*“it’s a control thing” Tali:596*), so it is in keeping that she turned to anorexic behaviours in an effort to re-establish control following treatment. In this way, as with Caroline, the coercive-controlling approach directly reinforced pro-anorexic beliefs: While, for Caroline these beliefs centred around anorexia fulfilling a perceived need for punishment, for Tali they centred around anorexia fulfilling a perceived need for control.

Taryn also felt the negative impact of a coercive-controlling approach. She describes her response to her new psychotherapist who refused to treat her unless she admitted herself into hospital:

"I just became increasingly frustrated and angry with not… it felt like I was being punished for having a body that I didn't think I had anyway." (Taryn:559)

Like Caroline and Tali, she experienced her therapist’s coercion as unjustly punishing rather than as worry for her physical safety. This was due to her not sharing the view she needed inpatient treatment on the grounds of her weight, and believing hospital treatment would cause more harm than good:

"I knew if I gave up everything at that point, as in if I suspended my studies, it was unlikely that I would find myself in a place twelve plus months later where I actually wanted to go back. I just knew that stripping everything out of my life in the way I was being asked to do would have left me with nothing." (Taryn:545-547)

Unwilling to acquiesce to inpatient treatment, and fearing the coercion would only escalate, she eventually decided to withdraw from treatment altogether. She has not had contact with ED services since, suggestive of the lasting negative effects coercion had on her attitude to treatment.

Maggie also felt coerced by her treatment team, who forbade her from attending school until she restored a certain amount of weight. She was desperate to return to school immediately and so, unable to dropout because of her age at the time, she resorted to deceptive tactics:

"To get everyone off my back I just started lying, a lot. I would put rocks in my socks, drink four bottles of water. Whatever it took to make it look like I was at this 80 per cent when I actually, really wasn't." (Maggie:70-74)

She makes a direct link between her team's coercion – an experience she compared to having them be 'on her back' – and her subsequent *"lying"*. In this way it suggests that, rather than the coercive tactics resulting in positive behaviour change, leading to weight gain, it actually served to shut down lines of honest communication and to new dangerous behaviours, such as water-loading[10], becoming established.

Tali resorted to similarly deceptive and dangerous behaviours in response to the coercive-control she experienced in hospital:

"We used to get weighed twice a week and I would set my alarm for half an hour before. I'd have hidden as much water as I could, downed as much, you know, I mean I'd be drinking 3 litres of water. I'd be wearing things under my pyjamas. I'd be doing everything I could to make sure that those scales meant that I could get leave" (Tali:150-153)

Tali said she did these things to "get leave", suggesting that, while the coercive approach correctly identified her desperation to regain freedom, its withholding of that freedom as a 'carrot'

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[10] Water-loading can lead to serum electrolyte imbalance and cardiac arrest (Vandepitte & Vandereycken, 2008)

to encourage weight gain backfired, as with Maggie. Indeed, Tali suggests the coercion, and her resultant deceit, made her anorexia worse:

"In that five months [in inpatient]… my anorexia just got so much worse. I hadn't been deceitful before because I hadn't needed to. You know I had been eating three times a day and my parents had not pushed me really to eat anything else or different. And therefore, I hadn't had to hide anything." (Tali:108-112)

A certain amount of 'pushing' is necessary for any change-orientated treatment, however, in the instances discussed, it was not perceived to be done in service of achieving mutually shared goals between patient and team, making it coercive. This resulted in participants feeling trapped, punished and alienated, and often contributed to a worsening of negative self-beliefs that reinforced their anorexia and the use of deceptive and dangerous behaviours to ensure their own goals were still met.

4.4.2 The Unsupported Patient

"You can either see the person who's never here…
or you can join the end of the waiting list'"

Suri, line 141

At the other extreme, participants also experienced a chaotic element to treatment, describing frequent cancellations, inadequate guidance and unreliable communication. These elements particularly affected the perceived quality of psychological support they received and gave rise to feelings of neglect, rejection, lost control and disempowerment in recovery.

Maggie said her first therapist "*used to cancel a lot"* which would *"really annoy" (Maggie:98)* her. On further exploration, she admitted:

"I used to get quite wound up about like getting weighed and quite anxious about it and then for her to ring up the day before, like 'oh, there's no appointment this week just come next week instead'. I'd be like, 'eh, okay'." (Maggie:104-107)

In interview, Maggie frequently described feeling *"annoyed"* at her treatment team before indicating the more vulnerable feelings lurking beneath, such as anxiety or perceived rejection. Here she revealed how her annoyance was the result of having to experience needless anxiety in the wake of a now-cancelled therapy appointment, while also having another week to get *through* before she could address it. Her *"eh, okay"* suggests incredulity and hurt that her therapist would be so, seemingly, dismissive of her feelings. This hurt likely undermined Maggie's trust in the therapeutic relationship and left her feeling emotionally unsupported.

Suri described feeling emotionally unsupported too, having had a therapist who frequently cancelled their scheduled sessions at the last minute. She described how she raised her concern with the program manager, only to be told *"you can either see the person who's never here…or you can join the end of the waiting list" (Suri:141).* Beyond the logistical inconvenience caused, her therapists' cancellations also seemed to reinforce pro-anorexic beliefs and behaviours. Suri shared the following extract from her treatment journal, which she had brought to the interview:

"I said: 'She'd been off for about five weeks. So I asked for a discharge, it's the only way I can stop myself from starving 'til next week. No weight loss feels low enough to convey how I feel.'" (Suri:112-118)

As her entry indicates, Suri felt an impulse to respond to her therapist's prolonged absence by starving herself, effectively turning her body into a distress beacon. She was evidently concerned by this – hence asking for a discharge – but also compelled to pursue it, presumably feeling it was the only method of communication she had left at her disposal. It is notable that she doubted any amount of weight loss could convey the extent of her feelings, as it highlights how unsupported she felt within treatment.

On many occasions during our interview, she voiced the belief that others thought her undeserving of support, so it is likely she interpreted her therapist's absence in this light. Her impulse to starve herself can perhaps then be interpreted as an attempt to prove she *did* need, if not deserve, reliable support. Possibly too, starving may have been her means of numbing the pain associated with believing her therapist thought her undeserving. Indeed, toward the end of our interview, she observed that one of the main reasons she restricted was to *"get rid of the noise" (Suri:652)* of her emotions.

Tali experienced similarly unreliable treatment, pockmarked by cancellations and broken promises. She gave the following example from her time as an inpatient:

"Yeah, so there was supposed to be one, one-on-one a week. But that often didn't happen. I would say, that would only happen two thirds of the time because otherwise the psychologist would be away or the… or she'd be ill or something would happen." (Tali:132-135)

Unlike Suri, Tali did not interpret the inconsistent care provision as an indication of her worth.

She was disappointed by the lack of psychological support, however, as she believed it was precisely this support she needed:

"I knew that I needed the mental, the psychology side. I knew that was gonna be what was gonna really. Because I knew my eating patterns weren't so ingrained that I couldn't, you know. But I really needed the motivation…" (Tali:772-774)

Tali recognised her biggest obstacle in recovery was her, at times, poor motivation to change, meaning she needed a treatment that provided consistent support in helping her enhance and sustain it. Indeed, since dropping out of NHS treatment, she has begun paying for private treatment in the hope it might offer more consistent support, allowing her to grow her motivation and take more risks in recovery:

"I guess, the challenges that I've gone through so far, I've been really motivated by certain things. But what I've recognised is that to get freedom in my mind more, I need to go through the things that are most difficult for me personally. So, that's why I've made the decision to go private." (Tali:483-486)

That is not to say that all of Tali's encounters with NHS ED services involved inadequate psychological support. She described in glowing terms the first program she attended as a daypatient, soon after leaving inpatient treatment:

"It has psychologists. It has assistant psychologists. It has an occupational therapist. It has rooms what are very fit for purpose. It has mental health nurses. Um, it does outings once a week to try and sort of, um… It has a community meeting once a week. It does a lot of group work. It does a lot of cognitive remedial therapy. It.. I <u>cannot</u> highly enough, say, you know it was <u>amazing</u>…." (Tali:177-181)

Her positive assessment of the service centered on receiving a comprehensive, predictable schedule of psychologically-informed treatments. Her enthusiastic emphasis of how 'amazing' she found the service to be stands in marked contrast to the way she experienced others she attended, lending credence to her criticism of them. Evidently, she was not anti- treatment *per se*, she was anti- treatment that did not meet her need for consistent, personally meaningful support.

It was not only psychological support that proved unreliable for many participants, many found the behavioural support similarly inadequate. Suri painted a chaotic picture of her daypatient program:

"They said it was a three-month program, but I think most people had already been there. And I was kind of like thrown in with… and I didn't have a key worker the first week. And I had no actual clue what was going on, and I was absolutely terrified. I think that's why I kind of stopped eating completely. And they gave you so little food, it was like two 200 calorie meals, or something, and you didn't even have to finish them. And I didn't have a meal plan, and I had no idea what I was supposed to be doing." (Suri:60-65)

She described, in strong terms, her 'terror' at not knowing *"what was going on"* or what she was *"supposed to be doing"*, highlighting the value she placed on doing things *correctly* and indicative of a perfectionist tendency common to many with AN. Whereas a key worker and a meal plan could have offered reassuring guidance, in their absence she turned to anorexia, perhaps seeking security in its familiar rules and path.

Tali and Caroline did not receive meal plans or progress reviews either, and they found staff to be unreliably transient. Caroline, for example, observed that within her inpatient program:

"A lot of the time they were like Bank staff who didn't really know the process and couldn't give support at meal times." (Caroline:245-247)

Tali described how she became *"furious"* at her treatment team when she perceived the far-reaching consequences that their chaotic approach could have on her physical wellbeing:

"I trusted that they would let me know if I needed to change anything. But after eight/nine months of being [there], when I went to discharge myself the key worker said […] 'just to let you know that actually you're the same weight as when you started'. Now, I had a bone scan last year and I've got early onset osteoporosis. And that was only from being underweight for a very short amount of time.... I was furious […] I was so angry at them that they had not allowed me to make changes." (Tali:498-509)

Her repetition of synonyms *"furious"* and *"angry"* emphasises just how strongly she resented her team for failing to address her poor weight trajectory over the course of treatment. Indeed, in mentioning that she *"trusted"* that they would have *"let her know"*, she shows that this was about her losing trust in them as appropriately supportive caregivers. Ultimately, their oversight appeared to leave her feeling unprotected and vulnerable. Her vulnerability was evidenced by her concern for the irreparable bone damage already caused by her low weight; while her specific reference to her team having not *"allowed"* her to make changes indicated that, as well as feeling unprotected by them, she felt they had prevented her from protecting herself too.

Indeed, inconsistent care denied participants' access to knowledge and tools that could have helped them help themselves. This denial of access appeared different to that which occurred within the coercive-controlling environments described earlier. In the chaotically unsupportive environments participants described, knowledge did not appear *intentionally* withheld by their team, rather it was not documented in the first place or its recognised value got lost amidst the maelstrom of cancelled appointments and irregular staffing.

While a chaotic environment seems relatively benign when compared to a coercive-controlling one, it proved similarly damaging for participants, limiting their access to the information and skill-building opportunities needed to take charge of their own recovery.

4.4.3 Summary

This theme described two extremes of treatment style – one coercively-controlling, the other chaotically unsupportive – that participants found equally damaging to their recovery. Whereas the former left them feeling trapped and punished, the latter left them feeling abandoned and ill-equipped to change. Both ultimately contributed to them feeling alienated from their treatment team, out of control within their environment, disempowered in their recovery, and risked the direct reinforcement of pro-anorexic beliefs and behaviours.

4.5 Protest and Protection: Dropping Out from Getting 'Worse'

Unlike the previous superordinate themes, which explored key aspects of participants' treatment experience prior to dropout, this final theme explores the meaning they gave to the act of dropping out itself.

Participants all considered themselves better for having dropped out from treatment. Perhaps this is unsurprising, given that each of the five participants described treatment as an environment that made them 'worse'.

"I learnt to be anorexic the first time I went in….and then it just got worse"
Caroline, line 152

"My experience of inpatient made me worse"
Tali, line 741

"It definitely got worse being there"
Maggie, line 351

"I had to get out …. they were making me worse"
Suri, line 105

"I just started getting worse and worse and worse"
Taryn, line 40

Figure 6: Participant statements about treatment making them worse

The construct of treatment making them 'worse' is one grounded in each of their accounts, making it a powerful one. The previous three themes illustrate the various ways in which participants came to construct treatment in this way, particularly by showing how their pre-existing pro-anorexic beliefs were reinforced through the interactions, interdependencies and identifications they had with both their peers and their treatment team. It is within this context that their dropout functioned as a response to getting 'worse'.

It can also be further interpreted as a means by which they both *protested against* and *protected themselves from* the treatment environment that made them worse. The element of protest is most evident in Tali, Caroline and Taryn's accounts, whereas the element of self-protection is most evident in Maggie and Suri's; however, to varying degrees, both protest and protection featured in all.

Tali, Caroline and Taryn described feelings of anger toward their treatment team for failing to acknowledge treatment's harmful effects and adapt their approach accordingly. This anger gave rise to increasing levels of protest that, having no discernible impact, eventually culminated in their decision to dropout.

For Tali, this decision began with her identifying that her peers were getting worse:

"People were falling out of the system, left, right and centre, they were either being discharged because they were not turning up because they weren't finding it useful. Or, they were deteriorating physically and getting sent to inpatient, or they started self-harming" (Tali:320-323)

She described how, initially, she tried to communicate her concerns and suggestions, but that chaotic elements within the service made it difficult:

“I did flag up the more important things that I thought they needed to be doing. And, sometimes it went down okay. And they only had, in my eight months there, they had one community meeting. And I was just like, how, they don’t… The head of day care […] was only there on a Tuesday afternoon when no patients were there. So, she had no idea.” (Tali:345-349)

It was when a friend in treatment died, a tragedy for which Tali held her treatment team partly responsible, that she felt compelled to move from attempts at dialogue into formal protest.

So, I ended up, with two of the other girls we did a PALS complaint […] Because after this friend dying we were like, this… Okay, cos we used to come out and go, ‘oh guess what they’ve done today’, you know like. And we had to joke about it. But I don’t think any of us really seriously thought that any of us would actually die. (Tali:324-331)

Understandably, her friend’s death cast her own predicament in a more serious light. Change had not been forthcoming following her communications with her team and so now she went over their heads, launching a complaint through PALS, the patient advocacy service. While she appeared motivated by a desire for collaboration, she noted that her team were *“were <u>very</u> defensive and they were <u>very</u> unreceptive” (Tali:353)* when approached by PALs. It was then that she realised they were not going to adapt and that, if she wanted to prevent things getting worse, she would have to go elsewhere. She describes how this realisation, coupled with the anger she felt toward her team, confirmed her decision to dropout:

“I already had been very angry at them. And things have just gone from bad to worse and I just, I recognised that I was getting… you know, I wasn’t making any more progress there so I needed to do something different if I wanted to continue my recovery.” (Tali:894-896)

While the fear of getting ‘better’ is oft touted as a reason for treatment dropout amongst anorexia patients, Tali makes it clear here that she dropped out to do just that. Indeed, at the time of our interview, two months after dropping out, she reported having improved her diet *“off my own back, not because of them” (Tali:509-514)* and had pro-actively enrolled in a private ED treatment program.

Caroline’s dropout comprised similar stages: moving from her identification of treatment being harmful to her, to attempted communication, to formal protest, to eventual treatment withdrawal.

Caroline identified her ED treatment service as harmful to her recovery following an emergency general hospital admission. She remained in hospital for three months to treat physical complications relating to her AN and was treated by a *“multi-disciplinary team” (Caroline:563)* using an approach she described as *“friendship and negotiation and chatting and giving me that support and allowing me time” (Caroline:562-563)*. She described this as a novel approach that contributed to her *“thriving” (Caroline:694)* and being *“on the road back” (Caroline:721)* for the first time. However, once physically stable, the medical team looked to discharge her back into the care of her original ED service providers. Her consultant psychiatrist there insisted she would have to return to psychiatric hospital as an inpatient because her weight, while much improved, was still low. Caroline was convinced that this would be detrimental to her fledgling recovery, especially now she had experienced the benefits of a very different treatment approach. Initially she sought to communicate her concerns:

"I had [laughs] probably my most heated argument with [the Consultant Psychiatrist] because he was saying, I had to go in. And I was saying, it's like almost signing my death sentence if you put me back in there. Because I have done this, this, this, I want to eat, I'm eating now, I've gained this much weight. I'm actually positive about like the future. I've got plans." (Caroline:745-748)

Her comparison of their inpatient treatment to a *“death sentence”* illustrates how negative an impact she believed it would have on her health. Her motivation for avoiding readmission therefore seemed to be a desire to protect herself from getting worse again. She also attempted to draw attention to the progress she had made while in medical hospital, in terms of her future-directed motivation as well as her weight and eating behaviour. However, as with Tali, when she realised her communication was proving ineffectual, she moved into protest:

"He was still really pushing and making my life really difficult which was annoying cos it was making me angry and frustrated. And so […] I'd written like all my like angry letters to all like the news. I in fact, got the [local newspaper], health representative, he came in and interviewed me, preparing to like broadcast this monstrosity thing that I'm being made to go back into a mental hospital.” (Caroline:774-784)

Like Tali, she felt *“angry”* toward her team, and her protest seemed similarly motivated by a desire to have them change their approach so that they could help rather than harm her recovery. Caroline’s situation differed though in that she feared another involuntary admission, her weight having not yet increased beyond a certain threshold. However, in a peculiar stroke of *“luck” (Caroline:803*), she contracted MRSA, meaning any transfer to the ED unit had to be delayed. This gave her an extra month, allowing her to cross *“the boundary weight-wise where they couldn’t legally force me to go in” (Caroline:802).*

While Caroline was evidently very unwell at the point at which she needed emergency medical care, and while it is therefore understandable that her ED team questioned her motivation for not wanting to return to their inpatient facility, her account suggests the alternative care she received made a genuinely positive impact on her, and that her desire to dropout of ED services in order to recover was a valid one.

Immediately after dropping out of the ED service, she started seeing a counsellor; someone she continues to see now, three years later. She reports that she reached and has maintained a healthy weight for the last two and a half years, is in full-time employment and a long-term romantic relationship. This considerable progress supports the notion that her dropout was a functional response, motivated by a self-protective drive.

For Taryn, dropout signified a similarly functional response to an environment she perceived to cause harm. Initially, she acquiesced to pressure to admit herself as an inpatient (*“I don’t want there to be nothing for me. So I will go to the assessments.” (Taryn:507-510)).* However, despite her desire for support, she became increasingly convinced inpatient treatment would jeopardise the healthy, positive aspects of her life that she had developed:

“Because what they were saying in the assessments was like ‘well, you need to commit to twelve months of this’, and I was like ‘but I am at uni, I am applying for my Masters right now. If I give up twelve months I have to withdraw my Master’s application, I have to stop my dissertation, I have to literally pull myself out of my life that for the first time since forever is going well.’” (Taryn:515-522)

Her description of needing to pull herself from a life that was *“going well”* in order to go inpatient illustrates her belief that treatment would be a harmful experience. As with Tali and Caroline, her next step was to try and communicate her concerns to her team. However, she too felt her concerns were ignored, leading her to protest:

"I think what really bothered me at the time and I think what kind of fuelled this complete <u>boycotting</u> of the services and just <u>ignoring</u> everything ultimately, was that I tried communicating to the psychiatrist and this new therapist and to the people that were assessing me, what was important to me […] And it was just like, it was just met with: 'Well, that is not what is important right now. What is important is that we can't work with you, with your weight being as it is.'" (Taryn:550-556)

Taryn's use of the word 'boycott' characterises her dropout as a form of protest against a system she believed to 'ignore' her. She came across less extroverted than either Tali or Caroline in her interview, and so it is in keeping that her 'boycott' was more quietly expressed than theirs. Unlike them, she did not launch a formal complaint or employ a media mouthpiece to amplify her voice; indeed, she took the opposite route – communicating her dissent through the very act of non-communication. She admitted:

"I found it quite difficult to, I guess, assert my voice in those situations, because it felt like there wasn't really the opportunity or a time that felt like I could, so I guess my voice was literally my absence." (Taryn:611-613)

This comment really struck me – finding herself voiceless, *her voice became her absence*. A running theme throughout has been the idea that participants felt themselves to be voiceless within treatment – be this due to their self-imposed silence in an effort to fit in, or because the treatment environment itself reduced and dismissed their experience. Without voice, as we have seen, many experienced an increasing dependence on their anorexia as a method of communication. Essentially, their voice became their absence of flesh. But here, dropout is presented as an alternative means of giving voice through absence – one which, while still providing a means of protest, is also, conceivably, more self-protective and thus empowering. Indeed, Taryn seemed empowered by her decision to dropout:

"In some ways I kind of enjoyed making that decision to not go back, because the worst thing in the world for me would have been to give up everything that had kind of slowly built and that I had not realised I was building." (Taryn:526-528)

It seems that Taryn's decision to dropout aligned with her desire to protect recently 'built', meaningful aspects of her life. This alignment of action and personal values made her dropout experience an enjoyable one and stood in marked contrast with the internal conflict she had previously experienced:

"There was just all this conflicting stuff going on like: 'Oh well, if you are going to send me for inpatient then fine, I will make myself really thin so it really seems like I have a problem then." (Taryn:559-562)

In light of such conflict, one can see how dropout served a self-protective function for her as well as a means of protest. While the prospect of inpatient treatment triggered a 'worsening' desire to pursue pro-anorexic goals, dropout represented the pursuit of more life-affirming ones. For Taryn, these goals included the continuation of her post-graduate studies and now, three years after dropping out, she has qualified as a psychotherapist and juggles her clinical caseload alongside work as a PhD student and university lecturer. She does not buy into the notion of full recovery, believing the risk of relapse is always there, but she now describes a situation where the desire to protect other aspects of her life, such as her career and her relationships, outweighs any desire she might have to return to the anorexic lifestyle she once had:

"I have to eat to get by, I have to eat to do my job, to survive, otherwise I can't give lectures, I can't see clients, I can't really function I guess." (Taryn:708-710)

"I am really aware that things can be up and down, but I am also really aware that I love my job and love what I do and those things are really important to me and I wouldn't…the worst thing for me would be to think that I could go back to those places again." (Taryn:749-752)

Taryn appears to have decided that she cannot restrict her food if she is to maintain her job and studies. Essentially, she has prioritised that which is most important to her self-identity and, perhaps, it was only by removing herself from the treatment environment that the non-anorexic aspects of her identity could grow and take on increased meaning and priority. Indeed, she spoke of having previously been "*immersed in…bubbles of eating disorders everywhere" (Taryn:698)*, conjuring up an image of containment within a space that, while superficially attractive and protective, constitutes an invisible barrier to the wider world and all it offers. Her dropout symbolised the bursting of these bubbles, giving her access to what she described as *"new ways of being and new ways of reflecting on yourself" (Taryn:698-699).* In this way, she experienced her dropout as empowering, it presenting her with new opportunities for self-development as well as serving a means of protecting those aspects of her life she already valued.

Maggie also dropped out for reasons of self-protection. She did not feel empowered by her decision to dropout initially, however, having been influenced by the belief that her treatment team had rejected her. She had been presented with an ultimatum: either curtail her over-exercising or leave treatment and, interpreting the ultimatum as proof *"they don't like me" (Maggie:436)*, she decided to leave. She explains her decision here:

P: "It did upset me a bit. But I didn't want to show that I actually cared so I was just like 'okay, I'll leave.'

R: How come?

P: That just felt embarrassing to be… to admit that I was actually quite attached to everyone. It felt embarrassing, so I was just like, 'I don't care anymore, I'll go if you like, I'll be fine on my own!'" (Maggie:441-446)

Maggie seemed to decide to dropout to protect herself from the embarrassment of needing people who, supposedly, did not like her. In this way dropout represented the taking up of a defensive position, protecting the vulnerable self from hurt.

Suri's reasons for dropping out reflected a defensive position too:

"They're gonna keep up what I thought was abuse. And they're not going to stop, so I had to get out" (Suri:162-163)

It seems it was the cumulative disappointments she experienced that shaped her view of treatment as abusive. These included the early departure of her psychologist (with whom she had been making progress), her replacement's frequent and prolonged absences, and her team's apparent lack of consideration for the effect the disruption was having on her. Like Maggie, Suri concluded her team disliked her and saw dropout as a means of protecting herself from hurt:

"I was, I guess, feeling like they really hated me…. Which is kind of a bit like what I felt at the beginning, like I shouldn't really be there… I just felt it was kind of, it was way too complicated, when I was trying to recover, this whole dynamic was just way too complicated. So yeah, I left." (Suri:150-154)

Suri shows herself here to have been very aware that, in protecting herself from perceived rejection, she was also protecting her efforts to recover. Indeed, she later noted:

"I was convinced I could recover if I could just get away from that place." (Suri:211)

Her decision to dropout was therefore motivated by a desire to protect herself from, not only negative feelings, but also the resultant temptation to retreat into anorexia. For Suri too then, dropout was self-empowering. Indeed, after leaving, she described resolving issues from her past with the help of a hypnotherapist, achieving a healthy weight and becoming pregnant with her second child. Reflecting on this period, she said:

"So, yeah, I lived really quite happily for quite a long time. I think again, [dropping out] definitely was the right thing, I don't know what would have happened if I'd stayed there. It was definitely making me worse." (Suri:251-252)

Maggie's dropout seemed less motivated by a desire to recover than Suri's but, nonetheless, within weeks of discharging herself, she too made progress. She spoke of how leaving treatment led to a re-evaluation of what she wanted:

"It was like: 'you've got rid of everyone, you keep just going lower and lower and lower and no one's gonna come and save you. You're just gonna die. And I'm not sure I want to die. So, I better start doing something different. That is what… the conclusion I reached." (Maggie:917-922)

Once again, one can see Maggie's self-protective instincts at play. She withdrew from treatment relationships when she started feeling hurt by them but, recognising that in getting 'rid of everyone' she had only herself left to ensure her safety, she also started considering her own needs. In this way, her dropout was self-empowering as it set the stage for her taking charge of her life's direction. Within a few weeks of leaving treatment, in February, she decided to sign up as a foreign aid worker for three months, a decision that she said gave her *"a reason to keep going" (Maggie:485).* With her place on the expedition confirmed within a few weeks of leaving treatment, she said:

"I did actually make a lot of progress between February and May […] I literally, like the day I left treatment I was just like, you're not sitting with me anymore, you're not making food for me anymore, I'm not following any kind of shitty meal plan, I'm going my own way. And I did [laughs]. And it was really really hard, really very hard… but I kind of managed it." (Maggie:493-500).

Her words reflect a similarly defiant attitude to that shown by the others, in their varying degrees of protest prior to dropping out. This makes me wonder whether a drive to push back against treatment conformity and go their 'own way' was crucial to each of their successes post-treatment, it allowing them to protect and develop those parts of self that extended beyond 'the anorexic patient'.

Maggie's decision to forge her own path and explore the wider world seemed to pay off. Having just returned from her expedition a week before our interview, she describes her experience:

"It was the best thing I ever did. And I made loads of friends. I was the most free I've ever been, in terms of eating." (Maggie:548)

She spoke of how this freedom developed in an environment where she was able to authentically and assertively express herself, independent of her ED, and have that be positively reflected back in the words and interactions of her peers:

“And just every day that I was there someone would be like, ‘oh you’re really beautiful’ or ‘you’re really funny’, ‘I like the way you do this.’ And I think I learnt a lot about myself as well. Like, I’d lead… because I’d worked in a hospital I used to lead the First Aid workshops. So, then I’d be there in front of 100 people answering questions […] And I just felt like everyone knew me for me. Not because I had an eating disorder or because you know. And any conversations I had were genuine meaning, not just conversations about myself or why I felt sad today" (Maggie:602-616)

This experience seems so in contrast with the treatment experiences described by her and the other participants. Within treatment, Maggie felt misunderstood, reduced by and, ultimately, rejected as a result of, others’ perceptions of her as ‘an anorexic’. However, here she felt accepted and empowered in her freedom to explore aspects of herself that had had no room for expression or acknowledgement within the treatment setting.

4.5.1 Summary

The women’s accounts suggested that dropout was not a precursor to relapse and ill-health for any of them. Indeed, within the context of a treatment environment that they perceived to make them worse, dropout appeared more to offer a means of getting better. It was experienced as an empowering decision because it emboldened their protest against a system that they experienced to reduce, control and neglect them, and also because it protected them from having their anorexia relationally reinforced.

While the literature tends to suggest that dropout is symptomatic of problems situated within the sufferer, and therefore predictive of their continued deterioration, the participants’ accounts indicated otherwise. For them, their dropout was symptomatic of problems that lay within the treatment system itself and, as such, predicted an improvement rather than a deterioration in their quality of life.

Suri’s advice for sufferers in treatment seems to sum up the collective sentiment well:

"If you feel like it's harmful, like, just listen to what you feel. And if it feels harmful, it might be that it really is. Because people might say, oh you know, oh that's the eating disorder speaking, or something, or it's trying to make you not gain weight. And I mean, that may happen, but sometimes you have a gut feeling that something is actually more harmful than good, and I'd say, kind of go with it.... don't stay in a difficult treatment situation." (Suri:679-685)

4.6 Concluding thoughts

The aim of this study has been to explore patients' experiences and perceptions of anorexia treatment and drop out. Participants gave richly varied accounts of their treatments but, when discussing the particular episode from which they had dropped out, their experiences were uniformly critical. It could be argued that this is to be expected from a patient group known to be ambivalent about recovery, but I believe the women presented their criticism constructively.

They described their treatment in terms of three broad areas. First, they described the perceived social pressures within treatment that led to them increasingly identifying with, and being identified through, anorexia. Second, they described their treatment team's lack of acknowledgment of their subjective experience, and an approach they perceived to be overly prescriptive, and excessively focused on addressing physical symptoms at the expense of their psychological wellbeing. Third, they described a disempowering treatment environment that was, variously, controlling and chaotic – both which contributed to an overall sense of lost control.

Transcending these themes was the notion that their treatment experiences reinforced pro-anorexic beliefs (e.g. 'my weight is the only important thing about me') and identifications (e.g. 'I have so much in common with the other patients because we are all anorexic') and therefore made them 'worse'. They made sense of their dropout in light of this construction, understanding it to be, both an act of protest against, and self-protection from, a harmful treatment environment.

A conceptual diagram illustrating how the women's treatment experiences contributed to their dropout can be found in Figure 7.

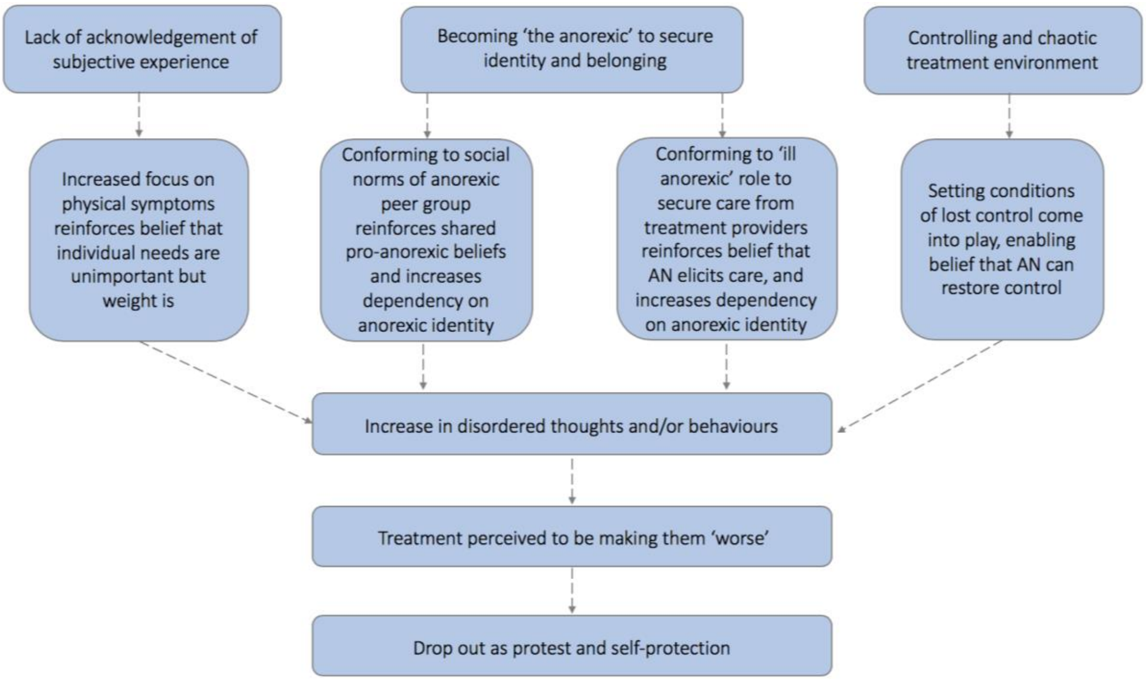

Figure 7: Conceptual diagram showing how treatment experiences contributed to dropout

Chapter 5. Discussion

5.1 Introduction

Within the ED literature, ‘dropout’ is almost exclusively constructed in terms of patient pathology and considered a predictor of poor prognosis, it removing the sufferer from the one environment wherein they might be helped to recover (Pike 1998; Beumont, Russell & Touyz, 1993). However, this study puts forth an alternative view, having chosen to explore the meanings that individuals themselves give to their dropout.

Its findings make an original contribution to the field as, while a few other qualitative studies have touched on treatment’s possible iatrogenic effects (e.g. Gremillion, 2002; Rich, 2006; Eli, 2014), and while a few authors have associated dropout with treatment dissatisfaction (e.g. Eivors et al, 2003; Dejong et al, 2011; Clinton, 1996), this is the first investigation to find that participants made sense of their dropout in terms of a treatment environment that they perceived to make them ‘worse’.

In this chapter, I shall explore the study’s themes in greater depth, considering the ways in which they support existing theory and research, whilst also drawing attention to areas where novel understandings or questions have emerged. I will then evaluate the study itself, taking account of its various strengths and limitations, and further reflecting on the impact that I have had on each stage of its process. It is my hope that the study’s findings will have practical utility and, ultimately, benefit those who struggle with anorexia nervosa and other forms of eating distress. With this in mind, some suggestions for clinical practice and future avenues of research are also offered.

5.2 Contextualising The Analysis

5.2.1 Becoming ‘The Anorexic’: Identity and Belonging

The findings show that the participants’ negative perceptions of treatment were about more than just ambivalence to change (Williams & Reid, 2009), they were about difficulties they experienced within the unique setting of treatment itself, a large part of which related to their anorexic identity and identification.

Some of the women described how they had found it validating to be first diagnosed with AN and offered treatment, taking it as evidence of their success in weight-loss. This echoes the findings of previous qualitative studies (Eli, 2014; Warin, 2010) and personal testimonies (e.g.

Krasnow, 1996; Osgood, 2014; Hornbacher, 1998) and also supports Bruch’s (1978) theory that AN develops as a flawed solution to impairments in overall identity development. Within this context, AN can become something by which a person defines themselves and can provide a sense of self-worth (Williams & Reid, 2009).

Interestingly, however, the participants did not experience their AN identity as something simply achieved and established through diagnosis and admission into treatment; rather, it required continuous negotiation and effort. Treatment, with its continuous definitional practices, became central to this effort.

Many authors have highlighted how the way in which anorexia is measured and defined in treatment largely ignores the social discourse around food and the body that prevail outside the clinical setting (Rich, 2006; Gremillion, 2003; Eli, 2014). Social discourse tends to frame thinness as a physical expression of personal expertise, responsibility, and self-control (LeBesco, 2011; Metzl, 2010). And, as Guthman (2009) points out, these are key tropes in our society – with its emphasis on the physical body’s productivity and malleability – thereby making deviation from a healthy weight seem to be a choice (p.1126). This provides one context in which participants had to negotiate an anorexic identity. Whereas they had previously been able to evidence self-discipline in their eating practices, treatment required them to redefine it as evidence of pathological incompetence.

Over the course of the interviews, participants showed how they resisted this medicalised definition by negotiating alternative self-identities, such as being *“fine”* (Maggie:71) or *“not mental”* (Caroline:327). Such statements could be read as misperceptions of self but they could equally be read as ways of problematising a treatment that defines them in such a way that everything they do and say is understood to be pathological (Boughtwood & Halse, 2010). Indeed, some academics have proposed that medical constructions of the ‘eating disordered patient’ render patients powerless as there is no discursive space in which they can express a valid view (Malson et al., 2004; Carney, Tait, & Touyz, 2006; Rich, 2006; Botha, 2015).

For the women in this study, their fellow patients were often experienced as valuable sources of alternative support, providing them with a sense of social understanding and belonging. This is in line with previous research which has shown how others’ perceived lack of understanding encourages those with EDs to seek out alternative relationships from which to derive more empathic support (Williams & Riley, 2013; Ransom, La Guardia, Woody, & Boyd, 2010) and also demonstrates the benefits of identifying with ‘similar others’ (e.g. Davidson, Abercrombie, Nitschke & Putnam,1999). Other eating disorder researchers have suggested the value of finding connections with an ED community, whether within clinical settings (Rich, 2006) or online

(Dias, 2003), but the findings from the current study further suggest that patients' very identity is altered through the process of seeing themselves in others within treatment. Tori, for example, observed: *"It wasn't until I was with other people that had really similar thought patterns that I thought this must be an illness because it's so... you have so much in common." (450-458)*

While peer relationships were often experienced as supportive, participants also highlighted how over-identification with other sufferers risked worsening their anorexia. This suggests a potential danger in treating anorexic patients together and raises a concern that other researchers have also voiced (e.g. Roots, Rowlands, & Gowers, 2009; Tierney, 2008; Colton & Pistrang, 2004; Offord et al., 2006). Schmidt & Treasure (2006) suggest that obsessive-compulsive traits common to anorexia can manifest in increased sensitivity to social hierarchies and through the desire to be accepted by conforming to social norms and, within the treatment environment, this can lead to individuals gleaning new ED behaviours from each other, resulting in patients competing or calibrating themselves against other patients. This shows one way in which patient-specific factors could interact with treatment-specific factors to produce iatrogenic effects.

From an interpersonal perspective, the Social Identity Approach (SIA) can also provide a useful paradigm (Tajfel & Turner, 1979). According to the SIA, either personal identities (self-definitions that derive from individual experiences) or social identities (self-definitions that derive from group memberships that are perceived to be psychologically meaningful) can be activated by cues within the social environment. Within a treatment setting that restricts expression of individuality, activation of a social identity is more likely, as in the case of the anorexic patient who finds support from her peers on account of their shared ED. This leads to their identifying as an anorexic group member. According to SIA, this identification then influences their behaviour and cognitions via depersonalisation, a process whereby their thoughts and behaviours become aligned to those of the group (Hogg & Reid, 2006). This is an important factor to consider in treatment as it suggests that it would be beneficial for the pro-anorexic norms and values held by the anorexic 'collective' to be publicly acknowledged and challenged within treatment.

The findings also highlighted ways in which participants' anorexic identity was negotiated, interpersonally, through relationships with members of the treatment team. Maggie, for example described how *"the relationships that I'd built with each person that worked [in treatment] depended on me being this small victim, the sad little anorexic girl that couldn't feed herself and they would be caregiver" (Maggie:507-508).* Whereas SIA speaks more to the influence of larger groups, role theory is perhaps a more helpful paradigm when considering the dialogic influence of the therapeutic relationship. Role theory proposes that social behaviour is socially prescribed, and that it can be seen as a performance whereby people just enact the roles in which they have been cast (Hargreaves & Colley, 1986). The theory also contends that social roles are made up of two constituent parts: social positions and social expectations. There are numerous social positions that one can take up, each carrying with them a particular set of expectations about behaviour (Hargreaves & Colley, 1986). With this paradigm in mind, clinicians need to be aware of the social positions they take up with their patients lest they develop relationships that inadvertently reinforce their patient's AN identity. While a number of studies have explored how connections with ED peers can maintain disordered behaviours through identity-based support and reciprocal social influence (e.g. Ransom et al., 2010; Williams & Riley, 2013; Rich, 2006), it seems little attention has been paid to the way in which connections with therapists and other members of the treatment team can also, conceivably, do this. Assuming that recovery requires an individual to relinquish their anorexic identity and develop, in its place, *"a new, but equally meaningful, recovery-oriented identity (Espíndola & Blay, 2009; Federici & Kaplan, 2008)"* (McNamara & Parsons, 2016, p.8), it is important we explore how therapeutic relationships can influence this process, both for better and for worse.

5.2.2 More Than Meets The Eye: The Unseen Subjective Experience

Another central feature to emerge from participants' accounts was the perception that treatment focused too heavily on their physical symptoms and neglected to acknowledge their subjective experience of AN and the psychological factors that contributed to it. This was a problem described at every stage of the treatment process, from pre-admission through to discharge. One ironic consequence of this was participants' perception that, in order to be supported, they had to continue to lose weight. This underscores Escobar-Koch et al.'s (2010) finding from their large-scale qualitative study that British participants saw weight-based treatment criteria to be a 'barrier' to people getting help. The finding also suggests that treatment providers are ignoring NICE's (2004) recommendation that: *"In anorexia nervosa, although weight and body mass index (BMI) are important indicators of risk they should not be considered the sole indicators"* (p.64).

Treatment systems that have a strong emphasis on weight and food can clearly have serious consequences for a population known to be competitive (e.g. Colton and Pistrang, 2004) and who are already highly motivated to lose weight (Rance, Moller & Clarke, 2015). Previous studies have shown some of the effects to include an increased sense of personal ineffectiveness, food restriction and reinforcing of AN behaviours (e.g. Gowers, Weetman, Shore, Hossain & Elvins, 2000; Eivors et al., 2003). Gremillion (2003) even suggests that *“current treatments for anorexia nervosa actually exacerbate the disease by encouraging patients to focus on miniscule changes in their weight and obsess over each morsel of food consumed”* (p.304). Meanwhile, Osgood (2014), writing of her own anorexia treatment experience, describes how, *“when the anorectic is admitted, she can speak in the argot of calories and serving sizes and grams of fat… she is in some sense comfortable because value is placed on all the things the anorexic places value on (namely, food, weight, and symptomology)”* (p.88). Similarly, this study’s findings suggest that treatment approaches that conflate body weight with perceived worthiness of support mirror anorexia’s own logic in such a way that individuals feel increasingly motivated to lose even more weight.

The finding that participants experienced too great a focus on weight within treatment also supports the growing body of research that patients with AN prefer a holistic treatment approach (e.g. Rance, Moller & Clarke, 2015; Smith et al., 2014, Rich, 2006). For example, in their review of qualitative studies which examined the views of adolescent patients towards AN treatment, Westwood and Kendal (2012) discovered a strong preference for treatments that consider patients’ social and psychological needs, rather than solely focusing upon their physical concerns. It is important to note here, however, that NICE guidelines do still require a focus on weight/food as critical for effective treatment for AN (NICE, 2017). Further, as suggested by Rance, Moller and Clarke (2015), AN patients may find it particularly difficult to discuss food/weight for fear of highlighting areas they might be expected to change, and about which they may feel ambivalent due to the egosyntonic nature of their condition.

Any such ambivalence could, of course, be addressed within psychological therapy but participants also criticised treatment for failing to provide more of this (see also Offord et al., 2006; Colton & Pistrang, 2004). This was particularly evident in their descriptions of inpatient treatment, where they were often told they would not have the cognitive function necessary for psychotherapy, on account of their low weight.

This illustrates how small the window of opportunity is for anorexia patients looking to access psychological support; too high a weight and they receive no support at all, too low a weight and they receive no therapy. There is some evidence to back the view that low weight impacts on psychological mindedness, with small but significant impairments in cognitive function having been found in those with AN (Tchanturia, Campbell, Morris & Treasure, 2005 Tchanturia et al., 2004). However, I am inclined to agree with Strober & Johnson (2012) when they suggest that an increasingly genocentric view of AN is responsible for the restriction of psychotherapy and that it represents an overinterpretation of scientific findings:

“There is no evidence - empirical or clinical - showing that normal weight is a necessary prerequisite for initiating meaningful psychological dialogue, or that psychotherapeutic dialogue

cannot be facilitative of weight change…. A patient 50 pounds below a BMI of 19 - confused, disorganised, unable to retain short-term information, and emotionally erratic - is unquestionably ill-suited for psychotherapy of any sort. But this patient is considerably different from one who is 30 pounds underweight, ingesting food, and though compelled by similar fears is nevertheless committed to an examination of the conflict that has taken hold of his or her mind. Simply stated, normalisation of weight is not the absolutely essential starting point for using thought, reason, and insight as foundations for change.” (Strober & Johnson, 2012, p.160)

Indeed, it seems like, in instances where patients voice a desire for psychological support, as did each of the women in the current study, treatment providers who choose not to provide it look a veritable gift horse in the mouth. It seems so counterintuitive that I cannot help but wonder whether the notion that psychotherapy is wasted on low weight patients also provides a convenient justification for what is actually more a budgeting issue, particularly in light of the current climate of austerity. In any case, inadequate psychological support offers a possible explanation for the poor treatment success rates common in AN treatment and highlights an important area to investigate further.

There have been many commentators (e.g. Botha, 2015; Bordo, 1993; Burkitt, 2001; Warin, 2010) who have suggested, similarly to Strober & Johnson (2012), that symptom-focused treatment highlights problems with the way in which AN is conceptualised. As described within earlier chapters, AN treatment draws heavily on the medical model, and a positivist and empirical epistemological position (Botha, 2015). Within these terms, AN is seen as a clinically diagnosable, internal and individualised pathology and, arguably, this perspective reduces individuals’ experience to objective symptoms, outside of context or personal meaning (Morgan, 2015). This, of course, means that treatment is not about listening and understanding, but about diagnosing and curing. Colton and Pistrang (2004) noted that the sense of neglect that their participants experienced as a result of not being listened to was *“striking and particularly worrying, in that it may exacerbate existing feelings of rejection or abandonment”* (p.314). These findings corroborate with those of the current study, but I further suggest that not being listened to, and over-emphasising symptoms within treatment, also reinforced participants’ dependency on AN by enabling the belief that an anorexic body offers a medium through which they can be heard.

When speaking of their relationships with individual members of their treatment team, the participants found rigidity, stereotypical assumptions and limited knowledge about AN particularly problematic. These findings support research which has highlighted the unhelpfulness of negative staff attitudes and their rigid use of techniques (Button & Warren, 2001), as well as the importance of the perceived competency of treatment providers (Swain-

Campbell, Surgenor, & Snell, 2001; Westwood & Kendal, 2012). Previous research on patient preferences (e.g. Gulliksen et al., 2012) has also identified a strong preference for practitioners to have expertise in treating AN. An important finding of the current study is a reason why this may be so important to patients – namely, to ensure practitioners have the necessary knowledge and skill to avoid reinforcing pro-anorexic beliefs (e.g. that their individual needs are unimportant, or that their weight is their singular defining feature).

Of course, patients' experience of treatment will also have been influenced by intrapersonal factors, such as personality traits and emotional style. As touched upon in the Introduction Chapter, an association has been found between anorexia and alexithymia (e.g. Schmidt et al., 1993; Taylor et al., 1996), suggesting that the participants may have found it particularly difficult to ask for what they wanted within treatment, or communicate with their team how they felt about treatment/recovery. If this is the case, it seems all the more essential that treatment providers establish an empathic environment in order to facilitate patients' recognition of their emotional needs and ensure they are met. It is also worth bearing in mind that psycho-developmental theories of AN consider alexithymic traits to develop out of an emotionally invalidating childhood environment (e.g. Bruch, 1978; Minuchin et al., 1978; Corstorphine, Mountford, Tomlinson, Waller & Meyer, 2007). Given this, in instances where treatment is experienced as invalidating of an individual's experience, the conditions that contributed to the development of their anorexia in the first place are recreated, making it, conceivably, more difficult to recover.

5.2.3 Disempowering Forces: Control and Chaos Within The System

As described, there were numerous occasions where participants experienced their treatment team to disempower them, either through excessive use of coercive-control, or else through a chaotic lack of support. Their perceptions of treatment being excessively coercive and controlling is in line with other studies that have explored ED patients' experiences of treatment, particularly within a hospital setting, where behavioural techniques are commonly used (Gremillion, 2003; Eivors et al., 2003; Boughtwood & Halse, 2010; Segal, 2003). Some participants in the current study emphasised how threatening they found this to be by describing their AN as having itself developed out of a subjective need for control. Control is a common theme to emerge within much of the theoretical literature on eating disorders and anorexia nervosa, in particular, is often described as an illness of pathological self-control (Bruch, 1978; Crisp, 1980; Lask and Bryant-Waugh, 1993; Lawrence, 1984). Some authors highlight a struggle for control within the context of the family dynamic (Selvini-Palazzoli, 1974; Bruch, 1978), while others focus on a struggle for control within a wider sociocultural/political context (Lawrence, 1984; Sesan, 1984; Orbach, 1986). Naturally, if anorexia is part of a broader strategy for asserting or maintaining control, patients will regard treatment as a threat, at least to a degree (Macsween, 1995). However, the participants highlighted some areas that seemed to exacerbate their distress unnecessarily, such as when Caroline spoke of not receiving emotional support after having an NG tube inserted. AN treatment may always require a certain amount of authoritative care, given the egosyntonic nature of the condition and the dire consequences AN can have if left to run its course, but research has shown how rules and boundaries can be implemented in a kind and compassionate manner (e.g. Tiller, Schmidt, & Treasure, 1993). Further, some clinicians have successfully employed therapeutic strategies that enabled their patients to retain a certain amount of control over their intake, even within more intensive treatment settings (e.g Vansteenkiste, Soenens & Vandereycken, 2005).

The findings further suggest that, when treatment interventions are perceived to be excessively controlling and punitive, they result in patients resorting to face compliance and deception or else active resistance. These findings support Lock, Epston, Maisel, and de Faria’s (2005, p.327) observation that anorexia patients have only two options available when subjected to controlling medical discourses within treatment: Either they unwillingly go along with treatment in order to ‘get out of there’ and get back to their ‘real life of being anorexic’; or, they resist treatment by resisting help, thereby producing an ersatz resistance through an increasing self-identification with anorexia, and enshrining anorexic behaviour as the ones means by which they can resist the dominant discourse in which it is embedded (Lock et al., 2005; Boughtwood & Halse, 2010). For the participants in this study, active resistance rather than face compliance became most prominent toward the end of treatment, shortly before they dropped out. In this way, dropout can be seen as a heightened expression of their resistance, and also a protection from the AN-enabling rebellions to which they were being drawn.

Moulding (2006) interviewed a number of ED treatment providers and noted that some recognised ‘resistance’ to be a consequence of the controlling forms of psychiatric intervention rather than just a symptom of AN. These treatment providers described how they made adaptations to their practice so that it was less weight-focused and rigid and more accommodating of patient wishes (Moulding 2006, p.802). Recognising how treatment and professional knowledge can be harmful is potentially one way in which to foster more trusting relationships with patients, which may then result in less use of coercion, less perceived coercion from patients, patients having more autonomy and power in decision-making processes, and more helpful treatment experiences.

Interestingly, these more helpful treatment experiences also featured in participants’ accounts as most of them described individual professionals within treatment that enhanced rather than impinged on their sense of autonomy. These were the treatment relationships in which they described experiencing the most motivation to recover and through which they made the most progress. This association between autonomy-enhancing relationships and motivation to change can perhaps be explained by Deci and Ryan's (2000) self-determination theory (SDT). According to SDT, a perceived sense of autonomy is critical to fostering the desire for therapeutic change (Vansteenkiste & Sheldon, 2006; Vansteenkiste et al., 2005). When patients fully endorse their decision to remain in treatment, as oppose to when they feel coerced, they are less likely to dropout and more likely to make therapeutic progress and display elevated well-being (Zuroff et al., 2007). Autonomy-enhancing techniques that seemed most appreciate by the participants included clinician's expression of empathy and respect, and their offering them choices when possible, and meaningful rationale when not.

In terms of chaotic elements within treatment, while other studies have highlighted issues with long waiting lists, inadequate care planning and irregular care (e.g. Leavey, Vallianatou, Johnson-Sabine, Rae & Gunputh, 2011), to my knowledge, none have highlighted the ways in which they can set up the conditions of lost control in which AN is likely to thrive. In the current study, perceptions of incoherent care had similar consequences for participants as did perceptions of coercive-controlling care, with both recreating feelings of disempowerment and lost control.

It may be that the chaotic, incoherent care described by the women here is an unavoidable consequence of the budget cuts that have taken place within the NHS in recent years. If this is the case, it is a particularly important area for future research, for we need to know the real-world effects that austerity measures may be having on patients, and also the potential effects that decreased resources may be having on our attitudes toward patients in our care (see Watts, 2018).

It is also worth keeping in mind that chaotic effects within treatment – such as when therapy sessions are cancelled without notice – may be particularly difficult for AN patients to tolerate. Neuropsychological research has shown that those with AN tend to exhibit traits of cognitive inflexibility or poor 'set-shifting' (Tchanturia et al., 2004; Tchanturia et al., 2005). This has good face validity as AN patients are often described clinically as having thinking styles that are rigid, persistent and obsessive (Davies, Laio, Campbell & Tchanturia, 2009). Set-shifting entails changing one's responses according to environmental contingencies, meaning that if a patient has poor set-shifting she is going to find it particularly difficult – and thus stressful - to adapt to the changing demands of an unpredictable treatment program.

5.2.4 Protest and Protection: Dropping Out from Getting ‘Worse’

The participants in this study all described the treatment from which they dropped out to have been making them ‘worse’. The notion that ED treatment can cause sufferers to get worse is provocative, but not entirely new. A number of researchers have already suggested that treatment can inadvertently recreate the conditions that support anorexia (Eivors et al., 2003; Rich, 2006; Schmidt & Treasure, 2006; Gremillion, 2002; Colton & Pistrang, 2004; Sesan, 1994). These can include hospitalisation, resulting in the loss of personal autonomy, ongoing evaluations (of the person and of weight), and the removal of the patients’ entitlement to her own experiencing (e.g. by suggesting she has lost her grasp on reality). What is unique to the current study, however, is the finding that participants made sense of their dropout in relation to these experiences. In particular, dropout seemed to represent both a protest against a treatment that worsened their anorexia, and a protection against it continuing to do so.

Only one previous study, conducted by Eivors et al. (2003), similarly set out to qualitatively explore themes associated with dropout from AN treatment. There were a number of similarities between our findings, but also vital differences. Like here, they also described accounts of treatment failing to acknowledge patients’ subjective experiences and focusing too heavily on symptoms. And they too described how these experiences gave rise to perceptions of lost control that exacerbated eating disordered behaviour. However, the direction their analysis took was distinct to the one taken here when it came to explaining how this contributed to participants’ decision to dropout. Noting their participants found it difficult to manage others’ perceptions of their ED within treatment as dysfunctional, Eivors et al. (2003) explained their participants’ dropout as a means by which they could reclaim the power to define their disorder as functional and, ultimately, re-embrace it. This explanation usefully highlights the role of patient’s subjective experience, but it does not examine dropout in relation to the unique identifications that patients encounter in treatment, nor consider it in terms of being a, potentially, healthy decision. Participants within the current study described their treatment experience in terms of an environment that reinforced pre-existing pro-anorexic beliefs and anorexic identifications. Within this context, dropout is then understood as a consequence of patients’ interpretation that they were getting ‘worse’ rather than better. Thus, whereas Eivors et al.’s (2003) findings support the prevailing view that dropout signifies relapse (Pike, 1998), this study’s findings challenge it. And, whereas Eivors et al.’s (2003) findings suggest dropout represents a pathological reaction to lost control, this study’s findings suggest it can represent a functional response to a treatment perceived to reinforce anorexia-maintaining beliefs, behaviours and identities.

One might expect that an individual who drops out from treatment to protect themselves from getting ‘worse’ would, thereafter, get ‘better’. Participants’ accounts of their life following their dropout from treatment suggested this to be the case, in contrast to that which is predicted within the literature (e.g. Beumont et al., 1993). However, they were also careful to emphasise that their experience of ‘getting better’ from an eating disorder was neither as linear nor as concrete as the medical model of AN would suggest. Rather than aligning recovery with achievement of a goal weight, their perspective of getting better focused more on how meaningful life experiences and relationships with others allowed them to develop new ways of thinking about themselves that improved self-esteem and lessened their dependency on anorexia. These accounts add support to previous qualitative studies which have illustrated that those who have recovered from an ED often view recovery in ways that differ significantly from medical or clinical perspectives, talking of recovery, not as an end point of illness but as, for example, an ongoing process where moving out of an ‘anorexic’ space entails (re-)connecting with the healthy self and others (Garrett, 1997; Malson et al., 2011). For the participants, these connections were often not possible within treatment but most were later able to find meaningful experiences and relationships outside of treatment that gave them the room they needed to move away from an anorexic position.

5.3 Evaluation of The Study

This study set out to explore the experience of anorexia treatment from the perspective of those who dropped out. Dropout rates stand at 50-73% (Sly et al., 2013; Fassino et al., 2009); sobering statistics given that AN is a potentially fatal condition with low rates of recovery. Research to date has not established why rate of dropout is so high, and there have been calls to facilitate patient-led explorations of the reasons behind it (Eivors et al., 2003; Zeeck et al., 2005; Vandereycken & Vansteenkiste, 2009). However, the focus of most research continues to be on demographic and clinical patient characteristics as possible predictors, with little attention paid to patients’ subjective experience. The current study aimed to address this gap by exploring the perspectives of those who dropped out from AN treatment in order to enrichen current understandings of the treatment experience and to gain a better insight into the meaning of dropout.

Using IPA, a number of salient themes were able to emerge directly from participants’ own accounts. I consider the study to have fulfilled its aims overall, albeit with some limitations, which will be expanded upon here.

5.3.1 Strengths, Limitations and Avenues for Future Research

The strength of this study lies in its qualitative approach as it is from the voices of the patients' themselves that new understandings of AN treatment dropout have emerged. In this sense the study is the first of its kind, as its participants made meaning of their dropout in relation to treatment rather than individual factors. This stands in contrast with the existing literature on dropout, which has almost exclusively related it to patient characteristics such as demographic, clinical features or personality factors (Vandereycken & Vansteenkiste, 2009).

It is important to note that the current study does not describe the participants' treatment as having been intrinsically 'harmful', rather it describes the perceptions that participants attributed to a particular treatment they received at a stage in time. Other patients may have had different perceptions and, indeed, a future avenue of research might involve analysing the accounts of those who both do and do not complete similar programs to look for convergences and divergences in their treatment perceptions. Additionally, while the women in the current study painted a negative picture of the treatments from which they dropped out, they also all spoke positively of relationships with certain individual clinicians, or with alternative treatments they experienced previously or subsequently. Unfortunately, due to time and space limitations, I have been unable to do justice to these comparative accounts but it may be that future research could explore the way in which such distinct experiences are constructed within individual accounts.

I consider the qualitative approach taken in this study to be one of its greatest strengths, it having permitted me to gather rich and meaningful data from participants. Nonetheless, there were also drawbacks to relying on individuals' recall and impression. Future qualitative research on treatment dropout could minimise the impact of bias by ensuring participants all dropped out within, for example, the past year.

Another area which I consider a strength is the research question itself – asking how patients experience AN treatment and make sense of their decision to dropout. The justification for this was to redress the balance within the literature where dropout had only really been considered in terms of patient deficits and demographics. A drawback to the research question, however, is that it will have primed participants to make sense of their dropout in terms of treatment factors. Still, I hope to have managed this bias within the analysis by also drawing on knowledge about cognitive, psychological and social maintaining factors in anorexia to interpret their accounts rather than remaining at a purely descriptive level.

This study is one of the few to have recruited from the community to consult former patients (e.g. De la Rie et al., 2008, 2006) and, as such, the sample represents a variety of treatment modalities and settings. I had originally anticipated including only those who had dropped out from less intensive treatment settings (i.e. outpatient and daypatient), these being the first-line treatments recommended by NICE (2017). However, during the recruitment process I discovered that those contacting me each seemed to have had a more convoluted experience of treatment and dropout, often moving from inpatient to daypatient to outpatient and back again. While the variety of treatment settings explored here confer a certain authenticity, the relative lack of distinction between them could be seen as a limitation. Future research could perhaps collect accounts from those who dropped out of outpatient vs daypatient vs inpatient treatment to see whether divergent themes emerge.

Another potential drawback to having recruited from the community is the possibility that individuals were more likely to participate when they had had a particularly negative treatment experience that they wanted to speak out about. Caroline suggested as much at the end of her interview, when she said *"that was partly why I was so drawn to your study. I was drawn to saying, speaking out about* <u>*my*</u> *(treatment) experience"* (Caroline:1066). For this reason, future research could pro-actively contact those who have dropped out from a variety of treatment programs to ask them for their perspectives on treatment and reasons for dropout. This will protect against the risk of there being an over-representation of people with a proverbial axe to grind.

In terms of the qualitative method used, the current study contributes to our understanding of the experience of being treated for AN and allows for a better insight into the meaning of dropout. Other qualitative methods could have potentially contributed something different. As discussed in the Methodology Chapter, a GT approach was very nearly chosen, given that dropout from treatment represents both action and process, and the central object of a GT study is to develop a theory to explain how these occur. I decided to use IPA, however, because my main concern was in understanding the way in which anorexia patients experienced treatment and made meaning of their decision to dropout, feeling that these were the critical areas that had been overlooked within the literature. GT is not so well suited to this. I do feel though that a GT study could complement this one, going forward, taking the ideas established here to contribute to the development of an emergent theory on dropout.

I also think that studies investigating treatment engagement more generally should bear in mind the treatment factors that participants described to have made them 'worse' and to have contributed to their decision to leave. Specifically, additional factors worth considering include:

1. The amount of surveillance, rigidity and coercion within treatment, which can lead to secrecy and feelings of lost control and punishment.

2. The degree to which members of their treatment team do, or do not, listen and respond to the patient as a person with individual needs rather than just another ‘anorexic’.

3. The extent to which treatment is reliably provided; this includes the timely provision of adequate care plans, length of waiting times and frequency of cancellations.

4. The ways in which AN is problematized or normalised within treatment, and the ways in which the identities of those diagnosed with AN are either threatened or affirmed.

Finally, given that the participants’ treatment experiences differed from those which one might expect were the NICE (2004, 2017) guidelines being adhered to, it might be useful to have a formal audit carried out to establish what treatments are actually being delivered to ED patients within our National Health Service

5.3.2 Reflexivity

While I have already described much of my reflexive practice already, there are a few final issues I would like to raise, following on from the analysis and its discussion.

As described, a noteworthy aspect of my relationship to the topic has been my own historical experience of it. This meant that I have been, to a degree, a cultural insider alongside my participants. Smith et al. (2009) suggest that this is useful for the IPA researcher as *“...the empathy provided by a shared humanity and common cultural understanding can be an important bridge between researcher and participant and a valuable analytic resource’’* (Smith et al., 2009, p.10). I do believe my own experiences helped me build a rapport with participants, and I was able to observe certain nuances of language and behaviour that might have otherwise been missed. However, I also believe that my insider status made me quick to interpret at times, particularly in interview when I closely related to an experience they described. This is something Oguntakun (1988) has described as “the seduction of sameness” and, recognising it, I was keen to avoid it. During the interviews, I did my best to bracket moments of over-identification so I could remain solely with the participants’ own account. After the interviews, I then recorded these “seductions” within my post-interview notes and explored them further within my self-reflective journal. Later, when I entered the more interpretative stages of my analysis, I returned to both my writings and to the data itself to check and recheck that the conclusions I was drawing had solid grounding. In this way I engaged in Finlay’s *“dialectical* *dance"* (Finlay, 2008, p.3), both restricting my pre-knowledge and employing it to interrogate meaning.

My insider status also meant I had to consider how much, if anything, to disclose to participants. It appears that many of the qualitative studies on AN are by academics who have themselves struggled with eating problems, and a number chose to disclose their experience to the participants in their study (e.g. Segal, 2003; Garrett, 1997; Thompson, 1994). However, I decided not to do this myself. My rationale was that I did not want my experiences to become a detour in my conversations with participants. Marshall's (1996) argument influenced my decision: *"to be interviewed by someone presenting their personal experience would not only have flouted role expectations but more reciprocal disclosure would have been experienced as obtrusive"* (p.80). I believe self-disclosure needs to be guided by context and, for this study at least, disclosure would have been both irrelevant and inappropriate. It would have undermined my purpose of exploring participants' individual experiences of treatment, because they could have wanted to know more about how my experiences compared with theirs.

Perhaps, for me, a more challenging part of the process was deciding how much of my personal experience to share with the reader. I remain unsure where the line between appropriate and indulgent self-disclosure lies, but have been keen to not overstep it; not least because the voice of the anorexic subject is often discredited as being deluded and disordered (Saukko, 2008) - hardly connotations associated with academic authority and insight. Nonetheless, I knew my personal experiences could not go ignored if I were to approach this work with sincerity and I can only hope to have gotten the balance right.

I have also recently reflected on another epistemological tension – that is, my use of the AN diagnosis as part of my inclusion criteria given the critical stance my thesis takes toward the medical construction of AN and, indeed, the critical stance my profession takes toward diagnosis as a whole. I originally incorporated the diagnostic criteria to ensure that those who participated were specifically able to provide accounts of AN treatment and AN treatment dropout. This is because I was interested in the way in which the treatment for AN may be uniquely experienced, in part due to the way in which those labelled 'anorexic' are conceived by others. So, while at face value, the inclusion criteria may suggest an uncritical attitude toward diagnostic classification, this is not the case. I prefer to view AN, not as a definitive state of being, but as a historically situated way of talking about the (real) act of self-starvation that has constitutive effects. In this way, I recognise the reality of the anorexic experience, while also remaining sceptical of the way in which anorexia is conceptualised; within society, generally, and, specifically, within treatment.

5.3.3 Ensuring Standards of Quality

This research project aimed to uphold the principles of ‘good practice’ for qualitative research as set by Yardley (2000). She sets out four key criteria, and I will now evaluate the extent to which I consider this study to have fulfilled each of these.

Yardley’s first criterion is sensitivity to context. This asks that the research be suitably grounded in related theory and in the philosophy of the approach. It also requires for the study to be aware of its sociocultural context and of the subjective context of the researcher-participant relationship. I sought to fulfil this criterion in a number of ways. The Introduction and Literature Review chapters presented the study’s links to the research literature, while the Methodology Chapter emphasised its underlying theoretical principles. In line with my critical realist position, I have also given much consideration to the socio-cultural influences on anorexia, treatment and dropout within the Literature Review, and is an area I continue to address within the following chapters. I have also explored socio-cultural influences as part of my reflexivity as a researcher.

Within my personal reflection, I have done my best to be sensitive to the social context in which my participants and I have been situated. I was aware of the perceived power imbalance existing between an interviewer and their interviewee, particularly when the former is billed as a doctoral student and the latter as someone with a psychiatric diagnosis. I also explored the impact my gender and body shape may have had on participants’ accounts, and the impact my own history of AN may have had on each stage of the research.

Yardley’s second criterion is commitment and rigour. This requires the research to show strong engagement with its topic, and competence in its chosen approach. It also requires a thoroughness and completeness to be displayed in the study’s data collection and interpretation. I like to think I have demonstrated commitment and rigour throughout the research. I reviewed scores of academic papers, media articles, biographies and historical texts and deeply engaged with the topic through the interviews and through the analysis of the data that followed. I also believe rigor and commitment are shown in the way I ensured that the emergent themes remained firmly rooted in the words of my participants, illustrated by the many direct quotes woven throughout the Analysis Chapter and within the subordinate themes.

I have also been committed to the wellbeing of my participants throughout the process – not simply in how I engaged with them face-to-face but also by doing my best to honour them as individuals within this piece of work, and protecting their right to anonymity by removing any parts of their narrative that might risk identifying them.

To ensure I approached my analysis with suitable rigor, I met regularly with my supervisor –over Skype and in person. I discussed with her my themes as they emerged and she guided me in labelling them and on justifying which to develop further.

The third criterion put forward by Yardley is coherence and transparency. Coherence relates to how persuasively one advances their thesis through their narrative. Essential to any such persuasion, is a good fit between the employed method, the research question, and its underlying philosophy. I gave considerable thought to each of these elements and discussed my decision-making process at length within the Methodology Chapter.

I sought to achieve transparency, meanwhile, through the explicit way in which I documented my process of data collection and analysis. I have, for example, provided copies of communications with participants, tabulated themes, annotated transcripts, multiple verbatim extracts and demographic details for each participant. Reflexivity is also required to demonstrate transparency and I believe the explicit discussion of my ontology, epistemology, history of AN and experience of treatment, all display how seriously I have taken this requirement. My use of post-interview notes and self-reflective journal also further helped me identify the experiences and motivations underlying my research process.

Yardley's final criterion, impact and importance, relates to whether or not a piece of research has practical utility. While it is perhaps more the reader's place to assess the impact and importance of a piece of work, I do believe that the findings from this study carry an important message. As a qualitative study, the findings cannot be generalised to all who dropout of AN treatment but there is always the possibility of "glimpsing something of the universal through the particular" (Coyle, 2015, p.27). The study can also provide a first step in building a more complete picture of ED treatment dropout; one which can be progressively built up through a series of complementary qualitative studies, with each contributing something new to its development. I therefore contend that the current study is important and potentially impactful because of its part in creating a new perspective that can be used to inform therapeutic intervention for AN and other eating disorders. It is my hope that this initial research will be published in academic journals for wider dissemination, and allow me to contribute to further research on the topic in the future.

5.4 Implications of the Findings for Counselling Psychology

5.4.1 Theoretical

Within the literature, AN is typically conceptualised as individual pathology. Correspondingly, within treatment, psychological change is seen to occur at the intrapersonal level, with the therapist helping the patient develop a 'more mature personality' (Abbate-Daga, Amianto, Delsedime, De-Bacco & Fassino, 2013, p.307) or build positive self-schemas (Stein, Corte, Chen, Nuliyalu & Wing, 2013). However, the results of the current study suggest that, by focusing upon change at this level, the interpersonal factors affecting individuals' relationship with anorexia are neglected.

Cognitive approaches imply that individuals will change once given the relevant information, but treatment services may be failing to do this by focusing only on food and weight and ignoring the social context and subjective experience of the individual. Psychodynamic approaches target ways in which social mechanisms become internalised as coping strategies, but they may be in danger of focusing on fantasised, past relationships (such as the one had in childhood with the 'controlling mother') rather than on real, present ones (such as the one currently had with the 'controlling' treatment provider or with the 'emotionally supportive' anorexic peer with which the patient identifies).

The findings from the current study suggest that interpersonal factors interact with intrapersonal factors to maintain AN within treatment. This is important for three reasons: Firstly, because it emphasises that AN is not simply a reflection of individual pathology; secondly, because it supports the theory that AN is maintained through ongoing processes rather than simply contracted when certain setting conditions are met; and, thirdly, because it suggests that the maintaining processes, which continue to operate within the treatment space, can be further enabled by the relationships and identifications encountered there.

Schmidt and Treasure (2006) developed a maintenance model of AN incorporating both intra- and interpersonal factors which can provide a loose frame for the findings here. The authors propose that AN is maintained *"intrapersonally, by beliefs about the positive subjective function of the illness [i.e. pro-anorexic beliefs] and interpersonally, by both positive and negative responses elicited from close others by the physical presentation and behaviours associated with AN, in individuals who are vulnerable because of avoidant and/or obsessive-compulsive personality traits and unknown biological factors."* (Schmidt & Treasure, 2013, p.345).

In other words, while someone may develop and maintain AN as a result of certain personality traits, biological factors and beliefs about anorexia's functionality, the way others respond to their anorexia also play a part. It is this latter point about interpersonal factors that is particularly relevant to the current study's findings as participants' experience of others' reactions to their AN within treatment contributed to their existing pro-anorexic beliefs becoming exacerbated, maintaining their AN or, indeed, making it 'worse'. While Schmidt & Treasure (2006) limit their discussion of interpersonal reactions to those of close family members, Treasure et al (2011) also wrote a brief article, entitled *'First Do No Harm: Iatrogenic Maintaining Factors in Anorexia'* which suggests that treatment providers could play a similar role. For example, they propose that hostility in the form of coercive refeeding in either a hospital or outpatient setting could strengthen conditioned food avoidance, while highly structured treatment environments could support the rigid attention to detail and inflexibility that is characteristic of people with AN, and allow these negative behaviours to thrive.

In line with this theoretical framework, the current study's findings imply that treatment experiences and likelihood of dropout are influenced by an interaction between an individual's personality traits (e.g. perfectionism), pro-anorexic beliefs (e.g. that an anorexic body is an effective means of communication), and the way in which others in treatment relate and respond to their anorexic symptoms. For the women in this study, their relationships in treatment seemed to enable them in expressing perfectionistic, obsessive-compulsive traits and reinforcing a number of pro-anorexic beliefs. This left them with two perceived options: get 'worse' or get out.

Given that we, as treatment providers, want our patients to stay in and get 'better', the implication is that we need approaches that can address eating disordered behaviour while also tackling the intrapersonal and interpersonal factors that maintain it. Recently developed first-line treatment approaches, such as MANTRA (see Appendix 2), draw on the latest neurocognitive research to address intrapersonal factors involved in AN (e.g. deficits in set-shifting, poor working memory, alexithymia), but they pay little to no attention to interpersonal and social factors[11]. If only we could also incorporate a theoretical focus on relational frameworks in which AN is maintained, we could perhaps address the problems of anorexia more comprehensively. As the findings of this study indicate, this should involve exploring relational frameworks within treatment itself but may also mean involving family, friends, GPs, and any others implicated in sufferers' maintenance of an anorexic identity. It may mean we also need to educate wider society about the possible subjective meaning of anorexia nervosa.

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[11] MANTRA does typically incorporate family therapy but this is more in the service of supporting the patient in making individual change rather than exploring the interpersonal interactions and social identifications that may be maintaining their AN

Opportunities for people to see beyond the anorexic's underweight body and understand the social influences that contribute to it will help create an understanding of its meaning for the individual rather than just a reaction to their symptoms.

5.4.2 Organisational

Within mental health in general (e.g. British Psychological Society, 2013) and EDs in particular (e.g. Fairburn & Cooper, 2014) there remains passionate debate about the validity of diagnostic terminology for understanding facets of human distress (Hastings, McNamara, Allan & Marriott, 2016). This study's findings contribute to the conversation by suggesting that, while the medical model of anorexia may provide a language for discussing individuals' difficulties and offer a pathway to treatment, it can also leave sufferers feeling pathologised and misunderstood. Furthermore, given that the medical construction of AN views sufferers as incompetent, it justifies a paternalistic treatment that employs coercion and restrictions on freedom 'for the good of the patient' (Kendall, 2014). The participants in the current study challenged this justification by suggesting that treatment of this nature actually increased their sense of disempowerment and lost control, thereby reinforcing unhealthy behaviours and contributing to their decision to dropout. The findings therefore raise questions regarding the current emphasis of medical models within treatment services and the ethical justifiability of paternalism.

The women in this study clearly wanted professionals to understand their ED more in terms of their subjective experience and identifications. Boughtwood and Halse (2010) suggest that recognising the differences between individual patients and respecting the meanings they attach to their illness is central to the therapeutic alliance in the treatment of anorexia. For some clinicians, a key challenge in achieving this is accepting that sufferers' experiences and perspectives are going to be radically different from the medical view of anorexia with which they are familiar. Such a paradigm shift may be difficult but, as this study's findings show, the alternative is a therapeutic relationship that is construed by patients as patronising, coercive and, ultimately, harmful. One aspect of establishing such a paradigm shift is recognising the limitations of current treatment regimes for anorexia, with no individual clinician nor field of research holding all the answers to what anorexia is or how to 'fix' it. This acknowledgement opens up a space in which patients can become involved in discussions about their treatment, and be supported in building autonomous motivation in a way that may reduce their need to sabotage, or else withdraw from, treatment (Sesan, 1994). As Tierney (2008) states:

"Even clinicians whose remit is to attend to physical functioning can attempt to adopt an interconnection with patients who have anorexia through listening to them and showing a willingness to understand the condition from their perspective" (p.374).

The findings also highlight that the very nature of treatment being ‘treatment for anorexia’ can limit patients’ opportunity to move away from an anorexic identity. This suggests that it might be useful for treatment to be reconceptualised as a starting point in a much longer journey toward recovery, the latter stages of which necessarily involve the patient not being in formal treatment. This also raises questions about what we, as Counselling Psychologists, can do to help improve sufferers’ chances of recovery as they continue on within the community. Perhaps, while still within treatment, we can encourage our patients to consider the social identities and life experiences they may seek to pursue after discharge. Perhaps, too, we can encourage them to develop and engage in non-traditional types of organised recovery support, such as body-positive online groups, or political movements that are personally meaningful and aid in them building alternative, more empowered identities. Indeed, these professional pursuits are uniquely well-suited to Counselling Psychologists, whose focus is on ‘hygiology’ (Zerbe Enns & Nutt Williams, 2013, p.487) rather than pathology, and who seek to help individuals draw on their strengths and resources, no matter their apparent degree of ‘dysfunction’ (see e.g., Howard, 1992; Strawbridge & Woolfe, 2010).

It is also important to consider participants’ accounts of their relationships with other sufferers and what implications these may have for institutional settings that treat AN patients alongside one another. Participants indicated that their shared anorexia-related identities promoted maladaptive behaviours (Vandereycken, 2011) but they also indicated that they offered a unique emotional support. It is possible that this emotional support could be used as a force for recovery, rather than disorder maintenance, if channelled correctly. McNamara & Parsons (2016) observe that “the extent to which social identities contribute to resilience or vulnerability depends on the norms and values associated with the specific group membership” (p.664), suggesting we should consider the identity content of the groups of ED patients that we treat together, and encourage them in developing a group identity based upon recovery values. Therapy groups could potentially help with the initial stages of identity transition necessary for recovery, provided they endorse norms reflecting health-enhancing behaviours (and avoiding any emphasis on the importance of a specific body shape or eating restraint, etc.) (Best, Beswick, Hodgkins, & Idle 2016), and are able to create a social context in which patients feel accepted and heard.

To provide a balance to the prevailing psycho-medical discourse, it may also be helpful to incorporate some sort of consciousness-raising group into treatment, whose aim it is to explore social and political issues around food and eating rather than individual psychology. These types of groups, based on the social action groups within the feminist movement in the 1960s, may help patients better understand the role conflicts they encounter within treatment and allow them to feel more empowered within the system. These types of group discussions and explorations may also encourage them to participate in social action once they leave treatment, thereby giving them a purpose and an identity that does not rely on them starving themselves.

5.4.3 Clinical

While it seems clear that treatment needs to move beyond the medical objectifying of AN patients as just 'thin bodies', rather than as complex unique individuals, it is understandable that well-meaning clinicians focus on the low weight of those they treat. Indeed, the medical consequences of AN can be fatal and clinicians have an ethical obligation to keep their patients safe or, at the very least, alive. For this reason, weight stabilization is always going to be an essential part of AN treatment, and sometimes this means the clinical imperative to keep patients medically safe will have to take precedence. The challenge is in getting the balance right, at the right time. As suggested by the accounts in the current study, treatment can sometimes become so mired in focus upon nutrition, behaviours, weight and symptom-management, that it risks colluding with patients' AN, allowing them to avoid exploration of difficult emotions and continue to conduct their lives and define their identity around weight and food.

The logic behind food refusal can be hard to fathom but, for the individual who engages in it, it holds both personal and social significance. The significance (for example, that they derive a sense of worth from being at an extremely low weight and restricting their food in a way most others could not sustain) needs professional acknowledgement and exploration, otherwise the core difficulty (feeling worthless) remains unaddressed, and the patient will likely return to restricting her food in order to obtain the perceived benefit of AN to tend to her underlying hurt. This is even more important once we recognise that the treatment environment could itself be an irritant to that hurt, such as by increasing feelings of worthlessness through limited professional interest in her as an individual, or by her relating to peers she perceives as 'thinner', and thus more worthwhile.

As Counselling Psychologists, we are already primed to explore personal meaning and develop shared understandings with our clients/patients, perhaps moreso than many others who work with eating disorders. Still, because there are not many psychological conditions we attend to with so visible a physical component as anorexia nervosa (Schmidt & Treasure, 2006), and because those with anorexia are reported to be emotionally avoidant (Geller, Cockell,, Hewitt, Goldner & Flett, 2000; Troop & Treasure, 1997), it might be easy to lose sight of our therapeutic objective.

The findings also suggest that clinicians need to be mindful of how their own reactions can potentially reinforce unhealthy beliefs that contribute to the maintenance of their patients' anorexia. For example, when faced with a patient who is struggling to gain weight, a clinician might develop unhelpful cognitions about needing to ‘save’ the patient, leading to unhelpfully overprotective interactions. These responses could risk reinforcing the patients’ belief that she is helpless, for example, thereby lessening her motivation to try and recover.

Another potential area of concern within therapy, highlighted by the participants’ accounts, is that of weight-monitoring. Current treatment guidelines recommend that patients have their weight monitored, whilst also receiving therapy (NICE, 2017). Often, weight-monitoring is undertaken by the same professional that provides the therapy, creating a dual professional role. Such roles may be in conflict if one of the therapeutic goals is to help the patient develop a sense of self that is not dependent on weight. For this reason, when weight needs monitoring, it would be sensible to have the patients’ therapist focus on the longer-term psychotherapeutic goals of treatment, while a separate professional manages weight and other medical symptoms.

Finally, despite all we may do to try and retain patients in treatment, sometimes they will dropout. How we conceptualise this occurrence is clinically important, mainly for how it impacts our management of those who have dropped out – both in the immediate aftermath, and also on those occasions when they might choose – or be compelled – to return. This study’s findings highlight how dropout may not be indicative of poor motivation for recovery at all, meaning that we should avoid conceptualising patients who dropout as resistant to change. This will help reduce the risk of them being stigmatised if they do return to treatment in the future, and will lessen the risk of them coming to view treatment as a hostile environment or themselves as unlikely to recover.

5.5 Final Reflections

The findings from this study have important implications, both for those who work with eating disorders and for the systems in which they work. It is hoped that the findings encourage the development of a more middle ground position whereby weight restoration is considered an aspect of treatment, but not its sole aspect; and that, by implementing more person-centred approaches, success rates rise and dropout levels fall. Finally, it is hoped that, in light of all that has been said, AN treatment dropout might be considered, not so much a sign of anorexic resistance, but a sign of an imperfect treatment system that does not always have the answers.

Chapter 6. References

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Chapter 7. Appendices

Appendix 1: Diagnostic Criteria for Anorexia Nervosa
Appendix 2: Firstline psychological treatments recommended by National Institute of Clinical Excellence (NICE, 2017)
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Appendix 1 - DSM-5 (2013) Diagnostic Criteria for Anorexia Nervosa

For the diagnosis of Anorexia Nervosa, an individual must present with the following symptoms:

i. Persistent restriction of energy intake leading to significantly low body weight (in context of what is minimally expected for age, sex, developmental trajectory, and physical health).

ii. Either an intense fear of gaining weight or of becoming fat, or persistent behaviour that interferes with weight gain (even though significantly low weight).

ii. Disturbance in the way one's body weight or shape is experienced, undue influence of body shape and weight on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.

Subtypes:
Restricting type
Binge-eating/purging type

Appendix 2 - Firstline Psychological Treatments Recommended by NICE, 2017

Eating Disorder Focused Cognitive Behavioural Therapy

CBT combines behavioural experiments with rational exploration of a person's beliefs. There are two types of CBT that have been manualised for AN – CBT-AN (Pike, 2003) and CBT-E (Fairburn, 2003). In clinical practice, they are very similar, aiming to reduce AN symptoms, encourage healthy eating and restore a healthy body weight by fostering a therapeutic alliance and the provision of psychoeducation, behavioural monitoring, nutritional counselling, behavioural experiments, cognitive strategies and relapse prevention. Both CBT-AN and CBT-E also monitor weight and typically consist of 40 sessions over 40 weeks. The main distinction between the two models is a theoretical one. Whereas CBT-AN specifically targets AN, CBT-E is based on a 'transdiagnostic' model, believing all eating disorders to be maintained by the same distortions in thinking. CBT-E also offers an additional core module that addresses mood intolerance as well as optional modules addressing clinical perfectionism, interpersonal deficits and low self-esteem (Fairburn 2008).

The Maudsley Model for Treatment of Adults with Anorexia Nervosa

The Maudsley Model for Treatment of Adults with Anorexia Nervosa (MANTRA; Schmidt 2012; Wade 2011) typically consists of 20 therapy sessions and addresses AN sufferers' inflexible cognitive style and alexithymia (Schmidt 2006; Treasure 2013). To do this it incorporates both emotion skills training and cognitive remediation therapy designed to improve cognitive flexibility, working memory and planning skills (Lock 2013; Tchanturia 2008). While it is a workbook-focused treatment, the individuals' specific symptoms and personality traits determine which modules are focused upon. Motivational interviewing techniques are used to help encourage behaviour change and symptom management, and family members are often involved to provide support.

Specialist Supportive Clinical Management

Specialist Supportive Clinical Management (SSCM; McIntosh et al., 2006) was originally developed as a comparison treatment for an AN treatment trial to represent what might be offered by a generic professional trained in eating disorders. It typically consists of 20 weekly sessions and combines features of nutritional counselling, behavioural weight restoration strategies and supportive psychotherapy.

Focal Psychodynamic Therapy

Unlike traditional psychodynamic therapies, FPT is a modified, standardised therapy. This makes it better suited to the current demands for evidence-based practice, being more readily disseminated and subject to empirical evaluation. The therapy consists of up to 40 sessions and, in contrast to the other recommended treatments, takes a non-directive stance. Instead it addresses, first, the meanings the sufferer gives to their symptoms in terms of their history and family experiences. It then explores with them the influence their symptoms have on current interpersonal relationships. Finally, it reflects on how this influence manifests within the therapeutic relationship.

Appendix 3 - Recruitment Poster

*formatted specifically for Beat’s research webpage

University Logo:

CITY UNIVERSITY
LONDON
EST 1894

Study Title:

An investigation into the treatment experiences of those who dropout of treatment for anorexia nervosa

Details of Author:

Name - Natasha Sutherland

Affiliation - Doctoral Student in Counselling Psychology at City University

Email - [redacted]

Synopsis

What is the purpose of the study?

We are interested in understanding the experience of undergoing treatment for anorexia nervosa in the UK and what might contribute to people leaving treatment early. Unfortunately, not only does anorexia have the highest mortality rate of all psychiatric illnesses, many of those in treatment leave before completing the full treatment program, potentially limiting their chances for full recovery. We hope that the findings from this study will help health care professionals develop better understandings of the difficulties involved in undergoing treatment for anorexia and contribute to the development of more effective and user-friendly therapies for sufferers.

Who can take part?

Participation involves a short phone call where you will be asked a few questions about your demographics (age, location etc.) and your history of anorexia and treatment. Following this you may be invited for a semi-structured interview which will last approximately 90 minutes. The interview will be 1-to-1 and focus on your experiences of anorexia and receiving treatment for it, as well as your decision to leave treatment.

If interviewed, you will receive £30 for your contribution.

How can you take part?

Participation is voluntary and you may withdraw at any point. All of the information you provide will be anonymous, will remain completely confidential, and will be used for the purposes of this study only.

For more information about this study, or to take part, please contact Natasha Sutherland by email at [redacted]

Appendix 4 - Information sheet

CITY UNIVERSITY
LONDON

My name is Natasha Sutherland, I am studying for a Professional Doctorate at City University and I would like to invite you to take part in my research. I am supported by my academic supervisor, [redacted].

Please read the following information about the study carefully, ask me any questions you like and take the time to decide whether you would like to take part.

What is the purpose of the study?

I am interested in understanding the experience of receiving treatment for anorexia and what might contribute to leaving treatment early. Unfortunately, not only does anorexia have the highest mortality rate of all mental health conditions, many of those who receive treatment leave before finishing, potentially limiting their chance of a full recovery. Hopefully, the findings from this study will help health care professionals gain a better understanding of the difficulties involved in undergoing treatment for anorexia in order for them to develop more effective and user-friendly therapies for sufferers.

What have I been invited to take part in this study?

You have been invited to take part because you are female, aged 18 or over, have been diagnosed with anorexia nervosa and have dropped out of treatment for your eating disorder. You may or may not now be recovered, and you may or not now be in some form of treatment. You will, however, need to be medically stable – or else medically monitored by a health professional – in order to take part.

What will I have to do?

You will be asked to read the informed consent form that you received with this information sheet and then speak with me briefly on the phone to confirm your eligibility. You may then be invited to participate in a one-to-one interview with me at City University in central London.

The interview will be audio-recorded for future transcription and analysis. All the information you provide for the study will be treated as confidential. Quotations from the interview could be used to illustrate findings in future reports or research publications but these will be anonymised so that you cannot be identified.

What will the preliminary phone call and interview involve?

My phone call should not last more than 5 minutes and I will just ask you some basic questions about your demographics, eating disorder diagnosis, treatment history and current status. The face-to-face interview will last approximately 90 minutes and I will ask you some broad questions about your experience of treatment within the NHS, as well as what prompted you to leave.

What are the possible disadvantages and risks of taking part?

There are no physical risks to you for taking part in this research. However, speaking with me on the telephone and, potentially, taking part in interview will require you to give up some of your time. Some of the questions will ask you to think about your personal experience in treatment and some people may find thinking about these issues upsetting. If you are currently back in treatment, some of the questions may influence how you think about it, so please think carefully before you decide to take part and consider discussing your decision with your current treatment provider(s).

You do not have to discuss anything that makes you feel uncomfortable and the questions have been designed to be sensitive to your feelings and concerns. It is quite likely you will not feel distressed at all. In the event that you do feel distressed, however, I can direct you to some support should you wish for it.

What are the possible benefits of taking part?

If interviewed, there is a monetary benefit of £30 for taking part. Most importantly though, in sharing your experience you will be contributing to the growth of knowledge that could help in the development of more sensitive and collaborative eating disorder treatment, benefiting all those who suffer. Somewhat surprisingly, the meaning of treatment dropout has not been explored from the perspective of the anorexia sufferer themselves. We hope your experience will increase our knowledge and understanding of why people make the decision to drop out of treatment, the impact their experience had on their decision and what can be done to help sufferers get the most effective and supportive help possible.

What will happen if I do not want to carry on with the study?

If you decide to withdraw before or during interview, you can do so. There will be no negative consequences to you if you decide to withdraw. You will also be able to withdraw any submitted data for up to two weeks following your participation. After this time, all data will have been anonymised and will therefore be untraceable.

What if there is a problem?

If you would like to complain about any aspect of the study, City University London has established a complaints procedure via the Secretary to the University's Senate Research Ethics Committee. To complain about the study, you need to phone [redacted]. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is *'An investigation into the treatment experiences of those who dropout of treatment for anorexia nervosa'*

You could also write to the Secretary at:

[redacted]
Secretary to Senate Research Ethics Committee
Research Office, E214
City University London
Northampton Square
London EC1V 0HB
[redacted]

What will happen to the results of the research study?

The results of the study will be presented both as a Counselling Psychology doctoral thesis at City University and, potentially, as paper(s) for publication in a scientific journal. Your individual responses or participation will not be personally identifiable in any way in any report. A copy of the study's findings can be provided by Natasha Sutherland, on request.

Who has reviewed the study?

This study has been approved by City University London Psychology Department Research Ethics Committee.

Further information

The Lead Investigator for this research project is myself, Natasha Sutherland. If you have any questions or require any additional information please get in touch with me by email at [redacted]

[redacted] is providing supervision for the research and you can also contact her at [redacted]

Appendix 5 - Consent Form

CITY UNIVERSITY
LONDON

An investigation into the treatment experiences of those who dropout of NHS treatment for anorexia nervosa

Please initial box

1.	I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records. I understand this will involve: - A brief preliminary phone conversation with the primary researcher who will ask a few questions about my demographics, my eating disorder and my treatment history - Potentially being interviewed by the primary researcher - Allowing the interview to be audiotaped	
2.	This information will be held and processed as part of a thesis in partial fulfilment of a Professional Doctorate in Counselling Psychology, and for the purpose of furthering knowledge about anorexia nervosa and its treatment from the point of view of sufferers themselves. I understand that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation. The only exemption to this would be in the very rare instance where there are serious concerns about my safety, the safety of other persons who may be endangered by my behaviour or the health, safety or welfare of children.	
3.	I understand that my participation is voluntary, that I can choose not to participate in part or all of the project without penalty. I also understand that I will be able to withdraw any submitted data for up to two weeks following interview. After this time, all data will be anonymised and therefore untraceable.	

4.	I agree to City University London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.	
5.	I agree to take part in the above study.	

Name of Researcher Signature Date

Name of Participant Signature Date

Appendix 6 - Preliminary Phone Call Screening Guide

- How old are you?
- Where do you live (county/city)?
- Have you ever been diagnosed with an eating disorder by a health professional? (e.g., psychologist, psychiatrist, general practitioner)
- If, yes to the previous question, what diagnosis/diagnoses did you receive?
- What treatment have you had for anorexia?
- Have you ever left outpatient treatment for anorexia on the NHS before finishing it?
- Was it your decision to leave treatment early?
- What services were involved in that treatment (e.g. psychotherapy, nutritional therapy, psychiatry)?
- Are you currently diagnosed with an eating disorder or are you recovered / in recovery from an eating disorder (i.e. no longer diagnosed with an eating disorder)?
- If you still struggle with an eating disorder, what is your current diagnosis and/or status?
- Do you currently suffer from any significant health problems as a result of your eating disorder? (e.g. heart rhythm abnormalities, organ damage)
- If you do currently suffer from significant health problems, are these being monitored by a qualified medical professional?
- If not, would you be willing to have a medical review with your GP and seek their sign-off in order to participate in this study?
- Are you currently receiving any form of treatment for an eating disorder or other mental health condition?

Appendix 7 - Interview Confirmation Email

Dear

Thank you for speaking with me on the phone yesterday, it was lovely to chat with you. I am just writing to confirm our meeting for interview at ___ on ____.

The address for our meeting is:
Rhind Building
City, University of London
St John Street
London EC1R 0JD
Google Map: http://bit.ly/2uNjixe

I will come and collect you from the main entrance of the building at ____ pm. There are some sofas there to wait on if you are a little early. The interview itself will last between 60 and 90 minutes.

If you have any questions about the study or have any difficulties on the day, please don't hesitate to call me on 07879 473 121.
In the meantime, have a good rest of the month and I look forward to meeting you in August.

Best wishes,

Natasha Sutherland
Doctoral Student

Department of Psychology
School of Social Sciences
City University London
[redacted]
[redacted]

Appendix 8 - Debriefing Sheet

CITY UNIVERSITY
LONDON

Thank you for your participation in our study, it is greatly appreciated.

Purpose of the Study:

We previously informed you that the purpose of the study was to learn more about the experience of undergoing NHS treatment for anorexia nervosa and what might contribute to people leaving treatment early. We hope that our findings will add valuable knowledge to the field of eating disorders and help direct future research so that we can develop more effective and user-friendly treatments for sufferers.

We realise that some of the questions asked may have provoked strong emotional reactions. As researchers we do not provide mental health services and we are not able to follow up with you after the study. However, we want to provide every participant in this study with a comprehensive and accurate list of resources of support that are available, should you decide you need assistance at any time. Please see information pertaining to local resources at the end of this form.

Confidentiality:

You may decide that you do not want your data used in this research. You can do this without penalty. If you would like your data removed from the study and permanently deleted please email the lead researcher, Natasha Sutherland, at [redacted] within two weeks following interview. Please note that, after this time, data will have been anonymised and will therefore be untraceable.

Final Report:

If you would like to receive a copy of the final report of this study (or a summary of the findings) when it is completed, please feel free to contact us.

Useful Contact Information:

If you have any questions or concerns regarding this study, its purpose or procedures, or if you have a research-related problem, please feel free to contact Natasha Sutherland, at [redacted]

If you feel upset following interview, talking with someone may help. Please find below a list of useful resources for eating disorder support. Alternatively, your GP can help you seek a referral for specialist treatment.

Beat

The UK's leading national eating disorders charity – visit their website for helplines, local support groups, a directory of eating disorder therapists, plus much more: www.b-eat.co.uk

Anorexia & Bulimia Care

Twenty-year-old eating disorder's charity which offers helplines, befriending, and nutritional support to sufferers: www.anorexiabulimiacare.org.uk

The National Centre for Eating Disorders

The NCED also has a helpline and a directory for helping you find eating disorder counsellors: www.eating-disorders.org.uk

British Association for Counselling and Psychotherapy

The BACP has a website dedicated to helping you find a counsellor: www.itsgoodtotalk.org.uk

NHS Choices

The Health A-Z section offers some useful information on eating disorders and their treatments, as does the Live Well section: www.nhs.uk

Appendix 9 - Interview Schedule

Could you give me a brief history of your eating disorder treatment?
Prompt: which of these treatments did you leave before finishing?

Can you tell me about how you came to leave outpatient treatment early?
Prompt: are there any other events that stand out in your mind? how did this/these affect what happened? did anyone influence your decision to dropout?

How did therapy feature within this treatment experience? What other services were involved?
Prompt: how did your experience of therapy compare to the other aspects of your treatment experience?

How did you feel before starting the treatment?
Prompt: some people find it a relief / a struggle. what was the source of these feelings? what expectations did you have? How were these coloured by your previous experiences?

What was it like for you going through the treatment process?
Prompt: physically, emotionally, mentally

What is it like for you now looking back on the experience?
Prompt: feelings / thoughts / memories

Given your own experience, what do you think makes for a good/bad outpatient treatment?
Prompt: what is helpful / unhelpful in therapy? what is needed / best avoided?

How do your current thoughts about treatment compare to when you dropped out?

How do you go about managing your eating disorder / recovery without treatment?

How might your current behaviour change if you were in treatment?
Prompt: how about if you were in therapy, specifically?

Do you think you’re more or less likely to try treatment again after your previous experience?
Prompt: how about therapy itself?

Has anyone/anything been a support, outside of treatment?

Prompt: has a particular person been supportive? books? charities?

If you knew someone who was about to get the same treatment you had, what advice would you give them?

Appendix 10 - Example of Stages Two and Three of Analytic Process

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Appendix 11 - Example of Stage Four of Analytic Process

Table illustrating cluster themes from Maggie's interview, along with their associated emergent themes, line numbers and quotes.

CLUSTERED THEMES	EMERGENT THEMES	LINE NO.	QUOTE
IMPACT OF PREVIOUS TREATMENT EXPERIENCE	Unsuccessful previous treatment experience impacts expectations	995	"I turned up at this day patient thing... and I found out xxxx was there, I was like, ugh, I hate that man. He was a CAMHS person, so I just automatically hated him."
COERCION INTO TREATMENT	Perceived coercion into treatment	23	"I didn't really wanna go there but it was that or... the other option."
	Forced to choose to enter treatment out of fear of being sectioned	31	If I had said no to that and I had said no to going into the kids' inpatient thing, they would just section me anyway. So it was, kind of like, well I have a choice but I don't really, sort of thing.
LOSS OF CONTROL/AUTONOMY IN TREATMENT	Not being in treatment associated with regaining feedom	541	"And then when I left I was kind of like... I didn't wanna do anymore treatment or anything. I was just... at first, I was like, yes, I'm free I never have to eat again."
DECEPTION	Deception presented as a game	77, 399	"I said, oh just take me to school, I'll eat whatever you want, blah blah blah. And, then, they sent me off to school with this packed lunch. It went straight in the bin [laughs]." "He tried to interfere a few times by moving my taxi forward. But then I'd purposely turn up late cos I'd just go for a walk anyway and rock up at 10 o'clock instead."
	Problem of treatment being "built on lies"	113	"I think it would have been more helpful if like I could have been more honest with her. But I think it started, because it was all built on lies, anything I ever said to her was just like... like I didn't take any of it seriously."
	Deception used to maintain/regain access to valued aspects of identity	48	"So like I didn't wanna drop out of sixth form. So then I used to blackmail my parents. And I would be like, oh I'll eat if you take me to sixth form and then my parents were like, okay, because they wanted me to eat."
VARYING ACCEPTANCE OF DIAGNOSIS	Not "feeling" sick means treatment is perceived as unnecessary	71	"*I* felt like I was fine. So, I was like, this is all so unnecessary."
	Motivation for treatment linked to felt sense of being in danger	222	"Whenever I left, I'd just go massively downhill then get scared and come back"
	Recognising the danger of ED provides motivation to change, independent of treatment	1094	"It was like: 'you've got rid of everyone, you keep just going lower and lower and lower and no one's gonna come and save you. You're just gonna die. And I'm not sure I wanna die. So, I better start doing something different."
LACK OF CONSISTENCY	Anger at professionals' freqent cancellations	118	"She used to cancel a lot, which used to really annoy me....I used to get quite wound up about like getting weighed and quite anxious about it and then for her to ring up the day before, like oh, there's no appointment this week just come next week instead. I'd be like, eh okay"
WEIGHT-MONITORING CAUSES STRESS	Being weighed causes anxiety	125	"I used to get quite wound up about like getting weighed and quite anxious about it"
	Being weighed perceived as being judged	731	"So if they weighed me I'd just feel really embarrassed if it went up cos I'd be like: 'oh well they don't think I'm a very good anorexic if my weight's gone up, that's just really embarrassing.'"

GUILT AND SHAME	Feels shame thinking about her behaviour toward others in treatment	975	"I think back now of the way I was and like how I spoke to some of the people who tried to help me. I'm just a bit disgusted at myself. I'm not a very good person really. Or I wasn't."
	Non-compliant behaviour is an attempt to regulate feelings of guilt	415	"I felt guilty about all the food I'd been eating. So, I just used to go for a walk and I used to get very anxious about just sitting down, that I just couldn't sit down."
	Guilt at not recovering for the therapist	1025	"I guess I feel bad that I never recovered because I feel like I owed him that. He put in so much effort. No matter how rude, cold...downright dickheadish I was to him, he was just always there for me. And always willing to try and I never gave him anything back and I feel bad for that."
CONNECTION TO THE WORLD OUTSIDE TREATMENT	Importance of maintaining connection to the world while in treatment	1316	"People who end up in treatment... its gets to the point where they just lose everything. And when you have nothing else, the eating disorder just grows. So if you are taken away from your family so you don't have a proper relationship with them. You are taken away from all your friends, you don't have a proper relationship with them. You don't have a job. Don't have anything else other than your eating disorder. There's just a big void to fill and you just fill it with your eating disorder."
SUBJECTIVE FUNCTION OF TREATMENT	Dropout linked to treatment losing its subjectively defined function	203	"I was like, oh, well I've finished exams now so I have to go."
	Safety of treatment	368	"It was kind of like they made it okay to like... eat, I guess"
	Treatment functions as "rescue"	1092	"No one's gonna rescue me now cos, you've got rid of everyone... this is what I was saying to myself. It was like: 'you've got rid of everyone, you keep just going lower and lower and no one's gonna come and save you."
ADAPTIVENESS OF TREATMENT	Patronised by overly manualised treatment delivery	246	"I just found it [MANTRA] really *patronising* .... The first bit was 'preparing to change' [sarcastic tone] ... and then it goes through and then last one is relapse prevention because you're suppose to have like... *recovered* at that point"
	Feeling patronised by overly manualised programme leads to angry disconnection	264	"It used to *piss me off*. But again, I don't know if I was just angry. Angry at this book trying to make me recover. But it used to have stuff, like it had one, it was a page and it had a cloud full of raindrops and it was like [said in sarcastic tone] 'your anorexic thoughts are like raindrops, they drip slowly at first and then they build into a puddle. And, I don't know it just used to really piss me off [laughs]... So, I didn't use to do it."
	Therapist better at adapting treatment delivery to meet individual need than dietician	1211	"She was just very insensitive and very pushy and I hated talking about meal plans and diets and like, stuff like that. So, I used to do all of mine with [my therapist]. And we would come o our own agreement about it. And then he'd tell the dietian."
	Tailoring treatment delivery in a way that interests the individual	1011	"He was very, very clever. And he used to do it more like, rather than treating me like a patient like everyone else, he would be like... he knew I was really interested in science. I found neuroscience really interesting and stuff. So, he'd present it more in that kind of way."
	Treatment adapted to individual need and motivational stage	184	"I think initially the agreement was, 'oh just come here and eat'. And I'm going, 'I'm not listening to any of your airy fairy conversations and I'm not interested in any of your bullshit recovery methods, like 'I'll just come and eat' because like I found it easier to eat there... The dude that runs the place who is called xxxx, he was really nice and he was like, 'okay, yeah we can do that and then re-evaluate in June'."

STUCKNESS IN TREATMENT	Either trapped in relapse or trapped in treatment	363	"I thought about leaving so many times but then I was just like I hate life when I relapse badly, it was so shit"
	Unable to change in treatment	504	"And [therapist] was like: 'are you willing to change and actually like really put in an effort and stop all these habits and stuff?' And I was just like, I don't think I can."
	Treatment keeps people stuck in a sick role	769	"Especially if it was the same staff that were there, I would just fall straight back in to playing that role. And I feel I'm not the only one who gets stuck in that role. I've watched a lot of people do it... but I don't think they're aware of it. So, that's why, I'm not really sure how much good eating disorder treatment does."
	Just 'existing' while in treatment	301	"It was kind of pointless because I wasn't even getting better. I was just maintaining, just existing."
INFLUENCE OF AN PEERS ON RELATIONSHIP WITH ANOREXIA	Perceived value of treatment impacted by poor treatment outcome of peers	770	"I feel I'm not the only one who gets stuck in that role. I've watched a lot of people do it... but I don't think they're aware of it. So, that's why, I'm not really sure how much good eating disorder treatment does."
	Anorexic competition develops when treated as a group due to something about the condition making them all perfectionistic and 'niggly' (obsessive?)	1309	"When groups of anorexic people get together, we are a bunch of competitive bitches [laughs]. I think there's something about the illness that make you just very competitive, very niggly and perfectionist and again, just anywhere where you get groups of those people together, there's always triggering and there's always competition."
	ED behaviours got worse due to competition with peers	422	"[Over-excercising] definitely got worse being there. Because it's then other people started copying me. So, if I'd be standing up, okay, other people started standing up as well. And then it would just be this weird thing of, well I'm not sitting down, she's not sitting down [laughs] So, I used to... I think, I set off other people and then that set off me even more and then, yeah."
	Inspired by positive behaviour of peers in treatment	372	"You were there with other people who were also struggling so you think, oh if they can eat then so can I."
ANGER AT BEING TREATED DIFFERENTLY TO OTHER PATIENTS	Anger at being treated differently to other patients	463	"They used to clamp down on a lot of the other stuff people were doing, like purging or whatever, so why was she allowed to get away with this habit."
PERCEIVED ROLE EXPECTATIONS OF OTHERS SHAPE ED BEHAVIOUR	Stepping outside of expected anorexic role behaviours would have caused guilt and embarrassment	1071	"I feel like I'd been there so long doing the same thing that there was no room for me to change as a person or change my behaviour. I would have just felt too guilty, too embarrassed. Like: 'oh they're gonna think I'm a right fat ass, cos I've stopped walking everywhere.'"
	Others not knowing about ED makes it easier to not engage in ED behaviours	561	"No one in the whole continent knew that I had an eating disorder or knew that I'd struggled with any kind of mental health stuff. So I was able to pretend a bit that it wasn't a problem. I didn't tell anyone until right at the end. I didn't... I just used to fake it. I'd be sitting there really bummed out and feeling guilty about breakfast but then someone would come over and be like, let's go the market, and you just think okay or, let's go for a walk in the jungle and I'd think, yeah."
	Relationship between others' reaction to ED and the compulsion to engage in ED	675	"Then my dad's like, oh, no you can't go to the gym. Oh, no you're not going out walking, mehmehmehmehmeh. I don't know. And the more they treat me like that, the more I feel like I have to react eating disorderdly." (675)

PLAYING A 'ROLE' IN TREATMENT	Struggle to change role within familiar treatment environment	627	"I felt like I could never break out of that role while I was in the same environment"
	Playing role of 'good anorexic' in treatment	729	"I feel like I would just fall straight back into that role of being, like that role you play for therapists. So if they weighed me I'd just feel really embarrassed if it went up cos I'd be like: 'oh well they don't think I'm a very good anorexic if my weight's gone up, that's just really embarrassing'"
	Playing a role as part of having an ED	743	"The whole time that I was in treatment I was just playing a role of, I don't know, I just used to let people walk all over me, I really have quite a bad victim mentality I feel. And obviously I'd be very small and quiet... I feel like so much of that role was tied up with my eating disorder"
VALUE OF BEING TREATED AS A PERSON RATHER THAN A PATIENT	Importance of being perceived as an individual not as an illness	733	"I just felt like everyone knew me for me. Not because I had an eating disorder. And any conversatons I had had genuine meaning."
	Being treated 'as a person' in treatment	1011	"Yeah, I guess he just treated me a bit more like a person than anyone else ever did."
PERCEIVED REJECTION FROM TREATMENT TEAM	Perceived rejection by treatment team	511	"Like I went there every day for a long time. And I dunno and then they just kind of were like, piss off."
	Perceived rejection leads to dropout	521, 528	"I just figured that if they were telling me to go then, they don't like me [laughs]. I know it wasn't like that. I know they're professionals. And like whatever. But it just felt like... 'You don't like me anymore, I'll leave.' "It did upset me a bit. But I didn't want to show that I actually cared so I was just like okay, I'll leave."
	Perception that treatment team "gave up" on her	404, 1042	"I hadn't really put on any weight and like... it was just the same old same old every day. And they *tried* and well they just gave up..." "When I read it [discharge letter] it was just like, wow, you really have given up"
CHANGING PRIORITIES AFTER TREATMENT	Becoming self sufficient through necessity	546	"Then, I was like like, well I haven't got anyone else now. It's just me. So, I've got to do it myself [laughs]"
	Reevaluation of focus after treatment	556	"I just thought I don't wanna stay at home. I don't really wanna... I don't want to just get a full time job at the xxxxx and I dunno what I'm doing with my life. So, I just signed up to [a volunteer abroad service]"
	New environment changes ED perspective	684	"Climbing a mango tree is much more distracting than playing scrabble [in treatment]. And just realising when I was out there, how irrelevant all of the things that I worry about every day are."
INCREASED SENSE OF SELF PURPOSE HELPS WITH MOTIVATION TO RECOVER	Increased sense of purpose helps with motivation to recover	1141	"I feel now like I'm more of a person and I have more in life to look forward to. So like it's I'm just determined not to let it ruin everything. I'll just have to survive because I just have to be okay. There's no choice"
	Importance of learning about self and unique contribution	717	"Every day I was there someone would be like, oh you're really beautiful or you're really funny, I like the way you do this. And I think I just learnt about myself as well. Like, I'd lead... because I'd worked in xxxx I used to lead the xxxx workshops. So, I'd just be there in front of 100 people answering questions."

RECOVERY ON ONE'S OWN TERMS	Self-defining the terms of recovery	594	"Like the day I left treatment I was just like, [mum] you're not sitting with me anymore, you're not making food for me anymore, I'm not following any kind of shitty meal plan, I'm going my own way. And I did [laughs]. And it was really, really hard, really, very hard... but I kind of managed it."
POSITIVE IMPACT OF RELATIONAL CONNECTION	Building "good relationships" lessens experience of anger in treatment	149	"I actually built quite a good relationship with my key worker and was a lot less angry"
	Positively 'carried by' other people's can-do approach to life	554	"Everybody who signs up for that sort of thing is very positive, very extroverted, very much I wanna change the world.... I was just around people who were positive and very invested in..... They were *good* people. And I don't know. I just let myself by carried by them I guess."
	Importance of positive relationships in finding freedom from ED	647	I think when I went out there, I was very, very lonely cos I'd spent a lot of time on my own....So when I got there I was really lonely, a bit depressed, obviously still struggling a lot with my eating disorder. It was just insane. The best thing I ever did. And I made loads of friends. I was the most free I've ever been, in terms of eating."
PROFESSIONALS LACK UNDERSTANDING	Anger at professionals' failure to recognise felt reality	101	"She once told me I looked like a cancer patient. I was like *fuck off*. It was such bullshit. And to me, I felt like, particularly when I was putting weight on, that I was huge. And then she'd be, oh well you're still too thin to go to school, it's good that you're staying at home in bed all day. I'd be like, *okay*. "
	Treating the physical without understanding the psychological aspect of anorexia	1201	"She [dietician] was just *really* insensitive. She just didn't *get it* at all. So, she'd be like: 'oh you need more in your snacks, shall we add some biscuits?' And I'd be like: 'I don't like biscuits. I don't feel comfortable eating biscuits.' And she'd be like: 'why not?' Biscuits are a good source of fat and..' whatever. And I'd be like: 'I don't care, I don't want biscuits. I don't feel comfortable eating them. I wouldn't eat biscuits at hom, I don't want biscuits.' And she'd be like: 'well, you need to have something, you don't want to *not* put on weight, do you?' And you'd be like: 'are you *stupid* ?!'"
MEANING OF DROPOUT	Dropped out in anger	912	"I feel like, I was so angry and emotional when I left."
	Perceived rejection leads to dropout	521, 528	"I just figured that if they were telling me to go then, they don't like me [laughs]. I know it wasn't like that. I know they're professionals. And like whatever. But it just felt like... 'You don't like me anymore, I'll leave.'" "It did upset me a bit. But I didn't want to show that I actually cared so I was just like okay, I'll leave."

Appendix 12 - Example of Stage Six of Analytic Process

Table illustrating the higher order themes for the group with exemplar quotes from each of the individual participants.

Table of Group Superordinate Themes		
1. BECOMING 'THE ANOREXIC': IDENTITY AND BELONGING		
i) Identity and the anorexia diagnosis		Line No.
Tali	" I remember being very, very shocked that I was now deemed anorexic, because I really didn't feel I met the criteria, weight wise… At that stage I was really pleased. The sense of satisfaction for me to have lost enough weight."	55
Suri	"It's always a continual thing that 'I'm a fraud, I could probably eat if I really tried.'	374
Taryn	"I knew that I had been restricting for a long time and I knew that I wasn't thin enough *for me* , and I knew that other people were worried, but I didn't think that I was ill."	52
Caroline	"They told me that until I was a BMI of about 13 that they wouldn't take it seri… well not take it seriously, but that it wouldn't be an issue…It just gave me a goal, and also reiterated to me that I wasn't ill."	12
Maggie	"*I* felt like *I* was fine. So, I was like, this is all so unnecessary."	**71**
ii) Acceptance and belonging		
Tali	"The only reason I kept going for as long as I did was because I got *such* good strong peer support from the other patients."	275
Suri	'They think I'm a fraud. They think I shouldn't be there, I'm too fat.'"	376
Taryn	"There was a community of people who were really struggling with their eating disorders in the unit and that is where I felt like I belonged."	79
Caroline	"I found a little community who loved yoga and they all just accepted me. It was nice, I found friends and it was good."	859
Maggie	"I just felt like they'd become a bit like family. I knew all the staff there really well and I knew all the ladies on reception. Like I went there every day for a long time."	510

2. MORE THAN MEETS THE EYE: THE UNSEEN SUBJECTIVE EXPERIENCE		
i) Professionals lack psychological awareness		
Tali	"This is gonna sound awful. But they're not very intelligent. They're not very tactful. And they just have... they talked about diets in front of us. They talked about really inappropriate things."	378
Suri	"I just kind of got the impression that she didn't actually get anorexia, and how it operated."	205
Taryn	"For me it didn't feel like anything I said mattered, especially because what I was saying were usually things that could be pushed away like trying to explain that I didn't feel a certain way or trying to explain that, simply, that I did not feel as poorly as they thought I was. It was like: "But you are, so...' 'But that is not what I am trying to explain to you.'"	578
Caroline	"Because you've lost weight for a reason in the first place. Yet they think when you get back to a weight, you're gonna feel great without any psychological input at all."	404
Maggie	"She just didn't *get it* at all... she'd be like: 'well, you need to have something, you don't want to *not* put on weight, do you?' And you'd be like: 'are you stupid?!'"	1201
ii) Standardised symptom-focused interventions		
Tali	"I mean that's what annoys me *so much*, this emphasis on weight because you know it's a mental disease and just because you've got a healthy body weight, it's the torture mentally and physically that you're going through."	105
Suri	"I said something about how things had been difficult, and she was like 'oh but you've obviously been eating well, you know, your weight's up', or something. I'm sure from her point of view, it was perhaps a misguided way of saying, 'oh look on the bright side, you know, don't be down, things are good in some aspects'. And I can see it, but it didn't feel even remotely like that at the time, it just felt like completely invalidating."	183
Taryn	"I think back to that time and I think that was years of therapy that, I think in some ways clouded the real issue because it was like: 'Okay, what are you eating? What do you weigh?'	278
Caroline	"They keep you 'til you get to a magic weight... They keep saying to you that once you get to this weight, you'll feel really happy and everything will change."	399
Maggie	"I just found it really patronising.... The first bit was 'preparing to change' [sarcastic tone] ... and then it goes through and then last one is relapse prevention because you're supposed to have like... *recovered* at that point"	246

3. POWERFUL FORCES: CONTROL AND CHAOS WITHIN THE SYSTEM		
i) The controlled patient		
Tali	"I was locked in for the first two weeks, I couldn't leave the ward and then I got a ten-minute benchmark. It sucks the like... Sorry, I get quite upset about it. And you know I was just in hysterics. I was *so* unhappy there [tearful]. I really... I don't want anyone to have to go through that. It was like we had done something wrong and we were being punished."	962
Suri	"And they were kind of like yelling at me for, like choosing the wrong things. You were supposed to like put double ticks next to various things, and nobody had told me like that, so I put a tick next to, like a protein thing, and a salad, and they were kind of like yelling at me. I felt like I'd fallen into this parallel universe... and the whole thing was just terrifying."	65
Taryn	"You know how when they say: 'Oh well, do this but if you don't do this, then we will section you' [laughs]"	544
Caroline	"When you compare it to like prison sentences, it was very similar. Like during the day, we couldn't go in our rooms, we couldn't use the internet, we couldn't do anything. We had a little garden which was like, barbed wire around the top. And you'd hope to get leave. Your family weren't allowed in your room. You had to go to a certain room to see your family."	378
Maggie	"If I had said no to that and I had said no to going into the kids' inpatient thing, they would just section me anyway. So it was, kind of like, well I have a choice but I don't really, sort of thing"	31
ii) The unsupported patient		
Tali	"Yeah, so there was supposed to be one, one-on-one a week. But that often didn't happen. I would say, that would only happen two thirds of the time because otherwise the psychologist would be away ... or she'd be ill or something would happen"	132
Suri	"I was kind of like thrown in... and I didn't have a key worker the first week...I didn't have a meal plan, and I had no idea what I was supposed to be doing."	61
Caroline	"And there was no support. There was nobody to talk to...A lot of the time they were like Bank staff who didn't really know the process and couldn't give support at meal times."	244
Maggie	"She used to cancel a lot, which used to really annoy me....I used to get quite wound up about like getting weighed and quite anxious about it and then for her to ring up the day before, like oh, there's no appointment this week just come next week instead. I'd be like, eh okay" (118)	118

4. PROTEST AND PROTECTION: DROPPING OUT FROM GETTING WORSE		
Tali	"In that five months, I did, my anorexia just got so much worse." "I was thinking, no one is recovering and I honestly you know was worried both for myself and for everyone else, about the service. So, I just kind of went, yeah, no, I'm not gonna come in."	108 355
Suri	"I think again, it definitely was the right thing, I don't know what would have happened if I'd stayed there. It was definitely making me worse." "They're gonna keep up what I thought was abuse. And they're not going to stop, so I had to get out"	250 162
Taryn	"I just started getting worse and worse and worse and worse." What fuelled my complete *boycotting* of the services and just ignoring everything was that I had tried communicating what was important to me. And it was just met with: "Well, that is not what is important right now…. So I guess my voice was literally my absence."	40 510
Caroline	"I learnt how to *be* anorexic the first time I went in….and then it just got worse." "I had [laughs], probably my most heated argument with Dr R because he was saying, I had to go back inpatient . And I was saying, it's like almost signing my death sentence if you put me back in there. Because I have done this, this, this, I want to eat, I'm eating now, I've gained this much weight. I'm actually positive about like the future. I've got plans."	152 745
Maggie	"[Over-exercising] definitely got worse being there." I know they're professionals. And like whatever. But it just felt like, 'You don't like me anymore, I'll leave'…It did upset me a bit. But I didn't want to show that I actually cared so I was just like okay, I'll leave."	422 521

PART C: Publishable Paper

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