Being and doing anorexia nervosa: An exploration of diagnosis, identity-work, and performance of illness

Lauren O'Connell

A thesis submitted for the degree of PhD Sociology

Department of Sociology

University of Essex

July 2020

Abstract

This research examines how individuals experience the diagnosis of anorexia. Specifically, it explores how individuals come to be diagnosed with anorexia and the meanings they attach to this process, how the diagnosis informs their self-understanding and identity, including in a treatment context, and how they manage and perform the diagnosis, both within and outside treatment. I used two qualitative methods; autoethnography and interviews. The former was a 'moderate' autoethnography. Drawing on memory, personal diaries, and clinical documents, I analysed my own experiences of being diagnosed with anorexia and undergoing four long-term inpatient admissions in an adult specialist eating disorder unit. I undertook the interviews, which were 'in-depth' and minimally structured, with 14 individuals. All but one had been formally diagnosed with anorexia and undergone treatment, and one was self-diagnosed. Analysing the data, I identify different routes to diagnosis, which involve varying interpretive processes and are associated with different subjective meanings of being diagnosed. Drawing on Brinkmann's cultural psychology of diagnosis, I also address the 'being' and 'doing' of anorexia. In terms of 'being', I show how individuals learn a diagnostically-informed anorexic identity in treatment contexts. However, diagnostic understandings are not necessarily wholly accepted or internalised. Rather, they are reflectively and critically engaged with, such that individuals may reject aspects of the diagnosis and associated clinical understandings. I argue that clinically-based 'anorexic scripts' inform how individuals relate to and 'do' their diagnosis. In valuing being positioned as anorexic, individuals sometimes seek to 'live up to' these scripts, monitoring their own illness-performances against them. The findings shed light on 'hidden' consequences of being diagnosed and related clinical activity, and on how individuals experience their 'symptoms' and engage with treatment.

Contents

Acknowledgements

Foremost, I am grateful to the people who participated in this research. You generously gave up your time to take part in an interview with me, and shared your experiences candidly, genuinely, and openly. I only hope that this thesis does your experiences justice.

I also wish to sincerely thank the following people –

Joan Busfield, for being an excellent supervisor from start to finish. I have been incredibly lucky to have benefited from your wealth of knowledge and experience.

My family and wonderful friends. For supporting me throughout, beginning with my decision to up sticks in pursuit of a PhD in the first place. And, importantly, for taking me away from work - for gigs, drinks, trips away and chats.

My daughter, for keeping me on my toes and for being a constant in my life that will always come before work and study. You remind me that there are always more important things.

All those who have given me academic guidance and taken an interest in my research, despite having no obligation to do so. You have been extremely kind by providing advice, encouragement, and feedback on my work. This includes (but is certainly not limited to) Ross Coomber, Ewen Speed, Amy Chandler, Oli Williams, Danny Taggart, Paul Atkinson, Esmée Hanna and Tracey Loughran.

Vasilios Ioakimidis and all of my colleagues in the School of Social Work at Essex for involving me in teaching and supporting me in my career.

And Aaron - for being a sounding board, keeping my worries in perspective and for your unwavering confidence in what I am able to achieve. (Also, for making me laugh a lot).

List of abbreviations

Abbreviation	Meaning
AA	Alcoholics Anonymous
ADHD	Attention deficit hyperactivity disorder
ARID	Avoidant/restrictive intake disorder
BMI	Body Mass Index
BPD	Borderline personality disorder
CAMHS	Child and adolescent mental health service
CBT	Cognitive behavioural therapy
DSM	Diagnostic and Statistical Manual of Mental Disorders
EDNOS	Eating disorder not otherwise specified
EDS	Eating disorder service
GP	General Practitioner
ICD	International Classification of Diseases
NICE	National Institute for Clinical Excellence
OSED	Other specified eating disorder
RI	Reinventive institution
SEDU	Specialist eating disorder unit
TB	Tuberculosis
UFED	Unspecified feeding and eating disorder

Chapter One

Introduction

Anorexia nervosa (or anorexia as I shall frequently refer to it[1]) is predominantly conceptualised as a clinical disorder rooted in individual pathology. It is typically understood as an object of the 'psy' and medical professions (Darmon, 2017) and much writing on the topic therefore has a 'strong biomedical contour' (Warin, 2010: ix). That said, there is an extensive body of literature on anorexia which spans a range of disciplines, including the social sciences. Sociological and anthropological approaches have challenged dominant medical conceptualisations of anorexia by focusing on the social and cultural aspects that constitute and influence the condition and its medical categorisation.

This thesis seeks to contribute to sociological knowledge by approaching the diagnosis of anorexia as a social process that influences the individual. The overall aim is to examine individuals' experiences of 'having' a diagnosis of anorexia, including in a treatment context. In particular, I explore personal meanings and functions of the diagnosis, how it informs a person's identity and identity-work, and interactional, performative dimensions of the condition. The findings shed light on 'hidden' consequences of being diagnosed and related clinical activity. These consequences have relevance for understanding how individuals experience their 'symptoms' and how they engage with treatment. This is important given the limited success of current clinical interventions. Anorexia is associated with high rates of 'treatment drop-out' and relapse (Eivors, 2003; Wallier et al, 2009; Surgenour et al, 2004; Bulik et al, 2005; Hubert et al, 2013), and chronicity (Walsh, 2013; NICE, 2017b). Family-

---

[1] In most places within this thesis, I refer to 'anorexia nervosa' simply as 'anorexia'. Anorexia is common parlance for referring to the condition, and was the phrase used by participants to refer to their diagnosis. However, I write 'anorexia nervosa' in full on those select occasions when it is necessary to be accurate with wording. This is usually when it is being discussed in relation to clinical literature or diagnostic manuals.

based therapeutic approaches have been shown to have some success in treating anorexia during adolescence (Zipfel, 2015; Lock, 2015; NICE, 2017b). However, no treatment programme for anorexia in adults, and/or those who have had the condition for longer than three years, leads to substantial levels of recovery (Le Grange, 2016; Treasure and Cardi, 2017) or has been identified as demonstrating sustained long-term benefits (NICE, 2017b). Moreover, both clinical and social scientific literature has suggested that there are iatrogenic effects of treatment for anorexia, especially inpatient treatment (e.g. Gowers et al, 2000; Gremillion, 2003; Treasure et al, 2011), and it appears that around a third of individuals who receive inpatient treatment go on to experience chronic anorexia (Keel and Brown, 2010). This research, then, is motivated by a need to better understand how being diagnosed with anorexia, and engaging with the diagnostic understandings that abound in treatment contexts, affect the individual.

The research adopts a broadly interpretivist approach, with a focus on understanding what events mean, how people adapt, and how they understand what has happened to and around them (Rubin and Rubin, 1995). I used two qualitative methods: an analytically-focused autoethnography and in-depth interviews. The autoethnography examines my own experiences of being diagnosed with anorexia and treated in an adult specialist eating disorder unit (SEDU) for four inpatient admissions, and draws on memory, personal journals, and clinical documents. The interviews were conducted with 14 individuals, 13 of whom had been formally diagnosed with anorexia (some had since 'recovered', some had not) and had undergone treatment on this basis. The remaining individual was a man who was self-diagnosed.

My direct personal experience of the subject matter and incorporation of autoethnographic methods mean that I am present within this thesis as both researcher and researched. This dynamic has added (often unforeseen) layers of complexity to the conduct of the research

since the outset, and has required constant negotiation. While challenging, I have sought throughout to make effective and productive use of my experiences. This is not only within the autoethnography, where I directly use my experiences as 'data', but also in the interviews, where I have drawn on my 'insider' positioning to facilitate the conversation with participants and better understand their experiences.

Aims and objectives

The aim of this research is to investigate how individuals experience the diagnosis of anorexia. Specifically, the research aims to explore:

- How individuals come to be diagnosed with anorexia and what meanings they attach to this event

- How individuals relate to the diagnosis of anorexia and how it informs their self-understanding and identity, and how these facets are influenced by the experience of treatment

- How individuals manage and perform the diagnosis, both in and outside of treatment contexts

The design of the research began with reflections on my own experiences. I was aware that being diagnosed and undergoing long-term inpatient treatment had significantly shaped my identity and experiences of self-starvation, including in ways that were problematic and that extended my distress. I believed that at the core of this, had been the strong 'anorexic identity' that I had developed in treatment and (ambivalently) come to value, and which made it all the more difficult to leave behind the self-starvation which I found both compelling and excruciating. Having spoken with other patients during treatment and read extensively about others experiences, I suspected that my valuing of an anorexic identity was not especially unique. Informed by these personal reflections, I questioned what the

diagnosis of anorexia, and the lay impressions and clinical knowledge(s) that surround it, mean to those who are diagnosed. With this in mind, I reviewed relevant bodies of literature and developed the specific foci of my research. Two significant theoretical and conceptual influences on the design of, and analytic framework within, this research, are the sociology of diagnosis, and Brinkmann's cultural psychological analysis of psychiatric diagnoses. I discuss these later in this chapter, but firstly I introduce the diagnostic category of anorexia and related epidemiological statistics by way of setting the context for the research.

The diagnostic category of anorexia

Anorexia is a psychiatric disorder which is characterised by a low body weight and restricted food intake, and is typically portrayed as having a pathological 'fear of fatness' at its core. Anorexia is somewhat unique in that, while it is a 'psychological' condition, it is primarily measured and made visible by its 'physical' manifestation (an underweight body). The stereotypical demographic profile of an individual with anorexia is a middle class, adolescent, white female (Dignon, 2007; Bordo, 2009). Indeed, anorexia has a distinctive place as a female mental disorder (Busfield, 1996) and has always been identified predominantly (although not solely) in females.

The clinical definition of anorexia nervosa in the fifth edition of the specifies the following diagnostic criteria:

> A. Restriction of energy intake…leading to a significantly low body weight… in the context of age, sex, developmental trajectory, and physical health. Significantly low weight is…weight that is less than minimally normal…B. Intense fear of gaining weight or becoming fat, or persistent behavior that interferes with weight gain…C. Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight (APA, 2013: 338 – 339).

The DSM-5 also distinguishes between 'restrictive' and 'binge/purge' subtypes, and categorises severity using body mass index (BMI) thresholds (for example, an individual with a BMI below 15 has 'extreme' anorexia). The DSM-5 definition broadens the diagnosis as compared to the DSM-IV (APA, 1994) (in ways I examine in the next chapter), reflecting the 'fluid' nature of the diagnostic category (Dignon, 2007; Micali and Hebebrand, 2015).

The incidence rate for clinically recognised anorexia in the UK and Europe in recent years is around 5 - 8 per 100,000 per year (Hoek and van Hoeken, 2003; Currin et al, 2005; Micali et al, 2013). Incidence rates for anorexia in the UK and Europe increased during the 20th century up until around the 1970s, but they appear to have stabilised since then (Turnbull et al, 1996; Hoek and van Hoeken, 2003, Smink et al 2012; Currin et al, 2005; Hudson et al, 2007; Micali et al, 2013; Keski-Rahkonen and Mustelin, 2016). Very recent research has suggested a slight increase in the incidence of anorexia, but this is likely attributable to the broadening of criteria in the DSM-5 (Vo et al, 2016; Micali et al, 2017).

Eating disorders are identified more frequently in young women in Western countries (i.e. Europe and the USA), however they are also identified in older males and females and individuals in non-Western countries (Hoek, 2014). Clinical samples suggest that approximately 10% of identified cases of anorexia are male (e.g. Hoek and van Hoeken, 2003; Micali et al, 2013) while community studies suggest higher rates of around 25% (Hudson et al, 2007; Sweeting et al, 2015). Anorexia is much more commonly found among younger than older age groups, with the peak age of diagnosis being 15 – 19 years (Micali, 2013). In line with these gender and age patterns, females in adolescence/young adulthood are typically identified as the most 'at risk' group for anorexia (Currin et al, 2005; Hoek and van Hoeken, 2003; Smink et al, 2012). Females aged 15 – 19 constitute around 40% of all clinically recognised cases (Hoek and van Hoeken, 2003; Smink et al 2012) and have the highest rates of hospitalisation for the condition (Holland et al, 2016; see also NHS Digital,

2019[2]). Smink et al (2012) argue that there is some evidence of an increase in the number of identified cases among this high-risk group, despite the overall incidence rate for anorexia having recently remained stable, and that this reflects either earlier detection of anorexia or an earlier age of onset. Regarding older age groups, Micali et al (2017) have highlighted that both chronic and new onset eating disorders, including anorexia, are apparent among women in the fourth and fifth decade of life; among their community sample of women in mid-life, 3.64% reported life time prevalence of anorexia.

Epidemiological findings, including those considered above, are problematic. This is due to broadening diagnostic criteria over time, changing diagnostic overlap between anorexia and other eating disorders and 'diagnostic drift', which reflects a heightened awareness and reporting among families and doctors (Brumberg, 1988).

A sociology of diagnosis

This research is situated in, and seeks to contribute to, the sociology of diagnosis. This addresses the social nature of medical diagnosis (Jutel, 2009, 2011; 2015; Jutel and Nettleton, 2011). Brown (1990) initially proposed a sociology of diagnosis in the context of psychiatry, outlining both "an approach to the study of diagnosis" and "an overall critique of modern psychiatry" (1990: 386). He suggested as loci of study such issues as weaknesses in diagnostic categorisation and the professional dominance of psychiatry. Brown (1990) noted that while primarily concerned with psychiatric diagnosis, many of the issues could be extended to medical diagnosis more generally, and in a later paper discussed a more general

---

[2]The latest available data showing rates of completed hospital admissions for a primary or secondary diagnosis of anorexia in the UK in 2018 - 2019 by gender and age group organises rates using the age groups 13 – 15 years, 16 – 18 years, 19 – 25 years, and others. Thus, while it is not possible to determine whether those in age group 15 – 19 have the highest rate of hospitalisation, the rate for females within this group is relatively high.

sociology of diagnosis (Brown, 1995). This paper took a social constructionist perspective, and highlighted the central role of diagnosis in constructions of illness.

Brown's initial suggestions for a sociology of diagnosis lay dormant until around 20 years later, when they were taken up by Jutel (2009; 2011; 2015). She outlines a case for the study of diagnosis as a specific sub-discipline, arguing that diagnosis is a "powerful social tool, with unique features and impacts which deserve their own specific analysis" (2009: 278), and that "the sociology of diagnosis offers a valuable vantage point from which to study health and illness" (2015: 841). Indeed, diagnosis makes an important contribution to both the social structure and to individual experiences. It does this by defining the roles of the medical profession, shaping the doctor-patient relationship, legitimising illness, providing access to treatment, affording power and authority to doctors, and structuring interaction in clinical contexts (Jutel, 2011).

She also argues that diagnosis has historically had an 'absent presence' within sociology (Jutel and Nettleton, 2011). It has not been clearly isolated and explored on its own, but has been concealed within other foci such as medicalisation, history of medicine and theories of disease (Jutel, 2009; 2011). Brown (1990; 1995) made a similar point, suggesting that while a considerable body of work existed that directly touched on diagnostic issues, "they are not usually considered specifically as such" (1990: 386).

Jutel and Nettleton (2011), building on Blaxter (1978), offer a framework for approaching a sociology of diagnosis which distinguishes between diagnosis as category, process, and consequence. The term 'category' refers to how diagnoses are defined, and corresponds with what Jutel (2011) describes elsewhere as 'creation'. The focus is on the classification of diseases and disease discovery processes, and the social contexts and relations that shape these. It is recognised that diagnostic classification systems have their own (politically

influenced) histories and serve their own purposes (Jutel and Nettleton, 2011). Jutel highlights how the boundaries of disease are ever-shifting, and argues that diagnoses are cultural expressions; they give an indication of what a society accepts as "normal, healthy, moral, and bearable" (2011: 139). However, she stresses that while diagnoses are always a social creation, this does not necessarily mean that the diseases the diagnosis refers to are not 'real'. Rather, it means that a disease needs to be visible, perceived as problematic, and understood as belonging to the field of medicine, in order to become a diagnosis.

'Process' refers to the implementation of a diagnosis (Jutel and Nettleton, 2011). Jutel (2011) refers to this as 'application', and describes it as the transfer of diagnosis from the medical domain to the lay person's experiences of illness. This process occurs within certain relations – between the patient and medical professional – and is influenced by the position and roles of both parties. It "may (or may not) take into account a lay of version of events, may (or may not) rely upon clinical judgement, or alternatively laboratory findings; and may (or may not) align with the patient's own version of her symptoms" (Jutel and Nettleton, 2011: 794). Diagnosis is recognised as a complex, negotiated activity which is impacted by the experiences of both practitioner and patient and is shrouded in personal meaning (Kralik et al, 2001; Jutel, 2011; Jutel and Nettleton, 2011).

Consequence refers to the implications that a diagnosis has for those to whom it applies (Jutel and Nettleton, 2011). It recognises the personal functions and meanings of diagnosis, its potential to legitimise symptoms and create stigma, and its role in personal sense-making and impact on identity. Research which has attended to the consequences of diagnosis includes that of Russel et al (2012), who frame the diagnosis of autism as a potential social influence on health, in that it may have implications for health outcomes. Kralik et al (2001), in an exploration of women's experiences of being diagnosed with a long-term illness, found that receiving a diagnosis was often a momentous event and chaotic experience. While their

experiences were largely negative, being diagnosed also led many of their participants to feel validated by medical science; the diagnostic label carried medical weight, meaning it was then perceived as 'real' by others, and also led to the possibility of cure and treatment. This suggests that medical labels can play an important role in transforming the lived experience of illness into a recognised disease or disorder. Kralik et al also highlight the significance of diagnosis for identity. For some participants, being diagnosed changed their self-perception dramatically. Karp's (1996) sociological study of the interpretive processes involved in developing a 'depression identity' addresses how being diagnosed can mark a significant turning point in this respect. Critical psychology literature has explored how receiving a psychiatric diagnosis can have various subjective meanings and be experienced both 'positively' and 'negatively'. This includes in relation to, for example, Attention Deficit Hyperactivity Disorder (ADHD) (Hansson-Halleröd et al, 2015); Borderline Personality Disorder (BPD) (Horn et al, 2007); depression (Shooter, 2010), and (more generally) 'severe and enduring mental illness' (Hayne, 2003).

Jutel also offers a summative model for a social understanding of diagnosis. This model recognises "the assemblage that constitutes diagnosis, the relational nature of the diagnostic moment, and the transformative potential of diagnosis as process" (2011: 143). Within this, she argues that the social framing of diagnosis, including the historical and contemporary classification systems, disease discovery, risk profiles and surveillance, and diagnostic technologies, has implications for the social consequences of diagnosis – in terms of allocation, exploitation, legitimization and stigmatisation: "Diagnoses are social categories that organise, direct, explain and sometimes control our experiences of health and illness" (2011: 145). The reverse is also true, because in turn, the social consequences then feed back into the framing of a diagnosis. This is a dynamic, circular process in which both 'sides' shape each other; it is what Jutel describes as a 'chicken and egg' situation.

The sociology of diagnosis, then, recognises the importance of examining the act of diagnosis, and its subjective meanings and potential personal and social consequences. There is a dearth of research specifically concerned with the processes and subjective meanings of being diagnosed with anorexia in particular. Existing research addresses, for example, how individuals manage their diagnosis of anorexia as an identity and an illness (Rich, 2006) and how one learns to 'internalise' institutional understandings of their diagnosis while in inpatient treatment (Darmon, 2017). However, research to date has tended not to specifically address the process of being diagnosed with anorexia, what this means to the individual at that time, and how it intersects with their experiences up until that point. This is particularly important given that individuals with anorexia may actually enjoy being defined as clinically ill (Dignon et al, 2006) and may wish to 'be medicalised' through the label of anorexia (Boughtwood and Halse, 2008). Moreover, the process of diagnosing anorexia is believed to be potentially complicated due to the individual valuing their illness and 'lacking insight', and thus not fully disclosing their motives and 'symptoms' (Garner, 1985; NHS, 2004; 2017b; Treasure et al, 2015). An exception is Lavis (2011). Her research explores pro-anorexia, defined as "a desire among some anorexics to maintain or enhance their existing illness" (2011: 3), and briefly considers being diagnosed from the perspective of the 'patient'. Here, she notes that the act of being diagnosed can in itself be "invested with pro-anorexic desire" (2011: 234), and suggests that this is due to the sense of legitimacy that the diagnosis confers, as being diagnosed can confirm an already existing sense of self.

My research attends to the need to better understand the act of diagnosis. This includes an exploration of not only the occasion of diagnosis itself, but the circumstances and experiences that precede it. My focus here is on the dynamic, interpretive processes involved in routes to help-seeking and reaching diagnosis. This focus contrasts existing research into help-seeking for eating disorders, which is usually conducted from a clinical,

service-focused, or 'psychological' perspective. Such research proposes psychological models of eating disorder related help seeking, which address attitudes, 'motivation', and other internal processes (Schoen et al, 2012; Gullisken et al, 2015). It also identifies 'barriers to treatment' and variables that influence the likelihood of help-seeking (e.g. Akey et al, 2013; Regan et al, 2017). For example, Regan et al reviewed empirical studies to explore "barriers and facilitators" to eating disorder treatment among young people. This included a review of quantitative and qualitative studies. Analysing the former, they identified factors associated with treatment seeking, and argue that age, ethnicity, type of eating disorder, specific eating related behaviour and time spent waiting to begin treatment have "some degree of predictive utility" (2017: 190). For example, older individuals are more likely to seek treatment, and those of an ethnic minority are less likely than non-minority individuals to do so. With respect to the qualitative research they reviewed, Regan et al identify an array of factors that participants in these studies had nominated or endorsed as barriers to seeking treatment. These included personal feelings of shame or fear, eating disorder related perceptions and beliefs, issues related to access and availability of treatment, and aspects of treatment itself. Factors identified as facilitating treatment seeking included health-related concerns, emotional distress, and support and encouragement of friends or family. However, such research can be considered deterministic, with complex beliefs and actions reduced to descriptive categories (Biddle et al, 2007), and this is a problem that my research aims to avoid.

This research is also concerned with the implications that the diagnosis, and the various understandings of it encountered in treatment, has for the individual over the longer term. Informed by Brinkmann (2016) (see below), this includes in relation to identity and illness sense-making, and performative aspects of the condition. In short, while the categorisation

and creation of the diagnosis of anorexia have been well examined (e.g. Hepworth, 1999), this research is concerned with the process and consequences of the diagnosis.

Brinkmann's heuristic model of psychiatric diagnoses

Brinkmann (2016) uses a cultural psychological analysis – informed by sociology and cultural studies – to explain, analyse and critique diagnostic cultures. The term diagnostic cultures refers to "the numerous ways that psychiatric categories are used by people – patients, professionals, and almost everyone else - to interpret, regulate and mediate various forms of self-understanding and activity" (2016: 1) and points to "the spread of vocabulary and associated social practices into new areas of sociocultural life" (2016: 11). Brinkmann suggests that in recent years there has been an increasing emergence of diagnostic cultures, referred to as diagnostic expansion. Parts of this process include an increase in the number of people diagnosed with psychiatric problems and an increase in the range of diagnoses it is possible to receive. Diagnostic expansion is linked to ongoing cultural processes of pathologization, in which many 'normal human problems' come to be diagnosed and treated as psychiatric disorders.

As part of his analysis, Brinkmann offers a heuristic model for understanding what a psychiatric diagnosis makes possible in the lives of those who are diagnosed, and highlights three interrelated dimensions to this: 'having', 'being', and 'doing'. The model is intended "to be used in qualitative studies of the lives of people with mental problems and diagnoses" (2016: 30).

'Having' refers to the entity aspect of diagnosis. Brinkmann describes how everyday language implies that psychiatric diagnosis is an identifiable object, such that we think about whether or not someone 'has' a psychiatric diagnosis in the same way that they might have a physical object. This is problematic, however, because whereas with somatic illness there is a

relatively clear distinction between the illness and its symptoms (for example, a broken bone is the illness and pain is the symptom), this is not the case for psychiatric diagnoses. For psychiatric diagnoses, symptoms and illness conflate; diagnostic criteria describe symptoms and also constitute the illness itself. Using Brinkmann's example, symptoms such as hyperactivity and inattentiveness "are not only symptoms of ADHD, they *are* ADHD" (2016: 31. *Emphasis in original*). This leads to a circular process whereby the existence of psychiatric illness is used to explain one's symptoms, and symptoms are used to prove the existence of one's illness.

'Being' addresses psychiatric identity and the extent to which one identifies with a psychiatric diagnosis. Individuals can be understood not only to have a diagnosis, but also to *be* the diagnosis (i.e. the person 'is' 'anorexic' or 'manic'). In Brinkmann's research into ADHD, this category is one way (among others) that individuals with the diagnosis self-identify. He explains how the diagnosis is one significant component that informs people's self-understanding - an observation which overlaps with his analysis of a diagnosis as a semiotic mediator, that I discuss below.

There is also an action aspect to a diagnosis, referred to as 'doing'. This incorporates the idea that diagnoses are "something people do or perform relative to specific categories" (2016: 31). A diagnosis conveys norms which define appropriate behaviours, and in doing so "provides a "script" for the proper performance of one's suffering" (2016: 32). In addition to acting in accordance with the norms of their diagnosis, individuals also come to act in ways that are situationally appropriate. They learn to perform their suffering differently across different settings, and therefore may do their diagnosis differently in a therapeutic support group as compared to when with family, for example. Ringer and Holen (2016) address related performative aspects of psychiatric diagnoses, and for example describe how mental health patients learn to outwardly display their symptoms in recognisable ways in

order to legitimise their need for care. The importance of 'correct' performances is highlighted in Chandler's (2016) research into self-injury. She examines how dominant narratives construct the notion that discrete and hidden self-injury is authentic, whereas self-injury that is revealed and obvious is 'attention-seeking'. Such notions inform how individuals perform self-injury, in terms of the practice itself, and managing scars and help-seeking in the aftermath. As Brinkmann notes, such understandings of how individuals do their diagnosis assumes an understanding of the individual as having "a large degree of responsibility understood as capabilities for action and reflexive self-consciousness" (2016: 32). He is clear that the doing dimension is not intended to suggest that individuals do not suffer. Rather, individual suffering becomes aligned with dominant diagnostic models via individuals' reflexive self-consciousness and capabilities for action.

Regarding diagnoses as semiotic mediators, Brinkmann identifies three specific functions of a diagnosis in people's lives. He mainly centres this discussion around ADHD, but suggests that the functions are likely also relevant to psychiatric diagnoses more generally. Firstly, a widespread function of the ADHD diagnosis is its use as an explanatory tool. It is typical for those diagnosed to adopt 'ADHD' as an explanation for their life experiences and problems, and the diagnosis mediates their personal understandings of these. Relatedly, Brinkmann argues that in contemporary diagnostic cultures, diagnostic systems offer a way for individuals to search for meaning and explain their suffering. A second function of the ADHD diagnosis is self-affirmation; the diagnosis tends to affirm itself. Brinkmann suggests that when interpreted through a diagnostic lens, a whole range of experiences (even those that might also have potential to counteract the diagnosis) come to be understood as 'symptoms'. Lastly, a diagnosis can have a disclaiming function, and this is a subcategory of the explanation function. Responsibility for a person's actions (or lack there of) can be

shifted from the person to the ADHD entity, and the ADHD diagnosis is sometimes used as exemption from common moral demands and responsibilities.

When summarising the above ideas, Brinkmann suggests that the ADHD diagnosis makes possible an understanding of oneself as being 'possessed' by an entity that interferes with one's life, and that this entity can be referred to to explain one's problems, sometimes in a self-affirming manner. In addition, the diagnosis can be used to disclaim responsibility. However, the ADHD diagnosis is not the only process through which diagnosed individuals mediate their self-understanding, because this emerges through numerous sources, languages and categories. In addition, Brinkmann stresses that the process is not deterministic; being diagnosed with ADHD does not automatically impose "some kind of "ADHD identity" (2016: 72). Understanding people as creative, skilled human actors, he argues that the diagnosis is instead used "flexibly and creatively" as an "interpretive resource".

In this thesis, I use aspects of Brinkmann's heuristic model as a "tool to think with" (2016: 30), and adopt notions of 'being' and 'doing' anorexia as a central analytic frame. I am concerned with how the diagnosis of anorexia informs self-understanding and identity (including in ways that relate to the entification of the diagnosis), and with the 'diagnostic scripts' that inform how individuals 'do' anorexia.

Thesis outline

In this chapter, I have set the disciplinary, theoretical, and practical context for this research. I have outlined the central research questions and introduced the methods I used to address these. I have also discussed two areas of literature that are central to this thesis; the sociology of diagnosis, and Brinkmann's heuristic model of psychiatric diagnosis.

In **chapter two**, I undertake a broader review of literature that underpins this research. This review is organised into four sections. The first two address anorexia, firstly from a clinical, and then from a sociological and anthropological perspective. In the third section I examine symbolic interactionist approaches to identity, a theoretical approach that influenced my analysis. Lastly, I review concepts in the sociology of health and mental health, making links to the above discussion of a sociology of diagnosis.

Chapter three addresses research methodology. I discuss the epistemological and theoretical underpinnings of my autoethnography and interviews, as well as describing the practical approaches I undertook. Throughout, I reflect on the challenges I faced and evaluate the research using method-appropriate criteria. I also critically address ethical dimensions of my research.

Chapter four presents my autoethnography, in which I closely examine my experiences of being diagnosed with and treated for anorexia, drawing on sociological and anthropological literature. The arguments I introduce in this chapter, particularly in relation to what I refer to as 'anorexic scripts', are later developed further in the analysis of participants' experiences.

The analysis of participants' experiences begins in **chapter five.** Here, I consider individuals' routes to obtaining a diagnosis of anorexia, including the extent to which they personally drove the help-seeking process. In addition, I address participants' subjective meanings of being diagnosed, and how these link to the aforementioned routes. This chapter also includes a detailed case study of one participant who was self–diagnosed with anorexia, and how his identification with the diagnosis emerged.

Chapter six concerns identity. I examine the role of clinical discourse in socialising individuals into diagnostic understandings of their experiences, and the differing extents to

which clinical discourse informs individuals 'anorexic identities'. This chapter also addresses the meaning of an 'anorexic identity' to participants. Returning to threads of ideas introduced in preceding chapters, I examine how anorexia can be a valued and sought-after positioning. This sets a vital context for the remaining analysis chapter.

The final analysis chapter is **chapter seven.** I address the different ways in which individuals move themselves towards and away from an identification with anorexia. The former facet involves examining how individuals 'do' or 'perform' in line with various conceptualisations of anorexia, seeking to align themselves with the diagnosis. The latter facet considers the reasons why participants sometimes work to disavow the diagnosis of anorexia, and the strategies they adopt to do so.

Chapter eight concludes the thesis. I summarise and link the main concluding points from each analysis chapter. I also consider their implications, for both clinical practice and social science knowledge. I suggest some further areas for research which would strengthen and expand the findings in this study. Lastly, I offer some concluding reflections on what this research suggests about the diagnosis of anorexia and the role it plays in individuals' lives.

Chapter Two
Literature Review

This literature review is organised around four areas: the clinical construct and treatment of anorexia nervosa; sociological and anthropological understandings of anorexia; symbolic interactionism and identity; and sociological approaches to health and mental illness. The first area offers insight into anorexia nervosa as a clinical object, examining the diagnostic category and related clinical knowledge and activity. The sociological and anthropological understandings reviewed in the following section stand in contrast with the clinical picture. They identify social and cultural tenets that shape lived experiences of self-starvation and its constitution as a diagnosis, and critically examine treatment environments. In the last two areas the focus is broadened away from anorexia. In the first of these, I review symbolic interactionist approaches to identity. The notion of identity, particularly diagnostic identity, is central to this research, and symbolic interactionism offers a sociological theorisation that has influenced my approach, especially in terms of identity-work. In the final section on sociological approaches to health and mental illness, I explore identity specifically in relation to mental illness, as well as relevant key concepts from medical sociology that have informed the sociology of diagnosis and this research. I conclude each section with reflections on how the literature reviewed relates to my research. Finally, I conclude the whole chapter by restating the intended contributions of my research in relation to existing knowledge.

The clinical construction and treatment of anorexia nervosa

Definitions and features of anorexia nervosa

The 'discovery' of what is now called anorexia nervosa and its delineation as a clinical entity occurred in the late 19th century and is usually attributed to William Gull (in the UK) and Ernerst Laseque (in France). Gull and Laseque introduced 'anorexia' to the medical

literature as a largely female condition with a basis in neurosis and hysteria (Brumberg, 1988; Hepworth, 1999; Dignon; 2007; Simonivic et al, 2015). After an unsuccessful search for organic causes, Gull added the concept of neurosis to define and explain anorexia and concluded that it resulted from 'perversions of the ego' and a 'morbid mental state'. At that time, neurosis was a predominantly medical term which, when applied to anorexia, classified it as a 'nervous disease' (Hepworth, 1999). Laségue considered anorexia a form of hysteria and often used the terms interchangeably (ibid). Hysteria was a popular concept at the time Laségue was writing (Simonovic et al, 2015). It originates from the Greek word *hysteria* meaning womb, and at that time was identified as the cause of nervous diseases in women (Hepworth, 1999). Indeed, Gull and Laségue both drew heavily on discourses of femininity to document and explain anorexia (Hepworth, 1999), defining it as primarily a female condition. Gull did recognise the existence of anorexia in males, and this was one of the reasons that he preferred the term 'nervosa' to 'hysteria' (Simonovic, 2015). None the less, he continually referred to anorexia as a female condition and treated the occasional male cases that he saw as having marginal importance, while Laségue made no references to male anorexia (Hepworth, 1999). Further, both physicians explained the aetiology of anorexia as related to the inherently irrational, emotional and unstable nature of women (ibid, 1999). There are cases of female self-starvation documented from as early as 1200. However, prior to the late 19th century, self-starvation tended to be interpreted in a religious context. Gull and Laségue, who drew on clinical and medical scientific discourse in their descriptions of anorexia, served to mark a shift away from religious discourse to medical discourse to explain self-starvation (Brumberg, 1988; Hepworth, 1999).

The specific term 'anorexia nervosa' was coined by Gull in 1874, and remains the diagnostic term in use today. Indeed, Gull's work has had significant influence on the subsequent historical development of understandings of anorexia (Hepworth, 1999) and his descriptions

still form the basis of modern-day definitions (Madden, 2004). The recent clinical definition

of anorexia nervosa in the DSM-5 (APA, 2013) was stated in the previous chapter, where I

noted that this is a broader definition than in the DSM – IV. Previously, the DSM-IV defined

anorexia nervosa as:

> a. Refusal to maintain body weight at or above a minimally normal weight for age and height (e.g…body weight less than 85% of that expected…) b. Intense fear of gaining weight or becoming fat […] c. Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the current low body weight [...] d. In postmenarcheal females, amenorrhoea (APA, 1994: 544 – 545).

The DSM-5 therefore broadens the diagnosis through the inclusion of a more

contextualised and less 'strict' criterion relating to body weight, by no longer specifying that

avoidance of weight gain need necessarily be motivated by 'fat phobia' (see Becker et al,

2009), by omitting the requirement of amenorrhoea in females (thereby making its

application to men easier), and omitting the terms 'refusal' (in relation to maintenance of

body weight) and 'denial' (in relation to recognition of the seriousness of the condition) (see

Micali and Hebebrand, 2015).

Anorexia nervosa is one of eight feeding and eating disorders identified in the DSM-5. The

others are: bulimia nervosa, binge eating disorder, pica, rumination, avoidant/restrictive

intake disorder (ARID)[3], other specified feeding and eating disorder (OSED) and unspecified

feeding and eating disorder (UFED). The latter two disorders are residual categories which

replace the DSM-IV residual category 'eating disorder not-otherwise specified' (EDNOS)[4].

Binge eating disorder is newly recognised as a separate disorder; in the DSM-IV, binge eating

was described in the appendix and diagnosable only as EDNOS. The inclusion of binge eating

---

[3] In the DSM-IV, Pica, rumination and ARID were categorised among 'Disorders Usually First Diagnosed in Infancy, Childhood, or Adolescence', a section that does not exist in the DSM-5.

[4] This change, from the designation 'not otherwise specified' to 'other specified' and 'unspecified', has occurred for all psychiatric disorders, including feeding and eating disorders.

disorder as a separate diagnosis in the DSM-5, as well as the broadening of criteria for both anorexia nervosa and bulimia nervosa[5], was intended to reduce the number of eating disorder cases diagnosed using the residual category; EDNOS was a widely used category, which accounted for at least half of all clinically recognised eating disorders (Fairburn and Cooper, 2011; Keel et al, 2011; Dell'Osso et al, 2016). This intention appears to have been realised, as studies show lower numbers of EDNOS diagnoses and higher numbers of bulimia and anorexia diagnoses when DSM-5 criteria are applied to eating disorder symptoms compared to DSM-IV criteria (Keel et al, 2011[6]; Vo et al, 2016). The changes in DSM-5 were also intended to better represent the psychopathology of eating disorders (APA, 2013; Dell'osso et al, 2016; Vo et al, 2016). Definitions of anorexia nervosa in the International Classification of Diseases (ICD) also require consideration. They are less widely utilised in eating disorder research than DSM definitions, but are used by many UK services in their clinical practice (Nicholls and Arcelus, 2010). The ICD-10 criteria for anorexia are:

> Body weight is maintained at least 15% below that expected, or [BMI] is 17.5 or less…The weight loss is self-induced…There is body-image distortion in the form of a specific psychopathology whereby a dread of fatness persists as an intrusive, overvalued idea and the patient imposes a low weight threshold on [him/herself]…A widespread endocrine disorder…is manifest [amenorrhoea in women and loss of sexual interest and potency in men]" (WHO, 1992: 177).

There are some notable similarities between the ICD-10 and DSM–IV criteria, for example a specific body weight and a 'fear of fatness' being necessary to the diagnosis in both definitions. The ICD–10 has therefore been subject to similar critiques as the DSM–IV was

---

[5] Bulimia nervosa is a condition which is clinically characterised by episodes of binge eating and compensatory behaviours such as self-induced vomiting. The diagnosis of bulimia nervosa has been broadened within the DSM-5 via a reduction in the frequency of binge eating and compensatory behaviours that individuals must exhibit in order to fulfil the diagnosis.

[6] This research was undertaken prior to the publication of the DSM – 5, but used the (then) proposed DSM – 5 criteria.

(Nicholls and Arcelus, 2010; Uher and Rutter, 2012; Micali and Hebebrand, 2015)[7].

Accordingly, the new ICD-11 represents a similar 'shift' to that seen in the transition

between the DSM–IV and DSM–5. It characterises anorexia nervosa as:

> Significantly low body weight for the individual's height, age and developmental stage
> […BMI less than 18.5 kg…] accompanied by a persistent pattern of behaviours to
> prevent restoration of normal weight […] typically associated with a fear of weight
> gain. Low body weight or shape is central to the person's self-evaluation or is
> inaccurately perceived to be normal or even excessive (WHO, 2018: n.p).

The ICD-11 retains a specific definition of low body weight, but the stated BMI is higher

than in the ICD-10. Both the ICD–11 and the DSM–5 remove the criterion relating to

amenorrhea and both seek to avoid statements regarding the intentions of individuals,

orientating more towards observable behaviour and cognitions. This is reflected in the ICD–

11 removal of the requirement of 'self-induced' low weight and the 'relaxation' of the 'fear

of fatness'. These changes are akin the DSM–5 offering a behavioural alternative to the 'fear

of weight gain criterion' and omitting the term 'refusal' in relation to low weight (Micali and

Hebebrand, 2015).

Anorexia is known to be a cause of significant physical and psychosocial morbidity (Zipfel et

al, 2015). Individuals with the condition experience a broad range of medical complications,

due to weight loss and malnutrition adversely affecting almost every body system (Mehler

and Brown, 2015). Anorexia also has a relatively high mortality rate (Crisp et al, 2006;

Berkman et al, 2007; Button et al, 2010; Arcelus et al, 2011) of 5.1% per decade (Arcelus et

al, 2011; Smink et al, 2012) and is often described (both within academic literature and

colloquially) as the 'deadliest mental illness'.

---

[7]For example, in relation to both the DSM IV and ICD – 10, it has been claimed that there is a need to merge
'eating' and 'feeding' disorders into a single category and both have been criticised for overuse of residual
eating disorder categories and too-specific and limiting criteria for anorexia and bulimia.

Comorbidity in anorexia has been described as "the rule rather than the exception" (Treasure et al, 2015: 1). Comorbidity refers to the occurrence of more than one distinct clinical entity in one individual (Maj, 2005: 67) and is now a commonly used idea in psychiatry (van Loo and Romeijn, 2015: 42). However, the application of the concept to mental disorders is controversial because it is unclear whether co-existing psychiatric diagnoses "actually reflect the presence of 'distinct clinical entities' or refer to multiple manifestations of a single clinical entity" (Maj, 2005: 67) and because comorbidity may be an artefact of diagnostic classification choices (Maj, 2005; van Loo and Romeijn, 2015). None the less, anorexia has been claimed to be significantly comorbid with psychiatric disorders such as anxiety disorders, obsessive-compulsive disorder, depression and personality disorders (Berkman et al, 2007; Hudson et al, 2007; Swinbourne and Touyz, 2007; Pancheko and Arnfred, 2015; Martinussen et al, 2017). Substance use disorders are also common in anorexia, although this is more so in subtypes that include bulimic symptomology (Root et al, 2010).

In a recent Spanish study, Andrés-Pepiñá et al (2020) examined 20-year outcomes for women who were first treated for anorexia in adolescence. Of the 38 participants, 34% presented with some degree of eating disorder, and 26% met full DSM-5 criteria. Of the 34%, 70% had another psychiatric disorder. Indeed, research suggests that despite recovering from anorexia in the long-term in the sense of no longer meeting full diagnostic criteria, many individuals cross over into a diagnosis of bulimia or 'partial' anorexia and/or experience long-term 'psychiatric disorders' (Hudson et al, 2007; Bulik et al, 2005; Button and Warren, 2001; Steinhousen, 2002; Berkman, 2007; Keel and Brown, 2010).

Anorexia is associated with high treatment drop-out rates and levels of relapse across Western countries, including the UK (Wallier et al, 2009; Surgenour et al, 2004; Bulik et al, 2005; Waller et al, 2009; Hubert et al, 2013). In a UK survey commissioned by Beat (a UK

eating disorder charity), around two-thirds of respondents with anorexia had experienced at least one relapse which required repeat treatment (Beat, 2015). Many cases of anorexia continue for decades, although this may include periods of remission and changing severity (NICE, 2017b). The terms 'chronic', 'severe', enduring' and 'treatment resistant' anorexia are used to refer to instances where individuals experience anorexia over an extended period of time and lack motivation to recover, despite attempts at treatment (Strober, 2004; Abbate-Daga et al, 2013; Fox and Diab, 2015; Lacey and Sly, 2016; Hannon et al, 2017). It appears that around a third of individuals who receive inpatient treatment go on to experience this course of anorexia (Keel and Brown, 2010).

Anorexia is sometimes described as 'egosyntonic'. This term describes an aspect of an individual's experience which is consistent with their personal goals and sense of self, and is used to refer to the personally desirable or acceptable aspects of psychiatric symptoms (Marchesi et al, 2008; Roncero et al, 2013). Describing anorexia as egosyntonic therefore alludes to the condition (or aspects of it) being valued by the individual (Garner, 1985; Vitousek et al, 1998; Roncero et al, 2013; Gregertsen et al, 2017). For Laségue, the valued nature of anorexia was a core defining feature:

> What dominates [in anorexia is] the state of quietude - I might almost say a condition of contentment truly pathological. Not only does she not sigh for recovery, but she is not ill pleased with her condition, notwithstanding all the unpleasantness […] In comparing this satisfied assurance to the obstinacy of the insane, I do not think I am going too far […] the whole disease is summed up in this intellectual perversion (Laségue, 1873/2016: 28 – 29).

Similarly, Orimito and Vitousek, writing one century later, argue that the pleasure and accomplishment that the anorexic finds in their pursuit of thinness is "the essential anorexic attitude" (1992: 87), and Schmidt and Treasure claim that "one of the most striking aspects in the clinical presentation of individuals with AN [anorexia nervosa] is the extreme degree to which they value and 'defend' their undernourished state" (2006: 343). The personally

valuable aspects of anorexia have also been clinically framed as 'maintenance factors' (Serpell et al, 1999; Norbdø et al, 2006; Schmidt and Treasure, 2006). These are factors which contribute to the persistence of anorexia over time, as opposed to factors which contribute to the initial development of the condition (Schmidt and Treasure, 2006).

Denial of illness and resistance to change are thought to be prominent features of anorexia which reflect the individual's attempt to preserve its valued symptoms (Vitousek et al, 1998). The denial of illness is such that the individual typically does not experience her/himself as 'sick' (Treasure et al, 2015). Relatedly, individuals with anorexia are often described as 'lacking insight' into their condition, and sometimes as having 'severe impairment of insight' (Konstantakopoulos, 2011). This suggests that they do not understand the 'reality' of their experience or health.

The egosyntonic nature of symptoms may contribute to the ambivalence typically experienced by individuals in treatment (Williams and Reid, 2010; Cokell et al, 2013), difficulties in therapeutic relationships and high rates of 'treatment drop-out' and relapse (Vitousek et al, 1998). Such treatment related complications and the individuals apparent lack of acceptance of 'illness' have led to anorexia having a "clinical reputation [as] one of the most frustrating and recalcitrant forms of psychopathology" (Vitousek et al, 1998: 391).

Gender, class and ethnicity

Anorexia is generally understood as a 'female' disorder. As discussed above, Gull and Laségue's descriptions of the condition construed it in this way (Hepworth, 1999). Subsequent theoretical developments in the 'psy' disciplines (and feminist critiques of these) have largely served to strengthen the association between femininity and anorexia (Till, 2011). Indeed, influential aetiological explanations of anorexia during the 20th century directly incorporated the gender bias of the condition. Anorexia has been understood in

terms of, for example, female sexual conflict (psychoanalysis), female family relationships and a weakening of autonomy (a characteristic which is traditionally associated with femininity (Bruch, 1974; Till, 2011), and the social, cultural and political position of women (feminist psychologists and sociologists). 'Psy' knowledge and practice has therefore served to construct a relationship between anorexia and gender. In addition, feminism has portrayed the idea that 'fear of fatness' (which is strongly associated with anorexia) is 'tied up' with femininity (Bell and McNoughton, 2007).

However, there appears to be increasing identification of anorexia in males and it is sometimes asserted that male eating disorders are becoming more prevalent (e.g. Strother et al, 2012; Sabel et al, 2014). Among males, homosexual and bisexual men have been said to be most 'at risk' of developing an eating disorder (Russell and Keel, 2001; Yelland and Tiggemann, 2003; Boisvert and Harrell, 2009). Between 10% and 40% of men with an eating disorder identify as homosexual or bisexual, and this is in contrast to much lower rates of homosexuality among the general population (Russel and Keel, 2001); in the UK, around 2.5% of males identify as gay or bisexual (Office of National Statistics, 2020).

An increasing body of clinical literature addresses male eating disorders. This has explored the 'clinical presentation' of male anorexia and how this compares to female anorexia (both similarities and differences have been asserted in this respect) (e.g. Guegen et al, 2012; Norris, 2012; Strother et al, 2012; Núñez-Navarro et al, 2012; Smith et al, 2013; Sabel et al, 2014) and treatment of male anorexia (Greenberg and Schoen, 2008; Weltzin et al, 2012; Robinson et al, 2013). Further, research has addressed media representations of male eating disorders and the potential for 'stigma' and cultural assumptions about the feminine nature

of eating disorders to impact diagnosis and treatment (Strother et al, 2012; Raisanen and Hunt, 2014; MacLean et al, 2015; Sweeting et al, 2015)[8].

Prevailing clinical and lay wisdom suggests that there is a higher prevalence of anorexia among middle and higher classes than lower classes (Gard and Freeman, 1996; Dignon, 2007). This supposed class – anorexia relationship has proven controversial however, due to methodological difficulties associated with measuring both social class and incidence rates of anorexia, and studies generating conflicting findings.

There is a clinical stereotype of the anorexic as middle class (Dignon, 2007). This originates from the creation of the diagnostic category, as it was mainly middle-class women who were diagnosed with anorexia when it was introduced to the medical literature in the 19th century (Hepworth, 1999), not least because they were more able to seek treatment. In the 1970s and 1980s psychologist and psychoanalyst Hilde Bruch published several works on eating disorders (1974; 1978; 1988) in which social class was a central facet to her descriptions and explanations of anorexia (see below). Among a sample of 51 anorexics whom Bruch saw in her clinic, 29 were 'upper-class', 18 were middle class, and only 4 lower class (Bruch, 1974). However, her sample likely represented a skewed impression, given that middle/upper classes will have had more money and cultural support to access treatment than lower classes (Bordo, 2009).

Gard and Freeman's (1996) and Dignon's (2007) reviews of epidemiological literature show that during the 1970s and 1980s, studies supported the view that individuals with anorexia tended to be from middle and higher class backgrounds (e.g. Morgan and Russell, 1975; Crisp et al, 1976; Szmulzer et al, 1986; Gower and McHowen, 1989). Crisp et al (1976), for

---

[8] Although Holmes (2016) notes that the suggestion that "treatment paradigms have been geared towards females" (Strother et al, 2014: 436) exaggerates the extent to which mainstream treatment programmes tailor towards a specific gender.

example, surveyed nine schools between 1972 and 1974. They found that severe forms of anorexia were relatively common in the private sector of education and argued that this suggested a class factor. However, the validity of such studies has been questioned due to methodological flaws. In the Crisp et al study, the researchers 'case-spotted' anorexia in collaboration with school teachers, and a greater awareness of anorexia among staff in the private schools may have increased the likelihood of them 'spotting' a case (Gard and Freeman, 1996; Dignon, 2007).

Gard and Freeman (1996) and Dignon (2007) both found that studies from the mid to late 1980s to late 1990s rejected the idea of a class-anorexia relationship (e.g. Leighton and Millar, 1985; Whitikar et al, 1989; Rogers et al, 1997). For example, in an exploration of levels of 'clinically significant' eating disorder behaviours, Rogers et al (1997) found no differences between working class and middle class subjects. Both reviews concluded that, on the whole, more recent literature did not support a clear class-anorexia relationship (Guard and Freeman, 1996; Dignon, 2007). However, McCelland and Crisp (2001) reject this view. They examined the social class of female patients with anorexia using a retrospective survey of a clinical database covering the years 1960–1993. They conclude that social class distribution is consistently weighted towards the higher social classes. They contend that the strength of the anorexia-class relationship appeared to weaken post-1985, but remained significant.

In addition to reviewing literature, Dignon (2007) directly 'tested' the class stereotype of anorexia. Examining a sample of 104 anorexics seen in a district general hospital between 1985 and 2001[9], she found they were from both middle and working-class backgrounds and that the class distribution did not significantly differ from that observed in the general

---

[9] The sample is made of 80 patients from the years 1985 – 1990 and 24 patients from 1997 – 2001.

population. Further, a more recent review of the epidemiology of anorexia which covered literature from the years 2000 – 2011 concluded that a relationship between class and anorexia was not established (Roux et al, 2013).

Eating disorders are typically understood as occurring among white, western, middle-class girls and young women (Bordo, 2009) and have been understood as a 'culture bound syndrome' (Swartz, 1985). There is an ethnic and cultural dimension to conceptualisations of the condition, in addition to those of gender and class. However, reviews of literature addressing the prevalence of eating disorders among girls and women of ethnic minorities in the UK and the US and in non-western countries over the past 30 years suggest that these are rising (Miller and Pumarega, 2001; Nasser and Malson, 2009), and that eating disorders cannot be considered exclusively western and white. Keel and Klump (2003) undertook a study involving a quantitative meta-analysis of incidence rates of anorexia and bulimia nervosa, qualitative summaries of historical evidence of eating disorders, and an evaluation of the presence of eating disorders in non-Western cultures. They concluded that bulimia nervosa is a 'culture-bound syndrome', but anorexia is not. They state that "epidemiological data not only support the existence of anorexia in non-Western countries but suggest that it's prevalence may be similar to that in Western nations" (2003: 755). Importantly, Bordo (2009) notes that early paradigms for understanding eating disorders were derived from populations that were skewed in relation to race and class. Clinical data came from white, middle, and middle – upper class patients (Saukko, 2009), because these groups were more able to seek treatment. As such, eating disorders were conceptualised around the presentations and experiences of these particular groups.

The diagnosis and treatment of anorexia in the UK

Most individuals with anorexia initially receive a clinical diagnosis and access to treatment in a primary care context (e.g. via a general practitioner (GP)). Clinical literature suggests that,

due to anorexia being egosyntonic and/or the individuals 'poor insight', initial contact with a health professional is often initiated by a family member (typically a parent) or friend (Vitousek et al, 1998; Schmidt and Treasure, 2006; NHS, 2017b). When an individual does initiate care themselves, they do not necessarily present with eating/weight related distress as their problem, but with a related concern (e.g. amenorrhea) (NICE, 2017b). They may also be reluctant to fully disclose their motives and symptoms, and this can delay diagnosis and the initiation of treatment (Garner, 1985; NHS, 2004; 2017b; Treasure et al, 2015).

Upon identifying or suspecting a case of anorexia, a primary care clinician usually makes a referral to secondary mental health care or a specialist eating disorder service (EDS). However, there is variation in the level of knowledge, experience and skill that primary care clinicians have in identifying anorexia and managing treatment referrals (Currin et al, 2009; NHS, 2017b). As we might expect, House et al (2012) found a greater likelihood of cases of anorexia[10] being identified and referred on for further help in areas with specialist outpatient EDSs as compared to those with non-specialist services[11]. Similarly, Hugo et al (2000) found relatively high rates of referral to eating disorder treatment centres by GPs in practices in close proximity to a centre. This may be partly due to heightened awareness and knowledge of eating disorder treatment among GPs who have links to specialist services (House et al, 2012).

Hugo et al (2000) and Schmidt et al (2006) found that female GPs were more likely to refer patients to an eating disorder treatment centre than were male GPs. However, other research has identified no correlation between GPs gender and diagnostic and treatment

---

[10] Or unspecified eating disorders with a presentation similar to anorexia
[11] Geographical variation in treatment provision is discussed below

decisions for eating disorders (Currin et al, 2007). Feeney et al (2007) identified such a correlation for binge eating disorder and EDNOS, but not for anorexia and bulimia.

Treatment for anorexia may be as an outpatient or inpatient, with either a generic mental health service or a specialist eating disorder service. The average length of NHS treatment for anorexia is 12.3 months (Beat, 2009). Treatment usually seeks to improve nutrition and increase body weight (known as 'refeeding') and engage the individual in psychological treatment. While inpatient care was central to managing eating disorders during the 20th century, more recently there has been a shift towards community-based provision in the UK (NHS, 2017b), a pattern which has occurred across mental health services (Fakhoury and Priebe, 2002). Inpatient treatment is now restricted to those with severe medical risk or those who have not responded effectively to outpatient care (NHS, 2017b). That said, rates of inpatient admission for anorexia and individual cases of multiple admissions appear to have steadily increased since the late 1990s (Holland et al, 2016; NHS Digital, 2018). The central goal of inpatient care is to reduce risk of physical illness and death through improved nutrition, usually via supervised meals (NICE, 2017b). The average length of stay in a specialist eating disorder unit (SEDU) is 18.2 weeks (RCP, 2012). Traditionally, inpatient treatment has sought to restore an individual's weight to normal, and this is often understood as the 'best' outcome of inpatient treatment. However, 'partial recovery' programmes involving short periods of inpatient stay and relatively low body weight at discharge are also offered by most UK adult SEDUs (Goddard et al, 2013; NHS, 2017b). Day care services or partial hospitalisation are sometimes used as an alternative to, or follow up from, inpatient care. Hay et al (2019) reviewed existing studies to assess the effectiveness of treatment for eating disorders across different settings, and found no setting to be notably more effective than others in respect to weight restoration. Assessing weight gain after 12 months, there was little or no difference between specialist inpatient care and active

outpatient or combined brief hospital and outpatient care. The proportion of eating

disorder inpatients legally detained under the Mental Health Act in the UK is around 8%

(RCP, 2012)[12], and these individuals tend to have more severe symptoms and longer

inpatient stays (Elzakkers et al, 2014). Severely medically ill individuals may also be admitted

to a general hospital for treatment of physical aspects of the condition (NICE, 2017a; RCP,

2014).

A notable feature of anorexia is its reputation as being 'difficult to treat' due to the

individual being considered unwilling to participate in therapy and/or because they are

manipulative and devious (Bruch, 1988). Individuals with anorexia "are notorious for their

often concerted resistance to therapeutic processes" (Gremillion, 2003: 3), and in hospital-

settings are generally defined as 'non-compliant' and 'difficult' (Darmon, 2017). It is claimed

that ambivalence about their condition leads 'anorexics' to actively subvert therapy and that

this can lead to difficulties in establishing a therapeutic relationships (Vitousek et al, 1998).

There is substantial variety in the care that individuals with anorexia receive in the UK and

this is linked to geographical inconsistencies in service provision (Beat, 2009; Escobar-Koch,

2010; RCP, 2012; NHS, 2017). Treatment variation is evident throughout the pathway of

care, from initial identification of the condition through to the termination of treatment

(House et al, 2012) and exists for both adults and children, and in relation to both

outpatient and inpatient services (NHS, 2017). The trajectory of an individual's 'care

pathway' (including whether or not they are referred for treatment and the type of

treatment they receive) can depend on geographical factors such as levels of funding and

local service availability (Hugo et al, 2000; House et al, 2012; NHS, 2017). As has previously

been discussed, GP's referral rates differ in accordance with the 'type' of locally available

---

[12] Although Elzakkers et al (2014) note that this is a crude figure.

services for eating disorders (Hugo et al, 2000; House et al, 2012). Parts of the UK have little or no specialist eating disorder provision (RCP, 2012)[13] and different areas adopt different referral criteria for entry into inpatient treatment (NHS, 2017). In some areas, specialist services (such as SEDUs) utilise strict BMI thresholds for admission due to limited funding (NHS, 2017).

Regarding the association between anorexia and high rates of treatment 'drop–out', Waller et al (2009) note that there is substantial attrition throughout all stages of the care pathway. In their sample of individuals referred to a specialist adult inpatient eating disorder service, only two-thirds of referrals resulted in an assessment, three-quarters of those assessed entered treatment, and half of those who entered treatment completed it[14]. Reasons for attrition included, for example, the individual declining treatment and unsuitability (due to e.g. moving out of catchment area).

There is significant variation in the therapeutic approaches offered to individuals with eating disorders, and in the skill set of the health professionals who deliver them (NICE, 2017b). The approaches most often offered by UK eating disorder services in the treatment of anorexia (either individually or simultaneously with other approaches) include cognitive behavioural therapy (CBT) (used by 84% of eating disorder services), nutritional advice and monitoring (82%) and family-based treatment (77%) (RCP, 2012). The approach offered differs across adolescent services and adult services (Treasure et al, 2005; Winston et al, 2012). Winston et al (2012) report that adolescent services tend to include family therapy, and parents/carers are encouraged to take control of the adolescent's eating. In contrast,

---

[13] The RCP (2012) report does not specify which parts of the UK have little/no provision.
[14] The researchers recognise that this may be a distorted representation, as some of the individuals in the research cohort were still in treatment at the time of addressing rates of drop-out (and may have eventually come to complete treatment).

adult services tend to encourage the individual to act autonomously and take control of their own eating.

The official guidelines for the assessment and treatment of anorexia in the UK are published by the National Institute of Clinical Evidence (NICE) and are based on clinical research findings. The newest version of these guidelines was published in 2017 (NICE 2017a; 2017b). When considering the recommendations in these guidelines, it is essential to note that there are significant methodological complexities which make the measurement of 'recovery' and/or successful treatment in research problematic (Khalsa et al, 2017).

NICE (2017a) advise that when initially assessing for an eating disorder, clinicians should consider a range of factors, including BMI, social withdrawal, and physical signs of malnutrition. Individuals with a suspected eating disorder should be immediately referred to a community-based eating disorder service for further assessment or treatment, and those with, or at risk of, severe emaciation should be prioritised for treatment. Weight gain is described as a 'key goal' in the treatment of anorexia, and necessary for psychological, physical and 'quality of life' improvements (NICE, 2017a).

NICE (2017a) suggest that an individual with anorexia should normally be treated as an outpatient, but when this is not suitable (e.g. if too medically unstable), day patient or inpatient services should be considered. It is advised that absolute BMI thresholds should not be used as the basis for admission to more intensive services, due to BMI having limited use as a single risk marker (Treasure, 2009; Treasure et al, 2015). The guidelines state that a patient who does not consent to treatment but is at serious medical risk and requires

inpatient treatment should be assessed under the Mental Health Act1983[15] so that they may be involuntarily treated (Treasure, 2009; NICE 2017a).

Eating disorder focused cognitive behavioural therapy, Maudsley anorexia nervosa treatment for adults, and specialist supportive clinical management are recommended as first line treatments for adults, based on a cost-benefit analysis (NICE, 2017a, 2017b) which includes an examination of clinical evidence (e.g. Dare et al., 2001; Zipfel et al., 2014). However, the apparent benefits of these therapies as compared to other psychological treatments are minimal[16], and none the less show relatively low remission rates and a failure to sustain long term benefits (NICE 2017b). Further, the quality of the evidence included in the cost-benefit analysis is rated as low or very low. Recent clinical literature concludes that, despite a recent increase in the availability of evidence relating to the treatment of adult anorexia, no specific treatment approach demonstrates clear superiority (Zipfel et al, 2015). No treatments used for adults (and/or those who have had the condition for longer than three years) leads to substantial levels of recovery (Le Grange, 2016; Treasure and Cardi, 2017). Indeed, NICE (2017a) state that despite the wide range of treatments available for adult anorexia, they are often ineffective.

With regard to anorexia in children and young adults, anorexia nervosa focused family therapy is recommended as a first line treatment. Family–based approaches were also recommended for this age group in the previous guidelines, and other recent reviews (in addition to NICE, 2017b) have also concluded that these are the most well-established treatments for children and young adults (Zipfel, 2015; Lock, 2015).

---

[15] This may be the Mental Health Act 1983/2007 or the Children Act 1989 in the case of children and young people, or may involve parents/carers consenting to treatment on the individuals behalf.

[16] The psychological interventions included in the analysis other than those that are recommended as first and second line treatments for adults "were not recommended because they were either not effective on remission, the sample size was too small, or the quality of the evidence was too low" (NICE, 2017b: 270).

Overall, clinical literature tends to suggest that treatment outcomes for adults are poor or not especially promising, but are better for adolescents (e.g. Fairburn, 2005; Goddard et al, 2013; Walsh, 2013; Le Grange, 2016; Zipfel, 2015; Treasure and Cardi, 2017). It is therefore frequently concluded that more effective treatments for anorexia are needed, especially for adults (Keel and Brown, 2010; Ziplfel, 2015; Le Grange, 2016; Treasure and Cardi, 2017).

Psychopharmacological treatment is recommended to only have a secondary role in the treatment of anorexia (Treasure et al, 2015; NICE, 2017a). However, drugs are widely used in the treatment of eating disorders (NICE 2017b) and research in the US[17] suggests that they are prescribed to most individuals with anorexia (Fazeli et al, 2012). Antidepressants and atypical antipsychotics are the main psychoactive drugs proposed for anorexia on the basis that they may promote weight gain and reduce 'anorexic' preoccupations and behaviours and mood and obsessive symptoms related to comorbid disorders (Treasure et al, 2015). However, systematic reviews conclude that antidepressants are not effective in treating anorexia, in terms of improving weight gain, reducing symptoms during refeeding, or preventing relapse (Fazeli et al, 2012; Treasure et al, 2015, NICE, 2017b). Regarding antipsychotics, research claims that a subgroup of individuals may benefit from a short-term reduction of symptoms, but that there is no evidence of long-term benefits (Fazeli et al, 2012; Treasure et al, 2015, NICE, 2017b).

Research suggests that UK clinical psychologists are inconsistent in their use of clinical guidelines (Court et al, 2017). It is unknown to what extent NICE eating disorder guidelines are implemented (RCP, 2012), although one study suggests that previous NICE (2004) guidance stating that high risk cases of anorexia should be referred to a specialist service was not necessarily enacted by GPs (Currin et al, 2007). It has been suggested that clinicians

---

[17] I was unable to locate any literature detailing the rates of drug use for anorexia in the UK.

treating eating disorders demonstrate good awareness of 'evidence based treatments', but that they use these treatments (and the psychotherapy manuals that underpin them) infrequently or in an adulterated and relatively ineffective form (Simmons et al, 2008; Waller et al, 2012; Waller et al, 2013; Von Ranson et al, 2013). This tendency may be related to the more general phenomenon of 'therapist drift', which has seen a substantial increase in recent years (Waller, 2016). This refers to therapists' not delivering evidence-based treatments effectively (or at all), due to factors that are personal to them, such as their personality, emotions, beliefs and attitudes (Waller et al, 2016).

Iatrogenic effects of treatment

There has been some clinical recognition of iatrogenic effects of treatment for anorexia. NICE guidelines recommend that clinicians

> […] take into account the risk that people with an eating disorder can become institutionalised by a long admission, and that a lack of change in their condition could indicate that inpatient treatment is harmful (NICE, 2017a: 34).

Treasure et al (2011) explore iatrogenic aspects of treatment in the context of a maintenance model of anorexia (Schmidt and Treasure, 2006). This psychological model addresses four domains of 'maintenance factors' (as defined above) and Treasure et al argue that iatrogenic harm can occur in relation to each of these. The domains are interpersonal factors, thinking style and obsessive personality traits, pro anorexia beliefs, and emotional style, avoidance and anxiety. In this discussion, I focus on the first two of these. 'Interpersonal factors' includes the tendency for others to react with criticism or overprotection, and to accommodate or enable aspects of the eating disorder. Regarding iatrogenic harm, services may act in an 'overprotective' manner through over-zealous use of inpatient care, limiting opportunities for individuals to develop 'real world' recovery skills. Treatment may be 'critical' if it is experienced as coercive and confrontational, leading the

patient to 'rebel' and not comply. Other clinically-oriented studies have also identified harm associated with 'punishing' treatment. Rigid treatment structure and highly standardised treatment programmes, especially those based on strict behavioural approaches, may be experienced as punitive and arbitrary and undermine therapeutic relationships and motivation (Bruch, 1978; Garner, 1985; Offord et al, 2006; Colton and Pistrang, 2004).

Treasure et al (2011) also suggest that inpatient environments may enable anorexia because of the tendency for those diagnosed to 'pick up' behaviours from other patients, and compare themselves to, and compete with them. The dynamics of comparison and competition among patients are well recognised in clinical literature, and have been suggested to lead individuals to learn new illness-related behaviours, seek to 'be the best anorexic' and ultimately to become 'more ill' (Colton and Pistrang, 2004; Offord et al, 2006). Additionally, services can enable anorexia when they become the main social network for the individual, as this encourages them to 'hang on' to their illness to feel accepted: "The sick role and benefits it brings may be part of the [eating disorder] aetiology and serves to arrest the need to take responsibility" (Treasure et al 2011: 299). Similarly, Gowers et al (2000) suggest that the care, support and feeling of safety that individuals experience during inpatient treatment may be greater than in the community, and that this can encourage individuals to seek a return to hospital after discharge by relapsing (see also Offord et al, 2006).

'Thinking style and obsessive-personality traits' is a maintenance model domain that addresses the rigidity and attention to detail which is believed to be exaggerated within anorexia. Treasure et al (2011) suggest that the highly structured inpatient environment, which is abound with rules and routines, can be valued by eating disorder patients with obsessive-compulsive tenancies. Further, the problematic belief of needing to be thinner to deserve help may be enhanced in scenarios where patients are not accepted into treatment

due to 'not being thin enough' to meet referral criteria. Relatedly, Rance et al (2017a) argue that BMI contingent admission to services within NHS treatment systems can incentivise weight loss[18].

Treatment which is perceived to incorporate too much focus on weight gain and food intake and not enough on psychological aspects of the condition may be ineffective and iatrogenic. Participants in a range of clinically-oriented studies report a preference for 'wholistic' approaches to treatment and perceive a disproportionate focus on weight and food as problematic (Eivors et al, 2003; Colton and Pistrang, 2004; Offord et al, 2006; Escobar-Koch, 2010; Rance et al, 2017a). This focus may inadvertently encourage individuals to continue their eating disordered behaviour by perpetuating concerns about food and weight (Rance et al, 2017a; Eivors et al, 2003). Enforced weight gain and a neglect of corresponding emotional support may also compound an existing sense of lack of control (Offord et al, 2006).

Clinical approaches: concluding remarks

In this review I have addressed clinical approaches to anorexia, including historical and current definitions, clinically recognised features of the condition, and its epidemiology and treatment in the UK. This has been crucial for contextualising my research, and for understanding the clinical construct that participants encountered when diagnosed with anorexia, as well as the treatment environments they were immersed in. In the following section, I review alternative approaches to understanding anorexia and treatment from within the social sciences.

---

[18] This research reported on women's perceptions of the NHS treatment that they received, and may not accurately reflect the way that clinical decisions were 'really' made. However, NHS (2017) do recognise that admission decisions are sometimes made on the basis of BMI, especially in areas where funding is limited.

Sociological and anthropological understandings of anorexia

Feminism

Feminism has made significant contributions to sociological theorising of eating disorders. Feminist scholarship (including feminist psychology and sociology) has collectively served to cast into doubt the 'psychopathology' of eating disorders and question the supposed boundaries between normal and pathological eating (Bordo, 1993). This 'rethinking' of an 'abnormality' is characteristic of much feminist work related to health (Brook, 1999).

There are two phases of feminist approaches to eating disorders; 'classic feminism' and 'critical feminism' (see Saukko, 2008 and Malson and Burns, 2009)[19]. The classic feminist literature emerged in the 1970s and includes, for example, Lawrence (1984); Chernin (1985) and Orbach (1978; 1986), all of whom were practising therapists who developed their theories in the context of therapeutic application and so drew on their experiences with individual cases. This literature focuses on the development and psychologies of women (Busfield, 1996) and explains anorexia in terms of 'traditional' feminist concerns such as women's (changing) social, political and economic positions, female subordination and patriarchal oppression. Since the 1990s, critical feminist literature has developed analyses of eating disorders taking its influence from post-modern and post-structural theory (e.g. Bordo, 1993; Malson, 1998; Hepworth, 1999; Saukko, 2008). It has examined the discursive construction and regulation of eating disorders. Malson and Burns suggest that classic feminist approaches viewed eating disorders as individual, pathological responses to patriarchal cultures, but that critical feminist literature sees eating disorders as "constituted within and by the always-gendered discursive contexts in which we live: (individual) 'disorder' is re-theorised as part and parcel of the (culturally normative) order of things"

---

[19] Although precise divisions cannot be drawn between the two.

(2009: 2). Critical feminist literature is more exclusively theoretical than the classic literature, having been developed at a 'scholarly distance' (Holmes, 2016) and not in a context of direct therapeutic application.

I begin this discussion with an overview of Hilde Bruch's (1974; 1978; 1988) work. Bruch was a psychoanalytic psychiatrist and psychotherapist and her ideas provided the foundations that were later built on by feminists (Busfield, 1996). I then consider Orbach's psychoanalytically-oriented work, as an example of classic feminism. This is followed by a review of Bordo (1993) who, in her critical engagement with post-modern and Foucauldian ideas, represents the beginnings of critical feminist approaches to anorexia (Malson and Burns, 2009). Lastly, I critically discuss feminist approaches, and draw on insights from critical feminists (Hepworth, 1999 and Malson, 1998) in so doing.

Bruch identified two processes in the development of severe eating disorders: an inability to recognise and adequately respond to hunger and a lack of self-identity (1974). She tied this abnormal development to family dynamics and interactional patterns with parents (mainly the mother) during childhood (1974; 1978; 1988). Bruch examined the family background of her 'anorexic' patients, noting that they came from upper middle class/upper class families (see above). These families initially seemed stable and well-functioning, affording their daughters many privileges and opportunities. However, she contended that patterns of interaction within the family during childhood had led to them (the daughters with anorexia) being confused in their concepts about the body and its functions, and deficient in their sense of identity, autonomy and control (1974; 1978; 1988).

Bruch described the mothers of her anorexic patients as conscientious and devoted to their children, but noted that they often provided for their child in accordance with what they felt was needed, and not with child-initiated cues. This led to the child's innate needs not being

properly attuned with the responses in their environment (1974), thus preventing 'healthy' conceptual development. In this context, hunger and satiety signals became misused, serving emotional and interpersonal (as opposed to physiological) needs.

As children, Bruch's patients experienced the privileges and opportunities they were afforded as a heavy burden and felt obligated to be 'someone special'. Their parents tended to exert excessive control over them and they were not acknowledged as an individual in their own right. They therefore 'over-conformed', and these experiences led them to develop an inadequate sense of identity, self-confidence and autonomy and precipitated anorexia. They became actively engaged in the process of anorexia in an attempt to fill a desire to be special and outstanding, and in a struggle "for control, for a sense of identity, competence and effectiveness" (1974: 251).

Susie Orbach's work *Fat is a Feminist Issue* was a self-help manual based on her therapeutic work with compulsive overeaters in which she adopted a "feminist rethinking of traditional psychoanalysis" (1978: 13). Orbach argued that women develop compulsive overeating as an adaption to sexist pressure, and it is therefore rooted in gender inequality. Compulsive overeating and fatness hold symbolic meaning, and may be a means of rejecting women's powerlessness, self-denial and limited social roles. Orbach argued that anorexia and compulsive overeating are both a response to the same oppressive conditions and are 'two sides of the same coin'.

In *Hunger Strike* (1986), Orbach focused specifically on anorexia and suggested that it is a form of active rebellion and attempt at self-assertion. She argued that contemporary western women experience profound confusion and face contradictory requirements. Focusing on gender roles, she suggested that women are culturally and psychologically prepared for a domestic life looking after others and that femininity requires that women

define themselves through their connections with others and that they anticipate others' needs. However, they are also 'teased' with the possibility of living life for themselves and becoming 'successful' outside of the home. Anorexia is a bodily transformation which reflects an attempt to deal with these contradictions, it being "at once the embodiment of stereotyped femininity and its very opposite" (1986: 30). Orbach also claimed that anorexia is an expression of a woman's internal struggle to negotiate her passions and desires. As women are socialised into meeting the needs of others, they are unfamiliar with their own needs and ashamed of their own desires and wants. The anorexic attempts to create a needless self and to establish a sense of control and autonomy over her emotions metaphorically through the external control of a strict diet.

Turning to critical feminism, in *Unbearable Weight* (1993), Susan Bordo's feminist analysis draws on ideas from Marxism and cultural theory. In this, she shifts the focus from gender roles to culture. She argues that slenderness is a contemporary ideal of female attractiveness and analyses how slender bodies are 'read'. She decodes the meanings related to what are perceived as the correct and incorrect management of desires that are perceived within the body, and argues that a slender body that is 'tight' and contained is perceived as being protected from internal eruption, and thus represents controlled internal processes of desire and impulse. The slender ideal also encapsulates the contradictions of 'being female' by being both a rejection of a domestic identity and an expression of discomfort with greater female presence and power. For women, these contradictions of femininity are layered with the contradictions of capitalism. While consumer culture encourages women to "let go" and indulge their desires, diet and exercise industries simultaneously code fat as undesirable and symbolic of laziness. In this context, at the "intersection of patriarchal culture and post-industrial capitalism" (1993: 32), it is difficult to negotiate a place of moderation and "easy to fall into disorder" (1993: xxi).

Bordo also addresses the impact of cultural images of 'ideal' bodies, which are more prevalent for women than men. She argues that digitally modified images alter our perception of a 'normal body' and raise our standards of bodily perfection. Further, she argues that while the medical model of anorexia has noted that culturally prevalent images of thin bodies play a contributory role in the development of eating disorders, it has failed to grasp "just how powerful, ubiquitous, and invasive the demands of culture are on our bodies and souls" (1993, xix). More recently, Bordo (1999; 2009) has also addressed the relatively recent exploitation of male body insecurity by cultural industries.

In *The Social Construction of Anorexia* (1999), Julie Hepworth argues that classic feminist literature inadvertently reproduced dominant medical scientific discourse, for example by retaining the category 'anorexia nervosa' and by focusing on the psychology of the mother-daughter relationship. Critical feminists, however, have been critical of the category 'anorexia nervosa' and the implication that it is a 'natural' pre-existing clinical entity, and have examined its discursive construction (Malson, 1998; Hepworth, 1999). Drawing on Foucault, Hepworth (1999) argues that anorexia is a product of medical science which cannot be separated from the social practices through which it became defined. The 'scientific discovery' of anorexia in the 19th century was made possible through a set of discourses and social practices which emerged in a particular historical, cultural and institutional context. These include discourses of femininity, hysteria, and discovery as well as medical scientific and clinical discourse.

A limitation of feminist approaches to eating disorders is the lack of insight into the diagnosis in males. Lawrence (1984), for example, argues that anorexia sometimes affects men because male and female psychology are not wholly distinct, and because the issues that are problematic for women are sometimes also problematic for men. However, her explanation is brief and does not account for the ways that gender may differentially shape

the experience of anorexia. Bell and McNoughton argue that feminists, through their commitment to the notion of patriarchy, have implied that an intense 'fear of fatness' is only experienced by females, and thus have failed to recognise that "reviling fatness is not a peculiarly feminine preoccupation" (2007: 108).

I suggest that it is questionable whether feminist interpretations of anorexia as an 'unconscious' rebellion or attempt to reconcile contradiction can be taken as 'correct'. These interpretations assume that the meaning of self-starvation is located within its feminist interpretation, thus divorcing the meaning from the 'conscious' motivations and lived experience of the 'anorexic' themselves. In this sense, feminism potentially imposes rather than 'unearths' meaning. This potential for imposed meaning is captured in Orbach's drawing of a parallel between anorexia and the suffragettes hunger strike, which "too readily attributes a political motivation to actions whose element of resistance does not have an equivalent conscious political intent" (Busfield, 1996: 183). Relatedly, Dignon argues that feminist literature has created a stereotype of the 'anorexic' as a "political protester reacting against society's oppression of women" (2007: 31), although this stereotype has been less powerful than clinical stereotypes. Despite the problems inherent in feminist perspectives however, these have none the less greatly enhanced understandings of anorexia (Busfield, 1996), and have been particularly valuable in challenging psychiatric explanations (MacSween, 1993).

The career and social space of anorexia

In *Becoming Anorexic: A Sociological Study* (2017) (originally published in French in 2003), Muriel Darmon departs from preceding sociological approaches by focusing on the *activity* of anorexia, and then analysing the specific 'social space' in which this activity occurs. She undertook interviews with 14 female adolescent 'anorexic' patients in France, some in a hospital and some in a psychiatric clinic, and interviews with three female former anorexics,

recruited via snowball methods[20]. She also undertook five months of observation in units where her interviewees were patients[21]. She utilises the symbolic interactionist notion of career (discussed later) to understand the activities involved in anorexia and the processual, temporal dimensions of the condition. Drawing on Bourdieu, Darmon then analyses the underlying social influences on these activities. Class, gender and age are framed not as 'causes', but as 'social conditions of possibility' for the activity that anorexia involves. She contends that anorexia is a process of self-transformation which follows sequential phases and involves specific and deliberate forms of work, and that the practices involved in this are characteristic of a specific gender (female) and class (middle/upper class).

Darmon identifies four phases in the 'anorexic career'. During the first phase ('beginning'), the individual 'takes themselves in hand' and commits to changing their habits. Some begin with a diet and some with accidental weight loss which is then continued with a diet. Others begin with a multifaceted self-transformation whereby the dieting occurs alongside an increase in other organised bodily practices (e.g. sports) and cultural practices (e.g. schoolwork). In all cases, there is a temporally situated, determined and efficient engagement into the anorexic career involving a deliberate 'break from the past'.

The second phase 'Carrying on (one)' involves distinct forms of learning, as the individual undertakes considered and determined work, including a rationalisation, intensification and more systematic implementation of techniques used during the previous phase, as well as new techniques. For example, the reflexive work of calorie counting and measuring is used to increase the knowledge base, guiding food consumption. The individual also learns to enjoy the effects of their practices, including the physical sensations associated with food

---

[20] Darmon also interviewed 'non-anorexic' secondary school pupils (11 interviews) and teachers who worked in a school attached to a psychiatric clinic (11 interviews).
[21] Details regarding the number of interviews are taken from an additional publication (Darmon, 2009) based on the same research.

restriction. During this phase, the techniques and practices that the individual has previously deliberately implemented come to create habits and long-lasting, embodied dispositions. These constitute an internal driving force which 'propel' them towards maintaining anorexia.

During the third phase - 'carrying on (two)' - the commitment to the anorexic endeavour is maintained, despite others labelling this as deviant and the individual being increasingly monitored. The phase begins when an 'alerter' (or successive alerters) such as a family member or friend publicly indicates that something is wrong. From this, a 'circuit of agents' develops, constituted of lay and professional individuals. This circuit employs various techniques to 'normalise' the individual and encourage them to end their commitment. The 'circuit of mediators' refers to the network of professionals involved in the individual's medical care, usually beginning with a GP and ending with a psychiatrist. As the individual travels through this circuit, a diagnosis emerges and the individual is eventually 'officially' diagnosed. Towards the end of the circuit, the threat of hospital comes into play, leading either to hospitalisation[22], or to the individual ending their commitment.

In the final stage – 'being taken in hand' – individuals give themselves over to the hospital institution[23], which works on them by redefining their existing dispositions as pathological, and replacing them with 'healthy' dispositions. This involves getting the individual on board, such that they eventually internalise the hospitals point of view and commit to a new form of work ('recovery'). Eventually, they actively engage in their own fight against their 'anorexic' dispositions, and so begin a new endeavour of self-transformation.

---

[22] This was the typical outcome in Darmon's sample due to most of the interviews being undertaken in a hospital setting.

[23] Darmon recognises that hospitalisation "can be part of a diverse and discontinuous medical trajectory" (for example, numerous admissions may occur) and that the exact nature of the experience can vary in accordance with different hospitals therapeutic orientations. Her analysis therefore focuses on common practices that occur across hospitalisations (2017: 158).

Darmon draws on Bourdieu to explore the 'social characteristics' of the activity within the first three phases, arguing that these tend to be middle/upper class, female and (to a lesser extent) 'young' practices. For example, she argues that the anorexic's food choices are not only driven by perceived impact on weight, but also reveal 'dominant tastes'; they eat food that tends to be associated with middle/upper classes (e.g. fish, lean meat, fruits) and reject food associated with working classes. Darmon argues that for women more so than men, the bodily changes that are pursued in anorexia are socially oriented towards 'excellence', because the body is more profoundly caught up in class categories for women than for men. She also analyses class in respect of the 'hospital phase' of anorexia, arguing that 'patient resistance' ('non-compliance') is class based. Middle/upper class dispositions (such as self-assurance and a sense of entitlement) account for the ways in which patients 'resist' medical authority. Thus, class, gender, and age are all social conditions of possibility for the work that anorexia involves.

Other scholars have also framed anorexia as a career (McLorg and Taub, 1987; Peters, 1995), however Darmon (2017) was the first to have focused on the activity involved. Her analysis of the 'social space' of this activity offers a novel way of approaching the epidemiology of anorexia, which avoids implying over simplified causal relations (Darmon, 2017). However, it is unclear to what extent the experiences of Darmon's participants are relevant to others. The findings may indicate the specific ways in which anorexic activity happened to manifest for her sample, who were female, upper/middle class and young. Rather than being a member of these groups facilitating an 'anorexic career', it might be that it allows for a particular manner of engagement. Alternatively, some combination of both dynamics might also be at play.

Anthropological approaches

Anthropological studies have examined institutional practices and embodied experiences of eating disorders. By theorising "how local, shared worlds shape disordered eating [and the] grounding of the disorder in social structures and relationships" (Eli and Warin, 2018: 443), they have challenged clinical and popular interpretations of anorexia. In this discussion, I focus on anthropological work from the past decade (Lavis, 2011; Warin, 2010; Eli, 2014b). This work addresses themes such as the value and meaning of anorexic identities, the power of the diagnostic category of anorexia, belonging and social relationships among individuals in treatment, and altered forms of relatedness in experiences of anorexia. I also incorporate insights from sociologist Rich's (2006) ethnographically-oriented study of young women's experiences of anorexia and identity. The findings from her research concur with insights made by anthropologists, and she draws directly on their work (specifically Warin).

Warin (2010) undertook an ethnography of people's everyday experiences of anorexia. This involved multi-sited fieldwork during the late 1990s and early 2000s. Locating sites for her ethnography, she began with hospital settings in South Australia, and then located two further treatment settings overseas in British Columbia and Scotland, based on their international reputation and innovative programmes[24]. Once based in these institutional locations, she then 'moved outwards' into domestic and public spaces. The focus was thus not only anorexia in clinical settings, but also in everyday life, in people's homes, employment, and relationships more broadly. Participants included 44 women and 3 men aged between 14 and 45, most of whom were single and had a range of economic and occupational backgrounds and living situations.

---

[24] These eating disorder programmes were considered innovative in their focus on outpatient treatment and because they incorporated a range of fields of knowledge for treating eating disorders, including feminism.

According to Warin, "relatedness […] is central to people's practices and experiences of anorexia" (2010: 3). She uses a broad anthropological conceptualisation of relatedness to refer not only to familial and social obligation and ties, but to the multiple elements and everyday acts that comprise these. This includes "the everyday exchanging and sharing of food and substances, living together, domestic arrangements, places, memories, emotions, and relationships" (2010: 3).

Warin found that her participants often negated 'ordinary', everyday practices of relatedness, such as social eating and the desire to have children, because, for example, they were experienced as threatening. However, they created new meanings and experiences of being related through the practices and identity of anorexia. Anorexia offered new avenues for relatedness through the concealment and revealing of anorexic practices, friendships, competitiveness, secrecy and shared experiences with others who have the diagnosis, and a personal relationship with anorexia. I focus here on three aspects of relatedness: a relationship with anorexia, the social relation of secrecy, and the 'hierarchy of anorexia'.

Regarding the first, anorexia was often personified as both friend and enemy. Individuals formed intimate connections with anorexia, which sometimes became central to who they perceived themselves to be and were thus pivotal to their identity. These connections were often valued and cherished, such that 'recovering' meant leaving behind a significant relationship and could entail an intense loss and sadness.

Social relations of secrecy concerns the concealing and revealing of anorexic practices. Warin describes how an element of concealment around anorexia was clearly evident in clinical settings, and that this led health professionals to view patients with suspicion. Outside of treatment, individuals were reluctant to reveal weight loss and food restriction to others. They used 'anorexic tricks' (such as drinking water before being weighed) to give

the appearance that all was normal and to hide the extremes they went to to lose weight. Warin argues that "the power of secrecy lies not only it what it conceals […] but also in what it reveals and creates" (2010: 85 – 86). It was the creation of meaning involved in secrecy and concealment that was important, more so than the content of what was being hidden. Performing secrecy was productive. It marked differences between those with and without anorexia and distinguished anorexia from other illnesses. In treatment settings, it facilitated the establishment of new relationships. Bodily practices were known and shared among those with anorexia, forming what participants referred to as the "secret language of eating disorders". Secrecy thus created exclusion, difference, and power.

Warin describes a 'hierarchy of anorexia' that exists in treatment settings. In this hierarchy, the top is represented by "pure" or "true" anorexia, which refers to "weight loss by total control through almost total abstinence from food and drink" (2010: 94). In treatment, individuals compete with themselves and others within the hierarchy, striving towards the top to become 'the best anorexic'. Being the 'most sick' and 'most thin' is appealing because it distinguishes oneself from other members of the group. In this context, serious medical complications make one more distinguished and give credibility to one's diagnosis.

Warin also found that the maintenance of anorexia, particularly in its earlier stages, created feelings of superiority over others and a sense of prestige. Anorexia was experienced by many as a desirable positioning and was something they worked towards. She describes how the diagnosis can offer symbolic power, and that this arises from its mark of distinction and sign of belonging to an elite group. Participants sought to mobilize the worth of the diagnostic label of anorexia such that they transformed it, and it became more to them than a medical diagnosis. Rather, it was "an empowering state of being, a friend, an enemy, and a way of life" (2010: 7).

Rich (2006) undertook a study of anorexia in which she drew on a range of ethnographic data and 'voices'. These data were primarily narratives from semi-structured interviews with young women (aged 11 – 17) diagnosed with anorexia and bulimia, all of whom were at different stages of 'recovery' in a UK inpatient treatment centre for eating disorders. Rich argues that the young women in her study had come to manage anorexia as an identity as well as an illness. They navigated the complexities of stigma attached to the label of anorexia, the ways in which they presented themselves to others, and the relationships they developed with others with anorexia.

Participants in Rich's research said they had often felt misunderstood by others (such as peers, teachers, family members and medical professionals) due to medical discourse positioning anorexia as a pathological and 'irrational' condition. The way that others 'read' their anorexic body and reduced anorexia down to an issue of weight meant that they felt disconnected from them. Given this, relationships with other patients in the treatment environment provided an alternative context in which they did feel understood, and were a source of valued understanding and support. Drawing on Warin's insights regarding secrecy[25], Rich describes how connections were built among inpatient peers through the sharing of eating disorder knowledge and practices. However, while largely feeling connected to other 'patients', they could also quickly move into feeling disconnected, and were sometimes 'competitive' and unfriendly.

Similar to Warin's 'hierarchy of anorexia', Rich (2006) suggests that being a 'successful anorexic' affords a certain status and sense of empowerment. The young women in her study managed the negative social positioning of anorexia by presenting alternative narratives whereby they are not 'abnormal' and attention seeking, but embodying

---

[25] Rich draws on earlier publications by Warin (e.g. Warin, 2002, cited in Rich, 2006), which describes the same research as the book (Warin, 2010) reviewed above.

extraordinary strength and finding 'empowerment' through anorexia. She also understands competition between patients in these terms, suggesting that competing could be about wanting an identity as an anorexic that is 'better' than others.

Eli (2014b) undertook interviews with thirteen individuals who had been hospitalised in an adult inpatient eating disorder ward in Israel. Her analysis focuses on how the dynamics of difference and belonging played out in various aspects of treatment. Her participants expressed ambivalence towards the identities, social environment, and regimented living constructed by the ward. Eli suggests that participants' ambivalent positionings can be understood through liminality, an anthropological concept which captures transitions and indefinitely marginal and ambiguous states.

She addresses participants' contradictory experiences within three facets: a sense of legitimacy and recognition, dynamics within the inpatient community, and boundaries vis a vis the outside world and one's own illness. Regarding the first, Eli found that her participants valued being hospitalised and treated for anorexia for the sense of recognition it afforded by affirming their eating disorder. In a context in which their eating disorder identities required ongoing negotiation and justification, being hospitalised fed into this continuous identity-work, by legitimising their eating disorder identity. However, some participants felt delegitimised in treatment due to being treated as part of an eating disorder collective, rather than as an individual. When this occurred, their individual sense of self was subsumed to an eating disorder diagnosis and they felt unheard.

Addressing dynamics within the inpatient community, Eli describes how being on the ward offered social belonging. Participants valued the sense of community, which contrasted the solitude of life with an eating disorder pre-hospitalisation. However, being on the ward also risked over-identification with, and worsening of, illness. "The community triggered

disorder-supportive desires" (2014b: 6) and living closely alongside other patients led to being exposed to, and embodying, their eating disorder logic and practices.

Regarding boundaries, participants described how the highly restrictive practices and routines on the ward created a bounded space which separated them from external forces. They expressed ambivalence towards these boundaries, which felt both sheltering and oppressive. Some found that regimented ward-life was comforting because it allowed them to 'let go' of aspects of their life (such as food) about which they had previously 'obsessed', or because it felt they were in a protective 'bubble'. Yet, others found these same boundaries exhausting and disempowering.

Lavis' explores 'pro-anorexia' which she defines as "a desire amongst some anorexics to maintain or enhance their existing illness" (2011: 3). Outside of her research, the term is often used in relation to 'pro-ana websites', which are used by individuals who "desire to maintain their anorexia and resist recovery" (2011: 14). Pro-anorexia websites have been well-researched by social scientists who have 'led the way' in defining this field of study (Casilli et al, 2012). However, Lavis' ethnographic study explores pro-anorexia both on the internet and in 'the clinic', in an English eating disorder unit. By using both as fieldsites alongside each other, she seeks to retain the connections between them, and avoid an artificial separation. I consider Lavis' research in detail here, because I draw on insights from it frequently in the analysis of my own experiences (see chapter four).

Within her ethnography, Lavis analyses the construct of a 'good anorexic' and the practices that individuals undertake to maintain themselves in line with this positioning. She contends that bodily thinness is important to being good at anorexia. It visually defines what it means to be anorexic and is the marker against which one's self is measured. Being good at anorexia entails a relentless, effortful daily enactment of surveillance over one's own

thinness. This surveillance "is an active modality of being good at anorexia" (2011: 96) not only in a manner that is secondary to the thinness it produces, but also in itself. Self-weighing is a part of this surveillance, as being good at anorexia requires both reducing the number on the scales and keeping it down. Given this, the distress that can occur as a result of even minimal weight gain can be understood as resulting from the potential for this to undermine one's sense of self as good at anorexia.

Lavis argues that a 'good anorexic' is enacted both individually and relationally; it is a positioning that can be 'made' or 'unmade' via mutually productive social and individual processes. One's sense of self is shaped by an awareness of the gaze of others on oneself; this has the power to confirm or undermine oneself as 'good at anorexia'. Bodily markers of anorexia such as weight or BMI are a part of this, as these threaten to (un)make one's anorexia when publicly known. These markers are treated as indexical to anorexia because they reveal the success of one's ability to self – starve. Related to this is the competitiveness that occurs among patients when they find their own anorexia 'falling short' of others'. These relational processes are intra-subjective as well inter-subjective, and individuals may use illness in others as a motivational tool for making oneself a 'better anorexic'.

Furthermore, Lavis suggests that there is sometimes a 'blurring' between the making of one's anorexia in appearance and in 'actuality'. Appearing to be good at anorexia, for example by appearing to be not-eating or to have lost weight (without these having 'really' occurred), can be one way in which individuals develop a sense of themselves as 'good at anorexia'. Indeed, *presenting* oneself as good at anorexia can *produce* oneself as this. This highlights the inseparability of individual and relational processes, as it suggests that others' gaze can (un)make you to yourself, as well as socially. Crucially:

> Being good at anorexia is […] always dual - a continual dialogue of social and individual, outside and inside, each shaping and making the other. Moreover, these dialogic transactions may continually journey back and forth with inferences and refractions coming into being on many levels at once (2011: 106).

Lavis also argues that inpatient practices perform anorexia in a certain way. Daily life in treatment assumes, produces and solidifies a conflation of anorexia with bodily thinness and equates 'more thin' with 'more anorexic'. Treatment also performs anorexia by replicating the practices that it assumes to be central to the condition. This occurs when 'anorexic behaviours' are pre-emptively responded to, for example through rules which prevent patients from hiding or otherwise not consuming even the tiniest amounts of food. Thus, patients come to learn what anorexia is and how it 'should' be done. She describes this clinical projection of anorexia as a 'hyperreal' (Baudrillard, 1983) anorexia that is "at once mimetic and nascent" (2011: 231), and which becomes the focus of pro-anorexic desire. When patients notice a comparative lack in their own anorexia, "many learn how to 'do' and 'be' the clinic's anorexia" (2011: 279).

Examining the diagnostic category of anorexia and the act of diagnosis itself, Lavis suggests that these "are invested with pro-anorexic desire" (2011: 234) due to the sense of legitimacy that they confer. Often, being diagnosed affirms to the individual "what is already felt to be there" (2011: 231). Rather than the act of diagnosis setting in motion a diagnostic view of oneself which changes the individual, it confirms ones existing sense of self as anorexic.

However, while being diagnosed can feel comforting in its indication that one is 'good enough' to be clinically recognised, it concurrently "carries with it a visceral anxiety about not being good enough" (2011: 238). Being diagnosed can generate a desire to live up to and 'prove' the diagnosis. The diagnostic category can become a tool against which one measures themselves, and is not passively done to individuals, but is actively done by them:

> [Diagnosis] is something that [diagnosed individuals] reach towards, feeling their away around its perimeters and, importantly, attempting to fit themselves into, and within, these (2011: 239).

Sociological and anthropological approaches: concluding remarks

I have addressed approaches to anorexia from within feminism and social anthropology, as well as Darmon's sociological theory. These approaches offer socially and culturally situated understandings of the diagnosis and stand in contrast to clinical conceptualisations. While the process of being diagnosed with anorexia has not previously been a substantial focus of social scientific research into anorexia, I have shown how Lavis (2011) addresses this briefly in her ethnography of pro-anorexia. I draw on and extend her insights in this research when examining experiences and meanings of being diagnosed. This review has also shown how the diagnosis may be valued by some as a source of identity, including in treatment contexts (Rich, 2006; Warin, 2010; Lavis, 2011; Eli, 2014b), and that individuals may learn new understandings of themselves and of anorexia as they engage in clinical environments (Lavis, 2011; Darmon, 2017). I incorporate these insights into the analysis in this research when exploring the meaning of the diagnosis to participants and the ways in which the it influences their self-understanding and performance of symptoms.

Symbolic interactionism and identity

Introduction to identity

Identity is a vague, intangible and 'slippery' concept[26] (Strauss, 1959; Lawler, 2008). Broadly, it is "a set of interrelated ideas about the self, the roles we play, and the qualities that make us unique" (Scott, 2015: 2). At the core of identity are processes of identification, which involve notions of similarity and difference, recognition, association and categorisation

---

[26]Different scholars use the term 'identity' (and other related concepts) to invoke varying meanings and they sometimes do so by relying on context and application to imply meaning. This can add to the intangible 'feel' of the concept.

(Lawler, 2008; Jenkins, 2014; Chandler, 2017). This research is concerned with individuals 'anorexic identities', including how they come to identify with the diagnostic category of anorexia, and what this means to them, in terms of how this is informed by clinical understandings.

Literature from a range of disciplines posits identity as important to understanding anorexia. Clinical research utilising patients descriptions of the meaning of their illness argues that anorexia is a means for constructing a new identity (Nordbø, 2006; Espindola and Bray, 2009). Health psychology literature, informed by individuals' personal accounts, has also recognised that anorexia is a means for developing a new identity (Fox and Diab, 2015). Patching and Lawler (2009) describe the 'whole journey' of anorexia (illness through to recovery) as entailing a 'strong identity component' and others suggest that recovery involves 'giving up' an anorexic identity, and building a new (or rediscovering an old) identity (Jenkins and Ogden, 2012; Dawson et al, 2014; Smith et al, 2014). In the anthropological literature above, we have seen that Warin (2010) points to the symbolic power and sense of distinction afforded by an identification with anorexia, and how the negotiation of an eating disordered identity is central to the experience of being hospitalised for anorexia (Eli, 2014b). Moreover, sociological work has described the social processes involved in the development of an eating disordered identity (McLorg and Taub, 1987). In respect to inpatient treatment, it has described the myriad of ways in which patients resist and manage pathologised and stigmatised aspects of an eating disordered identity, while sometimes also desiring a medicalised anorexic identity (Rich, 2006; Boughtwood and Halse, 2010).

The body of literature addressing sociological approaches to identity is large, and the concept has been used, theorised and challenged[27] from a range of theoretical and topical perspectives. I therefore restrict my focus to symbolic interactionism. This is the sociological approach that has most heavily influenced my thinking around identity, and I use the symbolic interactionist concept of 'identity-work' as a key analytical tool in this research.

Symbolic interactionist approaches

The development of symbolic interactionism was bound up with sociology scholars at the University of Chicago in the 20th Century, including W. I. Thomas, Park, Hughes, Becker and Strauss[28]. Additionally, social psychologist Mead and Blumer are frequently cited as the most important founders[29].

In symbolic interactionism, the self and identity are viewed as processual, reflexive, emerging in social interaction and, therefore, as *social* in nature. While 'identity' and 'self' are central concepts in symbolic interactionism, the perspective tends to lack a consensual definition of these terms and some authors are vague when using them (Weigert et al, 1986). However,

---

[27] Post-structuralists refer to discursively produced 'subjectivities' or 'subject positions' instead of identity. 'Subject' is believed to be a more precise term for addressing issues which are relevant to post structuralism (Belsey, 2002).

[28] Some of the authors whom I include under the heading of 'symbolic interactionism' (such as Hughes and Becker) may be more accurately described as 'interactionists'. Their work has been linked to a specific intellectual tradition which is separate (but linked) to the strictly 'symbolic' interactionist tradition which is more directly influenced by the social psychology of Mead (see Fisher and Strauss, 1978, 1979; Atkinson and Housley, 2003). However, I have chosen to avoid the complexities of these considerations as they are not relevant for my purposes and (like some others), I use the terms 'interactionism' and 'symbolic interactionism' interchangeably.

[29] Atkinson and Housley (2003) note that different accounts of the history of interactionism place varying emphasis on the importance of different scholars. Mead is frequently cited as the most significant influence, however his work has possibly shaped certain 'lines of thinking' within interactionism more than others (see above footnote). Furthermore, Atkinson and Housley (2003) note that Mead's role in the development of interactionism is contested, and that while he "is acknowledged as a founding figure, he may be viewed as a symbolic founding hero, invoked but with rather little direct influence" (see also Fisher and Strauss, 1978, 1979).

Thoits (1999) offers a clear definition of both self and identity deriving from symbolic

interactionist literature:

> The 'self' is that aspect of the person that has experiences, reflects on experiences, and acts upon self-understandings derived from experiences [and identities are] more specific understandings of oneself and one's experiences [they] are essentially parts of the self [and] understandings of ourselves as *specific objects* that can be named or classified (1999: 347. Emphasis in original).

Mead (1934), a founder of symbolic interactionism, argued that the self emerges from the

dialectic interplay between two components or 'phases'; the 'I' and the 'me'. The I is the

impulsive, responsive and automatic element of human action, and the me represents an

internalised other: "the organised set of attitudes of others which one himself assumes"

(1934: 175). The I and me phases occur in a continuous back-and-forth process; the I "both

calls out the me and responds to it" (1934: 178). We act automatically (the I), reflect on this

action via an internalised other (the me), and then respond back again in terms of the I. We

are not conscious of the I until it is reflected upon, such that "the I of this moment is

reflected in the 'me' of the next" (1934: 174). Mead notes that we are able to respond to

ourselves as an object, and that this allows us to control our actions and act in a 'minded'

fashion (Hewitt and Shulman, 2011).

Many authors have incorporated, extended and/or adapted Mead's ideas (e.g. Stone, 1962;

McCall and Simmons, 1966; Athens, 1994; Jenkins, 2014). While he has been criticised for

using vague and problematically defined terms (Meltzer, 1978; Kolb, 1944) and ignoring the

role of the unconscious (Meltzer, 1978), his social view of the self has been significant in its

influence on symbolic interactionist ideas regarding identity[30]. In the following discussion, I

---

[30] But see previous footnote.

critically review three identity-related areas of symbolic interactionism: role and performance, careers and labelling, and identity-work.

Role and performance

During the 1960s and 1970s, symbolic interactionists explored identity using the concept of role (Turner, 1962; Stryker, 1968; McCall and Simmons, 1978; Burke and Reitzes, 1981). Roles are the shared behavioural expectations that are associated with particular positions (Stryker, 1968), and role identity is "the character and the role that an individual devises for himself (sic) as an occupant of a particular social position" (McCall and Simmons, 1966: 68). Goffman (1961b) distinguished between 'role' and 'role performance'. The former is "the activity an incumbent would engage in were he (sic) to act solely in terms of the normative demands upon someone in his position" (1961b: 75) and the latter refers to "the actual conduct of a particular individual while on duty in his position" (1961b: 75). This differentiation neatly reflects the symbolic interactionist view that individual behaviour is not automatically determined by role expectations (Stryker, 1968). Rather, individuals are actively involved in *role taking* and *role making*. A role is a 'sort of ideal conception' that an individual uses to frame their behaviour during social interaction, thereby creating and modifying (*making*) the role (Turner, 1962).

Goffman's dramaturgical approach (1959) explores role performance using a theatrical analogy. He likens an individual's presentation of self to others across day-to-day social interaction to an actor performing for different audiences. He argues that through their strategically enacted performances, individuals give meaning to the particular situation and their own identity. An individual's performance makes an impression on the audience, whose reaction influences the success and perceived authenticity of the self-images and situational meanings being portrayed. How an audience receives an identity therefore has implications for the self. By recognising that identity is asserted in interaction, and then

validated (or not) by others, Goffman shows that identity is never unilateral (Jenkins, 2014), and that selves depend heavily on social cooperation (Branaman, 2009).

In *Stigma* (1963), Goffman addressed the impression management techniques used by individuals managing stigma. These are the methods one adopts to control the impressions they 'give' during a performance (Goffman, 1959). Stigma is 'spoiled identity', and it occurs when the image that an individual hopes to portray (their 'virtual identity') is undermined by a characteristic/s they possess (their 'actual identity'). Stigma arises from a 'deeply discrediting' attribute, but it is relational (it emerges out of interaction), and not a pre-given 'fact'. Goffman identifies three types of stigma: abominations of the body, blemishes of individual character (such as mental disorder) and tribal stigma (of race, nation and religion). He also distinguishes between attributes that are discrediting and those that are discreditable. Discrediting attributes are "evident on the spot" (1963: 14). Discreditable attributes are not immediately obvious and may be 'hidden' in social interaction. Goffman describes how living with either form entails careful impression management. Discreditable individuals control information about themselves as they negotiate social interactions and manage the problem of what to reveal and what to conceal from whom.

Role, once a central sociological concept, is now far less utilised in sociology. Chandler (2017) argues that it has been superseded by the notion of collective identity, because this is a more fluid concept than 'role', and better captures complexities such as rivalled interpretations of expectations. However, given the symbolic interactionist portrayal of role as a resource, symbolic interactionist ideas relating to role-identity perhaps do begin to allude to some of the complexities which Chandler credits to 'collective identity'.

Gouldner (1971) argues that Goffman failed to explore the reasons that particular selves are projected and then accepted or rejected by others, and did not systematically address how

the production of a self is affected by resources linked to power and wealth. Such criticisms

portray Goffman's work as apolitical. However, it has been argued that Goffman does

address politics in the context of everyday life and interaction (Jacobsen, 2009; Scott, 2015;

Brannamen, 2009). In *Stigma* (1963*)* and *Asylums* (1961a) Goffman demonstrates how

"inequalities in social status, power and resources constrain the selves people are able to

present and have supported by others" (Branaman, 2009: 236). I would contend that

Goffman's work has had significant influence in the field of micro-sociology. Despite societal

changes that have occurred since the time Goffman was writing that may have had

implications for identity construction (see Giddens, 1991), his insights have 'timeless

relevance' (Jacobsen, 2009).

Careers and labelling

'Career' refers to an individual's movement through a series of related, progressive social

positions (Aneshensel, 1999). The notion has been used broadly by symbolic interactionists[31]

to address "any social strand of a person's course through life" (Goffman, 1961a: 119). The

concept has been used to study occupational deviancy (Arnold and Hagan, 1992), deviant

occupations (Becker, 1963), drug and alcohol use (Jellinek, 1952), leisure (Hardie-Bick,

2005), 'physical' illness (Roth, 1963), mental illness (Goffman, 1961a) and 'personality traits'

(specifically, shyness) (Scott, 2007).

Career has two (linked) facets: the objective and the subjective (Stebbins, 1970). As

Goffman argues:

> One side is linked to internal matters held dearly and closely, such as image of self
> and felt identity; the other side concerns official position, jural relations, and style of
> life, and is part of a publicly accessible institutional complex (1961a: 119).

---

[31] See Barley (1989) for an historical overview of the development of the concept, and its application beyond
the scope of formal occupation by symbolic interactionism.

Symbolic interactionists use the concept to understand identity change over the life course (Scott, 2015), and Strauss (1959) was an early influence here. He conceptualised an individual's career as movement through various formal and informal status positions and social roles which shape their sense of personal identity. This movement is marked by 'critical incidents' which act as 'turning points' in the career. These are events that are significant to an individual's self-appraisal, and lead them to re-evaluate their self, resulting in a recognisable change in who they are. Examples include a change in relation with others and meeting a challenge.

 'Labelling theory'[32], an offshoot of symbolic interactionism, refers to a body of literature on deviance which concerns the nature, emergence, application and consequences of labels (Plummer, 1979), and includes the work of Becker (1963), Schur (1971) and Scheff (1966)[33]. A deviant label is a definition of a person which identifies them as having violated a social norm (Link and Phelan, 1999). It may be official or unofficial, and can include self-labelling (Thoits, 1985). Labelling theory contends that deviant labels are *potentially* consequential for the person to whom the label is applied in terms of shaping their sense of self, public identity and behaviour.

'Career' and 'labelling' are linked because labels play a role in the emergence of a deviant career. This is analysed by Becker (1963) who used the concept to understand the sequential development of deviance. According to Becker, the first step in a deviant career occurs when an individual or group breaks a rule. If others (agents of social control such as

---

[32] 'Labelling theory' is perhaps a misnomer on two grounds. Goode (1975), Becker (1973) and Plummer (1979) argue that the body of work to which the phrase refers does not constitute a 'theory' in the strict sense. Also, the use of the word 'labelling' has been recognised as problematic due to its tendency to distort the arguments that are made by so called 'labelling theorists' (Goode, 1975; Becker, 1973). Becker (1973) actively rejected being identified as a 'labelling theorist' and called his approach to deviance 'interactionist'.

[33] Plummer (1979) demonstrates that the 'labelling perspective' is diverse in theoretical orientation and is therefore not directly synonymous with symbolic interactionist approaches to deviance. However, the perspective is most closely affiliated with symbolic interactionism, and key contributors are at least partly influenced by symbolic interactionism.

the police) enforce the rule, then the individual is labelled as deviant. Being publicly labelled as deviant is claimed to be one of the most crucial steps in building a stable pattern of deviant behaviour because it can have consequences for self-image and future social participation and can change one's public identity. The deviant label can become a master status by 'overriding' other forms of identification, and this can lead to a self-fulfilling prophecy, whereby the individual's self-concept 'lines up' with the view that others hold of them. The final step in the deviant career occurs when the individual moves into an organised deviant group. This has a powerful influence on one's self-conception and strengthens the deviant self-view.

The concept of career is analytically useful in linking the individual to social structure, and the objective and subjective (Barley, 1989; Collins and Young, 2000). The notion of subjective career may be particularly useful in the study of deviance where there are not always objectively clear beginning and end points (Stebbins, 1970). Traditional symbolic interactionist uses of career have been criticised, however, for their lack of attentiveness to institutional change in relation to individual perceptions and subjective aspects of careers (Barley, 1989).

Labelling theory initially emerged as a 'radical' approach in the early 1960s, and by the later years of that decade had become incorporated into mainstream sociological thinking. However, heavy criticism also developed (Gibbs, 1966, Bordua, 1967; Gouldner, 1968; Mankoff, 1971; Davis, 1972; Gove, 1970). In turn, there were counter criticisms which defended the perspective (e.g. Plummer, 1979; Goode, 1975; Conover, 1976). These argued that many of the initial criticisms of labelling theory were based on narrow (mis)interpretations of the literature, and a tendency to accuse the theory of not achieving what it had never set out to achieve (Goode, 1975; Plummer, 1979; Becker, 1973).

Here, I will briefly consider one major criticism of labelling theory: the accusation of passive determinism[34]. Other criticisms include accusations of problematic definitions and concepts (Davis 1972; see also Goode, 1975), extreme relativism (Gibbs, 1966), 'underdog bias' (Gouldner, 1968; Liazios, 1972), lacking an explanation of reasons for initial deviance (Gibbs, 1966; Mankoff, 1971; Davis, 1972) and limiting methodology (Davis, 1972).

Labelling theory has been accused of positing deviant individuals as passive 'empty organisms' who are determined by societal reactions (Bordua, 1967; Gouldner, 1968; Schervish, 1973; Quadagno and Antonio, 1975)[35]. It "locates the fate of the deviant, and indeed his (sic) very development, in the acts of the reactors" (Bordua, 1967: 153). This deterministic view is arguably tacit in labelling theory's tendency to focus only on cases where societal reaction leads to career deviance (Bordua, 1967). Relatedly, labelling theory has been accused of exaggerating the extent to which labelling *necessarily* leads to career deviance, and failing to recognise that the 'effects' of labelling may vary for different types of deviance (Mankoff, 1971). However, Plummer (1979) notes that labelling theorists do sometimes identify instances which do not suggest passivity and determinism. While the notions of labelling and career declined in popularity during the 1970s, they continue to be relevant to sociological analysis (e.g. Scott, 2007; Pavalko, et al, 2007; Darmon, 2017).

Identity-Work

The concept of identity-work was first used by Snow and Anderson (1987) in their ethnographic study of homelessness. They defined it as "the range of activities individuals engage in to create, present, and sustain personal identities that are congruent with and supportive of the self-concept" (1987: 1348). Here, the self-concept is one's overarching image of themselves, including physical, social, spiritual and moral dimensions. For the

---

[34] The 'labelling debate' as it relates to the labelling of mental illness will be discussed later.
[35] See later for a discussion of this criticism specifically as it applies to labelling and mental illness.

homeless people in their study, identity-work was an attempt to generate an identity that provided a sense of meaning, dignity and worth. Snow and Anderson focused specifically on 'identity-talk', which is one way of doing identity-work and is defined as the "verbal construction and assertion of personal identities" (1987: 1348). They identified three common forms of identity-talk: distancing, embracement, and fictive storytelling. Distancing refers to 'role distancing' (distancing oneself from the occupational roles associated with homelessness); institutional distancing (distancing from the institutions that serve homeless people); and associational distancing (distancing from other homeless people). Embracement refers to expressions of *attachment.* Snow and Anderson found evidence of role embracement (attachment to 'the homeless role'), associational embracement (attachment to other homeless people) and ideological embracement (attachment to a set of ideas or beliefs, usually religious). Fictive storytelling "involves the narration of stories about one's past, present, or future experiences and accomplishments that have a fictive character to them" (1987: 1359), where the fictive elements ranged from minor exaggerations to fabrications.

Since Snow and Anderson, identity-work has been applied within a range of topics, such as mental illness (Estroff, 2001), social movements (Reger et al, 2008), gambling (Wagner, 2017) and sun bed use (Taylor et al, 2017). Reviewing this literature, I noted that the ways in which the term is applied varies, and it is not always used in precise ways. Considering this, I suggest that the term can be used to focus on three different (but related) dimensions of activity and processes surrounding identity; I call these performative identity-work, transformative identity-work and interpretive identity-work. All three elements are relevant to understanding experiences of anorexia and treatment, and I adopt the concepts of performative and interpretive identity-work specifically in the analysis in this research.

Performative identity-work refers to the activity that individuals engage in to *achieve* a particular identity in interaction and addresses the situation-specific efforts that people make to manage their identity. It therefore closely relates to Goffman's ideas about impression management (1959) and managing stigma (1963). Wagner et al address an example of performative identity-work in research on adult gamblers use of neutralisation techniques. They define identity-work as "the management of personal and social identities to control impressions of the self" (2017: 353). Neutralisation techniques are accounts of personal actions that attempt to nullify or excuse behaviours (see Sykes and Matza, 1957; Maruna and Copes, 2005). Gamblers in Wagner et al's (2017) study used neutralization techniques, such as 'claims of relative acceptability' (regarding gambling behaviour) and 'denial of self-injury' (regarding the impact of gambling), in an attempt to align their identities with socially acceptable standards.

Transformative identity-work includes more sustained, ongoing attempts to move towards a particular identity and involves a fundamental change in one's identity. Cain's (1991) ethnographic research into alcoholics anonymous (AA) provides an example. Over time, AA attendees not only changed their behaviour (by ceasing to consume alcohol) but also their identities. By learning AA beliefs and coming to understand themselves in new ways, attendees actively acquired a new identity as a 'non-drinking alcoholic'.

Interpretive identity-work refers to the processes of interpretation and meaning-making that individuals partake in as they make sense of their own identity. This includes reflecting back on and (re) interpreting past and current experiences. Scott addresses this aspect of identity-work when she describes how we "make sense of ourselves" by reflecting "upon key events and experiences and (interpreting) their significance in relation to our life as a whole" (2015: 141). I discuss two examples of research addressing interpretive identity-work (Karp, 1992; Estroff et al, 2001) in relation to mental illness below.

Scott's (2011) analysis of 'reinventive institutions' (RIs) highlights all three dimensions of

identity-work and their interrelations. She argues that since Goffman wrote about total

institutions in *Asylums* (1961a), this new form of institution has emerged. A total institution

is "a place of residence and work where a large number of like-situated individuals […] lead

an enclosed, formally administered round of life" (Goffman, 1961a: 11), and examples

include jails, army barracks, and psychiatric institutions. Goffman understood these to be

coercive institutions which stripped individuals of their individual identity. In contrast, an RI

is:

> A material, discursive or symbolic structure in which voluntary members actively
> seek to cultivate a new social identity role or status. This is interpreted positively as
> a process of reinvention, self-improvement or transformation. It is achieved not only
> through formal instruction in an institutional rhetoric, but also through the
> mechanisms of performative regulation in the interaction context of an inmate
> culture (Scott, 2011: 3).

Scott describes RIs as 'sites of biographical identity-work' that may have a religious,

disciplinary, secret, therapeutic, educational or virtual purpose. Examples include prisoner

rehabilitation programmes, weight loss camps, addiction treatment centres and eating

disorder units. The processes of "reinvention, self-improvement or transformation" to

which Scott refers is an example of *transformative identity-work*. Depending on the RI, this

could include a shift from being a 'drug addict' to a 'recovered addict', or in the case of

individuals diagnosed with anorexia, from being 'eating disordered' to 'recovered'. The

institutionally embedded processes of transformation that Scott describes involve sustained

interpretive identity-work. In therapeutic RIs, "recovery is framed as a journey of self-

discovery, to be experienced as both a personal triumph of identity-work and as a public,

socially negotiated career trajectory" (2011: 142). Here, interpretive identity-work is

integral to the 'self-discovery' that recovery necessitates.

Scott argues that whereas total institutions involved rigid hierarchical structures and overt authoritative control of inmates, in RIs a form of disciplinary power exists in peers' monitoring each other's conduct through dramaturgically enacted peer-to-peer surveillance. Scott describes this as "performative regulation" which includes the "performance of conformity" - an example of *performative identity-work* – and the mutual surveillance of this by peers. These identity performances involve inmates performing as 'rule followers' and playing the 'good inmate' role, and this is then scrutinised by peers. The overall effect of this performative identity-work is that peers shape each other's progress towards their shared goal.

Symbolic interactionism and identity: concluding remarks

Symbolic interactionism has been an important contributor to sociological analysis of identity in its portrayal of identity as being created, shaped, maintained, communicated, presented, negotiated and challenged in and by social interaction (Scott, 2015). In this research, I address the process and consequences of being diagnosed with anorexia via a focus on diagnostic identity and identity-work, and this is influenced by symbolic interactionist approaches. In this review, I have suggested that there are three dimensions to identity-work: interpretive, performative, and transformative. In this research, I use the former two dimensions in particular to understand how individuals are influenced by diagnostic understandings of anorexia and how they manage an 'anorexic identity'.

Sociological approaches to health and mental health

Key concepts in medical sociology

In this section, I review two major concepts in medical sociology – medicalisation and the sick role. These concepts are highly relevant to a sociology of diagnosis. In reviewing them,

and considering their place in this subfield of sociology, I therefore extend the discussion of a sociology of diagnosis that I began in the previous chapter.

The concept of medicalisation, first adopted by medical sociologists in the early 1970s, refers to the expansion of medical understandings and activity into increasing domains of personal and social life (e.g. Zola, 1972; Illich, 1975; Conrad, 1975; 1992). Despite critiques of the concept and proposals for it to be replaced with updated ideas (Rose, 2007; Clarke et al, 2003), it is still used and considered by some to have ongoing relevance for understanding the role of medicine in society (Busfield, 2017). There is a close relationship between medicalisation and diagnosis, such that Jutel suggests that this "may be the fundamental explanation of why a sociology of diagnosis has not [previously] had its own delineation" (2011: 9). Indeed, the creation and application of diagnoses are key activities within processes of medicalisation. Conrad stated that "Medicalisation consists of defining a problem in medical terms, using medical language to describe a problem, or using a medical intervention to "treat" it" (1992: 211). It is clear to see here that these processes (the first two especially) are tied up with, and reliant on, diagnostic categorisation and terminology. The recent extensive criticism and controversy surrounding the publication of the DSM–5 (see Kinderman et al, 2017) offers a contemporary example which highlights the relationship between psychiatric diagnoses and medicalisation. A major critique of the manual relates to the changes made to the diagnostic categories since the previous edition, in terms of both the addition of "new and bizarre 'illnesses'" and the expansion of existing categories "in a way that seems to defy common-sense" (Johnstone, 2014: 12). Accordingly, Johnstone (2014) argues that a general effect of the DSM–5 has been a massive expansion of psychiatric 'illness', leading to an increasing medicalisation of everyday life. As discussed in the previous chapter, the expansion of the number of diagnoses it is possible to receive is one aspect of what Brinkmann calls diagnostic expansion, a process he links to

pathologisation and of which he is critical. He argues that responding to existential, moral and political concerns as individual, psychiatric problems pathologizes human suffering and risks the loss of vital resources of self–understanding.

The sick role concept was introduced to medical sociology in the 1950s via Parsons *The Social System* and related publications (Parsons, 1951a; 1951b). It was one of the major concepts of the subdiscipline of medical sociology until the 1980s (Burnham, 2014). Parsons (1951a) understood illness as a form of deviance which is socially controlled via the sick role. Inherent to this role are norms which involve expectations for how the sick person should behave, in terms of both their 'rights' and 'obligations'. Specifically, the sick person is assumed the right to be exempt from their ordinary daily responsibilities and roles and to not be held personally accountable for their illness. They are also obligated to try to 'get better' and adhere to the advice given by the relevant legitimate social bodies (i.e. the medical profession).

The patient-physician relationship is integral to the sick role; the proper performance of the role involves the patient cooperating with the doctor's advice and respecting this expertise. The authority and relative power afforded to the medical profession is seen in their ability to legitimise illness, grant or deny entry to the sick role and provide access to relevant treatment. This authority is functional in terms of regulating deviance (in the form of illness) and hence contributes to the maintenance of the social structure.

Friedson (1970) contended that access to, and the nature of, the sick role depends on the seriousness and legitimacy of the medical condition in question. For conditions from which it is possible for the individual to recover, they have conditional access to the sick role, and for incurable conditions, the individual has unconditional access. Lastly, if the individual's condition is stigmatised, the condition is illegitimate and access to the sick role denied. In

addition, the seriousness of the condition – indicated by whether it is a minor or serious deviation – shapes what the sick role involves, in terms of the extent to which ordinary obligations are suspended and which additional privileges are afforded.

When the concept of the sick role was popular it was subject to extensive application, critique and refinement (see e.g. Twaddle, 1972; Segall, 1976). However, it fell in popularity in the 1980s and very little original work using the concept was subsequently published. This occurred amidst the advocacy of new, alternative ideas about illness such as those emphasising the social construction of health, political critiques of Parsons theories which accused his functionalist ideas of conservatism, and related misrepresentations and distortions of the sick role idea (Burnham, 2014). That said, the phrase 'sick role' – whether used in more or less in accordance with Parsons original description – remains in active use in the sociology of health and illness (see e.g. Perry, 2011; Higgens, 2014; Chrisp et al, 2013).

In respect to a sociology of diagnosis, the sick role concept points to the regulatory power of diagnosis. 'Being diagnosed' provides access to the sick role and "gives permission to be ill" (Jutel, 2011: 4). Jutel relates this to Parsons' (1951a) ideas about the 'claim for exemption' within the sick role. Moreover, diagnosis is functional in that it "enables the individual to reintegrate [with] a sanctioned explanation of what makes him or her different from everyone else" (Jutel, 2011: 4). In addition, Friedsons' differentiation between the 'types' of sick role available for different conditions highlights the different imputed meanings and impacts of different diagnoses.

Labelling theory of mental illness

Scheff originally published *Being Mentally Ill: A Sociological Theory* in 1966, followed by revised editions in 1984 and 1999. Informed by Becker's interactionist approach to deviance, he argued that psychiatric 'symptoms' are labelled violations of social norms and that 'mental

illness' is a social role. Scheff proposed that psychiatric symptoms, usually understood as indications of underlying biological illness, are incidents of residual rule-breaking. Residual rule-breaking involves the violation of fundamental social norms for which the culturally available category for interpretation is 'mental illness'. Residual rule-breaking may involve, for example, hallucinating, continual muttering, or posturing. Scheff argued that most residual rule-breaking is normalised and its significance is transitory. It is *primary deviance*, because it is not publicly labelled and has little significance for a person's identity (Lemert, 1972). Here, the individuals 'symptoms' may be interpreted as eccentricity, or the rule-breaking may end alongside the cessation of a causal stressor. However, when residual rule-breaking is responded to as symptomatic of mental illness, it develops into a stabilised pattern, and becomes *secondary deviance* (ibid, 1972). This involves the public labelling of deviance, and it has consequences for the individual. The labelled person adopts a deviant identity, is responded to differently by others, and alters their self-concept accordingly. Thus, the residual rule-breaker adopts the deviant status of 'mentally ill' and begins to play this role. Scheff emphasised the involuntary nature of this role-playing. The individual responds to others cues towards them, which serve to 'funnel' their behaviour into the recognised role of mental illness. When others uniformly act towards them as if they have a mental illness, this becomes the most convenient role available to them, and they come to fulfil it, even if they are not particularly interested to do so.

Scheff argued that stereotypes of insanity are key to these processes. Once a person is labelled as mentally ill, traditional stereotypes guide the expectations and responses of those interacting with the labelled person. The labelled person eventually internalises the stereotypes, which shape their self-concept and behaviour. The individual is then rewarded for successfully adopting the stereotyped role, and punished for any attempts to move away from it (these being seen to indicate 'a lack of insight').

To summarise, labelled individuals come to fulfil the deviant social role of mentally ill through the labels applied and enforced in social interaction. Fundamentally, Scheff argues that being labelled with a mental illness is one of the most important determinants of chronicity[36]. However, since its initial publication, labelling theory has been extensively critiqued and refined (e.g. Gove, 1970a; 1970b; 1975; Greenley, 1979; Weinstein, 1983; Thoits, 1985; Thoits, 2005; Thoits and Evenson, 2008). Two important criticisms are the accusation of exaggerating the amount of secondary deviance produced by treating someone as mentally ill (Gove, 1970), and assuming passivity in the person who is labelled (Quadago and Antonio, 1975; Thoits, 1985). Gove drew on existing empirical evidence and argued that individuals are hospitalised for mental illness when they have a difficult to handle "active psychiatric disorder" and that this distress is "quite apart from any secondary deviance that may be associated with the mentally ill role" (1970: 882). He also disputed the degree of secondary deviance associated with hospitalisation. While agreeing that hospitalisation (which Scheff frames as a part of the labelling process) can be debilitating and may encourage the adoption of an 'insane role', he also pointed to the beneficial, restitutive processes that occur during hospitalisation. Gove claims that labelling theory underemphasises the importance of primary deviance, over emphasises secondary deviance, and is "substantially incorrect" (1970: 881).

Quadago and Antonio (1975) argued that the labelling theory of mental illness portrays an overly passive view of individuals, whereby they have no choice but to conform to others' expectations. They claim that the theory fails to recognise the ways in which labelled persons reject deviant roles and identities, and identify examples of label 'resistance strategies' among their sample of female mental patients in a psychiatric institute. An

---

[36] In the original publication, Scheff claimed that among residual rule breakers, labelling is *the* most important cause of careers of residual deviance. In the 1984 version, he changed this to *among* the most important causes.

example of a resistance strategy is symptom denial. In its direct form, this involves the individual denying having ever partaken in residual rule-breaking. In its indirect form, the person does not deny deviance, but claims that the interpretation of this as a symptom of mental illness is incorrect. Quadago and Antonio give examples of two women who had been hospitalised for attempted suicide but claimed not to have had suicidal intentions, wanting their behaviour to be interpreted as insignificant and not the result of pathological traits. Another resistance strategy is normalisation. Here, an individual asserts that their problems are common place and experienced by many. Aligning themselves with other, 'normal' people is an attempt to be defined as normal themselves.

Link and colleagues (1989) proposed a modified labelling theory. This suggests that labelling may not *directly* create 'mental illness', but that labelling and stigma are influential in placing mental patients "at risk for the recurrence or prolongation of disorders resulted from other causes" (1989: 404). This occurs because people are socialised to develop negative views of 'mental patients'. When they take on this status themselves, they imagine that others will reject them, and adopt coping strategies such as withdrawal and secrecy. Over time, their beliefs about how others view them and their coping responses have a negative influence on their self-esteem, earning power, and social connectedness, leaving them vulnerable to new or repeat episodes of 'disorder'.

While largely unaccepted in its 'fullest' form, Scheff's theory made a significant contribution to the sociology of mental illness. Both labelling theory and modified labelling theory continue to be drawn upon and engaged with in contemporary research and have informed thinking in the sociology of diagnosis. For example, Russel et al (2012), who frame an autism spectrum diagnosis as a potential 'social determinant' of symptoms of autism, draw on Scheff's argument regarding a self-fulfilling prophecy to justify their research focus.

Mental illness and identity-work

In this section, I further explore symbolic interactionist work relating to identity and mental illness, with a focus on processes that I have described above as interpretive identity-work. In Karp's (1992) research into lived experiences of depression, he describes how a 'depression identity' develops overtime, and the processes through which this occurs. He suggests that a depression identity tends to emerge in a patterned manner and identifies four key turning points (Strauss, 1959) in a 'depression career'. During the first turn, the individual experiences a period of inchoate feelings but they lack the vocabulary or understanding to identify these as belonging to depression. During the next turn, they conclude that 'something is really wrong with me'. The third turn is a crisis stage, during which the individual has contact with therapeutic experts. Lastly, the individual 'gets to grips' with their illness identity and makes sense of what it means. This entails (what I have called above) interpretive identity-work. It involves the reconstruction and reinterpretation of past events, a search for the cause of one's current situation, the construction of new theories about the nature of depression, the establishment of modes of coping, and the evaluation of one's prospects for moving beyond depression. In theorising their own depression, most of Karp's participants developed a depression identity that was at least partially medicalised. Some wholly adopted illness metaphors to understand their experience, but most negotiated a position which drew partly on biochemical explanations while also distancing themselves from the idea that they *purely* have a 'mental illness'.

Estroff et al (1991) undertook a longitudinal interview-based study of illness identity-work among 169 individuals with 'severe and persistent mental illness' recruited from four different hospitals. The most common diagnostic groups were schizophrenias, affective disorders, and personality disorders.

They adapted Snow and Anderson's (1987) concepts of illness identity-work and illness identity-talk. Their description of illness identity-work alludes to my notion of interpretive identity-work. They define it as:

> The various enduring processes of biographical and autobiographical revision instigated by prolonged and severe dysfunction [and it] produces the words, ideas, images, actions and sentiments with which persons with disabling conditions reconstrue and get on with their lives (1991: 336).

Illness identity-talk is a form of identity-work in which individuals elicit accounts of their illness and may self-label as mentally ill. Estroff et al identified five types of illness accounts in participants' identity-talk. These were based on regularities in terms of where the illness or problem was located (the body, brain, or a psychological dimension), the 'ingredients' involved (what was thought to be unbalanced or affected, for example too little money or feelings such as anger), mechanisms (how the problem seemed to work, for example too much dopamine or too much stress), and terminology used to describe their illness (for example clinical terms such as schizoaffective, or spiritual terms such as 'voice of God').

The first and most common type of illness account was *medical/clinical.* These contained aspects of current biomedical and clinical formulations of psychiatric disorders. Individuals eliciting this type of account were most likely to self-label as mentally ill. *Emotional/developmental* accounts were the second most common. These drew on a mixture of ideas about emotional and developmental trauma in describing influences on current problems or illness, and were sometimes combined with medical/clinical accounts. This group were the second most likely to self-label as mentally ill. In *Social/situational* accounts, the individual identified social circumstances and factors (such as a lack of financial resources or needing somewhere to live) as reasons for having developed symptoms or having been hospitalised. In these accounts, causal influences were located externally to the person and individuals adopting them were unlikely to label themselves as mentally ill. A group who

were highly unlikely to self-label as mentally ill were those who offered *no problem* accounts, claiming that they had no problems, and thus giving no explanations. Lastly were *religious/spiritual* accounts. These were given by a small group who did not label themselves as mentally ill, but drew on spiritual ideas, or other ideas of nonnaturalistic origins, to explain their experiences.

Sociological approaches to health and mental illness: concluding remarks

In this section I have reviewed two key concepts in medical sociology: medicalisation and the sick role. This has broadened the understanding of a sociology of diagnosis which is a key body of knowledge underpinning this research. I have also reviewed labelling theory, which has relevance to this research given that the process of being diagnosed with anorexia is a fundamental way in which this label of mental illness is applied. Considering Karp's (1992) and Estroff et al's (1991) work has involved addressing the consequences of interpretive identity-work, in terms of the extent to which this leads to clinical/medical self-understandings. I examine this interpretive identity-work and its consequences in relation to the diagnosis of anorexia. In terms symbolic interactionist approaches to mental illness, then, these suggest that diagnostic labels may influence the trajectory of psychiatric 'symptoms' and personal identity, as well as the development of clinically-informed self-understandings. This research seeks to understand these processes specifically in relation to anorexia, by exploring how individuals interact with the diagnostic concept, and the ways in which the diagnosis influences one's performance of symptoms, identity and personal sense-making.

Conclusion

This research is concerned with social aspects of the diagnosis of anorexia nervosa. The focus emerged from a need to address the process and consequences of the diagnosis (Jutel

and Nettleton, 2011; Jutel, 2011, see chapter one). This literature review has examined anorexia as a clinical entity, and how it has been understood and theorised by sociologists and anthropologists. The latter body of literature has not previously incorporated the process of being diagnosed with anorexia as a substantial focus, and this is intended to be a key contribution of my research. However, insights from this body of social scientific literature, including those relating to the value of anorexia as a source of identity and the ways that individuals may learn ways to 'do' anorexia in treatment, were crucial to interpreting data. This review has also considered symbolic interactionist approaches to identity. These have shaped the analysis of diagnostic identity in this research, especially in relation to identity-work. In addition, the insights drawn from symbolic interactionist approaches to mental illness, including the potential for diagnostic labels to influence one's 'symptoms', identity, and self-understanding has relevance to understanding how individuals respond to, and make sense of, their diagnosis of anorexia. In this research, I address this aspect using concepts such as interpretive and performative identity-work (which I have reviewed here), and Brinkmann's notions of 'being' and 'doing' a diagnosis (see chapter one). I suggest that using these concepts sheds new light on how individuals relate to their diagnosis, and the consequences of being diagnosed.

Chapter Three

Research methods

In this research project I used autoethnography and in-depth interviews to investigate how individuals experience the diagnosis of anorexia. The autoethnography analysed my own experiences of the diagnosis and treatment, and I conducted interviews with 14 adults who had (or had previously had) a diagnosis of, and treatment for, anorexia.

This chapter begins with an overview of how I implemented the autoethnography and interviews. I then consider each of these approaches in detail, in each case justifying its suitability, discussing my epistemological stance, describing procedures used, acknowledging the challenges I encountered and evaluating the method. In the case of autoethnography, I start with a discussion of its methodological roots. Doing so is important, because the debates I trace informed the implementation of autoethnography in my own study. Lastly, I consider ethical procedures and concerns relating to each method.

Overview of research methods

The autoethnography I present is an analytically-oriented retrospective self-study, akin to what Wall (2016) calls 'moderate autoethnography'. This approach seeks to "combine the power of the personal perspective with the value of analysis and theory" (2016: 8). I used memory, personal and medical documents, and existing literature to reconstruct, 'tell' and analyse my personal experiences with anorexia, diagnosis, and treatment in a Specialist Eating Disorder Unit (SEDU). My own experiences acted as a vantage point for analysing broader sociological, theoretical issues (Vryan, 2006; Anderson, 2006a). Concurrently to producing the autoethnography, I undertook interviews with 14 adults (11 females and 3 males). Most had (or had previously had) a diagnosis of anorexia, and one was self-diagnosed. I conducted the interviews as a known 'insider'. I was open with participants

about me being a 'recovered anorexic' and sometimes shared aspects of my experiences with them during interviews. The analysis of myself (within the autoethnography) and of others (in the interviews) was intertwined and the two methods were iterative; insights from my own experiences shaped the interview process, and the analysis of interview material in turn shaped the autoethnography. In addition, I adopted various reflexive strategies to manage the dynamics of insider interviewing. These were a post-interview diary, post-transcription analysis, and 'asking interviewees' (all explained later).

Autoethnography

Introducing autoethnography

Autoethnography refers to research approaches which involve "the study of the self" (Reed-Danahay, 1997: 9). An exact, comprehensive definition is not possible, due to the vast variety of approaches that the term has come to encompass (Ellis and Bochner, 2000). However, it is fair to say that sociological autoethnographies "are highly personalised accounts that draw upon the experience of the author/researcher for the purposes of extending sociological understanding" (Sparkes, 2000: 21)[37].

The term 'autoethnography' has its academic origins in the work of Hayano (1979)[38], who used it to refer to the anthropologists' ethnographic study of their "own people", and applied it retrospectively to existing anthropological research (mainly ethnographic studies undertaken in the 1960s and 1970s). Towards the end of the 1980s, in a research context which advocated personal narrative, subjectivity and reflexivity (Adams et al, 2015), social science scholars began to adopt the term to describe their work which explored the interplay of introspective, personal selves and culture (e.g. Lionett, 1989 cited in Adams et

---

[37] See Muncey (2010) for a review of various definitions of autoethnography.
[38] The term was first used by Firth, to whom Hayano refers, in a seminar about structuralism in 1966. However, Hayano was among the first to have used the term in academic literature and is understood to have brought it into the academic mainstream (Hughes and Pennington, 2017).

al, 2015). In the 1990s, scholars such as Ellis adopted the term to develop a postmodern influenced approach to self-study ('evocative autoethnography' - see below), and the autoethnographic 'movement' began to flourish. Autoethnography increased in credibility and popularity substantially from the early 2000s onwards[39]. Since then the method has diversified, as authors such as Chang (2008) and Anderson (2006) created possibilities for autoethnography that depart from evocative autoethnography.

There are now numerous 'types' of autoethnography (see Ellis and Bochner, 2000; Hughes and Pennington, 2017). These vary in their emphasis on self, wider culture, the research process, traditional analysis, and the study of (and interaction with) others (Ellis and Bochner, 2000; Ellis et al, 2011). As Wall (2008) notes, autoethnography ranges from that which is (relatively) conservative and methodologically rigorous, through to personal but theoretically driven work, and to highly literary and evocative writing.

In particular, it is possible to contrast two opposing approaches to autoethnography within sociology; evocative autoethnography and analytic autoethnography. Evocative autoethnography[40], which is associated with scholars such as Ellis and Bochner (Ellis, 1995; 2004; Ellis and Bochner, 2000; 2006), is emotional, narrative, literary-based, postmodern-influenced and heavily emphasises self. Conversely, analytic autoethnography (Anderson, 2006a) is associated with traditional ethnography and more conventional research practice and has a strong emphasis on interpretation and analysis.

---

[39] During this time, there was a rapid growth in academic articles which cited 'autoethnography' as a key word (Muncey, 2010), and autoethnographic research approaches began to gain credibility and influence in top – tier social scientific research articles (Hughes and Pennington, 2017).

[40] This is an imprecise term which I use to loosely refer to a body of autoethnographic work which has certain distinctive tendencies, including evocation as a goal. It is a useful phrase for distinguishing this autoethnography from its other forms, although it has been used occasionally by some of its practitioners, generally they refer to their own work simply as 'autoethnography'.

I refer to the autoethnography in this research as a moderate autoethnography (Wall, 2016), an approach that sits somewhere 'between' evocative and analytic autoethnography. Later in this chapter I elaborate my approach and show how it fits with moderate autoethnography in detail. Firstly, I explain why I chose autoethnography in the first instance.

Choosing autoethnography

In choosing to use autoethnography in this research, my intention has been to illuminate in detail and depth one person's set of experiences. There is great potential value in utilising one's own life events as a source of sociological enquiry, especially when these events make deeply personal experiences unusually observable and provide access to data that is not otherwise available (Vryan, 2006; Chang, 2008). My experiences of anorexia and the associated documents provide an opportunity to gather rich data relating to the research aims. Self-study benefits from the absence of factors that, in other methods such as interviews and observations, can limit the depth of data. These factors include communication norms, emotions such as embarrassment and guilt, and a relatively limited sense of trust between researcher and participant (Vryan, 2006).

Numerous scholars have utilised some form of self-study in sociological explorations of illness and treatment (e.g. Rier, 2000; Blaxter, 2009; Plummer, 2012; Reissman, 2015), including eating disorders (Tillmann-Healy, 1996; Garrett, 1998; Saukko, 2008; Stone, 2009). Indeed, autoethnographic methods may be particularly suitable for illness-related experiences because they centralise the voice of lived illness-experience and avoid this being 'othered' by outsiders (Richards, 2008).

The subjective nature of self-study remains contested in some areas of social science. This is the case particularly in areas in which conventional 'scientific' notions of researcher

impartiality and silent authorship have pervasive influence; even where scholars do not completely accept traditional notions of objectivity, research practice still tends to be strongly affected by it (Hammersley, 2011). However, I agree with Wall (2008) that using the self is not a problem, but *how* the self is used does matter. Next, I explain how I used my own experiences in this research and describe my approach to autoethnography theoretically and practically. This firstly necessitates a fuller discussion of evocative and analytic autoethnography, so that I can explain my own stance in relation to them.

Evocative autoethnography

Evocative autoethnography seeks to "balance intellectual and methodological rigor, emotion and creativity" (Adams et al, 2015: 2). It emerged from a number of interrelated 'crises', concerns and 'turns' in the social sciences, which reflected new ideas about research, and recognised limits to scientific knowledge and traditional research practice (Ellis and Bochner, 2000; Ellis and Bochner, 2006; Ellis et al, 2011; Adams et al, 2015).

A postmodern inspired 'crisis of confidence' during the 1980s (Ellis et al, 2011) doubted universal claims to truth, 'master narratives' and the privileging of scientific knowledge (e.g. Kuhn, 1996; Lyotard, 1984). Postmodernism accepts many ways of knowing as legitimate (Wall, 2008), does not privilege one method, theory or genre over another, and therefore challenges the superiority of science (Richardson, 2000). Further, the 'crisis of representation' in social research which emerged during the 1970s and 1980s challenged the ideal of the neutral, detached researcher who remains separated from the research experience (Adams et al, 2015). There was also a 'narrative turn' in the social sciences during the last quarter of a century (Goodson and Gill, 2011), which included a growth in narrative inquiry which used personal narratives as the basis of research (Ojermark, 2007).

In this context, evocative autoethnographers emphasise their "link to arts and humanities rather than to Truth claims and […] science" (Ellis and Bochner, 2006: 434) and write narratively. Evocative autoethnography produces aesthetic and evocative descriptions of personal and interpersonal experiences using elements of story writing (Ellis et al, 2011; Richardson, 2000). Evocative autoethnographers do not engage in traditional analysis, but "use stories to do the work of analysing and theorising" (Ellis and Bochner, 2006; 436)[41]. They reject the idea of a distant, detached ethnographic observer, and instead accommodate intimate involvement, engagement and embodied participation (Ellis and Bochner, 2006). There is a significant body of work which utilises evocative autoethnography and, especially in recent years, it has become increasingly recognised as an important and legitimate method (Adams et al, 2015).

However, evocative autoethnography's rejection of mainstream social science values means that it remains marginalised in some areas of social science (Anderson, 2006). Indeed, its location on the margins of disciplinary boundaries has raised questions about what constitutes proper research (Sparkes, 2000). Evocative autoethnography is accused of being narcissistic, self-absorbed, self-indulgent, and navel gazing (Coffey, 1999; Madison, 2006; Atkinson, 2006; Roth, 2009; Delamont, 2009)[42], and of losing sight of valuable social scientific goals (Delamont, 2009)[43]. Atkinson (2006) contends that evocative autoethnographers have focused too prominently on the autobiographical, and that the

---

[41] However, some postmodern-influenced autoethnographers who may be associated with evocative autoethnography do explicitly analyse their personal experiences in relation to broader social processes (e.g. Ronai, 1995).

[42] Not all of these authors has specified particular reference to *evocative* autoethnography, however when taken in context, these criticisms do generally appear to be oriented towards evocative autoethnography, particularly those approaches which focus exclusively or most heavily on the researchers self. Also see: next footnote.

[43] Delamont specifies that her critique of autoethnography is centred on accounts where "there is no object except the author herself to study" (2009: 58), and the critique appears to be directed at evocative autoethnography.

privileging of evocation and the experiential value of writing undermines scholarly goals of analysis and theorising. Relatedly, Chang (2008) argues that a lack of cultural analysis restricts the writing to the level of descriptive autobiography. Evocative autoethnographers are also accused of being 'lazy' and not doing 'proper ethnography' due to the lack of substantial, laboured fieldwork, and because personal introspection is a poor substitution for data collection (Gans, 1999; Fine, 2003; Delamont, 2009). It is worth considering here what 'proper ethnography' involves. Although a contested term, ethnography is generally understood to be open-ended, small-scale, in-depth research involving an extended period of participant observation and often also other methods such as interviews (Hammersley and Atkinson, 2007)[44]. Ethnography is a heavily involved, labour intensive and time consuming research process, and evocative autoethnography is accused of lacking these features. An additional criticism from Walford (2009) concerns evocative autoethnography's tendency to embrace fictional elements of stories and distortion of the past. He suggests that it leaves readers in doubt about whether the events presented actually occurred and that research should not be ambiguous in this way.

Evocative autoethnographers have responded to criticisms by arguing that, because evocative autoethnography and conventional research have fundamentally different goals, the former should not be judged according to the same standards as the latter (Ellis et al, 2011; and see Sparkes, 2000; Holt, 2003).

Analytic autoethnography

Anderson developed analytic autoethnography in response to the success of evocative autoethnography, which he argued

---

[44] It is disputed whether or not research is truly ethnographic without participant observation (Hammersley and Atkinson, 2007; Atkinson and Coffey, 2002), and some authors argue that participation and observation are essential to ethnography (Atkinson, 2015).

> […] may have the unintended consequence of eclipsing other visions of what autoethnography can be and of obscuring the ways in which it may fit productively in other traditions of social inquiry (2006a: 374).

Accordingly, Anderson aims to define and demonstrate the potential of a type of autoethnography which he specifically positions as a specialised subgenre of realist, analytic ethnography (see Lofland, 1995). Analytic autoethnography therefore has obvious links to conventional ethnography, and differs only in its visible inclusion of the researcher's self in the data and heightened reflexivity (Anderson, 2006b). Anderson supports his claim for a conventionally-grounded autoethnography by arguing that there has long been various elements of personal connections and self-analysis in traditional qualitative research.

Anderson (2006a) delineates five key features of analytic autoethnography, the first of which is complete group membership. In conventional ethnography, the researcher has a role in the social world being researched (Hammersely and Atkinson, 2007), with possible roles ranging from those that are peripheral with little involvement to complete membership with full involvement (Adler and Adler, 1987). In analytic autoethnography, the researcher is always a complete member. The second feature of analytic autoethnography is analytic reflexivity. This necessitates a sustained and deep reflexive analysis of the researcher's connections to their work, their effects upon it (Davies, 1999), and the reciprocal influence between the researcher and other members. Relatedly, the third feature requires that the researcher be visible and active in the text; their "feelings and experiences are incorporated into the story and considered as vital data for understanding the social world being observed" (2006: 384). The fourth feature is dialogue with informants beyond the self. Including others moves the research beyond the subjective experience of one and recognises that researchers are only one part of the complex social world they are trying to understand (Atkinson, Coffey, and Delamont, 2003). The final definitive feature of analytic

autoethnography is its strong commitment to an analytic agenda. It aims to transcend the data to provide insight into broader social phenomena and contribute to theoretical development and refinement. The intention is to "gain insight into some broader set of social phenomena than those provided by the data themselves" (Anderson, 2006: 387).

There are stark differences between analytic and evocative autoethnography which derive from their divergent epistemological contexts. Predominantly, this is seen in analytic autoethnography's traditional analysis, as opposed to evocative autoethnography's narrative-focused analysis and refusal to "abstract and explain" (Ellis and Bochner, 2000: 744). Indeed, Ellis and Bochner (2006) contest Anderson's analytic commitment to developing theoretical understandings. They challenge his mode of analysis which they perceive to be based on impersonal abstraction and ignorant to the narrative turn. Similarly, Denzin (2006) perceives analytic autoethnography as an uncritical adoption of conventional approaches which negates recent antifoundational arguments (see also Ellis and Bochner, 2006).

Atkinson (2006) supports analytic autoethnography, and extends Anderson's arguments with further recognition of autobiographical aspects that have traditionally featured in ethnographic work (see also Coffey, 1999; Charmaz, 2006; and Walford, 2009). Vryan (2006) views analytic autoethnography as a viable method, but argues that rather than referring exclusively to a specialised subgenre of ethnography, analytic autoethnography should refer more broadly to any autoethnographic practice which orientates itself towards explicit analysis. He suggests that analytic self-studies need not *necessarily* include data from 'others'. Rather, for some topics, it would be possible to carry out effective analysis, generate useful conceptual insight and produce original knowledge with relevance to other people or contexts from self-generated data alone.

A moderate autoethnography

Wall (2016) acknowledges the polarized nature of the debate between evocative and analytic autoethnography, and advocates for a 'middle ground' approach that seeks to combine beneficial elements of each. This approach is moderate autoethnography, which

> Allows for innovation, imagination, and the representation of a range of voices in qualitative inquiry while also sustaining confidence in the quality, rigor, and usefulness of academic research (Wall, 2016: 1).

Her support for such an approach is set in the context of her concerns about existing autoethnographic work. These relate to, for example, a lack of analysis, and concerns about the quality and use of data more generally. The moderate approach she proposes seeks to overcome these concerns by including explicit analysis, but unlike analytic autoethnography, this is not required to be conducted as a part of traditional ethnography. The following table outlines moderate autoethnography in more detail by showing how it relates and compares to evocative and analytic autoethnography.

Table One: Key features of evocative, analytic, and moderate autoethnography.

	Evocative Autoethnography (e.g. Ellis and Bochner, 2000)	Analytic Autoethnography (Anderson, 2006)	Moderate Autoethnography (Wall, 2016)
Influences on development	Influenced by postmodern criticisms of conventional social research, and the 'narrative turn' and 'crisis of representation' in the social sciences.	Developed in response to success of evocative autoethnography.	Developed in response to polarised debates between evocative and analytic autoethnography, and limitations in existing practice
Epistemological underpinnings	Postmodern, emphasises links between social science and arts/humanities.	Realist/analytic ethnography.	Not strongly linked to specific epistemology. May suit a range of epistemological approaches.
Focus on self / others	Heavy focus on researcher's self – sometimes exclusively.	Emphasis on self <u>and</u> others. Focus is on a social group of which the researcher is a part.	Flexible: focus may be on self, or self and others.
Analysis	Narrative-based: "Use stories to do the work of analysing and theorising" (Ellis and Bochner, 2006; 436). Seeks to be evocative.	Strong emphasis on conventional ethnographic analysis.	Emphasises need for explicit analysis. Also allows for innovation.

When designing my autoethnography and critically reflecting on existing autoethnographic practice, I shared other's concerns regarding the limited analytic potential of (some) evocative autoethnography (Anderson, 2006; Atkinson, 2006; Chang, 2008; Delamont, 2009; Walford, 2009; Wall, 2016) and I wanted to distance myself from the postmodern sensitives associated with this approach. I was concerned that privileging evocation and the experiential value of writing could undermine the scholarly goals of analysis and theorising (Atkinson, 2006), and restrict the writing to descriptive autobiography (Chang, 2008). Analytic autoethnography resonated more strongly with my research values. However, I did not agree that it need be limited only to what is essentially heightened reflexivity and researcher visibility in ethnographic research (Vryan, 2006; Wall, 2016) and I needed an approach that would allow me to directly analyse my own experiences as a case in their own right (while also interviewing others). I therefore developed my own stance, that I later realised was akin to Wall's moderate autoethnography. My research is heavily influenced by analytic autoethnography in that it is orientated towards explicit analysis and seeks to address broader conceptual and theoretical issues (Anderson, 2006), but is not couched in traditional ethnography. Also, while evocation was not a central goal, I did not deliberately avoid it. I recognise that it is possible for deeply personal and emotionally impactful accounts to also be analytic and sociologically valuable (Vryan, 2006; Burnier, 2006; Williams and Jauhari Bin Zaini, 2016).

Autoethnographic documents

Before describing the procedures I undertook to conduct the autoethnography, it is worth critically considering the documents I used to inform the analysis. These were personal documents and medical records. Other sociologists have also used diaries and medical records in autoethnographies of illness and treatment (Rier, 2000; Greehalgh, 2001; Blaxter, 2009; Reissman, 2015). Both types of documents that I used were private due to their

closed access (Scott, 1990), unsolicited due to their 'natural' production (they were not produced for research purposes) (Berg, 2004) and primary because they were produced by individuals who directly experienced my illness and treatment (Mogalakwe, 2006). The documents were produced on a daily (or usually daily) basis during treatment and in this respect are a thorough record. I can be confident in their authenticity (Scott, 1990) because they were produced by me or relate to my experiences. I also benefited from not experiencing the access difficulties that are ordinarily associated with 'sensitive' documents (Barlow, 2016).

Personal documents can give insight into an individual's (then) definitions of the situation and how they made sense of their daily life (Berg, 2004). The diaries contain detailed accounts of my perceptions of treatment as they were experienced at that time. Both personal documents and medical records are highly subjective, and for my autoethnography, this was their value. That such documents

> […] reflect the subjective views and perceptions of their creators […] makes them useful as data in a case study. It is precisely through this subjectivity that these documents provide information and insight about the subject (Berg, 2004: 255).

Reissman (2015) suggests that personal diaries can act as a 'counter narrative' to medical records. The different authors of, and contexts for, each set of documents provided a source of comparison (see also Barlow, 2016). I was able to contrast the meanings attached to the same event from my personal, 'patient' perspective and the clinical, professional perspective.

I did not treat the documents as direct, unproblematic representations of events. They needed to be understood in relation to the purposes, processes and social contexts of their production (Scott, 1990; May, 2001; Prior, 2003). In the following discussion, I consider these issues firstly in relation to personal diaries and then medical records.

Personal diaries can be written for a range of purposes and audiences. Even when a diary is intended for personal use, it may be written with an imagined audience in mind (May, 2001; Reissman, 2015). My motivations for diary writing while in treatment varied. I wrote to pass time, alleviate boredom, work through ambivalence, assist in decision making and for 'therapeutic release'. I usually consciously wrote 'to' a current or future self, however I also sometimes imaginatively directed my writing towards staff (while not intending them to view it). These varying intentions shaped the content and tone of my writing. Further, personal diary writing has a performative effect and can work to create, claim and transform an identity (Reissman, 2015). Parts of my diaries functioned to sustain an anorexic identity, as I sometimes used diary writing to 'work up' and express an identity as a 'resistant patient' who desired anorexia. It may be understood as one means through which I performed an (anorexic) identity for which the usual channels of expression were restricted by my involuntary treatment circumstances.

Medical records are highly selective, highlighting only limited aspects of the patient and their behaviour, and they may be inconsistent in quality and quantity (Garfinkel, 1967; Prior, 2003). Garfinkel (1967) found that medical records were constructed in accordance with contractual issues in the practitioner-patient relationship. They were kept in such a way as to legitimate the clinicians actions, and "demonstrate that the 'right things were done to the 'right' person at the 'right' time." (Prior, 2003: 51). According to Prior (2003), Garfinkel's work provides an example of how records may be routinely used for quite different purposes to their original or 'face value' purpose.

Medical records are commonly perceived as simple representations of 'what has happened' during a patient's treatment, however they actively constitute (as well as record) medical practice (Prior, 2003). For this reason, the content of an official document is not necessarily its most important feature, and there is a need to consider how it is used within the

relevant organisational setting (ibid, 2003). The content of my medical records informed aspects of the autoethnography, but always in a manner which contextualised this content through an awareness of the documents functions in my treatment and the conditions under which they were produced.

Autoethnography procedures

Following the recognition of my own theoretical stance on autoethnography, a key challenge was to translate this into practice. There are no 'how-to' training courses for autoethnography as there are for conventional methods, and existing guidance and suggested techniques (e.g. Chang, 2008; Hughes and Pennington, 2017; Muncey, 2010) were of limited use. This was because autoethnography is as personal and idiosyncratic as the experience that it draws upon, and as such there could not be widely applicable guidance. My autoethnography is unique, and an implication of this is that the implementation of the method, in terms of the practical steps I took, proved highly emergent and was constantly (re)negotiated.

I began by writing the narrative of my experiences using memory, and my personal diaries and medical notes. Here, I 're-immersed' myself in my past and structured my memories into chronological order, in order to have an as accurate representation and understanding of 'what happened' as possible. The documents were vital in this process. They helped me to order and 'flesh-out' memories that were timeless and vague, and to trigger the recall of additional memories that otherwise would have remained forgotten. While writing my experiences, I began documenting initial analytic insights as I noticed connections to existing sociological and anthropological knowledge and generated ideas that were relevant to my research questions. Later, while analysing interview material, I added depth to the analytical aspects of the autoethnography, using insights generated from interviews with participants to make further sense of my own experiences. For example, participants' experiences and

conceptualisations of 'bad anorexic patients' – a patient role that I understand within this thesis in terms of 'anorexic scripts' – informed interpretations of my own experiences. I also incorporated my experiences into the analysis of interview material. In some places within this thesis, the iterative and 'joined up' nature of the analysis across the two methods is explicit. For example, while chapters five, six and seven predominantly pertain to participants' experiences and interview material, in these chapters I also sometimes reflect back on the autoethnography or include additional information about my own experiences. However, for the most part, the intertwining of the methods is not made explicit. This is because they were always 'joined up'. Learning about participants experiences will have affected my thinking about own experiences (and vice versa) in subtle ways that at times, even I may not have understood. The end result of the autoethnography is an approximately 12,000 word written piece that intertwines description, interpretation, and sociological argument.

Evaluating autoethnography

In this section, I begin by describing a challenge that I faced while conducting my autoethnography[45]. I then briefly reflect on Le Roux's criteria for assessing autoethnography in relation to my research.

A challenge that is unique to self-study is the revealing of information about myself to others through my research. Prior to undertaking my PhD, my experiences with anorexia were not 'common knowledge' and only close family and friends knew of them. Since beginning my research, I have regularly informed others of my identity as a 'recovered anorexic'. Among academic colleagues and peers, my previous experience of anorexia and treatment is well known, and it only takes a short conversation about my research with a new acquaintance

---

[45] This discussion of the challenge I faced revealing information about myself to others during my research has been published elsewhere (O'Connell, 2020).

at an academic conference for them to realise this. Revealing personal information about my past diagnosis to people I do not know well is sometimes uncomfortable. That said, doing this in academic contexts does feel relatively safe. Somehow, I imagine as if the information will be received through an academic lens, and thus more neutrally with less judgement (or at least with awareness on the part of the other person that they *ought* to treat the information in this way). However, academia is not the only context in which I discuss my research, and questions about what I do for a living (and consequently, my research) are raised in my 'everyday life' too. In these situations, I tend to reveal as little as possible, stating only that I am undertaking a sociology PhD in the field of eating disorders. This is in order to avoid the discomfort in revealing my past diagnosis. Interestingly, my selective revealing of information in this manner echoes the strategies that participants described in relation to the public management of anorexia (see chapter seven). In this sense, managing my identity throughout this PhD has been its own form of identity-work.

A number of authors have developed sets of criteria for evaluating autoethnography (Ellis et al, 2011; Chang, 2016; Le Roux, 2017). While Ellis et al's (2011) and Chang's (2016) are relevant to specific 'types' of autoethnography (evocative and analytically-focused respectively), Le Roux's (2017) are designed to be applied flexibly, in ways that are relevant to the autoethnographic stance in question. I apply these criteria here. They are: subjectivity, self-reflexivity, resonance, credibility, and contribution.

Subjectivity necessitates that "the self is primarily visible in the research" and that "the research […] retells a noteworthy or critical personal relational or institutional experience" (Le Roux, 2017: 204). In my autoethnography, I consider this not so much a criterion for evaluation, but a description of the end product. My self is visible throughout the autoethnography, which retells my critical experiences of clinical interventions.

Self-reflexivity "points to self-awareness, self-exposure and self-conscious introspection" (Le Roux, 2017: 204). I have sought to be self-aware throughout. This has involved continuous reflections on the potential criticism of my work being 'too subjective'. During the earlier stages of my research, I occasionally wondered whether my inability to 'step outside' of my experiences would reduce the quality of sociological analysis. However, I would now suggest that while my inescapable closeness to the subject matter directed the analysis and made it partial and highly specific, it also enhanced it. Beresford (2003) argues that the shorter the distance between direct experience and its interpretation, the less distorted the resulting knowledge is likely to be. I suggest that the directly lived, felt experiences on which I drew improved the depth of insight. In addition, self-exposure and self-conscious introspection have been inherent to the method itself, in both writing and analysing my experiences.

Le Roux states that resonance "requires the audience to be able to enter into, engage with, experience or connect with the writer's story on an intellectual and emotional level" (2017: 204). This criterion is best assessed by the audience reading my autoethnography, as I cannot know how it is experienced by them. However, I attempted to achieve resonance by being thorough in my personal introspection and memory recall, honest and detailed in the written descriptions of my experiences, and by drawing on academic literature in meaningful ways.

Credibility requires evidence of verisimilitude, plausibility and trustworthiness, and that the autoethnographic process is "permeated by honesty". Indeed, I consider honesty, as well as accuracy, central facets against which the three (closely overlapping) aforementioned dimensions of credibility can be judged. I have recalled events as honestly and accurately, and in as much relevant detail, as possible. The use of documents enhanced credibility, because they are primary and were highly beneficial in the recall of events. However, a limitation relates to my lack of anonymity. My awareness that others will read the

autoethnography knowing that I am the author means that there are inevitably very select aspects of my personal experiences that I have not shared – despite being honest and prepared to make myself vulnerable. These are aspects that are deeply private, and that I will never share with anyone. My autoethnography is a public narrative, and as such I unavoidably wrote it with an audience(s) in mind. I understand this as an unavoidable aspect of interpersonal communication. In addition, there were aspects of my experiences omitted, due the impossibility of sharing *all* relevant experiences. Crucially however, I do not consider that the aspects of my experiences that I have not shared, which are minimal in comparison to those I have, affect the quality of sociological argument made within the autoethnography.

Contribution relates to extending knowledge. The main sociological contribution of the autoethnography relates to the arguments I make in this thesis about 'anorexic scripts' (as will emerge in later chapters). In making these arguments, I draw on insights which begin in the autoethnography, and are further extended and broadened in the analysis of interviews. Therefore, the contribution to knowledge made within the autoethnography need be considered in the context of this research as a whole.

Interviews

Choosing to do interviews

Interviews have been described as a conversation with a purpose (Berg, 2004). In line with the goals of qualitative research more generally, this purpose is to elicit information to assist an interpretation of events from the perspective of the participant (Bryman, 1988). I chose to do interviews primarily because they are useful for understanding others' perceptions and the meanings that they attach to certain phenomena or events (Taylor and Bogdan, 1998), and were therefore well-suited to the aims of this research. In addition, I benefited from the

flexible implementation of interviews in a number of ways. I designed a semi-structured interview guide, in which there were some predetermined topics and questions, but I adapted these and generated additional questions in accordance with the circumstances of each interviewee (Berg, 2004). The open-ended questions allowed for interviewees to speak within their own frame of reference, and for 'new issues' previously unknown to me to emerge. I was then able to pursue these new issues further (Rubin and Rubin, 1995), both within the same interview and in later interviews with other participants. Indeed, as I moved through the interviews, I refined the guide to improve the relevance and quality of questions. In addition, I was able to be flexible in the ways and extent to which I shared my personal experiences with interviewees (I refer to this as interviewer self-disclosure). I made in-situ decisions about whether, when, and how much to self-disclose (Reinharz and Chase, 2003) based on my sense of what worked best for each interviewee. This was particularly in terms of encouraging them to share their experiences, as I acted in whichever ways seemed to best support the goal of the research interview – to understand the participant (Farnsworth, 1996). As I discuss later, this resulted in a variety of interviewing 'styles', and the use of self-disclosure in this manner seemed to prove beneficial.

Conceptualising interviews in this research

Two broadly opposing conceptualisations of the research interview can be identified – the interview as a *phenomenological report* and as a *discursive account* (Seale, 1998; Rapley, 2001; Talmy, 2010; Brinkmann, 2013; Brinkmann and Kvale, 2015). The attribution of a clear dichotomy between these conceptualisations is an over-simplification and they may be most usefully conceived as occupying either end of a continuum (Brinkmann, 2013). None the less, a direct contrast is heuristically beneficial.

The conventional conceptualisation of the interview positions it as a *phenomenological report*. The interview is conceived as an opportunity for *knowledge collection* (Brinkman, 2013;

Brinkmann and Kvale, 2015) and interview data as a direct representation of the interviewee's reality outside of the interview (Seale, 1998). The interview is utilised as a *research instrument* seeking to get as close as possible to the lived experience of the interviewee - the *'what'* of their experience (Talmy, 2010; Brinkmann and Kvale, 2015; Brinkmann, 2013). There is a primary concern for validity, whereby valid data is an accurate representation of what 'really' happened and what respondents 'really' felt (Talmy, 2010). Interviewers therefore seek to minimise interviewer effects, develop rapport, avoid 'leading' questions and assess the trustworthiness of the interviewee's account (Talmy, 2010; Brinkmann, 2013; Brinkmann and Kvale, 2015).

The opposing conceptualisation of the interview as a *discursive account* is influenced by the constructionist paradigm and positions that have been critical of conventional conceptualisations (Rapley, 2001; Talmy, 2010). This conceptualisation utilises the interview as a *social practice* and an opportunity for *knowledge construction* (Talmy, 2010; Brinkmann and Kvale, 2015). Interview data is conceived as a representation of the reality that has been jointly constructed by the interviewer and interviewee within the research situation itself (Seale, 1998). Rather than the interviewer being someone who simply collects data "as if picking daisies" (Nunkoosing, 2005: 703), the interviewer and interviewee collude to create and co-construct stories. Interview talk is a local-situational accomplishment, and both the interviewer and interviewee are involved in actively constructing data (Rapley, 2001; Talmy, 2010). Rapley (2001) focuses on the identity-work involved in interviews, pointing to their performative nature (see also Nunkoosing, 2005). Interviewer and interviewee are concerned with presenting themselves as certain types of people and in a morally adequate light (Rapley, 2001). When the interview is conceptualised as a discursive account, analysis contains at least some degree of focus on *'how'* people talk and interact in the interview, and not solely on *what* they say (Talmy, 2010; Brinkmann, 2013; Brinkmann and Kvale, 2015).

Taking either position to their extreme is problematic (Brinkmann, 2013; Brinkmann and Kvale 2015). Interviews do not provide unmediated access to lived experience, but this does not mean that they cannot allude to, and provide valuable insight into, lived experience outside of the research situation. While entirely' 'pure' and 'authentic' interview accounts are not possible, individuals can refer more or less accurately to their past experiences (Brinkmann, 2013). I adopted this 'middle ground' position, and conducted analytic approaches that allowed for: "the "what" and the "how" [to] fertilize each other in productive ways" (ibid, 2013: 40). Before I discuss my approach to analysis in detail, I describe the procedures used to recruit for and conduct the interviews, and the sample of participants.

Recruitment and interview procedures

I recruited participants in two stages. Firstly, I created a website that included an overview of the research and an invite for individuals interested in participating to contact me by email. I shared the website on my personal social media pages, where I already had links to networks of individuals whom I suspected would meet the inclusion criteria. When potential participants expressed their interest, I sent them a participant information sheet (see Appendix One). This provided further details about the research and the precise inclusion criteria for participation. The inclusion criteria were written as follows:

To participate in this research, the following should also apply to you:
- Age 18yrs or above and living in the southern or midland regions of England
- Have been diagnosed with anorexia by a health professional (you may or may not still have this diagnosis).
- Have received, or are currently receiving, treatment for anorexia. 'Treatment' includes any regular input from a health professional(s), for example: seeing your GP to be physically monitored, attending an outpatient or inpatient eating disorder service, appointments with a home treatment team, or time spent on a hospital ward.
- Not be feeling especially unwell or have very serious health complications.

In addition, I explained:

> I am interested in speaking to a range of people, including individuals who consider themselves to currently have anorexia, those who are in recovery and those who are recovered.

I deliberately used a broad definition of 'treatment', so as to encompass a range of experiences and levels of contact with clinical approaches.

This initial recruitment strategy proved successful and after one month, I had arranged and begun to conduct interviews with 10 participants. My second strategy was to recruit participants via the Beat website. Beat is a UK eating disorder charity, and its website includes a research page dedicated to recruiting participants for academic research. At this point, in seeking to increase gender and class diversity in the sample, I altered the inclusion criteria to specify males, and females with a highest level of education below degree level (taking educational level be an approximate indicator of class). I recruited two males and two females. However, it transpired during interviewing that the two females had previously begun to study for a degree but left university due to anorexia. This meant that the final sample was not as diverse as intended in terms of class (I discuss this further below).

I conducted the interviews at a time and location that was preferred by the participant. I met with eight participants in person, and this usually involved me travelling to where they lived and conducting the interview in their home or a private room in a university or public library. I conducted interviews with the remaining six participants over Skype, usually due to it not being practically viable to meet face-to-face. While there were minor and infrequent 'technical difficulties' using Skype (such as an occasional 'frozen screen'), I found that this method was a useful alternative to meeting face-to-face (Lo Iacona et al, 2016; Deakin and Wakefield, 2014; Hanna, 2012). Despite my initial concerns that building rapport may be

more problematic over Skype, I did not find this to be the case (see also Lo Iacona et al,

2016; Deakin and Wakefield, 2014), and the 'depth' or flow of conversation did not seem

negatively impacted.

Interviews lasted between 50 minutes and 2 hours and 45 minutes, with an average length of

around 1.5 hours. Two of the 14 interviewees participated in two interviews, and a further

three responded to further interview questions by email after their first interview. In these

five cases, the second sets of questions were 'follow-up' questions which I devised after

having reviewed the original interview. In addition, two participants (one who had answered

a second set of interview questions by email, and one who had participated in only one

interview), engaged in further, unstructured, 'naturally arising' conversation by email. In

these cases, I sought permission to use this content as per the interview material. All

participants were also asked two 'post-interview questions' by email, as part of a reflexive

strategy – this is explained in detail later (see Appendix Two for a summary of research

processes for each participant).

The 'style' of the interviews varied, and this partly related to the extent to which I self-

disclosed during the interview. Most interviews were largely conventional, but some also

moved towards containing significant elements of interactive interviewing (Ellis et al, 1997).

In conventional interviewing, the interviewer directs the interview, asks questions of the

interviewee in a non-reciprocal process, and does not disclose their own experiences. Here,

a "friendly but not too friendly" interviewing-stance is considered ideal (Oakley, 1981).

There is a hierarchical relationship between interviewer and interviewee, in that "the

researcher defines and controls the situation" (Brinkmann and Kvale, 2015: 6). An

alternative approach is interactive interviewing (Ellis et al, 1997). This undermines the

hierarchical dynamics of the conventional interview. Interactive interviewing is

> a collaborative communication process occurring between researchers and respondents […it] involves the sharing of personal and social experiences of both respondents and researchers, who tell [...] their stories in the context of a developing relationship (Ellis, 1997; 121).

All of the interviews in this research were largely conventional in that, for at least half of the interview (and usually more), I was directing the conversation, asking questions, and attending to interviewees experiences exclusively. However, all interviews to varying extents also included some element of self-disclosure, which in some cases moved aspects of the interview towards (but never entirely in line with) interactive interviewing. I examine the impact of my self-disclosure and 'insider status' in detail later.

Participants

I interviewed 14 participants, including 11 females and three males (see table two below for details of each participant). Interviewees' ages ranged from 21 to 52 years, with most being aged between 21 and 29. Most (13) participants had been formally diagnosed with anorexia, and one (a male aged 52) was self-diagnosed. The final sample were culturally homogenous; all were white, and might (crudely) be said to be lower middle, middle, or higher middle class. In focusing on white, middle-class experiences, I have unintentionally reproduced stereotypes of 'who has anorexia' and missed opportunities to explore how the diagnosis is experienced by other groups. This is a notable limitation of my research. Participants were mixed in terms of their current illness/recovery status and experiences of treatment. At the time of the interview, seven were currently receiving treatment for anorexia, two were 'in between' treatments (they had recently ended treatment and were waiting to begin a new phase), and five were not receiving any treatment. They had experienced a range of 'types' of treatment (inpatient and outpatient, NHS and private, generalised and specialist), and while some individuals' treatment was relatively short and transient, others had long and varied treatment careers. I have roughly categorised participants treatment trajectories into

three types: 'extensive'; 'fractured', and 'singular'. There were five participants with an extensive trajectory. They had undergone both inpatient and outpatient treatment over an extended period of time. They often completed or ended treatment, went for a time without any, and then re-entered treatment again. In the fractured trajectory there were 2 participants, both of whom also had more than one occasion of treatment over an extended period of time. However, compared to the extensive trajectory, these occasions were short lived and/or non-intensive. Regarding the singular trajectory (7 participants), experiences were linear in that participants had begun a period of specialised treatment (either as an outpatient only, or as an inpatient and then directly followed by outpatient) during which time they 'recovered' (or were currently in treatment and in the process of recovering), and then either finished treatment or progressively received less intensive treatment. It is also possible to categorise participants according to their descriptions of their current relationship to anorexia (although these categorisations are not absolute or 'neat'). Participants were either 'in recovery' (6), 'early in recovery' (3), or 'in relapse/struggling' (5). Those in recovery considered themselves to be relatively 'far along' in recovery and were at the end of treatment, or post-treatment. They often used the word 'managing' to describe their current relationship to anorexia. 'Early in recovery' reflects participants who still considered themselves to be 'in anorexia', but had come some way in getting better. Both the two participants in this category were undergoing outpatient treatment. Participants who were 'in relapse/struggling' described their situation mainly in terms of the struggle they were experiencing, and usually also in terms of it having recently worsened.

Table Two: Participant details

Partici-pant	Gender (Age)[46]	Age developed anorexia, age of diagnosis	Current treatment status	Treatment trajectory[47]	Relationship to anorexia[48]
Mia	Female (22)	Developed age 11 Diagnosed age 12	Outpatient treatment for anorexia	Extensive	In relapse
Anna	Female (37)	Developed and diagnosed in mid 30s	Recently discharged from outpatient treatment for anorexia	Singular	In recovery
Natalie	Female (28)	Developed age 16 Diagnosed age 18	No treatment	Extensive	In relapse
Kelly	Female (24)	Developed age 18 Diagnosed early 20s	Group therapy (not eating disorder specific) as an outpatient	Singular	In recovery
Sarah	Female (29)	Developed early teens Diagnosed age 16	No treatment, apart from very occasional private therapy	Fractured	In recovery
Claire	Female (21)	Developed age 12 Diagnosed age 16	No treatment	Singular	In recovery
Ben	Male (22)	Developed and diagnosed early teens	No treatment	Singular	In recovery
Naomi	Female (28)	Developed in teens ('traits' since child) Diagnosed early 20s	Outpatient treatment for anorexia	Extensive	In relapse

---

[46] These are approximate ages based on participants descriptions of when their eating disorder developed. However, they did not always identify a clear beginning. Beginnings were often vague and gradual, and the start of 'anorexia' not necessarily clearly distinguishable from 'dieting' or 'eating disorder traits'.

[47] Defined above

[48] Defined above

Michael	Male (52)	Developed age 30 Diagnosed early 50s	Appointments with dietician	Singular	Early in recovery
Amelia	Female (20)	Developed age 18, diagnosed age 19	Outpatient treatment for anorexia	Singular	Early in recovery
Jack	Male (21)	Developed age 17 Diagnosed age 19	No treatment (waiting to start therapy for anxiety)	Fractured	In relapse
Maddie	Female (23)	Developed age 20 Diagnosed age 22	Outpatient treatment for anorexia	Singular	Early in recovery
Lisa	Female (40)	Developed age 18 ('traits' since age 11) Diagnosed with bulimia age 22, diagnosed with anorexia age 32	No treatment (waiting to start outpatient following recent discharge from inpatient)	Extensive	In recovery
Hannah	Female (23)	Developed age 15 Diagnosed age 18.	Outpatient treatment	Extensive	In relapse

Interview analysis

Brinkmann and Kvale (2015) identify two broad approaches to interview analysis; those that focus on meaning and those that focus on language. The former includes techniques such as meaning condensation and meaning interpretation, and the latter includes techniques such as conversation analysis and narrative analysis. Meaning-focused analyses tend towards a phenomenological report conceptualisation of interviews and language-focused towards a discursive account conceptualisation. However, these distinctions are not strict and some techniques, such as 'meaning interpretation', are open to being implemented flexibly with respect to epistemological stance. Indeed, I used meaning interpretation techniques in this flexible way within my analysis.

Brinkmann and Kvale (2015) identify three different contexts for meaning interpretation. These are self-understanding, critical commonsense understanding, and theoretical understanding. A self-understanding interpretation involves formulating "a condensed form (of) what the subjects themselves understand to be the meanings of their statements" (2015: 242). A critical commonsense understanding goes beyond the subjects' own meanings by involving a wider frame of understanding. Rather than taking participants' statements at 'face value', general knowledge about the content of the statements and the context in which they are made can be used to amplify and enrich interpretation. Theoretical understanding refers to the use of a theoretical frame for interpreting meaning and involves the application of insights and concepts associated with a given theoretical perspective.

In my own analysis, I applied elements of all three contexts in such a way that I attended primarily to the content (the 'what') of interview data, but also to the social processes involved in the interview (the 'how'). I began by analysing participants self-understanding in two ways, both of which involved condensing the meanings expressed by interviewees into shorter formulations (Brinkmann and Kvale, 2015). Firstly, I condensed the meaning of the

entire interview into a 'summary overview'. This document reflected a shortened version of the interviewee's whole narrative. I offered to send this and the interview transcript to the interviewee to review, amend, or add to the content if they wished. This was for ethical purposes (ensuring that participants had included all aspects of their experiences that they wanted to and were content with what they had said), and a way of checking my interpretation of their experiences. Most participants opted to receive these documents and confirmed that they agreed with the content, and one participant added further detail about her experiences. Secondly, I worked through each transcript and broke the interview material into (what I judged to be) 'meaning units'. I then wrote a shorter, summarised version of each of these units, such that I was thematising the interviewees statements (Giorgi, 1975, cited in Brinkmann and Kvale, 2015).

A second layer of analysis explored 'outside' of participants' immediately intended meanings by drawing on wider sources of knowledge and insight to interpret in a critical commonsense context (Brinkmann and Kvale, 2015). This included noting contradictions and inconsistencies in what participants said, as well as addressing how the language used shaped and conveyed meaning. For example, in chapter six, I discuss how participants 'entified' anorexia (i.e. referred to it as an external being, such as through personification). Amelia stated that she did not personify anorexia, but in her explanation of this she actively personified it – thus the expression she used contradicted the meaning of what she said. I also posed critical questions to the interview content (see box one below). Some of these were theoretically informed, and therefore an element of theoretical understanding as a context of interpretation was also involved. These questions were developed and adapted in light of new insight and emerging analytic concepts.

More generally, methodological reflexivity also acted as a source of insight for analytic purposes. I describe the reflexive strategies that I used in the next section. Insights from

these strategies, which pertained to the impact of my identity and actions as an interviewer on the interviews, provided contextual information for interpreting findings. They meant that I was sensitive to the role of *my* identity, talk and actions in producing the form and content of the interview, and to the identity-work that was involved in the interviews, both on my part and on the part of the interviewee (Rapley, 2001; Talmy, 2010). As I later argue, interactional processes relating to identity and anorexia that form the substantive content of this research have been at play within the interviews themselves, and this was 'felt' by both me and the interviewees. Therefore, a consideration of the interview interaction, through reflexive strategies, assisted in generating analytic insight that directly addressed the research objectives. The table overleaf summarises the stages of interview analysis.

Box one: Critical and theoretical questions posed to interview content

What does this tell me about the participants:

a)   relationship to/meaning of a diagnosis of anorexia?

b)   self-understanding as 'anorexic' (anorexic identity)?

c)   the meaning/value of anorexia to them?

d)   personal construction of anorexia: what/where it is (e.g. entification)?

e)   interpretive identity-work in relation to anorexia?

f)   performative identity-work in relation to anorexia?

g)   construction of anorexic scripts?

Table Three: Stages of interview analysis

Stage	Task	Purposes
1	Transcribed interview recordings and wrote interview summaries (condensed meanings).	-Preparatory -Familiarisation with interview content. -Analysis - Interpretation context – self understanding
2	Sent transcript and summary to interviewee for them to review and comment on or amend if appropriate. Incorporated comments into transcripts/summaries if relevant (occurred for one participant)	- Checking meaning with interviewees – for ethical and validity purposes.
3	Asked interviewee the post-interview questions (a reflexive strategy, discussed later)	- Reflexive strategy
4	For each transcript: Divided into 'meaning units' and condensed content to thematise participants self-understandings	- Analysis - Interpretation context – self-understanding
5	For each transcript: Posed critical and theoretical questions (see box one above) Pursued other avenues of critical insight as appropriate Used transcripts, summaries, and responses to post-interview Qs, as appropriate.	-Analysis - Interpretation contexts – critical common sense understanding and theoretical understanding

Insider interviewing, interviewer self-disclosure, and reflexive strategies

The distinction between 'insider' and 'outsider' refers to a researcher's social position in relation to participants (Kirpitchenko and Voloder, 2014). An insider researcher shares with participants a relevant experience, identity or culture. I shared with participants the experience of being diagnosed with, and treated for, anorexia. However, in practice, insider and outsider positions are more fluid and multiple than a simple case of either/or (e.g. Eppley, 2006; Chavez, 2008; Dwyer and Buckle, 2009; Couture et al, 2012). While I shared aspects of experiences with participants, there were sometimes also clear differences, such as gender, age of diagnosis, and type of treatment, and various elements of similarities and differences moved in and out of focus during each interview.

The relative impact of insider and outsider positioning has warranted much methodological debate (Kirpitchenko and Voloder, 2014; Chavez, 2008). Most of this literature concerns insider research in ethnography or participant observation (e.g. Bonner and Tolhurst, 2002; Hodkinson, 2005; Chavez, 2008; Greene, 2014). However, a smaller body of literature has specifically addressed interviewing as an insider, and related to this, interviewer self-disclosure. This literature identifies a range of benefits and disadvantages of insider positioning and self-disclosure and tends to conclude that it is a 'double-edged sword' (Daly, 1992b; Farnsworth, 1997; Dwyer and Buckle, 2009; Pearce, 2010; Berger, 2015).

An aspect of insider research that concerned me from early on was the potential for my subjective position to problematically impede the interviews. I was concerned that my direct personal experiences might 'cloud' my perceptions of interviewees or unduly shape the interviews in lines of questioning or analysis of data (Daly, 1992a; 1992b; Dwyer and Buckle, 2009; Berger, 2015). Further, I was concerned that my self-disclosure risked overwhelming the participants narrative or 'closing down' interaction in the interview (Pearce, 2010; Abell et al, 2006). These concerns were especially pertinent given that I was not only an insider,

but also actively studying my experiences in the autoethnography. I read other's suggestions that studying the self detracts from a researcher's ability to understand others (Madison, 2006), and that the personal element of autoethnography can overwhelm and seriously impede the research, leading to 'concept tunnel vision' (Morse, 2002: 1159).

However, while these concerns needed consideration, it should be noted that they relate to issues of subjectivity and objectivity that have been long and widely debated in the social sciences. These issues are relevant to all research, not only autoethnography and insider research. The objectivity/subjectivity debate raises questions about how a researcher's subjectivity 'impedes' the research and what (if anything) can/should be done about this. In regard to insider research and that which involves self-study, the 'threat' of subjectivity is more obvious. Methodological discussions need to avoid the oversimplification of distinctions between insider research/self-study and other methods. All researchers hold particular beliefs, values, assumptions and ideas regarding their topic, and this subjective positioning alongside the researcher's personality inevitably influences the research process (Sword, 1999; Letherby, 2013). Importantly:

> Being an insider might raise issues of undue influence of the researcher's perspective, but being an outsider does not create immunity to the influence of personal perspective (Dwyer and Buckle, 2009: 59).

None the less, the degree to which the researcher's personal realities shape their expectations may be greater in cases where the researcher has direct experience of the topic in question (Daly, 1992b), and I sought strategies to manage this. These strategies incorporated reflexivity. Reflexivity involves the researcher turning a critical gaze towards themselves (Finlay, 2003), and engaging in explicit, self-aware, meta-analysis of the research process (Finlay, 2002a). It has been practised in a range of ways in accordance with differing

theoretical and methodological standpoints (Finlay, 2003; Gough, 2002; Lynch, 2000).

However:

> It is commonly viewed as the process of continual internal dialogue and critical self-evaluation of researcher's positionality as well as active acknowledgement and explicit recognition that this position may affect the research process and outcome (Berger, 2015: 220).

Reflexivity is thought to enhance the accuracy, credibility and quality of research (Berger, 2015; but see Pillow, 2003) and, crucially for me, has been identified as beneficial for managing the complexities of insider research (Dwyer and Buckle, 2009; Drake, 2010; Greene, 2011; Couture et al, 2012; Berger, 2015). Berger suggests that reflexivity in insider research "helps address the double edge sword inherent in the situation" (2015: 230).

Letherby's (2013) contribution to the objectivity/subjectivity debate has also motivated my incorporation of reflexivity. She argues that subjectivity is not inherently problematic, but is an inevitable part of the pursuit for objectivity. She frames objectivity not in the traditional, 'scientific' sense of value-freedom, but as value-explicitness. Value-explicitness is achieved through theorised subjectivity, which entails "the constant, critical interrogation of our personhood – both intellectual and personal – within the knowledge production process" (2013: 80). This critical interrogation is what I have pursued through reflexivity, because through this, "subjectivity in research can be transformed from a problem to an opportunity" (Finlay, 2002a: 531).

The reflexive strategies I adopted were:

1) Post-interview diary – I wrote down any reflections and 'senses' I had immediately after each interview. This included insights regarding the relationship between myself and the interviewee, the mutual meanings that emerged in our relationship, and the extent and

apparent impact of my self-disclosure (Finlay, 2002b). Berger (2015) described a similar reflexive strategy for insider research when she recommended keeping a 'log of encounters'.

2) Post-transcription analysis – I studied the content of the interview transcripts at least one month after the interview to attend to facets such as the impact of my self-disclosure. Returning to the interviews after time had passed offered an "opportunity to view the same material through a 'new lens'" (Berger, 2015: 230).

3) Asking interviewees – At the end of the interviewing process with each interviewee, I asked them two questions by email, namely, "how did you find it taking part in an interview with someone you knew to have a previous diagnosis of anorexia?" and "Do you feel that this affected the interview process?" (I here on refer to these questions as the 'post-interview questions'). Participants responses to these questions offered valuable insight into how they experienced my insider status and self-disclosure. This was a novel reflexive strategy that, as far as I am aware, has not previously been used.

These strategies did not make it possible to entirely 'put my experiences to one side' while attending to the experiences of interviewees (Fansworth, 1997), because it is impossible for me to escape my own positioning. Indeed, my reflexive analysis has been undertaken from the very subjective position that I am seeking to analyse, and I may not have a good understanding of my own bias and assumptions (Risjord, 2014). None the less, reflexive strategies have been valuable in developing an awareness of the impact of my personal experiences within the research.

Here, I draw on insights from these strategies to discuss the relative pros and cons of undertaking research as an insider. I address these in accordance with five (overlapping) facets; recruitment and making connections, interviewer skills, rapport and openness, interviewer-interviewee relations, and substantive insight.

Recruitment and making connections

My insider status likely benefited recruitment in that potential participants may have been more willing to share their experiences with someone whom they expected would properly understand and represent these (Farnsworth, 1997; DeTona, 2006; Chavez, 2008; Berger, 2015). As Hannah explained:

> I felt reassured and less judged once you said that you had been a sufferer yourself and that you would indeed then understand how it really feels to suffer from anorexia (email).

In addition, joint awareness of our shared experiences seemed to help us forge connections from the outset, 'easing' the process of recruiting, meeting, 'getting talking', and developing rapport (Fansworth, 1997; Berger, 2015) by providing "a common ground from which to begin the research" (Dwyer and Buckle, 2009: 58).

However, these recruitment-related benefits are not the whole picture. Sarah described how, while she ultimately decided prior to participating that our shared experience would be beneficial, initially she had considered this potentially problematic:

> When I […] read the bit when I found out that you'd had it, I have to admit at first I was quite surprised, and I thought [I] have to think very carefully, is that going to be OK, and then I thought yeah it is, it's fine […] actually I can say anything and you will understand (Sarah, email)

Sarah had described during the interview how, at the height of her struggles, direct comparisons with others diagnosed with an eating disorder created a powerful drive in her to 'become worse' (comparisons among individuals with anorexia are discussed in detail in chapter seven). It is to this that she referred when she questioned whether participating in the interview would be 'OK'.

Anna expressed similar concerns:

> When you sent the information sheet and mentioned you'd had anorexia, it was one of the things that made me pause for thought about whether or not I'd take part. I was a bit worried because my own recovery is in an early stage. I think I'd mentioned how I hate seeing other people with anorexia at the gym, I feel like they're bringing anorexia into my recovery space […] But also a worry that us talking about our anorexia could be too complicated. Sort of blurring the lines between empathising, comparing, competing, and that sort of complaining 'oh isn't it awful when… that also ends up celebrating something (email).

These extracts highlight how aspects of the experience of anorexia affected participants decision-making about participation. For individuals who are seeking to 'recover' from anorexia, being exposed to others who in some way embody or represent the diagnosis can feel difficult and potentially aggravate a desire to return to restricted eating/weight loss. Eli (2014b) explains that the 'eating disorder community' can trigger disorder-supporting desires, and for the above participants there was concern that the interview situation might engender similar feelings. It may be that some individuals chose not to participate for these reasons.

Interviewing skills

I felt that my 'insider understanding' facilitated my skills as an interviewer. I was aware of which issues needed to be addressed, and I addressed what otherwise may have been difficult topics with ease (Berger, 2015). It also provided me with a more nuanced and sensitive understanding of interviewee responses, including aspects that were 'hidden' or 'unsaid' (Chavez, 2008; Berger, 2015). As Berger explains in relation to the insider interviews she conducted with women with whom she shared migrant status, "I knew what to ask and how to ask it […] I was able to hear the unsaid, probe more efficiently, and ferret out hints that others might miss" (2015: 223).

Conversely however, I may have made assumptions about what I knew, and this may have led me to miss opportunities to properly understand participants responses or take up effective lines of questioning (Daly, 1992a; 1992b, Dwyer and Buckle, 2009; Berger, 2015).

While it did seem that my insider knowledge was greatly beneficial in terms of knowing which issues to address and understanding implied content (Berger, 2015), this very knowledge may have also led to blindness to important aspects of participants experiences (Daly, 1992b). I attempted to overcome this by checking the meaning of what interviewees said with them, or asking them why or in what ways something was the case, even if I thought I already knew. I also tried to avoid the potential pitfall of a skewed analysis which focused disproportionately on aspects of experiences that we shared, by ensuring that I also focused on difference and that I consistently pursued aspects of participants experiences with which I was unfamiliar.

Openness and honesty

The most significant way in which my insider status and related self-disclosure benefited the interviewing process was by facilitating rapport and encouraging openness and honesty, enhancing the depth of my research (Farnsworth, 1996; Dwyer and Buckle, 2009). Participants responses to the post-interview questions indicated that they perceived me as understanding due to my insider status, and that this encouraged openness because they felt less judged, that I would interpret their experiences correctly, and that I would be able to grasp 'small' matters that others would consider insignificant, as well as the complexity of the experience of anorexia. One participant understood my insider status as being essential to my ability to understand:

> Maddie: No matter how much you read or understand it from an outsider's point of view, unless you have been through it you can never fully appreciate the journey of what it feels like in the mind (email).

My self-disclosure at times appeared to play a crucial role in facilitating openness and honesty. I explored this by using the post-transcription analysis and insights from my interview diary to examine how my self-disclosure functioned during the interviews. One

way that it functioned was to create an atmosphere of non-judgemental sharing in which experiences that are ordinarily 'unspeakable', became speakable. This occurred in two ways. The first was by me using self-disclosure to 'speak it first'. I was able to 'offer up' an aspect of my own experience that I was aware was a matter that often remains hidden in the experience of anorexia, to make it 'OK' for the participant to reveal a related aspect of their experience. In the following example from Mia's interview, the usually unspoken issue in question concerned the 'self-consciousness' that someone undergoing treatment for anorexia can experience in terms of whether or not they are appearing to behave in an expected manner. Picking up on a point made by Mia, I told her I could relate to what she had said. Wishing to probe deeper into this, I described a similar experience from my own inpatient experience in which I had had to make a decision about whether or not to inform staff that they had given me a smaller sized meal than I was supposed to have. The following conversation ensued:

> Lauren: for me [this] was about that is not how somebody who is a patient, an anorexic patient doesn't behave like that, an anorexic patient needs to be rejecting the food not asking for it [I was] concerned about how other people saw me and I wondered, I mean your experience might be completely different […] but is that something you can relate to at all?

> Mia: Definitely. I think not last week but the week before, they sort of described me as chronic, and I'm just like I'm not, and you know what if you are going to describe me as that I am going to do it [Mia continues to explain her experience in detail].

By sharing my own experience of feeling worried about how I was 'seen', I opened-up the space for Mia to share a related experience. Like Daly (1992b), I found that raising a 'sensitive' issue within the interview based on my own experience enabled me to encourage the participant to reflect on this in a non-intimidating way.

The second way that my self-disclosure created a non-judgemental atmosphere was by me using it to show understanding. During the interview with Kelly, she had begun to describe

how she had wanted a diagnosis of anorexia when she first sought help from her GP. I had

then asked her if she could remember why she had wanted the diagnosis. The conversation

continued:

> Kelly: This is a really bizarre thing, and I really struggle to explain why, all I know is I
> kind of had this overwhelming feeling of really wanting to have the diagnosis. When I
> reflect on it I think it's because I really wanted to be it was, it sounds really sick to
> say […]

> Lauren: I guarantee it's not going to sound sick to say it

> Kelly: It's almost like, it's almost like a badge, kind of like a, OK this is like 'you did it'

> Lauren: Yep, it doesn't, it doesn't sound like a 'sick' thing, it's very relatable so, on a
> very personal level I can really, really relate to that [further discussion ensued]

At the point at which the participant became hesitant and was concerned about how her

experiences would come across, I interjected with reassurance that it would not 'sound

sick'. She responded by further explaining her experience, and I was then more explicit

about my own experience being similar to hers. My demonstration of understanding via self-

disclosure thus prevented the participant from restricting her response through fear of

negative judgement.

It need also be recognised that my insider status may have led interviewees to sometimes

explain their experiences less fully, due to them making assumptions about what I already

knew (Daly, 1992b; Dwyer and Buckle, 2009; Pearce 2010; Berger, 2015). As Natalie wrote:

"it made me not feel the need to give as "full" answers as I knew you would most likely

understand where I was coming from with it".

Also, when reviewing transcripts, I noticed occasions where my self-disclosure may have

unintentionally restricted participants ability to speak. This may be because in revealing

information about myself, I made them no longer feel as though they were being informative

by talking of their experiences (Pearce, 2010). Related to this, Abell et al (2006) suggest that a researcher's attempts to construct similarity via self-disclosure can sometimes construct the interviewer as having a greater entitlement to speak on the topic in question. In my post-interview diary, I also noted an occasion having left an interview and feeling I had spoken too much. Noting these concerns through the reflexive strategies, I was able to improve my interviewing skills over time.

The 'double-edged' nature of my insider status and self-disclosure meant that while this mostly appeared to facilitate openness and honesty, it may also have sometimes restricted participants answers. However, overall I found that "the deliberate use of the self in the research process helped to unravel the experience of the other" (Daly, 1992b), and that bringing in my own experiences to the interview yielded disclosure of more personal and deep stories than I imagine would have been possible using a more distanced stance (Berger, 2015).

Interviewer-interviewee relations

Self-disclosure seemed to be beneficial in terms of facilitating the developing relationship between myself and participants. Daly (1992b) explains that "a relationship within the research context is not unlike any other developing relationship, for which the reciprocity of disclosure is crucial for understanding" (Daly, 1992b: 110). In the post-interview question, Natalie stated:

> You were quite open to sharing your experiences in the interview […] I'm not sure exactly what it did, but it did something useful for me. I guess it made me feel like I got to know you a little bit? (email).

One of the impacts of 'getting to know me' seemed (to me) to be a reduction in the hierarchical power relationship that usually manifests in the expectation that the interviewee will reveal detailed, personal information while the interviewer remains relatively

anonymous and 'closed' (Oakley, 1981). By sharing 'unspeakable' aspects of my experiences, I made myself vulnerable and risked judgement, and this perhaps helped to 'level the playing field'. That said, interviewer self-disclosure can only go so far in reducing power inequality in an interview, given that there are other dimensions of power to consider, such as the interviewers' academic, institutional status (Ross, 2017). In addition, my self-disclosure was highly self-selective and in this way I had more control over what I revealed than interviewees.

Competitiveness and comparisons

I discussed above how participants were initially concerned that being interviewed by me may trigger a desire to return to restricted eating/weight loss. These concerns allude to the interpersonal dynamics of comparing and 'competing' that can occur among individuals with anorexia, and I explored these dynamics in the substantive content of my research. Participant's responses to the post-interview questions therefore sometimes acted as material for answering research questions, as well as being a methodologically focused reflexive strategy. This can be seen in chapter seven, where I draw on insights from participant's responses to the post-interview questions in my analysis.

Evaluating interviews

In various places in the proceeding discussion, I have recognised challenges, strengths and limitations linked to the interviews. In this section, I draw on some of these (and other) insights to evaluate my research in terms of validity and reliability. I apply these terms in ways influenced by Brinkmann and Kvale (2015). They suggest that validity in interviews can be assessed by *quality of craftmanship*, and that it is processual in that it derives from all stages of the research project. They describe aspects of validity in relation to seven stages: thematizing, designing, interviewing, transcribing, analysing, validating, and reporting. In the following, I reflect on select stages of this 'process validity' in relation to my own research

(see Appendix Three for details on evaluating all seven stages). I provide only brief summary points as I draw back on issues already discussed elsewhere in detail.

Designing – validity depends on adequacy of the design and methods used for the subject matter.

Interviews were the most appropriate method for gaining insight into participants' subjective experiences and understandings of the diagnosis of anorexia. The flexibility of the interview guides and interviewing styles was highly suitable to the subject matter.

Interviewing – validity pertains to the trustworthiness of subjects reports and the quality of the interviewing, which should include careful questioning to the meaning of what is said and a continual checking of the information obtained.

The interview design, including my status as an insider and the flexibility of questioning, likely facilitated the trustworthiness of accounts. My insider status and knowledge assisted in generating rich, detailed interview material. However, my insider status may have sometimes limited what interviewees felt able to share (as discussed above), and my skills as an interviewer were sometimes limiting. When reviewing interview transcripts, I noticed places where I felt that my questioning seemed to 'cut interviewees short', or that it interfered with their narrative. I suspect that my self-disclosure also did this on occasion. I 'checked meaning' with participants during the interviews (for example, by repeating back to interviewees my interpretation of what they had said), and afterwards, by providing them the opportunity to review the summary overview of their interview.

There is also an epistemological point to note here. While it is important that the interview material is trustworthy, insight was sometimes derived from the meanings inherent in the verbal descriptions and contradictions used by participants, more than the content of what they said. This element of analysis does not require interviewee 'honesty' as such.

Analysing – includes whether the logic of the interpretations made is sound.

Careful and thorough analysis, in which I employed reflexive strategies to assist interpretation, sought to lead to sound interpretations. In addition, discussions with my supervisor acted as a weak form of triangulation.

Reliability in interviews "concerns whether the interview subjects will change their answers during an interview and whether they will give different replies to different interviewers" (Brinkmann and Kvale, 2015: 281). My insider status impacted on the interview processes such that that it is likely that different interviewers would have obtained different responses. However, it is precisely my insider status that assisted the depth of interview material generated, and allowed the interviews to 'reach' aspects they otherwise would not have done. Therefore, while the interviews were not reliable in terms of consistency across (hypothetical) interviewers, I do not consider this a problem.

Ethics

Ethical approval was obtained via the University of Essex[49]. Ethical guidelines which governed this research include the British Sociological Association (2017) *Statement of Ethical Practice*. No serious ethical concerns arose, but there were ethical challenges to navigate. In the following discussion, I address these firstly in relation to autoethnography and then interviewing, as well as considering ethical dimensions of these methods more broadly.

The ethics of autoethnography

Tolich (2010) delineates ten foundational ethical guidelines for novice autoethnographers (see Appendix Four), and places these under three broad headings; consent, consultation, and vulnerability. I used the guidelines in a flexible manner, with recognition that they had to

---

[49] I also had approval from Beat in the second round of recruitment.

be adapted in terms of my own specific case. I base the following discussion of ethical issues in my autoethnography loosely around the three aforementioned broad headings.

Consent

Ethical complications arising from autoethnography that relate to consent concern the identification of others aside from the researcher. Using personal experience implicates others. Due to the researcher being identifiable, others are identifiable by association. Further, the content of an autoethnographic account may problematically impact the 'implicated others', especially if deals with 'sensitive' concerns. Ellis (2007) refers to the researcher's responsibilities to 'intimate others' who feature their writing as 'relational ethics'. Autoethnographers have detailed their grappling with these concerns in relation to topics such as illness, abuse and intimate relationships (Medford, 2006; Ellis, 2007; Jago, 2002, 2011; Chatham-Carpenter, 2010; Tamas, 2011).

I avoided others being personally identifiable by keeping them anonymous, restricting information about personal characteristics, and omitting select details of the SEDU I was in. Medford (2006) refers to this difference between what an autoethnographer 'knows' and what they actually write as '*mindful* slippage'. It has been argued that these protective devices could problematise the integrity, interpretation, and authenticity of the research (Ellis et al, 2011; Delamont, 2009). However, while I restricted information to protect others, this did not affect the key analytic insights I made.

Autoethnographers can obtain retrospective consent from others by seeking their permission for the account to be published (Tolich, 2010). The 'others' in my account are mainly patients and staff involved in my care, and obtaining consent from them was not feasible. However, the limited extent to which I directly discuss specific others means that I do not consider this ethically problematic.

Consultation

Tolich recommends consulting with others regarding ethical concerns. In my case, it was suitable to discuss ethical issues with my supervisor. Tolich also recommends a general principle which I applied, and that is to not publish anything that I would not (hypothetically) show to the persons discussed (Medford, 2006; Tolich, 2010).

Vulnerability

Tolich urges a consideration of 'internal confidentiality' (Tolich, 2004). This concerns the potential for 'insiders' to identify each other within the publication. Most of the information concerning insiders in my account is that which other insiders already know (or could be reasonably expected to know) due to them having 'been there'. However, I took care not to reveal information about particular individuals which is not 'general insider knowledge'.

Autoethnography also raises concerns about vulnerability and protection from harm regarding the researcher themselves (Tamas, 2009; Pearce, 2010; Chatham-Carpenter, 2010; Tolich, 2010; Dashper, 2015). Conducting self-study can be an emotionally draining process which places demands on the researcher's mental wellbeing (Pearce, 2010). Chatham-Carpenter discusses the difficulties she faced conducting autoethnographic research on anorexia. Retelling her story, confronting past behaviours and speaking to others who had experienced anorexia renewed her desire for thinness, and she felt compelled to return to anorexia. I did not experience this. When I began my autoethnography, I had been 'recovered' from anorexia for approximately seven years, and was adept at coping with 'triggers'. Undertaking this research was not the first time that I had thought deeply about my past experiences or confronted anorexia in another person. That said, being heavily immersed in my past for a significant amount of time was not always

easy and could be emotionally challenging. Importantly, any difficulties were short-lived and have not had lasting impact.

I also had to consider the *future* personal and professional impact of autoethnography (Jago, 2002; Tolich, 2010; Dashper, 2015). Dashper (2015) urges autoethnographers to consider the aftermath of publication. She found that the personal nature of her autoethnography about a facial injury led her to feel vulnerable and exposed when others responded to her work. I carefully considered this issue prior to undertaking my research and I judged then (as I do now) that on balance, the perceived benefits of my autoethnography outweighed any personal or professional risks.

The ethics of interviewing

In accordance with widely accepted principles of ethical research conduct, written informed consent was obtained from interviewees prior to participation in the study, interviewees' information was treated confidentially, and their identity was not revealed to others at any point during the research process or in the publication of findings[50]. Interviewees were informed about the nature of the research[51] and the potential consequences of taking part in writing when deciding whether or not to participate, and verbally at the beginning of the interview. They were also informed of their right to withdraw from the research at any time and without detriment, and were debriefed after the interview. As previously explained, I asked interviewees if they wished to have a copy of their interview transcript and the summary overview to review and alter content if they wished. I also made sure participants

---

[50] While confidentiality cannot strictly be assured (Wiles, 2013), I used all reasonable means to prevent interviewees from being identified.

[51] There are limitations to just how 'full' informed consent can really be, especially in qualitative research (Wiles, 2013). It may not be easy for a researcher to fully convey the time and effort that a depth interview will involve, what the emotional costs will be and exactly what the interview will reveal (Lee, 1993). Further, an interviewee is unlikely to be informed about all of the technical intricacies of research (Valentine, 2007). However, it is necessary to inform the potential participant of what is reasonably to be expected and to inform them of those aspects of the research that seem most relevant for ethical purposes.

knew how they could seek help if they were unexpectedly distressed after the interview, and provided them with information for accessing support from Beat.

The interviews may be considered 'sensitive' because my research "potentially pose[d] a substantial threat to those who are or have been involved in it" (Lee, 1993: 4). While it is important not to make simplistic distinctions between sensitive and the implied category of 'non-sensitive' research (Coomber and Letherby, 2010), it was vital to recognise the threats that the research posed to interviewees. These were of an intrusive nature, because the interview addressed private and potentially stressful and emotionally charged topics (Lee, 1993). Interviewees may have felt uncomfortable, distressed and/or embarrassed during (or after) the interview and there was also a risk of 'eating disordered thoughts' being 'triggered'. In order to minimise these risks, especially vulnerable individuals (those who expected that participation would be difficult or challenging and/or those with severely compromised health) were not recruited (see participation information sheet, appendix I).

However, interviews may have been unexpectedly difficult, and I could not know in advance how each person would respond to participation in my research (Lee, 1993; Valentine, 2007; Wiles, 2013). On two occasions, interviewees cried during the interview. I was careful in how I responded to these overt signs of emotion. I decided that I need not suggest that the interview be terminated, but instead responded to them in a sensitive and non-judgmental manner, and attempted to empathetically 'share' their pain (Lee, 1993). Interviews such as these were also challenging for me, as it can be difficult to manage one's own emotions while also 'taking on board' interviewee's distress (Bloor et al, 2007; Wiles, 2013).

Interviews that address personal or 'sensitive' matters may be unintentionally experienced as therapeutic by interviewees (Oakley, 1981; Birch and Miller, 2000; Rossetto, 2014;

Valentine, 2007; Grace et al, 2017). While this can be beneficial for them (or for the research), when researcher-therapist roles 'overlap', the researcher enters "ethically murky territory" (Ross, 2017: 6). I recognised that my responding to potential requests for information, advice, and support from interviewees (Sword, 1999; Ross, 2017) could be problematic if it contributed to a definition of the situation as 'therapeutic'. However, I did not wish to refuse such requests, because I agree with Oakley (1981) that interviewers have an ethical obligation to respond to (reasonable) requests of these sorts to reduce the exploitative nature of interviewing. Given these complexities, I sought to limit the possibility of me overstepping boundaries by clearly stating the limits of my role to participants (Daly, 1992a). I explained that the goal of the interview was not therapeutic, that interview participation was not a substitute for treatment (Grace et al, 2016), and that any personal experiences I shared were particular only to me (and should not be taken as any sort of advice or suggestion). In practice however, it was sometimes difficult to maintain clear boundaries, and I wrestled with a desire to help. This was particularly the case with two female interviewees who were both younger than me and 'in the grips' of anorexia. These participants asked me questions about my recovery, and I sensed that they were looking for guidance from me. As Daly (1992a; 1992b) notes, there is a greater likelihood of 'role confusion' when the interviewer has familiarity with the subject matter and insider status, because they may be perceived by the interviewee as an 'expert' with lived experience who is able to provide answers. During the course of interviewing these participants, I came to care about them as people who were struggling, and felt a strong desire to emotionally support them. I therefore attempted to be empathetic, caring, and understanding, and I answered their questions honestly, but did not offer any direct advice.

My self-disclosure during interviews required ethical consideration, because there is potential for this to emotionally burden interviewees (Valentine, 2007; Ross, 2017). I judged

the appropriateness of self-disclosure 'in the moment'. I became especially aware of my

need to be sensitive to the unpredictable ways in which my self-disclosure could impact

participants following the second interview (with Anna), after feedback I received from her

about my mentioning of my binge-eating during recovery:

> Anna: The only thing that was trickier I think was your mentioning after how you left treatment and did go through a phase where the 'wolf' [urge to eat] came out and your eating disorder continued but because you were no longer low weight you were considered recovered. This has been a huge fear of mine since I began restricting, that fear 'If I start eating, I'll eat and eat and never stop.' […] But it's also reassuring in a way for you to see this fear as actually realistic […] your mentioning it was like a reminder that that fear still lurks in the back of my mind (obviously you didn't put it there!) (email).

Chapter three summary

In this chapter, I have examined the methods used in my research, namely, autoethnography

and interviews. This has included a justification of my decisions to use these methods and of

the theoretical orientations and practical strategies I adopted within them. I have also

evaluated my use of each of these methods. A key point that can be drawn from these

evaluations is that, while my personal experiences and subjective positioning have needed to

be reflexively managed and have at times added complexity and challenge to the research,

they have also been a valuable resource. In the autoethnography, they have acted as

research material for direct interpretation and analysis. In the interviews, I have been able to

draw on them in such a way as to better understand participants.

Chapter Four

Becoming a diagnosis: an autoethnography

In this chapter, I 'retell' and analyse my experiences of anorexia drawing on material from my medical notes and diaries. I begin by addressing the emergence of my eating related struggles, and the circumstances and processes through which I sought help for these, was diagnosed with anorexia, and came to draw the diagnosis into my self-understanding. I then address how, around the time of being diagnosed, I developed ambivalence towards anorexia, and in this circumstance agreed to an inpatient admission at an adult SEDU. This is followed by an examination of my experiences of inpatient treatment, with a focus on the ideas and meanings of anorexia that I encountered, and how I engaged with them. I then turn to explore how, over time, being positioned as 'anorexic' and experiencing the restrictions of being in hospital under section became increasingly problematic and exacerbated aspects of my distress. I conclude using aspects of Brinkmann's (2016) heuristic model of living with a psychiatric diagnosis as a broad framework for making sense of my experiences, especially in terms of 'being' and 'doing' anorexia. In addition to sometimes quoting material from my medical notes and diary extracts, I also include 'memory recalls', presented in italics. These describe subjective experiences from the past, but are written in the present tense, as if I were writing the extract at that time.

Coming to identify with anorexia

It is difficult to define the beginning of anorexia (Darmon, 2017). I could begin with the period in which I first recognised myself as 'eating disordered'. Or I could begin with the time when 'symptoms' first began. I could reach further back still, to concerns about my body size in my early teens, or back yet again to my childhood where the roots of my

anorexia possibly lie. It is fair to say that there are many possible beginnings, and here I have chosen one; my first decision to diet.

> *I am 16 years old shopping with my boyfriend when I go into Topshop to try on a pair of jeans. As I stand in the changing room wearing them, I turn to look in the mirror and am struck by how fat I look. Upset, I leave the shop quickly and insist that we head home. We go back to the car and I cry, telling my boyfriend how unhappy I am with my body. I feel utterly miserable on the drive home. As I sit in silence and ruminate over the image in the mirror, it occurs to me that I will go on a diet and lose weight. In this moment of realisation, I sense a definite shift occur in my mind. I don't take time to consider how or whether the dieting will work, I simply know that it is going to happen. I plan to eat Ryvita for lunch* (memory recall).

During the five or so years prior to my decision to diet I had increasingly considered that my peers were slimmer than me and that I was 'too fat'. My upset in the changing room that day was an eruption of the sadness and shame about my body that had been building for some time. Like many who come to be diagnosed with anorexia, I had had a history of 'normal' dieting which gradually transformed into an unrelenting pursuit of weight loss (Walsh, 2013). Darmon (2017) suggests that this dieting is part of a deliberate and determined self-transformation in which the individual makes a direct break from the past and initiates engagement into a longer term 'anorexic career'. The aspect of self-transformation that I had consciously sought through dieting was focused on my physicality; I had wanted what I regarded as an acceptable body.

I dieted by restricting my intake of 'fatty' foods. Adopting the dominant 'diet thinking' of that time, I created my own set of rules to avoid fat, such as not consuming more than 30 grams of fat per day, and eliminating food such as cheese, chocolate and butter. My dieting was 'successful'; it wasn't too arduous, I lost weight, and occasionally received positive comments from peers. McLorg and Taub (1987) explain such comments in terms of the initial dieting conforming to cultural values of slimness. However, they note that as this weight loss increases, it starts to transgress social norms, and others may then respond to it

as deviant (McLorg and Taub, 1987; Darmon, 2017). On this occasion, my dieting did not reach the point of 'deviance', because I still ate a 'normal' amount and the foods I restricted were those that were considered by many to be 'unhealthy'. The diet lasted around a year before I reverted back to eating 'normally'.

At age 19, I left the family home to move in with my best friend and go to university about an hour away. A year prior to this, aged 18, I had returned to dieting, again motivated by a sense that I was 'too fat'. This sense had been heightened by spending time with a new friend to whom I directly compared myself; she was smaller than me and would openly comment on her weight and eating habits. During this bout of dieting, I experienced occasional episodes of overeating in which I would break my self-imposed diet rules – which continued to be based around the avoidance of fat - and eat beyond fullness. Over the next three to four years, during the period in which I first left home, I lived out a cycle of dieting and overeating - and accompanying weight loss and gain – which became increasingly intense. Strict dieting led to overwhelming hunger, and this in turn led to overeating, panic, further overeating, and attempts to fix the problem through stricter dieting. During these years, my mum commented on my weight loss when this occurred, but did not seem to show any outward concern. My close friend did show some concern, and occasionally pointed out how unusual my eating habits had become. I did not consider myself to have a 'clinical eating disorder', but my eating did feel problematic. Retrospectively, I view my binge eating as an understandable physiological and psychological response to my restrictive eating. However, I made no link between the two extremes of behaviour at that time. Instead, bingeing felt like a personal moral failing which interrupted my otherwise successful dieting.

On a number of occasions I sought help, motivated by a desire to end the binge eating. At the age of 18 I saw a GP who described me as having "an eating disorder – like - bulimia and

anxiety" (Medical notes, GPs, 30th July 2003). On two occasions I was referred for therapy (such as cognitive behavioural therapy) but did not continue beyond the initial appointments. The nature of my eating was repeatedly shifting – from under eating to over eating - and accordingly so was my motivation to engage with help. When my dieting was successful, I had no reason to change. Here I remember my thoughts when I was 20:

> *I am in the third year of my degree and living in a shared student house. I spend a lot of time focusing on my studies, which I am taking increasingly seriously. When I go to bed at the end of each day knowing I've worked hard on my assignments and eaten little, I feel satisfied. For the first time, I am incorporating exercise into my attempts to lose weight and I go with a housemate to the gym. At the induction a member of staff weighs me and notes that I am slightly underweight for my height, but that it isn't a cause for concern. I would prefer to be more underweight and for it to be a cause for concern, but the realisation that my weight is getting down into new lows is thrilling none the less. I catch myself in the mirror and notice that I look unusually and pleasingly thin* (memory recall).

Later that year:

> *I have recently finished my degree and am at home packing boxes ready to move out of the student house. I am stuffed full of food, nauseous and unable to concentrate on the task at hand. Driven by an overwhelming urge to taste and chew food, I go to the shop next door and buy sweets which I eat alone in my bedroom. I finish them and feel immense self-disgust. I lie on the floor of the packed-up room, dig my nails into the carpet and cry through sheer frustration at my inability to stop myself from eating* (memory recall).

Still aged 20, towards the end of the last year of my degree, I began to develop a sense that I was struggling with a 'mild eating disorder'. I had bought a self-help book for 'overcoming binge eating and bulimia', and strongly identified with the first-hand descriptions of the chaos and shame involved in bingeing. I also noticed a difference in my relationship with food compared to those around me, and was unable to recall the ability to be 'careless' like they were. How could my housemates (who were other university students) simply order a takeaway, enjoy it, and then stop eating? Others had also started to comment on my weight and behaviour. A notable memory is of me sat on a train reading the calorie content of

foods in a nutrition book. My then boyfriend, who was feeling exasperated by my growing 'obsession' with food, pointed out how abnormal this was. I had not thought it abnormal until he said this.

Motivated by worry about gaining weight by bingeing, I attended an appointment at a local charity-run eating disorder service. I explained my eating habits and concerns that I might have an eating disorder like bulimia (minus the vomiting). The counsellor suggested that perhaps it was not bulimia I was experiencing, but anorexia. I was surprised. I knew that my dieting was extreme, but I had not thought of it as anorexia. Surely I wasn't thin enough, and surely I liked food too much?

Thinking of myself as 'anorexic' felt presumptuous, and like an overstatement of my weight loss. Further, maintaining food restriction was like walking a tight rope; at any moment I could slip, lose control of my eating and gain weight. Associating myself with the diagnosis invoked anxiety that I was not good enough to warrant it (Lavis, 2011), and I was therefore wary of doing so. Yet, to some extent, I also wanted to identify with anorexia. The word felt rewarding, marking out a level of seriousness I had never thought I would achieve, and offering a valued sense of distinction (Warin, 2010). I liked the idea that I had taken food restriction far enough to be defined as clinically ill. I recall as a teenager about 14 years of age, being fascinated by a magazine article about a young woman who had 'recovered' from anorexia. The 'before' and 'after' pictures juxtaposed images of her obviously emaciated body against how she looked once 'recovered'. Reading the article, anorexia had seemed other-worldly. When the counsellor had used the word to describe me, she was suggesting that I had somehow stepped foot into that other world - that ordinary Lauren had achieved something extraordinary. In addition, I had attended this appointment thinking of myself as experiencing some variant of bulimia, and considering it as anorexia instead seemed preferable. This accords with literature which suggests that bulimia is often culturally

understood, and experienced by individuals with eating disorders as, 'failed anorexia' and a 'lesser' diagnosis (Squire, 2003; Eli, 2018; Frey, 2019).

After the diagnosis had been suggested, I did not continue with appointments. I moved out of the county temporarily to work as a waitress over the summer, and also experienced some distressing binge eating whereby my worries about losing my thinness were confirmed. It became too painful to 'face up' to my eating patterns and I no longer wanted help.

By the age of 21, my eating had settled back down into a relatively 'normal' pattern. While living with my partner and studying for a Masters degree, I started work as a research assistant and shortly afterwards developed an abscess on my gums. This made eating difficult and I consequently lost a little weight. This unintentional weight loss pleased me and motivated a further period of food restriction which eventually led to intentional, sustained and marked weight loss. One evening I had been unable to finish eating a slice of pizza because of the pain from the abscess. Three to four months later, I was meticulously monitoring and severely restricting my calorie intake. I was thrilled by the discovery that I was able to lose significant amounts of weight. Intoxicated by new extremes of food refusal, my enamour fuelled its escalation.

> *I am lying with my boyfriend in the park on a sunny day. I am happy. I weighed myself this morning and the number was a new low. As I lay on the grass with the warm sun on my skin, I think about how I have been feeling increasingly physically weak recently. I am aware that my food intake is very restrictive and that there is now a whole range of foods I will not eat. It is getting harder now, but it seems worth it. I just need to keep it up* (Memory recall).

Gradually, my restricted eating shifted from being something that I simply wanted to do (despite it posing some difficulties), to something that I wanted to continue but also found extremely problematic. I started to feel constantly weak, everyday tasks became arduous, I

struggled to concentrate on work, and I was no longer finding pleasure in activities that I had previously enjoyed. Recognising the extent to which I felt 'stuck' in my restrictive eating patterns and was obsessively concerned with my weight, I gradually came to understand myself as someone who was suffering with anorexia. I had begun to understand my restricted eating in terms of the diagnosis since it was first suggested by the counsellor and this understanding strengthened as my weight loss became more extreme and problematic and I read more books about anorexia. Four months into this bout of weight loss, I started weekly appointments at the eating disorder charity I had attended previously and went to my GP, where a diagnosis of anorexia nervosa was officially recorded for the first time. When seeking help on this occasion, I described myself as having anorexia, and the diagnosis was immediately assumed and referred to in appointments. Around the time I reinitiated help-seeking, I also began keeping a diary, something which in itself reflects the new meaning that food restriction and weight loss had taken on.

Over the following three to four months, I continued with weekly appointments at the EDS and with my GP, where I expressed a desire to change due to how much I was suffering. I was lacking energy and feeling light-headed and constantly cold. Life was now very restricted and monotonous. My mood flattened, I lost interest in anything other than food and weight, and others commented that my personality had left me. Nothing made me happy anymore. Yet, I simultaneously did not want to stop restricting food. I was captivated by weight loss and unable to imagine living without this exciting 'thing' in my life. I relished the secrecy and privacy; I had something that was mine and that no one else could touch. The private knowledge that I was successfully starving felt like a reassuring, comforting presence. The big and important things that had previously mattered – such as academic achievement and doing something meaningful with my life - did not matter so much, so long as I was losing weight. With anorexia, I felt less raw, less threatened by the risk of failure. No matter what

else happened, I had this. Torn between staying in my pseudo-protective state of starvation, and an ever-increasing sense of guilt for the 'proper life' I was not living, I was highly ambivalent. Ambivalence is a commonly recognised experience among individuals diagnosed with anorexia, and results from a recognition that one's self-starvation performs apparently 'useful' functions, in addition to being intensely problematic (see e.g. Colton and Pitrang, 2004; Williams and Reid, 2010; Lavis, 2011). Anorexia is "a form of distress that can make its sufferers feel better as well as worse" (Rance et al, 2017b: 127).

At the eating disorder service I was given guidance on increasing my food intake, which I intended to follow, but did not. Undercutting the meal plan became a way of reproducing the safety that anorexia offered (Lavis, 2011).

> I haven't tried to lose more weight, but I consciously let it happen. I want to get better but the relief at seeing the scales go down (or stay the same) and the sense of achievement that comes with the feeling of emptiness and hunger in my stomach builds a big security blanket that I don't want to let go of. If I'm not restricting calories; counting calories; weighing myself; thinking about what I eat, then I feel scared, anxious, out of control, panicky and lost. I can literally feel the anxiety wash away when I count up a days calories and realise I've 'beaten' my 'target' (I've eaten less than what is set out on the eating plan) (Diary, 22nd July 2006).

Over time, my identification with anorexia strengthened all the more. This is reflected in my diary entries, which refer increasingly to 'my anorexia' and to disorder-based understandings of my struggles:

> The conflict between the want to get better and the need to be thin makes me question a lot about my 'disorder'. How much is this disorder mine? How much is it something externally imposed on me? Can I get better through a series of choices? Or is there too much in the way of making these choices? […] What am I – who am I – what do I have if I let go of my 'disorder'? (Diary, 26th July 2006).

About three months after the diagnosis had been recorded, the GP asked me whether I would consider an admission at a SEDU. Wanting to change but unable to do so alone, I agreed. In the six-week wait to be admitted, I became increasingly desperate.

I am at home in my flat having a shower on the evening of my 22nd birthday. My friends are in the front room, they have come to see me. I have the shower water very hot in an attempt to warm me up. This is futile. The cold, seemingly impossibly, continues to radiate from the inside, even while the scorching hot water creates red marks all over my skin. I begin to feel sick and faint and decide to climb out of the shower. I am weak and breathless with a constant buzzing ringing through my ears. As I bend down while drying myself, the veins in my arms bulge from my skin as if they might explode. I feel unreal. I stand on the scales and the red digits flash a new number; I have lost another pound. In that moment, I don't feel the euphoric elation I usually do when losing weight. Instead, I think: 'What am I doing to myself? I really should eat.' It occurs to me that I cannot. I go to my bedroom, sit on the bed, and cry (Memory recall).

Despite my desperation, I questioned the legitimacy of my anorexia and need for inpatient treatment. Making reference to a lay construction of the diagnosis, I considered I fell short of what I thought of as 'proper anorexia'. I imagined this involved being emaciated to a greater extent than I perceived myself to be, and actively fearing food. Not only did I not fear food, but I desperately wanted to eat it, I just could not allow myself to for worry about weight gain. I also imagined that proper anorexia occurred for people who were so deeply troubled that they lacked appetite, whereas my struggles involved me trying to squash and contain a desperate appetite. There therefore seemed to be something pretend about what I was doing, and as though my anorexia was not serious enough for inpatient treatment. In emails to a friend (who was also diagnosed with an eating disorder and whom I had met online), I explained:

I am too fat to stay as an inpatient. Inpatients are usually desperately thin, on their death bed, shockingly emaciated, I'm not […] my BMI is 13.6, which must be wrong. That is not me with a distorted anorexic way of thinking; I'm just not that skinny! Very thin, yes […] completely emaciated and in need of hospitalisation I am not! (email, 3rd October 2006).

Waiting to begin treatment, I was caught up in two opposing but simultaneous positions in relation to the diagnosis of anorexia. I strongly identified with it, recognising as I did the nature of my suffering in the clinical, self-help and autobiographical books I read about

anorexia. However, I also doubted it. I did not match up to the idea of anorexia that I had in mind, which I understood as considerably more severe.

Admission to the SEDU: Encountering anorexic scripts

I arrived at the unit on a Monday morning, and a few hours later ate my first lunch sitting with staff. I will never forget that meal (I can still remember exactly how it tasted) and I struggle to fully comprehend how I simply sat down and finished it all, having found it impossible to increase my food intake at home. However, it is likely that I was so bound up in the expectation that this is what I would do (completing meals was non-negotiable, and it is what all the other patients did), that it did not even occur to me that I might not.

During the first few weeks I gradually got used to the hospital routines and learned what was expected of patients. I did not want to gain weight, but in some respects enjoyed eating and was grateful that I 'had to'. I worried that this enjoyment of food proved the fraudulence of my anorexia. Aware that a patient in an SEDU should be *not* wanting to eat, as appeared to be the case for other patients, I kept these concerns to myself.

> After so long of being so very hungry and eating very limited food stuffs, being forced to eat a (half-sized) normal meal was almost a welcome relief […] A proper anorexic would no way be pleased at the sight of the plate of food I just ate […] I'm a greedy person who wants to stuff their face in the body of someone with a low BMI (Diary, 9th October 2006).

My diaries from this time allude to the two subjective positions that I constantly shifted between; one was that my anorexia was fraudulent and pretend (I was not anorexic *at all*), and the other was that I was not a 'good' anorexic (I was not anorexic *enough*).

> The fact that I'm not trying to get out of eating butter when I eat a meal here means I'm not trying hard enough. I was never a good anorexic in the first place because surely then the butter would be harder? I'm a fraud case, I'm not anorexic. I want my anorexia (Diary, 14th October 2006).

These positions were heightened by comparisons with other patients, who concerned me immediately upon being admitted. On the second day, having spoken with them, I described my comparative sense of inadequacy:

> All the other girls have been loads skinnier than me. Some of them have been in [general] hospital because they've been that underweight. And then there's me. Thin, but not exactly emaciated (Diary, 10th October 2006).

This sense of inadequacy was also enhanced by well-meaning comments from staff. I was told that I had a good chance of recovery because this was my first admission and first phase of severe anorexia. I had voluntarily sought help, too; these were good signs. I took this to mean I was not as anorexic as other anorexics.

Initially, the weight gain did not feel too difficult. I knew that I did not want to lose my thinness, but something about the change in context (hospital rather than home) made the scale reading relatively meaningless to me. However, a few months in, I began to see the changes on my body, and things became hard:

> Struggling today with my size. I feel so much bigger these last few days […] There have been two new admissions in the past few days and I hate it. It really screws me up seeing extremely thin people, especially when they so openly struggle […] I don't feel deserving of time and attention from staff, especially in comparison to new admissions […] they are pleased they are not as fat as I am (Diary, 18th January 2007).

New admissions reminded me of what I no longer was. Extremely thin, noticeably struggling patients who appeared to need care were the embodiment of anorexia, whereas I was not. The more the patient struggled with eating, and the thinner they appeared, the more they threatened the legitimacy of my own struggles and the less I rightfully belonged to anorexia. Describing a newly admitted patients 'non-compliance', I wrote in my diary:

> The new admission is a complete nightmare. She refused to eat all of her food and somehow got away with it?! Then she spent ages kicking up, screaming and crying. I just cannot stand it. It's fucking typical that [my named nurse's] other patient is that kind of patient. It makes me feel so fat! […] I wish I could wear clothes that just hid me completely so that no one could see any of me, ever. So that I didn't have to see myself (Diary, 30th January 2007).

As I continued treatment and started to approach a 'healthy' weight, I felt increasingly conflicted. Continuing weight gain involved an ongoing search for (what I referred to at the time as) 'permission'. This meant being able to make choices that worked against anorexia, without entirely undoing my sense that I was anorexic, and overlaps with what Lavis (2011) calls 'compromise'. She details how individuals in treatment use compromises, such as relinquishing responsibility for their eating, to allow them to consume food but prevent it from breaching their sense of self. One way I searched for permission was by convincing myself that I simply 'had' to continue to eat. In the example below, I was going home on leave for a weekend and was struggling with the idea of adhering to my meal plan, something that I enabled myself to do by positioning myself as not having a choice.

> If I don't gain my set kilo a week by deliberately not eating enough, then I will be discharged. So *I had no choice* but to go home and eat everything (Diary, 25th February 2007).

The ability to locate responsibility for eating in the treatment programme was a compromise that, in some ways, made inpatient treatment appealing. Early in my admission I wrote:

> I would probably cope here with weight gain, because the fat on my body wouldn't be down to me - it would be in the control of someone else so I could just blame them. You're in a shell, protected from the rest of the world. You don't have to face all the consequences of fatness, just being fat and hiding away (Diary, 15th October 2006).

Nearing 'normal weight' also made it even more difficult to be around other patients.

Describing a therapeutic group, I explained in my diary:

> [We were] looking at pros and cons of changing anorexic behaviours […] Makes me feel like shit because I'm sat there blatantly one of the fattest people in the room and it looks to an outsider like I don't have any anorexic behaviours (Diary, 7th March 2007).

I considered that my size revealed that I was bad at anorexia. If thinness is indicative of one's successful moral resolve against hunger (Lavis, 2011), being (or nearing) a 'normal' weight belied my lack of success. Body fat indicated my disloyalty to anorexia, and disloyalty felt like an immense loss.

After twenty-four weeks in treatment, I temporarily reached a BMI of 19 before deliberately undercutting my meal plan. As I neared the end of my admission, my weight was becoming my own responsibility again (I was now eating away from staff), and accordingly my 'permission' frittered away. Further, my partner and I split up, in part (I feel) due to my preoccupation with self-starvation, and the time I spent away in treatment. This made my imminent discharge feel even more uncertain.

> I'm absolutely dreading being discharged […] I don't want anything - the job, friends – nothing (and) I don't want to have to find somewhere new to live. I have actually considered, like properly considered suicide as a real option, but I don't want to die […] I just don't want to have to deal, cope, get by etc in the real world when I feel this depressed (Diary, 27th April 2007).

Being an inpatient for eight months had disconnected me from 'the real world'. I had previously wanted to recover for the sake of my personal relationships, job and other interests, but over time these lost their motivational influence. Rather than being immersed in 'normal life', I had been in a unit where anorexia was ever present - in other patients, in the treatment programme, in my daily interactions. I was used to anorexia being the standpoint from which I related to others, and the way that I understood myself. It was now even more familiar to me than ever before. Not only this, but I had also been exposed to a new, 'other' anorexia, which was more than my own self-starving. It was an anorexia that

was bound up with clinical activity and involved being *really sick* - multiple hospital admissions; concerned doctors; deathly low weights; being detained; physical complications; bed rest; threats of tube feeding[52]. I suggest that this 'serious anorexia' can be understood as an 'anorexic script' (Brinkmann, 2016). 'Anorexic scripts' emanate from the diagnosis of anorexia and ascribe expectations of how the individual with anorexia behaves, their physical appearance and motivations, and how their distress psychologically manifests. There are numerous overlapping 'anorexic scripts' which informed my own (and, as I show in chapter seven, also participants') self-understandings and the performance of the diagnosis in important ways. 'Serious anorexia' is a script dictating absolute committal to food refusal, extreme self-starvation and emaciation, and – crucially - clinical recognition of physical illness. I saw this anorexia in others and their treatment and I heard it in their histories. I saw it in the 'high dependency' rooms on the unit, with special mattresses for the *other* patients whose weight was so low they would otherwise get bed sores. It was detailed to me by staff, who told of the threats anorexia posed to me in the future if I did not 'recover' now. The SEDU privileged this 'serious anorexia', which for me carried intangible overtones of success and achievement. As Lavis argues, the clinical practices associated with anorexia form part of the desire for it: "through both its legitimisation of, and intervention into, 'anorexia-as-illness', the clinic itself […] is central to pro-anorexic desire" (2011: 279). To me, it seemed remarkable, and was elusively appealing. Beginning with this first admission, gradually (and imperceptibly at that time), my 'wanting' was shaped by the SEDU and clinical discourse I was immersed in. My sense that I needed to lose weight was no longer *only* about wishing to return to the 'psychological benefits' of extreme food restriction. It was

---

[52] 'Tube feeding' refers to the use of a nasogastric feeding tube to "promote weight gain and to correct severe nutritional deficiencies" (Kells and Kelly-Weeder, 2016: 450). It is a practice used in the treatment of 'severe' eating disorders, clinical guidelines for which state that "the preferred route of feeding is oral. However, some patients fail to gain weight when fed orally […] Others may resist weight gain by any means and in such cases compulsory treatment (always under the relevant mental health legislation) using nasogastric intubation and feeding may be necessary" (RCP, 2014).

also about desiring the diagnosis of anorexia itself (Lavis, 2011), and the construction of it I had encountered in treatment.

Once discharged, I continued the weight loss that had begun on the unit, although I was not really sure why. None the less, two weeks later, I was back at work and had moved in with my close friend. However, I felt incapable of doing my job, struggled to adjust to life out of hospital, and was extremely lonely. An unshakable feeling of displacement cemented my continuing weight loss, and I began to more actively seek a return to anorexia, now with a clear picture in mind as to how this should 'look'. I restricted my diet much faster than I had previously, and as a result felt far worse physically and was utterly miserable. I had constant nausea and a low-pitched hum ringing through my head, which I imagined to be a physical manifestation of my low mood. As others (friends, family and my community team) expressed concern that my rapid weight loss would continue, I felt anxious about not losing enough weight to meet this expectation. "[I'm] concerned that everyone is concerned. In case I don't lose more and all the fuss is over nothing (what a terrible anorexic!)" (Diary, 29th May 2007).

My community team seemed exasperated, as I was not only very open about my weight loss, but also about the fact that I would not even try to stop it. Their concerns for my physical health escalated when a blood test indicated muscle wastage and eight weeks after I had been discharged from the unit, a referral was made for me to return.

> Relapse of anorexia […] Has ruled out any possibility of community-based treatment working […] weight almost certain to go down further […] mood blunted with little emotion evident. Rational acknowledgement of the consequences of continuing as at present but inability to do anything to change things (Medical notes, community team, 3rd July 2007).

At my pre-admission assessment at the SEDU, I was told that the speed of my weight loss meant that I risked being sectioned and admitted elsewhere (to a general ward or

psychiatric unit) if I did not agree to an admission. I agreed, and used the three-day wait to be admitted to lose more weight. I wrote in my diary that I needed "to be as low weight/look the thinnest possible for my admission". I had wanted to show through my body that I deserved to be called anorexic (Warin, 2010), and that my admission to the unit was justified.

The first few days of this second admission I was utterly disoriented and confused, and as I began eating, overwhelmed by the sensation of food in my stomach. I wrote in my diary:

> I don't even know what the date is. I hardly even know what's going on. It's been horrible. I feel like I've just been thrown in and everyone assumes I know what I'm doing because I've been here before […] I am so not with it. I feel completely hideous for the food I've eaten […] My head is somewhere else, my leg muscles feel strange, I feel a bit high like I've taken something (Diary four, 12th July 2007).

Medical notes from the same day state:

> Anxious and tearful young Caucasian female […] rapport – poor (tearful and unwilling to speak) […] mood low, judgement and insight partial (recognises her poor health and inability to cope well) (Medical notes, SEDU, 12th July 2007).

I immediately compared myself to other patients:

> There are some girls here who are so, so, thin. Wish I was more like them, so that maybe people would care that I am eating, or I would feel more justified in looking like I don't want to eat. I feel as though everyone thinks I am putting on a show (Diary, 12th July 2007).

The culture on the unit was different from how it had been previously, due to there being some patients who were under section and (more or less openly) not 'complying with the programme'. Their presence underlined to me the possibility of being on the SEDU as an involuntary patient. I found the idea that, in contrast to them, I was *choosing* to be in treatment and therefore choosing to eat, distressing:

> Lauren spoke about feeling undeserving and confused about why she's here i.e. feels 'normal' and 'too big' etc […] expressing much distress at 'choosing' to be here, much guilt after and during eating (medical notes, SEDU, 13th July 2007).

In response to this distress, on the third day, I did not finish my breakfast. By the next day, I had almost entirely stopped eating and was covertly exercising. I was then told that I would be sectioned if I did not eat my lunch, but I could not wholly believe this would happen (not to me; I was not a serious-enough anorexic). This ultimatum that had been given to me by staff defined the 'anorexic' option for me, and I now 'had' to *not* eat, otherwise I would be taking the less-anorexic route. So I did not even try. Medical notes from this time describe:

> Lauren lacks the ability to 'hear' how ill she is […] she cannot hold the distress of having to eat herself to better health. Her reasoning is illogical, she refuses to let herself be encouraged to be fed […] (she) is currently physically unstable and lacks the insight to agree informally to treatment (Medical notes, SEDU, 16th July 2008).

That afternoon I was placed on bedrest and constant observations[53] and sectioned[54], on the grounds of an abnormal electrocardiogram (ECG) reading, my BMI dropping below a certain critical level and staff's resulting wish to be able to tube feed me against my will if I did not eat.

I stayed on bedrest for a week. During this time, I was taken to the general hospital site for a heart echo and scan of my lungs, due to health concerns including a suspected blood clot on my lungs. During the heart echo I lay on my back topless on a cushioned, cold bed, a nurse from the unit to one side, and the clinician performing the test stood to the other. In

---

[53] 'Constant observations' is terminology which refers to the mental health nursing practice of 'special observation'. This involves "maintaining an increased level of observation over particular patients when they are acutely ill […] with the purpose of maintaining safety and reducing the risk of adverse incidents" (Chu, 2016: 21). The SEDU I was in adopted a commonly used framework of 4 different levels of observations of patients. Level 1 was 'General observation', level 2 'Intermittent observation', level 3 'within eyesight', and level 4 'within arm's length'. The latter two levels were known as 'constant observation', because these involve the nursing staff remaining in very close proximity to the patient at all times (Chu, 2016).

[54] I was placed on a section 3, also known as a 'section for treatment'. This is used to detain someone for 6 months.

this situation, I no longer felt like the 'stubborn anorexic' I was becoming on the SEDU, but like a compliant and potentially critically ill patient. None the less, I still did not feel like I belonged here. I looked down at my body, and no matter how hard I tried, I could not see the deathly thin anorexic body that I imagined this situation required. *They don't think I am thin enough for this*, I thought. Looking at the black and white 3D image of my heart on the screen, I momentarily felt differently about my body. The very private 'psychological' experience that was my anorexia had been transformed into an organic reality on the screen in front of me, to be experienced by others, as well as me. I temporarily saw my body not as an entity to will against, but as biologically dependent and mortal. Briefly, death felt like a possibility as opposed to some abstract, meaningless threat, and I felt sorry for my body, as if it were another person I had mistreated.

I recall an occasion from this time when my psychiatrist stood talking to me while I was on bedrest, and told me starkly 'Lauren, your anorexia is killing you'. In that moment, I wanted so badly to connect to what he had said, to find something to cling to amidst the precariousness of the vision I had of myself as properly anorexic. Indeed, serious medical conditions, in playing the fine line between life and death, can give more credibility to the diagnosis of anorexia (Warin, 2010). But the words were ghost-like and ungraspable, unable to do the job of confirming my anorexia.

The results of the heart echo and scan were 'clear', but due to ongoing concern for my physical health, staff decided to tube feed me. When I was told, I was overcome with distress and sedated. The idea of gaining weight was difficult enough, but, following such an intense period of starvation, the thought of not even having the consolation benefit of eating food was unbearable (although believing that an anorexic should not be wanting to eat, I could not have actually said this). I also felt overwhelmed by the idea of liquid calories

entering into my body without my actions (eating) mediating the process. It seemed that being tube fed would completely unravel me.

Due in part to my persuasive negotiations with staff, I was not fed through the tube for long, although it stayed in situ for a few weeks so that it could be used if needed (if I refused to eat). Over the next few months, the tube, along with completion of meals, bedrest, constant observations, cigarette breaks and my use of the wheelchair, became sites of negotiation with staff and were utilised in the micro-boundaries instated to manage my behaviour. The tube was sometimes reinserted for one-off 'feeds', and I was occasionally 'controlled and restrained' and 'force fed' using the tube.

Wearing the tube allowed me to negotiate my positioning, both personally and socially, as someone who was eating but none the less 'good at anorexia' (Lavis, 2011). I could attribute my eating to the threat of being tube fed, positioning me as someone who 'had no choice', and allowing me an important compromise by locating the responsibility for my eating elsewhere (ibid, 2011). It carried pro-anorexic desire (ibid, 2011) and functioned as a "personal and public signifier of [my] anorexia" (Halse et al, 2005: 11). Thus, the tube crucially enmeshed with my identity (Halse et al, 2005), and the same was true for other practices that were, for me, invested with similar meanings (such as bedrest and constant observations).

In addition, the tube signified a particular 'type' of patient; the 'bad anorexic patient' who is defiant, non-compliant and refuses to eat at all costs. 'Bad patient' is, I suggest, another anorexic script, one that overlaps with 'serious anorexia'. In chapter seven, I examine the 'bad patient' script in detail, noting how it overlaps with ideas about being 'good at anorexia', and understanding it in relation to a 'good anorexic patient' script. However, for now it is helpful to highlight how the 'bad patient' script is evident in clinical discourse. In

hospital-settings, those diagnosed with anorexia are generally assumed to be 'non-compliant' and 'difficult' (Darmon, 2017) and are "notorious for their often concerted resistance to therapeutic processes" (Gremillion, 2003: 3). Clinical literature describes how 'anorexics' are 'difficult to treat' due to them being manipulative and devious (Bruch, 1988) and actively subverting therapy (Vitousek et al, 1998). The 'bad patient' script was certainly evident to me in the inpatient environment. Especially from my second admission onwards, I lived alongside other patients who were publicly known to be 'non-compliant'. Moreover, the script was reflected in the preventative rules on the SEDU. These rules, such as having to be observed post-meal and not being allowed free access to water, were designed to prevent 'deceitful' behaviours such as water loading[55], hiding food and vomiting after meals. Often, it was the very existence of these rules that made me aware of the behaviours. Discussing water loading, Gremillion notes that treatment environments "underline this as a possibility for patients by institutionalising a response to it" (2003: 14). Crucially, I experienced these possibilities as expectations. When I was exposed to the suggestion of such behaviours but was not engaging in them, I found my anorexia wanting (Lavis, 2011). The SEDU assumed how individuals with anorexia behave (i.e. deceitfully), and embedded this assumption in its treatment responses and everyday dialogue on the unit. These assumptions informed the anorexic scripts that I drew on and tried to fit myself into, so that when I acted in accordance with them, it strengthened my alignment with anorexia. Indeed, especially during later admissions, there were numerous 'secretive' behaviours I engaged in, such as exercising (detailed below), hiding food, and water loading. These behaviours were intended to maintain my anorexia by resisting weight gain, but they also impacted my sense of self. They were productive because they allowed me to reassert my self-determination and

---

[55] Water loading refers to the practice of distorting one's weight so that it appears higher, by consuming large volumes of liquid prior to being weighed.

retain my anorexic identity (Rich, 2006). I felt empowered by the knowledge that I was acting in these 'extreme' and secretive ways. Witnessing myself acting how a 'serious' and 'non-compliant' anorexic acts felt comforting and affirming and allowed me to embody my diagnosis.

About two weeks into my second admission, I started to regularly exercise in secret. This increased rapidly and led me to avoid weight gain for seven weeks, despite eating a weight gain diet. My 'need' to exercise moved fluidly between being driven by *me*, because I wanted to keep the number on the scales down, to being something that I could not prevent and which overwhelmed me. On one level, it felt like a crucial lifeline, the only thing holding me together and stopping me from completely losing myself. On another, it was torturous. I wanted to rest and my body ached. Each day I woke up early and exercised in secret, moving between different rooms as staff did their checks to avoid being caught. And each time I woke, I was awash with dread about all of the exercise I would have to do that day, and anxiety about how I would manage to achieve it without being stopped. Eventually, having not responded to numerous exercise 'care plans', I was put on bedrest and constant observations and given a diet increase to force me to gain weight. I was also prescribed regular Lorazepam to reduce my distress.

The initial weight change during bedrest was unbearable. More so than at any previous time, I could not tolerate the numbers on the scales increasing.

> Yes, the inevitable happened, I gained weight and I can't cope with it. I can't even write about it yet because I can't accept it […] I feel like I'm cracking up (Diary four, 18th September 2007).

Partly, weight gain was intensely difficult due to my awareness that I was losing the thinness that made me feel psychologically safe. In addition, the sensation of becoming larger was intolerable and led my mood to depress significantly. But more than this, weight gain was

hard because it meant treatment was 'taking away' my anorexia. I knew that the weight gain following one week on bedrest was not visually noticeable. Yet, it made me feel I was 'cracking up' because it was symbolic of my undoing (Lavis, 2011) and undermined my belonging to anorexia. Fox and Diab (2015) suggest that it is superficial to reduce the distress associated with 'refeeding' to a symptomatic 'fear of gaining weight'. Rather, they argue, it results from the weight gain challenging the way that one perceives oneself and undermining one's 'anorexic identity'. I also felt that weight gain invalidated my suffering. In the SEDU, 'more thin' was equated with 'more anorexic' (Lavis, 2011), and as such a higher BMI positioned me as less deserving of care. I wrote in my diary "I guess what I fear is not only me getting fatter but also the fact that when my but BMI is higher I won't be able to struggle as much" (Diary, 25th August 2007).

On bedrest, there was nothing I could do to prevent weight gain so I stopped fighting it, but not without expressing how much I hated it. I was frustrated, and the tensions between myself and staff increased as their more immediate and blatant policing of my behaviour so obviously positioned us as working against each other. I spent many hours writing in my 'red book', a personal diary for which staff were an imagined audience. I wrote about 'my anorexia' and why I missed it. I expressed my intense anger and sadness and how hard it was gaining weight. In my references to what 'they' were 'doing to me', I reinforced a particular relationship to staff and the treatment programme – one in which I was being forced to give up anorexia against my wishes.

Over the two to three months following bedrest, I got used to my weight steadily increasing and came to begrudgingly accept the inevitability of the process. In the main, I complied with treatment. This allowed me to negotiate with staff a BMI target of 16, by persuading them that I would maintain my weight at this level. They agreed but labelled it 'against medical advice'.

During the latter stages of this admission when I was maintaining my weight, being reminded of the earlier stages invoked feelings of loss and sadness:

> There is a new girl here being tube fed and on 1:1 nursing. Don't like the feeling it brings about seeing someone this ill. I think it is jealousy? I walked past and the image of her laying on that bed in the room I was in – it was like a twist in my gut. As horrible as 1: 1 was, I guess it reminds me of that nice secure place that was the height of my illness. There is no guilt because you are in a situation where there is literally nothing you can do to lose weight, it's all out of your hands (Diary six, 17th December 2007).

Towards the end of this admission, I was very uncertain about what to do next. I felt compelled to lose weight, but also miserable about the impending hunger. On the day my section was lifted, I made an in-the-moment decision to stay in treatment and gain more weight. However, when it came to it, I could not shake the guilt that came with voluntarily eating more food, and one week later, I self-discharged. As I was now a voluntary patient, I was allowed to go home.

> Feel like shit […] Stuck and depressed. It's no good being here […] can't tolerate any more weight gain! I want to go backwards. Don't want to eat less and go hungry but do want to lose weight (Diary six, 27th January 2008).

> I did it, I discharged myself and I am back at home! It was all very easy […] [psychiatrist] simply asked "why do you want to be discharged" and I said "I can't tolerate any more weight gain"-there was no trying to convince me or anything (Diary six, 31st January 2008).

Upon returning home, I immediately began losing weight. I suspected that this would lead to a return to being an inpatient, but it still seemed preferable to trying to live 'normally'. I only wanted to be 'anorexic Lauren', because this was an identity that had come to offer me a sense of belonging (I explore this further below), and inpatient treatment was a part of that. After six weeks of intentionally rapidly losing weight, my community psychiatrist sectioned me and I went back to the unit.

> She is medically now at risk [and] unwilling to go into hospital despite being aware that she faces a life-threatening situation. Admission is the only way to keep her safe […] In the absence of a section Ms O'Connell would probably not co-operate while in hospital (Medical notes, community team, 4th March 2008).

I knew that being under section was suffocating and the source of much distress. However, I was unable to agree voluntarily to an admission, because I could not be seen to be agreeing to eat.

> *I am lying on a bed in one of the high-dependency rooms on the unit. I have just begun my third admission. It is teatime. Lauren doesn't begin admissions and simply eat. So I refuse to eat. They say they will have to tube feed me. I agree. I know I will begin eating tomorrow, but I have to not-eat just this one time. I have to be seen to be acting how Lauren acts. As I quietly lie in my bed, I can hear the rhythmic turning and ticking-over of the machine which slowly feeds the liquid-feed down the nasogastric tube, into my stomach. Here we go again. Time to un-do the hard work of starving. Time to gain weight again. The thought of the liquid feed entering my stomach is nagging and biting at the edges of my mind. In these moments, anorexia feels like the very centre of who I am. Seeing myself in this way is all-encompassing, comforting and euphoric* (memory recall).

In situations such as these, I moved fluidly between feeling empowered and disempowered. The situation was disempowering; I was legally detained, unable to make decisions for myself, and physically restricted. Yet, personally and secretly, the sense of mastery I felt having become this sick gave rise to rushes of elation that at times made me feel 'high'. Warin (2010) discusses the symbolic power offered by anorexia, that arises from its mark of distinction and sign of belonging to an elite group. For me, this distinction came largely from clinical intervention. The fact that others needed to intervene, that I could push the boundaries so far that I was forced into having to *be fed*, was empowering. There was also something very comforting and validating about engendering concern in clinicians. I felt better when I worried them.

By my third admission, which began five weeks after my previous one had ended (which had been six months long), the diagnosis of anorexia had come to offer me a place in the world based on psychiatric disorder, and this in some ways felt easier than the anxieties of

ordinary life. On the one hand, identifying with the diagnosis, and being Lauren-in-hospital-with anorexia, provided a sense of belonging that was hugely comforting (Warin, 2010); I belonged to the world of psychiatry, inpatient treatment, and medical monitoring. Yet on the other, it made me different, and allowed me to avoid the expectations and uncertainty that I felt were placed on me as an ordinary person. The diagnosis of anorexia, and the anorexic scripts I encountered, offered me a blueprint for who I could be, when I otherwise felt very unsure. During my second admission, I wrote:

> I don't really know who I am. I have no centre or core to my personality. I don't know how to be. I seem to spend my life pretending and flipping between different Laurens, depending on who I am with […] This leaves me feeling that no one really knows or understands me (how could they when I don't understand myself?). They are fluid, transient identities, they are not solid or anything to build yourself around. Anorexia, however, that is something real. It is authentic. I don't know who Lauren is, but I do know Lauren the anorexic (Diary, 17th September 2007).

I had come to value an identity based on 'serious anorexia' and being a 'bad patient', and was highly self-conscious regarding how I was performing it. Inpatient admissions had become an integral manner through which my anorexia was validated. However, over time, the more I acted in accordance with 'serious' and 'bad patient' scripts, the more problematic these positionings, and the experience of inpatient treatment became, in ways I address next.

Hospital restrictions and a pathologised identity

During my third and fourth admissions, my struggle against the treatment programme that had occurred previously continued. However, in these later admissions, staff increasingly saw me as 'risky', not only due to being 'medically unstable', but also because of my mood, self-harm and because I was as perceived as a potential suicide case.

An example of how this played out can be seen at the start of my fourth admission. I was admitted voluntarily (under non-forceful but persuasive coercion, whereby the 'threat' of the Mental Health Act was invoked) and once on the unit did not eat (having not eaten at

the beginning of my second admission, I felt I had to 'keep this up' in all admissions). Notes

from my ward round on the second day describe me as having 'significant compromised

health' and as 'a massive risk to herself'. I had left the meeting distressed, and the notes

indicate that following this, the whole staff team were informed that I was at risk of

absconding, self-harm and suicide, and that I met the criteria for detention under a section 5

(4)[56] I was indeed sectioned later that day, after being 'safe held' (physically detained) by staff

when I tried to leave. I was initially detained under a section 5 (4), followed shortly by a

section 5 (2)[57], and was then placed under a Section 3 the following day. Notes from the

Section 3 paperwork state:

> Has ischaemic heart changes on ECG and has been manipulating her weight to prevent readmission. She has suicidal ideation […] her BMI is around 12. She needs urgent refeeding, this will only be possible if detained. [Lauren] was tearful throughout the interview and labile in mood (Medical notes, SEDU, 20th November 2008).

During the latter two admissions especially, my mood was indeed extremely low. My inner

world had become bleak and chaotic and I felt increasingly desperate. My treatment

reflected this, as it became ever more restrictive and I had increasingly less 'freedom'.

The more I adopted the 'anorexic role', and the more time I spent in hospital under

restrictive conditions, the more I became distanced from 'normal life'. In turn, I sought to

grip more tightly onto anorexia. Lavis (2011) describes how a recognition of the damage

that anorexia has done to one's life can serve to increase pro-anorexic desire, to the extent

that anorexia seems necessary. At one point, I had lost all desire to pursue a career, had no

home, no partner, and was accustomed to living in an institution. In these conditions,

seeking to do anorexia well (instead of normal life) made sense. Seed et al (2016) note that

---

[56] A section 5 (4), also known as 'nurse's holding power', is used to detain someone for up to 6 hours.
[57] A section 5 (2), also known as 'doctor's holding power', is used to detail someone for up to 72 hours.

the loss of friendships, normal life and life skills that results from being in inpatient treatment for extended periods of time and from being repeatedly detained under the Mental Health Act can contribute to dependence on the treatment environment and relationships. This in turn impacts on one's illness trajectory, making it harder to 'let go' of one's 'anorexic self'. I certainly felt this spiralling impact.

I spent the last two admissions feeling entirely 'stuck'. I continued to want anorexia, and as alternative options seemed to narrow off, I reached a point of being entirely unable to imagine life without it. With anorexia seeming inevitable, I was overcome by a pervasive hopelessness, as I saw an extremely bleak future. For many months, change did not seem possible, and I felt psychologically overwhelmed by the idea of eating and living 'normally'. However, during the last two to three weeks of my final admission, my perspective began to gradually shift, largely due to a wish to avoid future hospital admissions. I was now finding the treatment environment, and the lack of autonomy that came with being under section, utterly intolerable.

I had often felt it unjust when staff used pre-emptive responses and, for example, increased my observation levels due to perceived risk. It felt as though I was being punished for emotional responses that I thought were quite understandable, given my situation. Taking an example from my last admission, I had submitted to staff numerous requests for greater freedom prior to a meeting. These included being allowed home leave and to prepare some of my own meals. At this point, there was an expectation that I would be discharged eleven days later, so I argued that these requests would be helpful preparation for going home. During the meeting it was decided that my section would be lifted but that my requests would not be met. Notes made by staff during the meeting state:

> She is not close to recovery […] she is very impulsive […] she is manipulating her weight to keep out of maintenance range […] [Psychiatrist] explained that this unit is not the right place for Lauren, as she is eating, but not doing the psychological work. Plan: [Psychiatrist] will take off section today, no leave […] no preparing meals (Medical notes, SEDU, 6th January 2009).

To staff, I was behaviourally complying with meals, but not taking on the unit's definitions of progress and recovery (Darmon, 2017). I was upset that my requests were not met and could not understand how I was being discharged in a few weeks yet not allowed any 'freedom'. Feeling unfairly treated, I declared that I would go on leave anyway now that my section was lifted. In response, they reversed their decision about the section. I then became even more upset, in turn increasing how 'risky' I was judged to be. Staff reacted by changing my cigarette breaks from 'unescorted' to 'escorted', and my upset deepened further:

> Lauren has been really angry since her review especially since her cigarette breaks have to be escorted again. She has been unable to channel the anger appropriately at this time (Medical notes, SEDU, 6th January 2009).

I recall well how asphyxiating and disabling this series of moves felt, with staff reactions to my distress and frustration only increasing my distress and frustration.

Being unable to make my own decisions significantly undermined my sense of agency and I felt positioned in a child-like role, which I found humiliating. I also frequently felt 'unheard' and my reasoning invalidated due to my inability to escape an anorexic framing. False accusations of 'non-compliance' felt impossible to refute, and this can be understood in terms of Goffman's (1961a) 'looping'. Here, my reactions to my situation were collapsed back into the situation itself; my denial of 'anorexic behaviour' was interpreted in terms of the pathology of anorexia. With my behaviour being viewed as 'symptoms' (Dobransky, 2011), I was unable to defend myself in the usual way (Goffman, 1961a). A memorable example is from my last discharge meeting. The psychiatrist opened this by challenging me

on my recent request to change care-coordinator. I had cited the reason of a 'personality clash', having felt unable to develop rapport with her and finding her manner patronising. At the start of the meeting, I was questioned as to my 'true' intentions and accused of wanting a new care-coordinator because 'the anorexia' wanted someone new to manipulate. As a 'deceitful anorexic', finding a way of believably rejecting their suggestions was impossible.

Despite sometimes seeking to be positioned as a serious, defiant anorexic, this identity was also extremely problematic. Indeed, much of the experience of anorexia is contradictory (see e.g. Fox and Diab, 2015; Warin, 2010; Rance et al, 2017b). In treatment, anorexia was reductively constructed as a pathologised, medicalised condition, and while in some ways affirming, this also sometimes led me to feel misunderstood, invalidated and stereotyped (Eli, 2014b; Rich, 2006; Malson, 2004; Boughtwood and Halse, 2010). Anorexia became the overriding source of my identification, leading to my behaviour being automatically interpreted as symptomatic of illness, and resulting in me feeling powerless and discredited (Malson, 2004; Eli, 2014b; Boughtwood and Halse, 2010; Smith et al, 2014; Seed et al, 2016). I therefore also sometimes attempted to manoeuvre out of a 'purely' anorexic positioning, in order to regain voice and a sense of legitimate personhood.

Eventually, I came to realise that the longer I was in and out of treatment, the further the walls would close in. Sensing that I should try something different, I gradually, tentatively opened up in my mind to the idea of letting go of anorexia.

I was discharged for the final time with a plan in place dictating that should my weight drop below the agreed range, I would be admitted to the local psychiatric unit or a general medical hospital for 'refeeding'. In the immediate months following my discharge, I maintained my weight as required. It was hard, but I was motivated by the novelty of being out of hospital for a long period. However, after roughly three months, I began to binge eat.

I would feel an intense desire for food that was so overwhelming it was impossible to think about anything else. I would then eat in a wildly out of control manner, abandoning the rules and restrictions that ordinarily directed my eating. These episodes felt freeing and elating at first, and a huge relief would wash over me as I gave into the needs, desires and urges I had suppressed for years. However, the aftermath was horrific. I was in physical pain and full of shame, regret, and self-hatred. It is difficult to fully convey just how distressing bingeing was. It was confirmation that I was greedy after all; my anorexia *had* been fraudulent. I had expressed a fear of bingeing when I was in treatment, but this was invalidated and I was told that it was 'just my anorexia talking'.

During this time I was still attending appointments with the community mental health team. Bingeing was much harder to explain to professionals than starvation and I sensed that they hardly cared, because at least now I was eating. I felt enormously misunderstood and fed up with having to explain myself. I was also intensely ashamed attending appointments now that I was no longer 'anorexic'. It had felt justified to be sat in a psychiatrists waiting room while I was extremely thin and starving. It was painful to be sat in the same room bloated from bingeing and twice the weight I had previously been. I wanted nothing more to do with services, so I used my weight gain to claim wellness, and six months after discharge from the SEDU, my psychiatrist was easily convinced to discharge me from community services:

> Her weight is now normal and has been for 6 weeks […] There is no evidence of anorexic behaviours. Overall I found Lauren extremely well settled and I don't really see a role for myself to continue to be involved in her care at the moment (Medical notes, community team, 11th August 2009).

Two months later, I returned to university to finish my Masters. The bingeing continued in a fluctuating pattern, sometimes happening on a daily basis, and sometimes 'only' once or twice a week. By one year after discharge from the unit, I was 'overweight'. I struggled massively with my new body size, and the speed with which my previous sense of self (as

anorexic) had been ripped away from me. It was unbearable. Feeling the need to do

something extreme in response to my own desperation, I took an overdose. I went to a

shop, bought paracetamol and food, came home, binged, overdosed on paracetamol, left the

house and called an ambulance. I was admitted to Accident and Emergency overnight, where

I was visited by the hospital's psychiatry service.

> Alongside her feelings of worthlessness she was particularly upset by the shift in her
> eating disorder […] When not distracted her thoughts are about food and suicide
> and she is struggling with this and is reluctant to ask for help […] her mood was
> objectively and subjectively low and she presented as tearful throughout (Medical
> notes, hospital psychiatry, 21st March 2010).

I was advised to see my GP to have my anti-depressant dose increased and an emergency

outpatient appointment with a psychiatrist was organised. I had that appointment two weeks

later, with a locum psychiatrist:

> Lauren […] still feels detached about the event [overdose] saying that she has just
> carried on without any particular feeling that she wishes she was dead or alive […] I
> did ask her gently about the actual binge episode, and she understandably said how
> painful it was to actually describe them, with real sense of shame attached […] her
> thinking showed evidence of the old imprints of black and white thinking e.g. that she
> is either totally well and in no conflict […] or there is no hope for change (Medical
> notes, outpatient psychiatrist, 31st March 2010).

This psychiatrist later wrote a letter requesting that I was offered help with 'stabilisation' on

the basis that I was now struggling with bulimia and risked retreating back to anorexia. A

few months later I moved to a different county and informed my new GP that I did not need

support. Just prior to moving my eating had become slightly less chaotic and the frequency

and intensity of my bingeing reduced. After I moved, I learned about, and attempted to

adopt, intuitive eating practices. This involved eating in accordance with my natural hunger

and fulness signals rather than externally defined 'rules'. My binges reduced further as a

result, and my eating patterns and weight began to normalise.

Conclusions: being and doing anorexia

Through this autoethnography, I have addressed the 'being' and 'doing' (Brinkmann, 2016) of

my anorexia diagnosis. Over time, I came to value an anorexic identity, and this had

implications for how my suffering was 'done'. The diagnosis of anorexia was invested with

desire; it was a positioning I strove towards and which sometimes felt empowering (Warin,

2010; Lavis, 2011). As such, I sought to inhabit my diagnosis. This involved an anxiety

provoking, self-conscious monitoring of whether I was doing anorexia 'properly', and I did

this in relation to the anorexic scripts that were detailed to me in treatment. As I moved

through treatment, I learned new ways of doing anorexia, living up to the SEDUs implicit

expectations of how 'an anorexic' behaves and how anorexia manifests psychologically

(Lavis, 2011). In accordance with anorexic scripts, clinical recognition of my anorexia

became such an essential part of doing anorexia, that they were largely one and the same; I

needed to 'be medicalised' and recognised as 'difficult' in order to materialise my diagnosis.

I was aware throughout my admissions that I was making efforts to cultivate anorexia (both

in 'actuality' and appearance) that aligned with available scripts. In part for this reason, I felt

that my diagnosis was fraudulent. I imagined that if I had 'real' anorexia, I would not need to

try so hard. This was despite seeing 'real' anorexia in other patients, while knowing that

they too were highly self-conscious about how they came across. In this context of concern

about fraudulence, clinical recognition of anorexia (such as tube feeding and having a low

BMI) became central to its performance. These acted as identity markers, because they

proved my anorexia and warranted it a 'serious' status (Seed et al, 2015; Halse et al, 2005).

Yet, they also somehow never fully did their 'confirming' job. Any sense of having done

anorexia well enough was only ever fleeting and fragile. At the height of my illness, it was as

if my destination was always just there in front of me, visible but perpetually out of reach

(Lavis, 2011). As I strode towards it, achieving the markers I would have at previous points

imagined to be indicative of having reached my destination, these markers somehow lost their impact, and I never got there. This made leaving anorexia all the more difficult, because there was a sense that if I did it again, just one more time, I might get there.

I have paid attention to the self-conscious, performative aspects of anorexia. However, I do not intend to reduce my experiences down to an agentic performance. Rather, this was only one facet of my experience. It was important and impactful, but it did not constitute anorexia in and of itself. Rather, there was a 'core suffering' to my experiences that the self-conscious, performative aspects directed and 'policed'. My self-conscious monitoring of both my internal world and my outward appearance smoothed over the messy edges of my experiences and channelled them into a recognisable 'anorexia'(s). Moreover, I actively and meaningfully engaged in this process because 'being anorexic' served a purpose at that time, by providing me with a distinct, personally empowering identity (Warin, 2010) and a clear role, in a context of long-standing anxiety about who I was, my place in the world, and fears of not being 'good enough'.

Chapter four summary

In this chapter, I have conducted an autoethnographic exploration of my own experiences of being diagnosed with and treated for anorexia. I have detailed how I came to be diagnosed with anorexia, and what this meant to me at that time. I have also shown how I came to value an identity based on anorexia, and that this had implications for how my suffering was 'done'. I have used Brinkmann's conceptualisation of 'having' and 'being' a diagnosis, to show how, in seeking to hold on to a positioning as a 'successful anorexic', I sought to live up to the 'ways of doing' anorexia that I learned in treatment.

In chapter five, I move on to examine the different routes to, and experiences of, receiving a diagnosis of anorexia for participants. In later chapters, I use concepts of 'being' and 'doing' a

diagnosis as broad frames for examining participant's experiences. In particular, in chapter six, I explore participants 'anorexic identities', and in chapter seven under the frame of 'doing', I explore how the various 'anorexic scripts' that they encountered informed the ways in which they managed and performed their diagnosis. In each of these later chapters, I occasionally return to and further examine and draw on my own experiences, such that these are understood alongside participants' experiences.

Chapter Five
The process of being diagnosed

This chapter is concerned with the processes through which individuals come to be diagnosed with anorexia and what being diagnosed means to them at that time. I begin by examining participant's various routes to diagnosis. In doing so, I illuminate the different interpretive processes and circumstances whereby individuals' initial experiences of food restriction and weight loss led to help-seeking and were in turn recognised as 'anorexia' by a professional. I then turn to explore participants' subjective meanings of being diagnosed and recognise how this intervention intersected with their experiences up until that point. Lastly, I use a case study to examine one man's experience of coming to identify with anorexia but *not* being diagnosed. Michael was self-diagnosed, and I examine his case to shed light on the factors that shaped a trajectory of a 'missed diagnosis', and the subjective meaning of a potential diagnosis.

Routes to diagnosis

The route from the experience of 'symptoms' to being diagnosed with anorexia varied for participants, and was shaped by factors such as the subjective interpretation of 'symptoms', participants' social and relational circumstances, and the understandings offered by medical professionals. I identify and use three categories to describe the various routes; *self-directed and active*; *other-directed and passive*; and a *mixed route* of both self and other-directed, and both active and passive. For each category in turn, I summarise the key features, explore a case study example in detail, and then illustrate the category more broadly with reference to further participants.

Self – directed and active

There were five participants in this category. All were women who were first diagnosed with anorexia in their early 20s or in their 30s[58]. All had sought help via a GP after recognising themselves as struggling with a problem that was detrimentally impacting their lives, and for which they needed professional input. Four of them – Anna, Kelly, Maddie and Lisa - had thought of themselves as having an eating disorder (or a problem of this nature) at the time they initially sought help, or by the second time. The remaining participant, Naomi, had only a vague idea that an eating disorder might be the explanation for her difficulties, instead adopting an understanding of her problems as being more exclusively 'physical'. Once they had sought help, Anna, Kelly and Naomi all experienced a relatively straight forward route to being diagnosed, in that there were no significant protractions or problems experienced during the process. For Maddie and Lisa, the period from initial help-seeking to being diagnosed was more problematic. None the less, all alluded to a sense of choice and agency in their descriptions of the help-seeking and diagnostic process, in that they actively drove this and independently made decisions within it.

Anna is the case study example I have chosen for this route. She was 37 years old at the time of the interview and studying for a PhD. She had recently (within the previous month) completed one year of outpatient treatment for anorexia at a local EDS, having sought help from a GP approximately eight months prior to starting treatment. Anna positioned herself as *largely*, but not *entirely* 'recovered', recognising significant improvements in daily life since beginning treatment, but also the ongoing effort and strategising involved in recovery.

---

[58] Three participants were diagnosed with anorexia aged 21 or 22. One was diagnosed with anorexia in her mid-30s, and one was first given a diagnosis of bulimia in her 20s and then, approximately 10 years later, a diagnosis of anorexia.

Anna's experience of anorexia began in her mid-30s. She described 'disordered eating patterns' from a young age, such as eating irregularly due to a lack of interest in food or eating only a limited range of foods. However, she distinguished this from the development of anorexia which she described as her mind "latching on" to something and becoming the "focus of [her] attention" in a way that it had not done previously.

While Anna described herself as having been a "very skinny" child who under ate, the changing nature of her eating habits during adulthood meant that by the time she began her PhD, she was "fairly overweight". At the start of her PhD, she found it hard to adjust to the new 'social world' she was in, which she experienced as high pressure and competitive. During her first year, she made a significant effort to socialise and build a social network. She found this difficult and felt alienated by the unfamiliarity of the social settings and what she saw as an elitist academic culture. About half-way into her second year, in response to "intense feelings of stress and isolation", she began enacting a "plan". This involved controlling her eating and exercise and socially withdrawing. She experienced this 'plan' as all-encompassing and compelling, and as a useful way of dealing with the difficult circumstances she was in:

> I was eating, I was exercising, I was controlling, and the more I became obsessed with planning all of this, and monitoring everything and checking everything and weighing everything […] it just absorbed me and at first I found it really exhilarating, and it made me feel that everything had been terrible and then suddenly – I knew things were still terrible, I still felt terrible, but in a way I had this like little outlet for it.

With hindsight, Anna understood the implementation of this plan as a shift in the focus of her efforts; she entirely 'gave up' on working hard to fit in, and put significant energy and "exact attention" into weight loss instead.

Anna also found that as she lost weight, others stopped asking her how things were going, something she had previously found stressful. She felt that this was because they had assumed that the weight loss signalled that things were going well:

> For the first good stretch of it people just thought I was getting better, like I was losing weight down to a healthy weight […] they just assumed that I looked on top of everything and acted on top of everything.

She continued with her academic work during this period, although in hindsight she recognised that the plan had required so much time, energy and attention, that it slowed down her progress on her PhD.

Anna described herself as having been an acutely anxious person since childhood. Anxiety was also a significant aspect of her experience of anorexia. For example, constantly checking her weight and her body for signs of thinness felt reassuring and anxiety-reducing:

> I was so absorbed, that it was like the anxiety went away […] in the short term it seemed like this amazing solution I found for these really intense and overwhelming feelings of being anxious, and of failing and of not having things under control.

However, it was also an overpowering and excruciating experience:

> You have all the physical things of being very intensely hungry, and your body is bombarding you with thoughts of food and you cannot rest for a single second […] it is so intense.

Anna's weight loss continued at a rapid rate, and this prompted her to seek help from a GP. While things had been difficult for a long while, her restricted eating and weight loss was the more tangible aspect of her struggles than for example the loneliness she had experienced, and was something that she could 'take' to a doctor. This was a motivating factor for seeking help:

> I know when I started the [non-] eating that everything was terrible […] it's just that it became an extra thing of like now everything is really terrible and this is the part that I can actually explain to people […] it got to the stage where it was another terrible thing on a whole bundle of terrible things.

Anna deliberately sought out a GP who specialised in eating disorders, to whom she openly explained her ambivalent position. She said to the GP: "I'm losing weight fairly rapidly and I can't seem to stop myself from doing it […] I don't want to continue, but also I don't want to stop".

She described her weight at this time as 'not terribly low', and explained that for this reason, the GP monitored the situation for a few weeks before referring her directly to an EDS, and to her university's counselling service. She recalled that the word 'anorexia' was used by the GP almost immediately, after she had enquired about her weight history. Anna attributed the doctor knowing the 'signs' of an eating disorder and the details of the referral process to her specialist understanding.

Anna saw a psychologist at the university a short time after seeing the GP, and he confirmed anorexia. She described this as an "informal" diagnosis, due to it not being done "through the NHS". Anna then waited three months for an assessment with the EDS, after which she was given an 'official' diagnosis in a letter. She began outpatient treatment with the service a further four months later.

Anna had self-initiated help-seeking due to her personal recognition of herself as struggling. This recognition appeared to relate to a changing interpretation of her experience of weight loss, restricted eating and exercise from something that was performing useful functions which alleviated her pre-existing difficulties (such as anxiety), to something that had come to add to these difficulties. In addition, the eating part of her struggles felt like a more tangible and appropriate problem to 'take' to a GP than her other difficulties.

Thoits' (1985) symbolic interactionist conceptualisation of self-labelling illuminates the processes through which Anna came to recognise her struggles as a potential eating disorder. According to Thoits, when the individual self-labels they take the role of the 'generalised other', and "reflexively assess the *meaning* of one's actual or contemplated behaviours" (1985: 222, *emphasis in original*). If the individual observes themselves to be repeatedly breaking 'residual rules' (Scheff, 1966), they may understand themselves as disturbed, and thus seek professional help. Thoits conceptualises 'residual rules' in terms of emotional deviance, but recognises that other difficulties (for example cognitive problems) also lead to self-labelling.

Self-labelling seems particularly important for Anna, given the extent to which she understood herself as having a potential eating disorder largely in isolation from others. She had "totally socially isolated" herself, suggesting that her behaviour was not highly observable to others and that others' definitions of her behaviour were not a significant influence on her self-definitions, apart from imaginatively. This is also suggested in her descriptions of how others had tended not to interpret her weight loss problematically (at least initially).

There was a sense of personal agency and autonomy in Anna's account, which positioned her as an active decision maker. This is reflected in, for example, the fact that she was the only actor involved in the initial decision to seek help, and in her deliberately seeking out a specialist GP. Her experiences are suggestive of Pescosolido et al (1998)'s identification of a route into mental health services defined by 'choice'. Pescosolido et al identify a range of different routes, including 'choice', 'coercion' and 'muddling through'. Individuals whose routes to services are defined by choice actively seek help, and they make a decision that they want, or at least explicitly agree, to care. In contrast, the coercion route occurs when an individual resists care, but is (more or less overtly) 'forced' into it by others. 'Muddling

through' attests to routes in which the individual neither seeks nor resists treatment. Instead, they 'bounce around' and 'off' circumstances, without either they or others being identified as having directed the process.

Turning now to the active and self-directed category more broadly, one of the defining features is the self-recognition of a problem. All those in this category had come to interpret their own experiences as problematic, and made a decision to seek help. For Anna, Kelly and Maddie, there appeared to have been a more or less gradual 'tipping point' (or points) in which their experiences relating to food and weight took on a meaning as signs that something was wrong. For Anna, this process involved a recognition that the enactment of her 'plan' was adding to her pre-existing problems. For Kelly and Maddie, factors such as noticing a more problematic reaction to being 'made' to eat, and the manifestation of physical problems that interfered with everyday living (as opposed to purely 'psychological' distress) were important.

Taking Kelly as an example, her struggles with food had started as a 'normal diet'. Initially, when others encouraged her to eat more, she would feel uncomfortable, but none the less oblige and 'move on'. However, over time, her reactions to such situations changed:

> The point at which *I started to realise this isn't good* is occasions like my birthday, and someone would bring me a cake and I started to feel panicky and it wasn't kind of like 'oh I don't want to eat this', it was more about 'this is really terrifying I don't want it near me' (Kelly, emphasis added).

She explained that while she had experienced mental distress regarding food for some time, her decision to seek help from a GP, and her belief that she might have an eating disorder, were related to her development of physical symptoms.

> I was visibly really underweight and lots of people started worrying about me […] I was physically really exhausted and couldn't really go out and do much, couldn't really work anymore because I was so tired, and I think that's what spurred me on […] there was a lot of mental distress for a really long time, but it was only when the physical symptoms started, part of that was […] possibly me being less concerned, about being taken seriously […] it was the only thing that convinced me that I had an eating disorder because I think I was so used to viewing one image […] I kind of thought, 'oh I fit that bill now'.

Naomi had sought help for 'tummy problems' and rapid weight loss that was causing her distress. At this time, she had only very uncertainly considered the possibility that she had an eating disorder, but she knew that she wanted "something to stop what was happening". When anorexia was first suggested by her GP and she was advised to read books about anorexia, she immediately and readily identified with the diagnosis.

Lisa's experiences were different in that an identification with the idea of anorexia had come *before* the development of distressing 'symptoms'. At age 11, she read about a character with the diagnosis in a book. For many years following this, she 'fantasised' about the idea of becoming like this character, and began restricting her food intake and infrequently purging food. At age 18 she recognised a worsening of her struggles when she attempted to 'eat normally', but found herself unable to. She was "calorie counting obsessively", and bingeing and purging on food had become a "much bigger problem". Lisa initially sought help from a private counsellor, mainly for her struggles with anxiety and self-harming. While seeing the counsellor she also sought help from a GP for physical problems that were manifesting as a result of her struggles with food, and for medication for anxiety.

Regarding the process of reaching a diagnosis of anorexia after initial help had been sought, for Anna, Kelly and Naomi, this was straight forward; there were no significant protractions or problems and the first diagnosis they were given was anorexia. All had anorexia referred to or implied during initial GP appointments, and then an official diagnosis given at a later date by a specialist eating disorder service (for Anna and Naomi) or private psychiatrist (for

Kelly). They had all been referred to a specialist service by the GP from whom they had initially sought help, and reaching a diagnosis then involved waiting for, and attending, appointments with the relevant services.

Naomi was diagnosed approximately three months after she had seen her GP, and she described this as having happened 'quite quickly'. Anna, who was referred directly to an eating disorder service by her GP, also waited approximately three months for an assessment and diagnosis. She described this as 'agonising', however this seemed to refer more to the waiting involved in beginning treatment (which occurred a further four months after she was officially diagnosed), rather than for the diagnosis itself.

Kelly found herself significantly struggling and "really poorly" during what was expected to be a three month wait for an appointment with an EDS. In collaboration with her mum, she sought help from a private psychiatrist to eliminate the waiting process. The psychiatrist diagnosed her with anorexia and referred her for inpatient treatment. Despite this 'departure' in Kelly's experiences, there was still a sense of the process being linear in that there remained an 'expected' and successive progression from an initial suggestion of anorexia by a GP to an official diagnosis by a specialised professional.

For Maddie and Lisa, reaching a diagnosis of anorexia following help-seeking was more problematic. After Maddie's initial appointment with the GP in which she was 'dismissed', she returned to the GP on numerous occasions. However, the idea of an eating disorder "never really got discussed", and she was repeatedly offered other explanations for her struggles (such as 'stress'). She therefore had to keep 'pushing' for appropriate help, and this exemplifies the self-driven aspect of her route. However, she was also influenced by her family, as Maddie described her repeated returning to the GP as involving "a little bit of that

strong arm" from them. Eventually she was referred to a specialist service by her GP and diagnosed with anorexia.

At age 22, the GP whom Lisa saw while receiving private counselling offered her a referral to an EDS where she was diagnosed with bulimia. Lisa had sensed that this was not the 'correct' diagnosis, but explained that it is likely that she was given it in part because of how she had presented her struggles; she had 'downplayed' the extremes of her problematic eating at the EDS assessment due to feeling ashamed. Being diagnosed with bulimia was problematic because it emphasised to her that her binge eating was the problem, rather than her restricted food intake. The diagnosis of bulimia also "entrenched and compounded" her confusion, and "the feeling the anorexia was a figment of [her] imagination". About 10 years after the bulimia diagnosis, Lisa's struggles with food and weight had worsened, and she was offered another referral to an EDS when she saw a new GP. This time she was diagnosed with anorexia binge/purge sub type[59].

To summarise, participants in this category had self-driven help-seeking after identifying themselves to be struggling. The decision (or repeated decisions) to seek help occurred largely independently. Some experienced a straight-forward route to being diagnosed after they had sought help. However, largely due to the alternative interpretations made by medical professionals, two found reaching a diagnosis of anorexia more problematic.

My own experiences fit within this category. The occasions I had sought help for my eating related struggles had been self-driven and I had arranged appointments independently. Age 21 when I saw the GP and presented with anorexia, I identified with the diagnosis having

---

[59] In the DSM-IV and DSM–5, anorexia nervosa has two subtypes: restricting type and binge eating/purging type. The former is diagnosed when the individual has "not regularly engaged in binge-eating and purging", and the latter when they *have* "regularly engaged in binge-eating or purging" (APA, 1994; APA, 2013).

gradually come to understand my restricted eating in these terms during the months prior. From this point, reaching a diagnosis was unproblematic in that it was 'given' immediately.

Other-directed and passive

There were three female participants and one male participant in this category (Claire, Mia, Natalie and Ben). All were aged between 11 and 18 and lived with their parents or had recently left home when they were diagnosed. This category includes those who, at the time of initial help-seeking, had not personally understood themselves to have a problem that required intervention, and for whom others initiated the help-seeking. The initial recognition of a problem came from either parents, or staff at school who quickly informed parents. A striking feature of the descriptions given by these participants was their lack of agency in, and meaningful identification with, the process of help-seeking.

The case study chosen here is Mia, who at the time of the interview was 22 years old and living in her family home with her parents and younger brother. Mia described herself as having a chronic relationship to anorexia. She was first diagnosed aged 11 and had experienced repeated periods of anorexia and recovery. She had undergone both outpatient and inpatient treatment and had moved 'in and out' of different treatment arrangements as she recovered, relapsed, and was judged (by herself and professionals involved in her treatment) to be not 'working hard enough' at recovery. At the time of the interview, Mia was 'relapsing'; she was 'not managing' and her struggle had become significantly worse within the past month. She was seeing a doctor at an EDS for fortnightly appointments and having weekly counselling sessions at a charity.

Mia described having a 'fine' childhood prior to the onset of anorexia. However, she recalled a difficult transition from primary to secondary school which led her to feel panicked, and implicated this as a contextual factor in the development of her anorexia. She

also explained that, by the time she reached secondary school, she was frequently comparing how she looked to how her peers looked.

Mia further explained that in the lead up to her developing anorexia, she had fallen out with her friends and was not feeling 'socially accepted'. This prompted her to 'diet' and eat 'more healthily'. Over time, her dieting increased and then transitioned into (what she later identified as) anorexia: "It was like well as teenagers do, I'll go on a diet, and start eating a bit healthy and it got a bit out of hand. Then that mechanism came and the voice came".

As the above extract suggests, at this time she experienced anorexia as a person who was physically present nearby and encouraged her to restrict her eating. She emphasised how at this time, the focus of her experience was on the physicality of her body, and that she "just wanted to lose weight."

Over time, Mia's parents became concerned about her eating habits, and arranged a GP appointment. She stated: "I was sort of taken to the GP by my mum and dad because they were concerned that I was kind of being a bit silly and being a bit picky with my food for no apparent reason". Mia explained that she hadn't been remarkably underweight at this time, but that "in my head" there was definitely a "mechanism that wasn't right".

She did not agree with her parents that she needed to see a GP. She was aware that she was actively trying to lose weight, but did not identify this as a problem requiring change. Rather, her parents were the "ones with the problem". She became angry at them because the GP visit made it more difficult to continue restricting her food intake; the doctor had noted that Mia was underweight, and her family responded by monitoring her eating more intensively, and attempting to increase her food consumption:

> I had to be watched when I ate, things had to be added in, and then the games commenced really with hiding food, picking the lowest thing […] I just felt I was constantly in a battle.

Mia's weight was then monitored by the GP every two weeks and she kept a diary recording her food intake and feelings around this. During this monitoring period, which lasted for two months, she did not "make any change" to her eating, and as such was referred to CAMHS (Child and adolescent mental health service) where she obtained a diagnosis.

Mia's experiences resonate with the third career stage in the process of 'becoming anorexic' described by Darmon (2017) (see chapter two). During this stage, an initial 'alert' is raised by another person (or persons), who is concerned about the individual's wellbeing. In Mia's case, this was her parents. The individual is then labelled as 'deviant' and increasingly monitored. This monitoring involves a 'circuit of agents' who employ techniques to 'normalise' the individual's behaviour. For Mia, this circuit involved her family and GP, who attempted to normalise her diet. A 'circuit of mediators' then develops, and as the individual moves through the circuit, they are eventually diagnosed. The GP was the first medical professional in Mia's circuit, which then expanded when she was referred to CAMHS and diagnosed.

Mia identified her parents as being in control during these processes and implicated herself as passive. She described feeling privately angered by what was happening, while outwardly 'complying' and attending appointments. Her experience can be understood as incorporating an element of extra-legal coercion (Pescosolido, 1998). Coercion occurs when "social control, rather than free choice, is the dominant mechanism that pushes the patient into the health system" (1998: 281). The social control element was her parents, who were in an authoritative position and made decisions about her healthcare (Mia was only 11 or 12 years old at the time). She outwardly complied in the process, and in this respect was arguably 'agreeing', however her compliance was entirely passive.

The recognition of a problem by another person is one of the key features of this category. All participants here had not considered themselves to be experiencing an eating disorder (or any other significant problem that required intervention) when help was sought. Rather, others (family members or staff at school) recognised a problem and began the help-seeking process.

For Mia and Claire, there was not only a lack of identification of a problem, but also an active rejection of the definition and interpretation that was being imposed by others:

> Claire: I didn't feel like I was underweight […] I felt like what I was doing was completely normal as well […] and I think that it did make me feel really good, I didn't want it to be taken away from me at that point.

Natalie and Ben indicated less of an absolute opposition to others' interpretations. Natalie for example had had a sense that her restricted eating and exercise were not entirely 'normal' and needed to be hidden, but none the less did not think of herself as having a problem that needed to change:

> I wasn't thinking about how to hide my body because I didn't see myself as being underweight at all […] I was just thinking […] how am I going to hide [not eating and exercising] so I knew but I didn't, I didn't see really what was going on.

It is interesting to note, however, that while Natalie did not understand herself as 'anorexic' when she was taken to the GP, at a different point in the interview she mentioned having engaged in eating disorder communities online *prior* to having been diagnosed. This suggests that she may have previously - fleetingly or ambivalently - considered the possibility she had an eating disorder. However, it was clear in the interview that her overriding memory of the immediate lead up to being diagnosed was of not believing herself to have anorexia, and not 'connecting' to what was happening.

Brossard and Carpentier (2016) suggest that the pathway to a diagnosis of dementia involves a trouble-observability-interpretation convergence. The trouble-observability aspects are helpful for understanding how a problem was identified for participants in this category. Brossard and Carpentier use 'trouble' to refer to something 'going wrong', and suggest that a trouble must be observable (to the person themselves or to others) if it is to lead to a medical consultation. Given that these participants did not personally experience their eating and weight loss as problematic, these did not become a 'trouble' until they were interpreted as such by someone else. For this to occur, the behaviour or 'symptom' in question had to be both visible, and occur in a social configuration that allowed it to be seen (Brossard and Carpentier, 2016). Due to the participant's ages, most of them were living at home with family members and attending school, meaning that 'symptoms' were potentially highly visible. Thus their age-related social and relational circumstances shaped their route to diagnosis.

For Natalie, who had recently left home to attend university, it was a change in her social configuration that triggered the help-seeking process, as this made her 'symptoms' observable. She had returned home from her first term at university for the Christmas break when her mum immediately noticed that something was wrong, and 'marched her to the GP'.

The participants in this category (and also some in the mixed route pathway) were a child or adolescent at the time they were diagnosed, unlike those in the self-directed pathway who were adults. These age differences reflect the claim in previous NICE guidelines:

> Typically individuals are persuaded to seek help by concerned family members, teaching staff or GPs with whom they consult about the physical consequences. Sometimes, however, the person begins to appreciate the damaging effects of the disorder and may seek treatment in their own right. Children and adolescents are almost always brought to treatment, very rarely actively seeking help initially and can present more complex diagnostic challenges […] The diagnosis of anorexia in its typical form is a relatively straightforward one in older adolescents and adults (NHS, 2004: 14).

However, the suggestion of the diagnostic process being problematic was mostly not borne out in participants accounts. Indeed, once help was sought, reaching diagnosis was mostly straightforward. As with three of the participants in the previous category, there were no significant delays, problems or barriers to being diagnosed. Claire, Mia and Ben were firstly monitored by the primary service with whom help had been initiated (a GP or school health service) and were then referred to a specialist service (CAMHS) where they were diagnosed. Claire explained that it took "quite a long time" to get a diagnosis, due to being monitored by a GP for a while who was "not very good". However, this did not appear as an especially significant problem in her recounting of her experiences, and once referred to a specialist team, she was quickly diagnosed. Natalie had been diagnosed by her GP at the initial appointment, and promptly referred for 'emergency' inpatient treatment.

In summary, participants in this category had not recognised themselves as having a problem; others had initiated the help-seeking process, which they had passively adhered to. However, once help had been sought, reaching a diagnosis of anorexia was mostly unproblematic.

Mixed route

The final category is a mixed route. It includes four participants (Amelia, Jack, Sarah and Hannah) who were aged between 16 and 19 when diagnosed. The picture here is complex in that, in different ways for different participants, there were features of both of the two earlier categories. Most described a 'mixed' sense of agency in terms of the extent to which

they directed or actively chose to participate in the process of help-seeking. Most were largely encouraged and directed by others (family/school) who played a significant role in recognising that there was a problem. However, they did not attribute the whole of the 'doing' of the process to others, and to some extent had recognised there was a problem. One participant clearly understood himself to have an eating disorder, but was 'mixed' in terms of his desire for help and his active instigation of this process. Participants in this category also experienced a more problematic route to being diagnosed after help had been sought.

I have chosen Amelia as the case study for this route. She was 20 years old and living at home with her parents and siblings when interviewed. She had been undergoing outpatient treatment for anorexia with an EDS for approximately one year. This involved undertaking CBT and seeing a dietician and psychiatrist. She also saw her GP on a monthly basis. Amelia described herself as 'in recovery', having recently become more 'motivated' in this respect.

She identified her anorexia as having first developed when she was 18. During her A-Levels she had begun exercising regularly as a form of 'stress release'. This escalated, and began to incorporate food restriction, towards the end of her A-Levels when a close family member died:

> The stress of that sort of allowed the anorexia to develop and was probably the reason why it wasn't caught necessarily as quickly by my family, because for them it was grief […] that was a reason why I was allowed to not be quite myself.

Amelia went on to lose a significant amount of weight during the following summer. She described this experience of weight loss as her being "possessed", and explained that she had not lost weight deliberately:

> It was never a weight thing […] if I looked at myself I was just me, there was nothing wrong with me and I didn't understand why people were treating me differently and asking me if I was OK […] it was definitely a control thing, I needed to control everything I ate, and all of the activity I did.

However, when later directly questioned about whether or not she had any history of poor body image or dieting, she indicated that she had been concerned about body fat in recent years:

> I was so happy with my body, however having said that do you know what, on reflection […] I definitely had a fear of being fat, and I hadn't acknowledged this until about the past month […] to me it was always a negative like you're less of a person if you are overweight, I know that's engrained in me and I didn't think that was the trigger but now on reflection I think potentially it was. And I never thought myself overweight but I remember being like 'I want to be more toned' […] I wanted to be attractive and fit.

Towards the end of the summer, Amelia saw a GP after being persuaded to do so by her parents. She had gone on a family holiday, and this was the first time during that summer that she had spent an extended amount of time with them. According to Amelia, while on holiday her parents noticed that she did not want to eat or socialise:

> [They] said look I think you really ought to see a doctor, can you please, please go and see a doctor and I think it was that family support and encouragement that made me go, right, maybe I should just go and see one and see what they say.

At this time, Amelia recognised that there was a problem but did not think of it as an eating disorder. She stated: "I knew that something was wrong […] I knew that I wasn't right and I wasn't happy […] I wasn't me. But I wasn't really prepared to admit that I was poorly".

All that Amelia could recall of seeing the GP, was him saying "you just need to eat more", which she found unhelpful. In addition to stating that she had not thought of herself as having an eating disorder at that time, Amelia later explained that she had searched for information about anorexia online directly following the GP appointment. This suggests that

she perhaps had a vague idea that she might be experiencing an eating disorder, and she confirmed this was the case when I directly asked about this.

At the end of the summer, Amelia left the family home to attend university and her situation worsened. While there, she saw a GP weekly, because her parents had set this as a condition. This GP informed her parents that she did not have an eating disorder, claiming that she would not be attending appointments voluntarily if she did. The GP had asked Amelia to keep a food diary, and in this she exaggerated the amount of food she was eating. Amelia suspected that this further convinced the GP that she did not have an eating disorder:

> [She thought] it's definitely not anorexia because she is eating [and] she's asking for help. Because I was going 'I know I really need to put on [weight]' […] I must have just been so convincing […] she just thought 'if she wants to put on weight then she's not got an eating disorder'.

When Amelia came home during the Christmas period, her parents realised the extent of the problem and their concern increased. In the January, she was called in to see a GP (whom she had not seen before) after a check of her records 'flagged up' problematic blood test results. Her Dad went with her to this appointment and told the GP that Amelia was "not right at all". Amelia explained that due to this and her low weight, she was offered a choice of either being referred to an outpatient EDS or being hospitalised. After being persuaded by her Dad, she agreed to outpatient treatment: "I remember my Dad saying don't be ridiculous Amelia, just let her refer you and it […] took me a good hour or something to actually say 'OK'."

She attributed her need to be convinced to her lack of desire to change:

> I thought OK maybe there's something a bit wrong, but […] I thought I could survive like this […] if I was there on my own it wouldn't have happened, I'd have probably been in hospital […] I think maybe I accepted I was anorexic, but I wasn't bothered.

Amelia was referred to the EDS where she was diagnosed with anorexia and began therapy.

I have shown that Amelia first saw a GP after being persuaded by her parents to seek help. However, while they played a significant role in this, unlike participants in the previous category, Amelia was not entirely passive in the process. She did have some recognition that seeing a GP might be a good idea, and also an ambivalent and vague idea that she might have an eating disorder. Her decision to seek help can be understood using Zola's (1973) description of 'sanctioning'. Zola argued that experiencing medical 'symptoms' does not directly influence decisions to seek help, but that these are mediated by a range of non-physiological factors. One of these factors is 'sanctioning', which occurs when a decision to seek help is encouraged or 'pushed' by someone else.

Amelia's route to being diagnosed after initially seeking help was problematic in the sense of being protracted. It seems that the first GP implied that there was nothing seriously wrong, and the GP she saw at university did not interpret her struggles as anorexia. It was not until clinical tests revealed physical health problems and she saw a different GP that she was diagnosed.

Looking at Amelia's route to diagnosis as a whole, her shifting interpretations of her own situation are notable. She adopted different positions at different times, in a contradictory and ambivalent manner. Unlike those in the self-directed and active category, she did not clearly identify herself as having a problem for which she needed help, and unlike those in the other-directed category, she did not dis-identify with the idea that she had an eating disorder. Amelia's recounting of her experiences position her as somewhere *in between* active and passive, and as both recognising a problem, and also not doing so.

This mixture of both active and passive, other-driven and self-driven help-seeking, and accompanying ambivalence, is a key defining feature of this category. Hannah and Sarah had

also first sought help following pressure from others. For Hannah, as for Amelia, other people's interpretations of her behaviour and 'pressure' from them to seek help influenced the help-seeking process. Yet, Hannah was not entirely passive or in disagreement with this, and she did recognise that she had a problem. She also sometimes made independent decisions during the help seeking process, such as not agreeing to see certain professionals. Sarah's first occasion of help seeking had been heavily encouraged by her friends, who had told her that they thought she had an eating disorder. Sarah had ambivalently agreed that something might be wrong and that it might be worth seeking help and arranged to see a counsellor.

Jack's experiences were different in that he clearly understood himself to have an eating disorder. Yet his route to diagnosis was still mixed, and strongly characterised by ambivalence. This was in relation to his desire for, and instigation of, help. He had begun developing 'eating disorder symptoms' at age 12, in tandem with health problems related to his bowel. At 17 years, believing himself to be struggling with an eating disorder and feeling unable to cope, he went to his parents for help. They organised for him to see a GP, who referred him to CAMHS. However, by the time of his appointment, he had "come out the other side" of wanting help, and felt fearful about having to change. He therefore deliberately convinced the professional at CAMHS that his bowel was the source of his weight loss, and thus actively avoided a diagnosis of anorexia. Jack felt that his gender made it easier for him to "make an excuse", with professionals being less likely to assume an eating disorder in a male. This resonates with Raisanen and Hunt's (2017) research. They found that young men with eating disorders sometimes felt that professionals had been slow to recognise their symptoms as belonging to an eating disorder because they were men, and in some cases they had been misdiagnosed. Jack's views also speak to other literature which suggests that anorexia goes underdiagnosed in males (Strother et al, 2012), and that GPs are

more likely to interpret 'symptoms' as an eating disorder in female rather than male cases (Currin et al, 2007). About a year later while away at university, Jack's struggles had worsened, and he was admitted to hospital for two weeks with problems with his heart and kidneys resulting from weight loss. Here he was seen by a crisis team, who he continued to see every fortnight for about 6 months until he discharged himself from their care. The first four months of this involved them reaching a diagnosis of anorexia. Jack found this problematic and felt that it *worsened* his struggles:

> I don't think they knew what they were doing with me […] I don't think they really had a male person on their books ever [because] my receptiveness lasts a month or two [it] was actually making me worse rather than better.

In varying ways and extents, all in this category had relatively problematic routes to being diagnosed. For Jack the problem was waiting a long time for a diagnosis. Other problems included initially being described by a professional as not having an eating disorder (Amelia and Hannah), and being 'put off' help-seeking (and the pursuit of a diagnosis) due to a difficult first experience seeing a professional (Sarah).

In this mixed-route category, participants' experiences sit somewhere between the other two categories. They incorporated changing, and sometimes contradictory positions regarding their recognition of an eating disorder, and / or a desire for help. They also tended to have more protracted and problematic experiences of reaching a diagnosis of anorexia.

Meanings of being diagnosed

This section is concerned with the 'application' of a diagnosis - the transfer of a diagnosis from the medical domain to the lay person's experience of illness (Jutel, 2011). Diagnosis is a complex, negotiated activity which is impacted by the experiences of both practitioner and

patient and is shrouded in personal meaning (Kralik et al, 2001; Jutel, 2011), and it is to this personal meaning that I now turn.

Firstly, it is necessary to note the ways in which the act of diagnosis differed for participants. Most identified a specific occasion in which they were diagnosed with anorexia, either by their GP or a specialised mental health or eating disorder service. However, three of them, all from different routes (Hannah, Mia, and Maddie), did not describe a specific occasion in which they were diagnosed. Rather, the diagnosis had been applied to them *in effect* through clinical activity. In these cases, the word anorexia began being used during appointments or started appearing on official paperwork, and participants differentiated this from the idea of a 'sit down diagnosis'. As Hannah, for example, expressed:

> No one officially ever said, as in they talk the whole time now about my anorexia, but no one actually officially ever sat me down and said you have anorexia. It was just assumed.

However, even when there was no specific act of 'being diagnosed', participants still identified a (more or less specific) time that the diagnosis came into play.

Across the sample, there were three broad meanings assigned to being diagnosed: *diagnosis as a useful way forward*, *lack of identification with the diagnosis*, and *diagnosis as a marker of success and recognition of suffering*. As might be expected, participants who experienced the other-directed, passive route to help-seeking did not identify with the diagnosis. This was also the case for some in the mixed route category, and one in the self-directed category. Conversely, those who followed an active route to help-seeking often perceived the diagnosis as a useful way forward. For one participant in the active route, and one in the mixed route, the diagnosis was valued for providing a desired status.

For each of the three broad meanings, I firstly detail a relevant case study by way of a contextualised example. I then illustrate the meaning further with reference to additional

participants. The case studies include two I have used previously - Anna and Mia – and a new one, Kelly.

Diagnosis as a useful way forward

A diagnosis of anorexia had initially been suggested to Anna by the GP, and was later confirmed by the psychologist at her university and the EDS. She experienced these confirmations as a relief, because they provided access to the treatment she desperately wanted. However, the diagnosis also provoked anxiety, because she felt she needed to continue to 'live up to it' to qualify for treatment. This feeling emerged from her conceptualisation of anorexia as something that one actively does and continues to do over time, as opposed it being something that one simply has:

> I remember just the kind of relief, but again the anxiety that I'm still going to have to prove this, like I'm still going to have to work really hard to make sure that they don't take this away […] it wasn't something that felt static, it's like something you do.

This conceptualisation is also recognised by Lavis (2011), who describes how maintaining anorexia involves continual, daily self-surveillance (see chapter two).

After the diagnosis from the EDS, Anna waited a further four months to begin outpatient treatment. During this waiting period, she wanted to keep her weight stable so that she could avoid inpatient treatment. However, she did continue to lose weight – albeit more slowly – and she referenced a number of reasons for this. Partly, she felt compelled by the 'logic' of anorexia:

> I could only at that time conceptualise the stability as being slightly downwards […] it had to be within the framework of losing weight […] even recovery had to happen inside the anorexia logic.

Anna's sense that she needed to be seen to be 'doing anorexia' in order to 'keep' the diagnosis fed her desire for continued weight loss:

> I had this obsession that if I ever went to the doctor and my weight was higher than it had been the week before she would decide that I didn't have anorexia anymore and that she would withdraw me from treatment […] I felt like I had it, but only if I worked really hard.

At one point, Anna positioned this interpretation of the diagnosis (as something that she needed to prove) as part of the illogic of anorexia, describing it as a "weird thing" that sounds "ridiculous". On another occasion, she explained this interpretation using 'logical' (as opposed to 'anorexic') reasoning. She recognised the impact of scarce treatment and stated that "people are effectively competing for treatment with their BMI" and "you do to some extent have to prove it". However, she then repositioned this 'understandable reasoning' back into 'anorexic logic':

> It kind of reinforces back into that space […] where you're not getting treatment, and you have an overwhelming logic that says you need to lose weight, and other people are kind of saying yeah you kind of do, even though they are definitely saying it to your face that they are not, you know in the back of your mind that there is a logic that goes into your logic.

For Anna, then, being diagnosed offered the route to the treatment that she wanted, and in this respect was valued as a way out of her struggles. However, it was also a status that she felt she had to work hard at in order to retain to access treatment.

Maddie also saw the diagnosis as a potential way forward. She had wanted an official diagnosis of anorexia because being told "what it is" would offer a route to improving her situation. She summed this up by stating "If I knew what it was, I could fight it". For Naomi, the diagnosis acted as an explanation for why she was struggling. She had presented to the GP with 'tummy troubles', but identified with the diagnosis of anorexia upon reading books that her GP recommended. The diagnosis offered her a different way of understanding her struggles that she readily took on board and was an explanation of her distress which

suggested a route out. This meaning remained with her, as she explained "I suppose it [the diagnosis] gives an explanation for why I struggle and its helpful in that sense".

Similar meanings may be attributed to other psychiatric diagnoses. Hansson-Halleröd et al (2015), researching adults experiences of being diagnosed with ADHD, found that the diagnosis was experienced as an "explanation for difficulties" and that this could be a relief. Horn et al suggest that being diagnosed with BPD can provide someone a new way to think about their difficulties, and can bring about "hope and the possibility of change" (2007: 262). Being diagnosed with a psychiatric illness can be experienced as useful for the knowledge it represents, and this 'knowing' can be a way to take ownership of one's struggles (Hayne, 2003). By making illness evident and treatment and cure possible (Shooter, 2010), being diagnosed can offer a way of healing that cannot be provided in any other way (Hayne, 2003).

Lack of identification

After being monitored by her GP for two months, Mia was referred to CAMHS. During an initial appointment, the word anorexia was used for the first time. This stood out in her memory because of the impact it had on her mum: "That was sort of where the word anorexia was first used. Because I can remember it upsetting my mum. But I still wasn't 100% sure because I was only like 11 or 12".

At this time, she did not relate to the idea of having anorexia. She explained that she did not really know what anorexia was, although she had been introduced to the term in the book she had read in primary school which included a character with the condition. Further, she only understood her own experience as being about wanting to avoid being 'fat':

> I definitely don't think I fully understood it, I think just being that young age I thought it was just clearly I didn't want to eat because I didn't want to get fat. That was all […] I knew.

Rather than associating herself with the diagnosis, she saw it as a way for other people to decide what to do: "I thought it was just a branding to help everyone else then work out what to do with me next, and know what treatment I was going to follow".

Looking at the meaning of diagnosis for Mia, then, there was a lack of understanding of what it meant. She therefore did not personally identify with it, and she understood her experience as being about *nothing other* than a desire to lose weight. She perceived the diagnosis as being for other people; its purpose was for her parents and clinicians to know what to do.

This meaning was also relevant to six other participants. Three of them (Claire, Ben and Natalie) are the remaining participants in the other-directed, active pathway. Two of them (Amelia and Jack) are in the mixed route, and the remaining participant (Lisa) was in the self-directed category.

Claire was taken to her GP by her parents aged 16. At this time, she was deliberately pursuing weight loss, but did not perceive herself as underweight, and understood her behaviour "as completely normal". When she was diagnosed at an appointment with CAMHS, it did not make sense to her:

> I didn't think I was unwell […] I thought I was still really overweight and in the media obviously people who have got an eating disorder are all like stick thin and I was like I don't look like that *it can't be right*" (emphasis added).

Hannah similarly described how, at the time that the diagnosis was first used, she did not feel that she "fitted that bracket". This was because her personal experiences did not 'match up' to her idea of what anorexia was. Ben, who recalled the time around being diagnosed as "very confusing", explained how he personally actively rejected the diagnosis, refusing to align himself with it due to 'personally stigmatising' the idea.

Natalie's lack of identification was a passive lack of 'connection' with what was happening when diagnosed. She was diagnosed at her first appointment with her GP and referred for an emergency inpatient admission. When I asked what she thought when she heard the diagnosis, she responded: "I didn't really hear it. I was like, I didn't hear it, I wasn't really thinking, I was just, honestly, I disengaged".

Similarly, when Amelia attended her first appointment at the EDS, she was diagnosed with anorexia and formally admitted as an outpatient. She described this occasion as a "blur" and said:

> I don't feel like I was me, at all when I was there […] I just remember being in floods of tears because the anorexia was just so strong and saying like 'you [staff at the EDS] can't do this to me'.

At this appointment, she and her parents were informed of what she was not allowed to do at home (for example, her exercise was restricted). It seems that Amelia was overwhelmed by these stipulations on her behaviour which were her overriding concern. She did not especially recognise, or place significance on, the diagnosis being officially confirmed.

For Jack, being diagnosed by the crisis team had been a long and drawn out process that he found problematic, and the diagnosis itself meant "absolutely nothing" to him. He explained:

> They put too much emphasis almost on the diagnosis rather than trying to actually treat the symptoms as early as possible […] if you can treat the symptoms it doesn't matter what you've got. You've got an eating disorder, why does it matter what sort. Treat the person rather than the label.

Jack also implied that the diagnosis was about the crisis team's processes and needs, rather than being about him. For example, he said: "they were just trying to put me in a section in *their* book of treatments […] but I wasn't really fitting any of *their* pre-specified moulds (*emphasis added*)".

Lisa struggled to identify with the diagnosis of anorexia. That she had initially been diagnosed with bulimia influenced the meaning that she attributed to her later diagnosis of anorexia. She was surprised to be diagnosed with anorexia, expecting instead to have been diagnosed with bulimia for the second time. It took a long time to 'accept' being treated as 'anorexic' instead.

Jack's view of the diagnosis as 'meaningless' resonates with research into ADHD and BPD which suggests that individuals given these diagnoses sometimes question their importance and usefulness (Horn et al, 2007; Hansson-Halleröd, 2015). Horn et al's (2007) research into BPD also reflects Jack's view of the diagnosis as being more about the health professionals than about him. Horn et al found that individuals diagnosed with BPD sometimes viewed the diagnosis as simply what 'they' (professionals) were calling it, implying that the diagnosis did not have meaning beyond this.

Claire and Hannah did not identify with the diagnosis because they did not see themselves as 'matching up' to their pre-existing idea of anorexia. Similarly, in McLorg and Taub's research into the development of eating disorder identities, participants had initially "vigorously denied the label" (1987: 247) of anorexia after it was applied by family, friends, or medical professionals. This was often because they felt they were not 'anorexic enough' or 'skinny enough' to match up to the bodily appearance they associated with anorexia.

This making reference to a broader construction of anorexia was also alluded to by other participants when they described other points in the route to diagnosis (and not only when formally diagnosed). I have shown that one of the reasons Kelly decided to see a GP was because the physical manifestation of her struggles had reached a point where she was able to see herself as 'fitting the bill' of the 'one image' of anorexia that she held in her mind. Around the time when Maddie first sought help, she knew she had a problem but had also

not thought of herself as fitting what she associated with an eating disorder: "I'd always associated it with you had to be thin […] you were either making yourself sick or you were really, really thin".

Similarly, Naomi (who initially saw a GP with 'tummy problems') explained why at this time she did not think of her experience as anorexia:

> I remember kind of reading things about anorexia or hearing people talk about it and kind of thinking well that sort of sounds a little bit like me but, I don't look […] someone wouldn't look at me and think that would fit.

This suggests that a lay construction of anorexia as entailing an obviously remarkably thin body and/or serious physical complications acted as a resource which participants drew upon in making sense of their own experiences, and which influenced decisions and experiences of help seeking and the personal meaning of 'being diagnosed'.

Diagnosis as a marker of success and recognition of suffering

I have described above how Kelly had sought help from her GP after recognising herself as struggling with an eating disorder. She described this encounter as a "really good experience". The GP had weighed her, explained that she was "clearly underweight" and that she was very concerned, and went to get another doctor. The doctors asked a lot of questions and Kelly initially felt this intrusive, but also that it demonstrated that they wanted to offer the right care. The doctors referred her to an EDS, informing her that there would likely be a three-month waiting list, and suggested she return for a check-up in a few weeks. Anorexia was mentioned in conversation between the two GPs, but she was not 'given' the diagnosis. When asked how she felt about this, she explained that she had been disappointed and she had "overwhelmingly" wanted to be diagnosed:

> I really struggle to explain that feeling in hindsight, but I definitely felt like because they hadn't kind of given me one, and I knew that I would have a big wait […] I remember just feeling quite disappointed.

When asked to expand on why she had wanted the diagnosis, Kelly recalled her feelings as 'bizarre'. She also indicted some concern about how she would come across when explaining this, stating that 'it sounds sick to say it'. Following some reassurance that it would not, she went on to describe how she had wanted the diagnosis for the recognition it offered:

> It's almost like a badge, kind of like, OK this is like, you did it […] I think you seek validation because […] at the time I had no idea how ill I was, like absolutely no clue […] I think you just feel like you want somebody to […] validate you and you want somebody to say no, you are suffering.

While waiting for an assessment at the EDS, Kelly's struggles worsened. She became "really physically poorly" and had to stop working due to struggling to walk. She recalled an occasion when she left a social gathering looking for somewhere to make herself sick, after feeling panicked about something she had eaten. In this moment, Kelly 'stepped outside of herself', and noticed how extreme her behaviour had become. She then contacted her mum, and together they organised for her to see a psychiatrist privately, about one month after she had seen the GP. At this appointment, physical complications emerged such as 'problems with her heart', and she was diagnosed with anorexia binge-purge sub type. Kelly explained how she felt at this appointment:

> I want to get back to that feeling of reinforcement [with] the diagnosis and kind of like the word anorexia itself. It was almost a bit of a badge […] there was like OK so you are having physical symptoms […] it's kind of like reinforced the fact you do have an eating disorder but I think what it also did was, everyone around me was really worried [and] one doctor told me 'if you carry on you are going to die', and I knew that my heart wasn't good and I wasn't scared […] I just kind of felt a bit, almost happy.

Kelly's description of the diagnosis being like a 'badge' that offers validation integrates two related ideas about anorexia: that it is an achievement that one has to 'work at' ("you did

it"), and that it recognises and names suffering, confirming that one is 'really' ill. Clinical

recognition of her physical ill health fed into the confirming and pleasing effect of the

diagnosis, as it provided further recognition of the extent of her struggles and further

legitimised 'anorexia'.

Sarah also positioned the diagnosis as a desirable, earned status. It offered her a meaningful

sense of achievement and "satisfaction":

> [Being diagnosed was] like I've reached the point where someone has, I must look
> good enough to be classed as something beginning with A […] Satisfying I would say
> the word would be […] a sense of achievement, and feeling like I had sort of, weirdly
> joined this club and reached this kind of level of […] other people who perhaps
> don't eat that much or look a bit small, they haven't got this label and I have and
> that's good and yeah definitely I felt really pleased, but then also felt very defensive
> and like no one would take it away that label, but also really happy to have it.

However, Sarah was also concerned that others would respond to the diagnosis by 'trying

to fix her', and saw it as a way for them to enforce change:

> If I admit to that word, that's a label and people will try and fix me for having that
> label, they will try and take that away from me, they can put me in a kind of category
> and be like right, what we need to do to someone in this category is do this, and I'm
> not going to give in to that.

Sarah's valuing of the diagnosis also led her to feel as though it was something that she

needed to continue to work at: "So that [having the diagnosis] was good, and now I need to

make sure that that continues to happen, and that I don't lose that diagnosis". We saw

previously that Anna also felt that the diagnosis was something she had to work at.

However, the motivations behind this were different for Sarah. It was about keeping the

diagnosis for the sense of achievement it awarded her, rather than in order to access

treatment.

This meaning of diagnosis speaks to anthropological research that was discussed in chapter

two. Lavis' (2011) shows how the act of diagnosis itself can become invested with pro-

anorexic desire, due to the sense of legitimacy that it confers. Similarly, Eli's (2014b) research indicates how in inpatient settings, anorexia can be experienced as an 'earned title', and that the naming of anorexia that occurs via hospitalisation can feel valuable for its affirming and legitimising effects. Indeed, individuals undergoing inpatient treatment are sometimes invested in 'being medicalised' via the diagnostic label of anorexia and express an 'enjoyment' of being defined as clinically ill (Boughtwood and Halse, 2008; Dignon et al, 2006). Further, Warin (2010) describes how the diagnosis of anorexia can feel empowering because of the sense of distinction that it offers. For Sarah especially, we have seen that this sense of distinction can be profound. My own experiences of being diagnosed can also be understood in terms of this meaning, as I valued the diagnosis for the recognition and distinction it offered (see chapter three).

Further reflections on being diagnosed

Literature suggests that being diagnosed with a psychiatric illness can be 'sharply penetrating news', resulting in one's identity being 'snatched away', confusion and distress (Hayne, 2003; Johnstone, 2014). Dignon (2007) discusses how this may be the case for individuals diagnosed with anorexia. She suggests that being diagnosed may force the individual to confront the reality that they have a serious psychiatric illness, leading them to feel shocked, and acting as a form of biographical disruption (Bury, 1982).

However, these ideas do not particularly resonate for participants in this research. In many cases, they did not (fully) identify with the diagnosis at the time, or they placed a desirable value on it (as a useful way forward, or an earned title), and hence it was not 'disruptive'. In addition, the act of being diagnosed was not 'sharply penetrating' because it tended not to be especially distinctive in terms of the 'newness' of the information that it communicated. Being diagnosed did not always represent a significant departure or 'turning point' in terms of there being a clear distinction between not having and then having the diagnosis. This was

due to the individual already having an idea that they had an eating disorder, and therefore to an extent expecting the diagnosis, and/or because the diagnosis had already previously 'come into play'. In the case of the latter, being 'officially' diagnosed marked a sort of end-point in a more gradual or accumulative diagnostic process. An example of this is Naomi. Her GP had already suggested that she might have an eating disorder and had recommended a self-help book for anorexia. Thus, the diagnosis had already been 'brought into play' in the proceeding clinical activity, and the later diagnosis was formal confirmation of this suggestion. Lavis (2011) similarly found that for her participants, being diagnosed with anorexia often affirmed to the individual what they already felt to be there. Thus, the act of diagnosis tended to confirm to them an existing sense of themselves as 'anorexic', rather than it bringing about change and being the starting point for a different view of themselves.

Self-diagnosis: a case study

Michael was a man in his 50s who was self-diagnosed with anorexia, having come to identify with the diagnosis since around three or four months prior to the interview. With hindsight, he understood himself to have had anorexia for around 25 years. He had recently sought help from his GP and was regularly seeing a dietician for guidance increasing his weight. However, these professionals understood him as someone who was underweight, but not as someone who had an eating disorder. Michael had lived with *potentially* diagnosable anorexia for many years. In this case study, I examine how his trajectory of a 'missed diagnosis' took shape, and how he came to self-diagnose and seek help to gain weight. I also examine how Michael made sense of his lack of diagnosis, and what a potential formal diagnosis meant to him.

Michael began the description of the development of his eating disorder with his time at university, around 25 years prior to the interview. At this time, he had decided to take up

weight training and "bulk up" (gain weight and muscle), with this being the only free sporting activity available at university. Prior to this, he had been a keen cyclist, so when someone "fairly close" to him commented that his increased size from weight training would make him less effective at cycling, he decided to lose weight again. He stated that "something clicked in my head, and I thought 'I need to get rid of this'".

He spent a few years gradually losing weight until he went to work abroad. While there, he experienced problems with his bowel. He linked this to his weight loss, and identified losing weight as a likely causal factor in him developing gastroparesis[60] (Michael's understanding of the links between his weight loss and other medical problems are addressed in the next chapter). He went on to experience increasingly severe medical problems, whereby his intestines "twisted" and he was hospitalised. These problems led him to become significantly underweight, such that when he was discharged from hospital, he was advised by a doctor to increase his weight. He began to do this, but after gaining around one stone (reaching a point where he was still "medically underweight"), he stopped: "all I could see was blubber around my middle so just automatically thinking 'Gosh I'm getting fat, I better stop here'".

He then spent the next few years deliberately eating and exercising so that he maintained his low weight. He saw his GP for ongoing problems relating to his bowels, and noted an occasion when the GP commented on his weight (stating that he was "a bit light"), but was easily convinced that there was no problem.

About 15 years after being at university, Michael got married, and this was helpful for slightly increasing his weight because it enforced some regularity and familial sociability around food. However, he still had "rules" about what he could eat and still maintained a low weight:

---

[60] Gastroparesis is "a syndrome of objectively delayed gastric emptying in the absence of mechanical obstruction. Cardinal symptoms include early satiety, postprandial fullness, nausea, vomiting, bloating, and upper abdominal pain" (Myint et al, 2018).

> I wouldn't eat potatoes, I wouldn't eat bananas, I'd have a very light breakfast […] we'd go out the whole day cycling […] I was more than burning it off, my weight went up a tiny bit but stayed pretty level.

He also had ongoing problems with his bowels and about three years after getting married, had an operation to remove some of his large intestines. Following this, he was again advised to regain lost weight. As previously, he experienced this weight gain as him 'getting fat':

> My weight started to go back up, I got to about 9 stone and like I did before, I saw myself getting fat, I thought 'oh I'm getting fat, I'd better stop here.' So I just bang, I just made that decision, this is what I eat in order to maintain the weight I am now.

He deliberately maintained a low weight for three years after the operation. Then, following further complications with the remaining part of his large intestines, he underwent an operation to have this removed too. This increased the range of foods he was able to eat, but he continued to restrict his overall food intake:

> It didn't do anything to get rid of, and now I know what it is, this anorexia nervosa, but at the time it was just me […] although I was eating a wider range of stuff, you just fit it in to your system, this is how much food you can eat.

This continued up until around three or four months prior to the interview, when he lost significant amounts of weight during a bout of flu and a stomach infection and decided to see a GP:

> I couldn't eat for a couple of weeks, weight just flew off, went back to the doctors, and for some reason I just said 'oh no, here we go again'. I don't know why, but I just said to myself 'I need to try and get this sorted, I can't go through the rest of my life, you know I'm in my 50s now I'm fed up with this'. I said to the doctor […] 'look I've lost weight again, you know is there anybody I can see'?

The doctor referred him to a dietician, whom he had been seeing for a few months. She gave advice regarding increasing his calorie intake, and he worked at increasing his diet

incrementally. He described the 'battle' with himself that he has experienced during this process:

> It's been very instructive in seeing two parts of your persona, there is the logical part that says 'right you've got to eat this […] your body will heal', but when you actually go and [eat more] you think 'what am I doing'.

He found that seeing the dietician was helpful for making his decision to gain weight "real":

> The fact that I am seeing her has made it real. If I had just said to myself 'oh I think I better eat more', I would be more likely to slip […] you know having the dietician there making it real.

Around the time that he sought help from his GP, he began to understand himself as having an eating disorder. For the 25 years prior, he had thought of himself as a "fussy eater", and had "buried" his disordered eating and disguised it with the medical problems linked to his bowel:

> The term I gave myself was fussy eater, and I now know the word is an eating disorder […] I could always cover it under the veneer of 'oh I've got bowel problems', I could always excuse it. I recognise now I've had an eating disorder since my mid-20s but I've always, I've never let it be entertained because I could excuse it, I buried it very, very quickly.

Michael did not pinpoint anything specific that led him to initially suspect the possibility that he had anorexia. This process was likely subtle and did not entail any clear-cut 'turning points'. However, information that he read on the internet played a key role in him strengthening his understanding of himself as having anorexia, and in understanding what weight restoration would involve:

> It was actually only in reading [a *Psychology Today* article] that it really gave me an insight into the psychology behind somebody who chooses to eat in a certain way, eating disorders, and I certainly saw myself in that, and that's been really helpful in making me realise that there are going to be physical changes.

He described having been "googling the subject" when he came across the *Psychology Today*

article which made reference to Keys et al's (1950) Minnesota starvation experiment[61]. He

related to this because it described men's experiences of starvation and recovery:

> For the first time it was a load of blokes, so rather than being a 15 year old girl it
> was actually men […] it was like somebody had taken a blind off my eyes, I thought
> 'oh my Gosh, why didn't someone tell me this earlier' […] that's me, it was like,
> glorious […] that made me see right, I can now see that this is the road that I need
> to tread in order to recover.

The information he gleaned online allowed him to view weight gain and 'getting better' in a

new way. It was also significant to his self-understanding in that it informed the idea that he

was different to most others with eating disorders. In the representations of anorexia he

usually encountered, he saw a particular demographic (young, female) with a particular 'type'

of experience – one that was different to his:

> The You Tubers and bloggers that I've looked at in the last few weeks, a lot of them
> are young ladies [it's usually] a 15 year-old girl, where as a 50 year old geezer is, you
> know. So although I've been informed, it's being informed about something that's so
> removed from who I am […] they all sort of fit into the same sort of thing you
> know, teenage angst, losing weight, body image problems […] most people seem to
> go into it and come out of it again within you know, between a 2 and a 5 year span
> […] I've held onto it for a lifetime.

Not seeing his situation in the information he read also meant that he felt uncertain about

his recovery:

> So I'm at the beginning of what I hope will be a recovery […] I haven't seen or read
> yet of anybody who has had an eating disorder for this long and has chosen to come
> out of it so it's almost like unchartered territory.

In line with Michael's experiences, literature suggests that representations of eating

disorders in media reinforce the idea that they are predominantly female disorders and that

---

[61] Keys et al's (1950) experiment investigated the physical and psychological effects of starvation and recovery
using a sample of 36 men. During the starvation phase of the experiment, the sample consumed a starvation
diet for 24 weeks, such that on average they lost 25% of their body weight. During the recovery stage, they
followed various re-nourishing diets.

this may be problematic for males. For example, MacLean et al (2015) suggest that representations of male eating disorders in UK newspapers reinforce messages that eating disorders are inherently female. Robinson et al (2013) undertook research with male participants being treated for an eating disorder, and found that they felt that there is a lack of visibility of male eating disorders in media. In addition, research suggests that male experiences may not be adequately addressed in information about eating disorders provided by professionals and that this is problematic for males who are seeking more personally relevant information (Robinson et al, 2013; Raisanen and Hunt, 2014). In addition to this being the case for Michael in relation to information on the internet, it was also discussed by Ben. He described how, in his experience, information about the 'biological impact' of anorexia tends to be aimed more at females than males (I discuss the impact of this on Ben's identity in chapter five).

Michael explained that he enjoyed being recognised as very thin by others:

> Lots of my friends would jokingly say 'oh I wish I was your size, I could eat what I wanted', you know for me that's a big tick, it's a big tick you know, aren't I amazing because I'm so skinny.

He also described a situation in which he appreciated medical recognition of his thinness. When in hospital for reasons related to his bowel, Michael was recognised as having very low blood pressure and a slow pulse. On one occasion, a nurse was very alarmed about this, but he explained to staff that it was because he was very fit and doing a lot of cycling. He also thought to himself: "Aren't I a hero because I've got low blood pressure and I'm really skinny" and stated "I always gave that to myself as a real brownie point" (I return to this aspect of Michael's experience later in chapter seven).

He described how others, including friends, family and medical professionals, had never challenged him for being underweight or for what he ate. In retrospect, he thought this

surprising. Referring to the occasion when staff had been concerned about his blood

pressure, he explained:

> Now I realise they should have said you know, I'm not congratulating you, I'm telling
> you off you know, but nobody ever did! There was never anything about 'you are
> underweight, you ought to eat more'.

Michael understood the reason he had never been diagnosed with anorexia to be related to

the length of time he had been consistently underweight, and to him never having had any

rapid or sudden weight loss. This understanding was informed by what he had recently

learned about why he was not eligible to be prescribed nutritional aids. When he "looked

into the reasons", he found that in his county, he needed to be diagnosed with an eating

disorder and to have had a recent sudden weight loss to be eligible. He contrasted this to

his experiences and explained:

> I've got like a 25-year history and I've maintained this thing. I don't tick that box […]
> I don't officially have an eating disorder because my weight hasn't recently changed. I
> know I have got an eating disorder, as far as they are concerned I don't tick their
> NHS box.

He also applied this understanding retrospectively to numerous past occasions when

healthcare professionals had not diagnosed him:

> I've had a number of times people have asked me, have you recently lost weight, if I
> had said yes at any of those times they probably would have sent me to the relevant
> things […] Nobody ever questioned me on what I eat. The only question that I got
> repeatedly was have you recently lost weight which I always said no […] I've never
> been diagnosed simply because I come in as low, I go out as low.

Here, it is worth noting the similarities and differences between Michael and Jack's

experiences. For both, the development of their eating disorder was intertwined with

physical health complications relating to their bowels. Both had also had encounters with

professionals who had not diagnosed anorexia when they presented with potential

'symptoms'. However, Jack had actively sought to ensure that he was not diagnosed with an eating disorder, but Michael had not. I have shown that in hindsight, Jack understood his (initial) 'missed diagnosis' as linked to gender, and that his understanding is reflected in literature (Currin et al, 2007; Strother et al, 2012; Raisanen and Hunt, 2017). In contrast, Michael, despite being aware that he did not fit the 'typical demographic' for someone with an eating disorder, did not frame his lack of diagnosis in gender terms. Instead, he understood it as related to his pattern of weight loss.

The interpretation component of the trouble-observability-interpretation convergence (Brossard and Carpentier, 2016) is useful for understanding Michael's experiences. A trouble needs to be both observable *and* interpreted as a medical problem that requires assistance, if it is to lead to a medical consultation. Michael had observed his own undereating and recognised that he was underweight for many years, but his interpretation of this was that he was a 'fussy eater' and it was 'just the way he was'. There was a normalisation of his behaviour and 'symptoms' by both himself and others (Brossard and Carpentier, 2016). Normalisation occurs when 'residual rule breaking' or potentially 'troubling' behaviour is unrecognised or rationalised away (Scheff, 1966). Moreover, the normalisation of his behaviour by others seemed to inform his own understanding, in that others' not defining the situation as problematic contributed to him also not defining it as such. The following quote suggests that the lack of challenge from others contributed to him 'brushing it under the carpet'.

> Admittedly when I look at pictures of myself in a pair of shorts and a vest or something compared to my peers, I think 'Gosh don't I look skinny', but then within an instant I just sort of brush it under the carpet and say you know, it's just me, nobody has really challenged me.

However, he began to interpret his experiences as a trouble that required assistance when he recently experienced a bout of weight loss and illness. This shift seemed to result from

the repeated nature of his periods of weight loss, and the fact that these had continued into his 50s. Coinciding with this interpretation of weight loss as a 'trouble' was his increased engagement with the idea that he had anorexia. Having reached a point where help with weight restoration felt necessary, the diagnostic category of anorexia offered a new framework for understanding his ongoing, long term experiences.

Raisanhen and Hunt's (2017) research also reflects Michael's experience. In their study of young males with an eating disorder, they found that their participants did not initially recognise their symptoms as an eating disorder, and that they presented to professionals late in the trajectory of their illness. The authors attribute this to the widespread construction of eating disorders as a female problem. Their participants explained that they had lacked awareness of eating disorders in men and that this meant that an eating disorder diagnosis was not readily considered as the explanation for their struggles. For Michael, as with his understanding of why he had not been diagnosed by a professional, he did not directly draw on gender as an explanation for why he did not recognise an eating disorder in himself earlier. None the less, it is possible that had male eating disorders been a more culturally available narrative during the initial 25 years of his restricted eating, he might have suspected anorexia sooner. Like Michael, Raisanhan and Hunt (2017)'s participants also seemed to have had their initial lack of recognition of an eating disorder compounded by a lack of recognition by others in their social networks.

Michael was ambivalent regarding a potential future formal diagnosis. On the one hand, he felt frustrated that his eating disorder had gone undiagnosed for 25 years and that it would be helpful if he were to be diagnosed and given access to psychological support. On the other hand, he expressed being unsure about whether he wanted a diagnosis, and felt he could manage his recovery without one.

Regarding his frustration at the lack of a diagnosis, he stated:

> It might be nice if somebody did diagnose me as having an ED, but I know that if they did, at the same time I'd be really angry, thinking why didn't you tell me this 25 years ago?

He felt that had he been diagnosed with anorexia in the past, he might by now be recovered. While he was currently finding the dietician helpful for 'making real' his need to gain weight, he also felt that some aspect of psychological input specifically for an eating disorder would be beneficial. He framed the diagnosis as desirable in its potential to give access to this. However, at other times he asserted that he could manage without a diagnosis and psychological support so long as he had access to information and someone to whom he could be accountable. When I directly asked Michael if he wanted a diagnosis, he responded in a way that reflected his overall uncertainty:

> I suppose yes, but at this stage I don't know if it would be helpful or not. I suppose what I would really like is the opportunity to talk with people who have gone through it and come out the other side […] so it would be helpful to have a diagnosis if in having a diagnosis it led to me being able to be helped psychologically.

An official, formal diagnosis applied by the medical profession is generally understood as more legitimising than a self-diagnosis. That an official diagnosis is awarded by a 'knowing' professional, as opposed to a lay individual, affords it 'weight'. Being formally diagnosed thus comes to confirm that one is 'really' ill (Kralik, 2000), and in service-user mental health communities, there is a reverence for official diagnosis (Giles and Newbold, 2011). However, Michael did not seem to afford this reverence to a (potential) formal diagnosis. He firmly understood himself to have anorexia, and did not indicate that he thought himself any 'less anorexic' for not having been diagnosed by a professional.

Chapter Five Summary

In this chapter, I have shown how individuals reach the point of being diagnosed via different routes, whereby one's self and others play differing roles in defining the situation as problematic and initiating help-seeking. These different routes to reaching a diagnosis are linked to different experiences of being diagnosed. The diagnosis held different meanings for individuals, partly depending on the extent to which they believed themselves to have a problem and wanted help. Individuals who had self-driven their help-seeking, often perceived the diagnosis as a useful way forward, whereas those for whom help-seeking had been driven by others did not identify with it. In addition, this chapter recognises how some participants (and I) experienced the diagnosis as a marker of success and a validation of their suffering. In this meaning, we begin to see the emergence of anorexia as a valued identity and social positioning, and this is explored further in the following two chapters. I have also examined the situational and interpretive processes involved in the trajectory of a 'missed' diagnosis for a male participant. In this case, as well as in relation to the other two males, I have begun to illuminate some gender dynamics in relation to the diagnosis.

Chapter Six

Being anorexia

This chapter is concerned with diagnostic identity - the 'being' dimension of a diagnosis of anorexia (Brinkmann, 2016). As noted in previous chapters, a psychiatric diagnosis can be an important influence on one's identity (Karp, 1996; Brinkmann, 2016), and research suggests that individuals diagnosed with anorexia come to manage and embody it as an identity as well as an illness (Rich, 2006; Warin, 2010). In this chapter, I am concerned with the ways in which participants related to the diagnosis of anorexia, how the diagnosis (and associated clinical knowledge) informed their self-understandings, and the value and meaning of an anorexic identity. The previous chapter has already begun to address some facets of this. I showed how identification with the diagnosis emerged for participants in the self-directed pathway, and how this influenced their help-seeking. In an examination of the meanings they afforded it when first diagnosed, the chapter also revealed how individuals initially related to the diagnosis.

I begin this chapter focusing on those participants who did not identify with the diagnosis at the time that they were first diagnosed. I address the question of when and how they did eventually come to identify with it, and the interpretive processes and social circumstances involved. I then turn to explore their identification with anorexia over time. This includes a consideration of how their identification sometimes fluctuated, and how it was expressed through the personification of anorexia. Following this, I explore how clinical understandings were incorporated into individuals' personal sense-making about their diagnosis, and how this informed anorexic identities that were variously clinical and 'critical'. Finally, I address the ways in which individuals sometimes valued (and even sought) being positioned as 'anorexic'.

Coming to identify with anorexia

The previous chapter identified a range of meanings attributed to the diagnosis on the occasion that individuals were first diagnosed. For six participants (Claire, Hannah, Ben, Natalie, Amelia and Mia), this meaning was a *lack of identification* with the diagnosis of anorexia. I now follow up on this meaning and examine when and how – if indeed at all - these participants recalled that they *did* subsequently identify with the diagnosis. The development of an identification with a diagnosis and related self-understandings may be gradual, subtle and influenced by factors of which participants themselves may not have been aware. The focus here, then, is on what participants retrospectively recall as significant in this regard.

Claire, Hannah, and Ben recalled having eventually begun to identify with the diagnosis during inpatient treatment. When Claire described the time that she first started to see herself as 'anorexic', she referred to her having had no choice but to be hospitalised, and the views of other patients - which were taken as more trustworthy than clinicians' - as important influences on this:

> I only accepted that I had something wrong with me when I started going to the hospital full time, and actually had no choice about that […] something that helped me actually was when other people who had eating disorders told you that you looked like you had an eating disorder, I felt like I was more able to believe them just because they had been through it already as well, so I trusted their judgement a bit more than the professionals.

Hannah's first course of treatment was as an outpatient for a few months. As her situation worsened, she progressed to day-patient treatment for two weeks and then a 6-month inpatient admission to an adult SEDU. Prior to being an inpatient, Hannah had not been sure that she fitted "an anorexia bracket". Like Claire, spending time with others also diagnosed with anorexia appeared to have influenced how she viewed herself:

> When I became inpatient that was the first time I really understood, when I met other people who shared similar things […] Also there I felt different in some aspects. But it's sort of like progressed as it's gone on. My last admission I definitely was considered, like I definitely considered myself anorexic […] from being an inpatient and with all the other girls […] in groups and listening to them, you can definitely get a sense of how your eating disorder relates to theirs, and see the differences.

Seeing aspects of her own experiences in others influenced her view of herself, and she recognised being in hospital as having influenced her increasing alignment with the diagnosis over time.

Ben had been referred to a child and adolescent psychiatric unit about three to four months after an initial appointment with CAMHS. He described how, when he was first diagnosed with anorexia and admitted, in part due to his young age, he struggled to articulate his experiences. He felt that this led him to be more open to take on the diagnostic definitions offered by others during inpatient treatment:

> I didn't have the vocabulary to say sort of at the time this is really what I find difficult about food […] I think a diagnosis then perhaps just sort of you know, this is what's the problem […] I think I mainly took other people's definitions as opposed to my own.

However, Ben did not meaningfully internalise the definitions offered to him by others; he only vaguely identified with the idea of anorexia at the time of inpatient treatment, and after his admission remained distanced from the diagnosis (discussed in detail later).

Claire, Hannah and Ben's experiences can be understood in terms of what I call diagnostic framing. This is the process by which clinical knowledge of anorexia, in all the various ways it manifests and is communicated during treatment, offers a new interpretation of one's experiences and recasts them as belonging to the category of anorexia. Through this process, what individuals once experienced as 'normal' or unproblematic, gradually come to be understood as 'anorexic'. Darmon's (2017) description of the final stage of the 'anorexic

career' is relevant here (see chapter two). This stage involves the individual entering and being 'taken in hand' by the hospital institution. The hospital seeks to reverse the individual's commitment to anorexia by *redefining* their existing dispositions as pathological, and replacing them with 'healthy' ones. In gradually getting 'on board' with this process, the individual internalises the hospitals perspective, and actively invests in 'recovery'. Recognition of oneself as 'anorexic' is a necessary first step in this process, and occurs as part of the redefinition – or diagnostic framing – that takes place.

Claire and Hannah identified 'seeing' the diagnosis in others as playing a role in diagnostic framing. They will also have been exposed to ideas about 'what anorexia is' more variously and generally, such that they were gradually socialised into a new way of understanding their experiences and themselves. In addition, Amelia, who had only ambivalently understood herself as having anorexia prior to being admitted to outpatient treatment, alluded to diagnostic framing when she explained that "[treatment] made me realise I was poorly".

For Claire, Hannah, and Amelia, the newer interpretation of their experiences – that is, the understanding of themselves as 'anorexic' - was retrospectively (at the time of the interview) understood as the 'correct' interpretation. In the quote from Claire above, her use of the words 'accepted' and 'helpful' imply that she viewed the understanding of herself as having an eating disorder as the 'true' position, that before hospitalisation, she had not yet realised (but needed to). This is in contrast to Ben, who indicated a more 'neutral' take on diagnostic versus non-diagnostic interpretations, by seeing these as different but neither 'more true'. Here, then, is an initial glimpse into the different ways that anorexia entered into individuals' current self – understandings, with some more readily or 'wholly' incorporating dominant diagnostic discourse than others. These different self-understandings are discussed in detail later.

In contrast to Claire, Hannah and Ben, Natalie was clear that she did not identify with the diagnosis until *after* she left inpatient treatment:

> Even during all of the treatment like I never really identified with having anorexia […] it's only really since I've left treatment that I've begun to identify more with it […] I remember getting letters from the eating disorders service and they would have it written on the letters, and I couldn't read it, I couldn't even read that it was from the eating disorders unit […] I don't know whether I didn't want to recognise that I had an issue […] whether I was in so much denial about everything […] it's only really after all of that that I have kind of slowly started to identify with it.

Natalie's description suggests an element of resistance to thinking of herself in terms of the diagnosis, which dissipated after she left inpatient treatment. However, when describing her experiences of inpatient treatment, she frequently alluded to her then-awareness of notions of 'wellness' and 'sickness', and her attempts to align herself within these different positions. This suggests a possible distinction between thinking of herself as unwell in some way, and as having the specific diagnosis of anorexia; the former may have occurred before the latter. However, even her recognition of herself as 'sick' while an inpatient was a position that she questioned, often feeling as though this was a 'façade' (discussed further later).

Mia's descriptions of how she had begun to identify with the diagnosis were less definite. Like others, she began to understand herself as 'having a problem' while in treatment, but this understanding was fluctuating. During her first bout of outpatient treatment in which she undertook CBT, she did sometimes shift towards seeing herself as 'having a bit of a problem', but largely did not accept herself as 'having anorexia':

> There were times when it was like OK, maybe I do have a problem, but then there were other times when it would just be like, because still at that age, it was very much mum and dad that actually took me […] I didn't choose to be there […] I might as well engage in it but sort of maybe not fully accept it.

Mia recalled a later occasion, when she had relapsed and was waiting to begin inpatient treatment the next day, as a significant moment in terms of her accepting the diagnosis and

the need for treatment. However, despite recognising such occasions as moving her towards 'acceptance', and despite describing herself as having 'chronic anorexia' at the beginning of her interview, her identification with the diagnosis was ambivalent and inconsistent. At one point, she suggested that she had only very recently accepted the diagnosis. She then directly followed this claim with a description of how she still currently actively rejects or negotiates it:

> I don't really know if I accepted it until kind of recently […] because every time the word is bought up I sort of will just answer back with a 'but' kind of thing, not really listening to what has just been said to me and wanting to quickly cover that over because actually no I don't because such and such.

I have explained previously how Lisa had initially identified with the *idea* of anorexia aged eleven, and that her desire to become like the 'anorexic persona' (as she described it) she had read about in a book motivated her to begin restricting her food intake. Lisa was eventually diagnosed with anorexia in her early 30s. It took a long time for her to 'accept' this diagnosis, in part because she had initially been diagnosed with bulimia. A bulimia diagnosis had reinforced her belief that the binge eating aspect of her struggles was 'the problem', as opposed to the food restriction associated with anorexia. It also reinforced her belief that anorexia was a figment of her imagination. Indeed, 'being anorexic' had for many years been part of a "secret fantasy" that existed only in her mind, and was therefore difficult for her to accept as 'real'. When she was eventually diagnosed with anorexia and advised to begin a programme of day treatment, Lisa found this hard to accept:

> I couldn't really believe that it was being said to me because it felt like stuff that I'd read about in books and that happened to other people […] it just felt very weird, and it took quite long to reconcile to the fact that it was happening in reality.

Gradually, over the course of around eight years and various periods of day patient and inpatient treatment, she came to relate to the diagnosis:

> In the last few years since getting the diagnosis and being treated for anorexia […] I think I do identify with it in a way, in a more healthy way […] I accept that actually I have suffered with it for many, many years […] including before I was diagnosed with it.

However, like Mia, there was also ongoing ambivalence in this respect. Early in the interview, Lisa explained:

> I don't like the idea of me being anorexic. I still find it a little bit hard to believe that it is the case sometimes […] particularly now I feel like I'm kind of quite well.

She felt that her positioning of herself as anorexic shifted and that while at times she strongly identified with the diagnosis, at others she found it difficult to believe.

Diagnostic identity

At the time of the interview, most participants identified themselves with the diagnosis of anorexia, and the diagnosis informed their self-understanding and experiences in important ways. In general, these participants spoke about the diagnosis of anorexia as if it were something that they had or were recovering from, and as if diagnostic understandings were the natural and 'common sense' way of accounting for their experiences (Dignon, 2007). To some extent, this was engendered by the interview situation itself; participants were being interviewed precisely because they had (or previously had) a diagnosis of anorexia, and as the interviewer, I implied a 'diagnostic reality' simply by referring to 'anorexia'. However, throughout the course of the interview, participants were encouraged to speak within their own frames of reference and were given space to reflect critically on the diagnosis, enabling them to detach themselves and/or their experiences from it. Three participants did do this (in different ways and to different extents), and these participants' interviews reflected more 'critical' narratives. However, most did not reflect critically on the diagnosis, or at least not to a great extent.

Despite predominantly identifying with anorexia however, participants also sometimes

doubted their diagnosis and an identification with anorexia was not always consistent over

time. I have explained how this was the case for Mia and Lisa, both of whom recognised the

fluctuating and complex ways in which they understood themselves as truly 'anorexic'. Anna

similarly explained that there was a "big part" of her that didn't "quite believe" she had it

"all the time". She made reference to her (previously described) conceptualisation of

anorexia as something that one actively *does* on a daily basis to explain why, now that she is

no longer losing weight, she sometimes doubts that she has anorexia. Further, she explained

how she sometimes struggles to make sense of the diagnosis due to it being indistinguishable

from 'just who she is':

> I just kept constantly having that scepticism that I still have now, that I don't quite
> believe [I have anorexia] it's just a smaller part of how I think on a bigger scale about
> lots of different things, I can find that quite hard to spot as a tangible part of myself.
> Thinking in certain ways, being really anxious about things, judging myself quite
> harshly are just things that I've always done, and so it can be really hard to separate
> as a thing that is separate from just who I am.

Related to this doubt about their diagnosis, it was common for participants to describe

sometimes feeling they were not 'sick enough', not 'doing' anorexia well enough, or that

their anorexia was fraudulent. These issues, discussed in depth later, are relevant here as a

contextualising point. In the following discussion, I focus on the eleven participants who

identified with the diagnosis of anorexia and explore the processes through which they

related themselves to, and internalised, a diagnostic and clinically informed understanding of

their experiences. The contextualising point that it is important to hold in mind is that these

identification processes often occurred against a backdrop of doubt about their claim to

anorexia, and were therefore not consistent or absolute in terms of what they meant for

diagnostic identity. The identity processes I discuss are 'entification' (Brinkmann, 2016),

diagnostic framing (introduced earlier) and interpretive identity-work. After this discussion

of identification with anorexia, I move on to discuss the more critical narratives of the three participants (Sarah, Natalie, and Ben) who tended not to currently identify with the diagnosis.

Entification

'Entification' occurs when a psychiatric diagnosis is treated as if it were a discrete object as opposed to a clinical label, and is a way of invoking a diagnosis as an explanation of one's struggles (see chapter one) (Brinkmann, 2016). In anorexia, entification may be encouraged by therapeutic processes which seek to 'externalise' anorexia so that it can be resisted (Winston et al, 2012). Such approaches tend to derive from narrative therapy (Weber et al, 2006; Scott et al, 2013), and often involve personifying anorexia by imagining it as a separate person who is both friend and enemy. Personification is sometimes also encouraged in treatment discourse more generally, for example via staff telling those with the diagnosis that their 'anorexia is talking' when they express apparently 'irrational' ideas (Lavis, 2011). In addition, some individuals directly experience anorexia as if it were a person or voice that they feel affiliated to (Tierney and Fox, 2010; Pugh and Waller, 2017). This was the case for Mia, Sarah and Claire, who described having (at least at some point) directly experienced anorexia as a person living alongside them (or a voice in their head) who encouraged them to restrict their food intake.

Entification was one way in which participants related to anorexia and expressed their identification with the diagnosis. Most who identified with the diagnosis entified it to some extent during their interview. Sometimes this was only 'slight', and occurred for example via occasional reference to 'the anorexia' or 'the eating disorder' that positioned it as a 'thing'. For five participants, entification was more significant. Here, anorexia was referred to as a separate entity that acted *on* them, interfered with their true self and desires, and that had its own agentic capacity, needs and goals. Here are some examples:

> Claire: I think the anorexia makes you do things that you wouldn't probably normally do and it makes you act in certain ways that you might not […] the anorexia made me do really nasty things.

> Jack: I can be quite manipulative and I guess that's one of the main factors of it, the eating disorder can make you very manipulative how you do things, very secretive […] the eating disorder is controlling you.

> Naomi: I think the problem with being someone that's very able, very capable is that the eating disorder will hijack that. I can be trying hard to find ways to protect myself from the eating disorder behaviours […] but as quick as I come up with a way the eating disorder finds a way round it.

Amelia described 'the eating disorder' as something 'evil' that had 'possessed' her, and implied that it was potentially separable from her 'true' self by stating "It's engrained within your body to the point where you don't know what's you, and what's anorexia anymore".

I therefore directly asked her whether she understood anorexia as something separate. In response, she described how 'separating out' anorexia was something she had attempted in the past (and implied that she does not do this currently). Interestingly though, when explaining this, she inadvertently engaged in the very process she implied she was *not* engaging in, by personifying anorexia via a description of it 'playing a game':

> When I first started recovery I tried to say it, this is the anorexia, this is me. But that was, that was the anorexia playing a game […] as in trying to convince everybody else that I was getting better when really I wasn't.

She also directly contrasted her own desires to those of 'the anorexia'. For example, when describing her realisation that she was the longest-term patient among a particular group at the eating disorder clinic, she stated: "The anorexia was pleased about that. I was mortified. I was like oh my God, I'm still here what the hell am I doing".

In addition, she implicated anorexia as having its own needs. With reference to the support she has from her parents, she explained: "I think because part of the illness has been this

fear of being independent. The illness is now thriving on that. It needs, wants this continuous support from them".

Maddie also contrasted anorexia's desires with her own and located apparently 'pathological' needs within anorexia (as opposed to herself):

> [Being treated like a child] probably feeds the eating disorder more because I think it craves that attention and it craves that approval […] it wants you to not grow up and it wants that support and validation and I was trying to break free of that mould, I was trying to come back to being an adult and being myself.

Maddie later explicitly addressed her personification of anorexia, explaining "I look at it as two people [anorexia and her] and I do I give it a different identity almost".

It is important to note however, that even for those participants who sometimes spoke about anorexia as a separate entity, they did not do so consistently. Taking Jack as an example, in addition to sometimes referring to anorexia as a controlling, outside entity, he also very much firmly located an 'eating disorder drive' within himself and his own thinking. When responding to a question about the extent to which his anorexia felt like a 'conscious decision' that he willed, Jack explained:

> I'm consciously doing an amount of exercise so it's an exact precise amount […] It's not I'll do 'about that', I'll do an exact amount. I'll be at the gym for an exact amount of time […] The reasons behind it are probably more sort of […] in the background, but the actual doing it is a very conscious decision.

Given that the personification of anorexia is sometimes encouraged in therapeutic and clinical discourse, it is likely that the entification of anorexia was learned during treatment, and/or engagement with clinical knowledge outside of treatment contexts. It can therefore be understood as potentially being a part of diagnostic framing and interpretive identity-work, both of which are discussed next.

Diagnostic framing

I introduced the concept of diagnostic framing when addressing how participants initially came to identify with anorexia during treatment. To recap, this is a process in which clinical knowledge offers a new framework for understanding one's experiences and recasts them as belonging to the category of anorexia. This concept is also relevant to understanding how participants (increasingly) aligned themselves with the diagnosis over the longer term, and how they incorporated diagnostic-based understandings into their personal sense-making. I have chosen Anna as a case study to illuminate this. This is because, in her interview, she addressed the relevant issues explicitly, talking through many specific examples. For others, diagnostic framing was addressed more implicitly.

For Anna, the clinical knowledge of anorexia that was bought into play during sessions with her therapist encouraged her to understand more of her experiences as 'anorexic'. For example, her therapist pointed out that her feelings that she needed to lose weight in order to 'keep' her diagnosis were part of the mentality of anorexia, and this was a happy relief to her:

> They were like that's part of the anorexia […] I thought it was proof that I didn't have it, and they were like this is just further proof, people seeing recovery as a strategy to lose weight.

Further, her therapist's reaction to her extremely detailed recording of her food intake led Anna to realise that this was 'weird' and an 'anorexic behaviour'. Discussing her food diary, she explained:

> I'd counted every gram, every calorie, mathematically, all mapped out, really neatly […] I didn't even notice it was weird […] until he said it to me, and he was like, you like detail don't you, and then I just clicked a little bit back and was like 'oh yeah'.

Such processes of realisation also occurred when her therapist drew on his understanding of anorexia to recognise something that she was potentially struggling with, without her raising it first:

> He just asked me 'are you ever afraid of wasting calories', and I was like 'what does that mean'? He said 'some people, they wouldn't want to drink alcohol because if they are going to have those calories they are going to make it count'. I was like 'Oh. That's a thing (laughs)?' […] I felt like I was keeping aspects of the eating disorder secret from him but he knew a lot of the time […] I would always be ashamed until, he would just be really matter of fact about it.

Learning that worry about 'wasting calories' is a "thing", shifted the meaning of this experience; rather than being an idiosyncratic and shameful experience, it became a shared 'symptom' of anorexia and was thus diagnostically-framed.

Diagnostic framing can reinforce a diagnostic identity. Brinkmann (2016) describes how psychiatric diagnoses can be self-affirming. That is, the interpretation of phenomena through the lens of a diagnosis can transform them into 'symptoms' that in turn confirm the diagnosis - even phenomena that might ordinarily count against the diagnosis (or be considered irrelevant to it). Brinkmann gives an example based on his research with individuals with ADHD. A participant in his research explained his orderliness as belonging to the ADHD diagnosis, by describing it as a way of avoiding the 'chaos' of ADHD. However, *dis*orderliness and forgetfulness are usually considered 'symptoms' of ADHD. With regard to diagnostic framing, others (in Anna's case, her therapist) may be instigators of this process. So too is treatment discourse more generally.

Mia described how being exposed to new ideas in treatment led her to not only *understand* her struggles differently, but to in turn *experience* them differently. Prior to identifying with anorexia, Mia had thought of her self-starvation as 'a physical thing', with her focus being a

desire to lose weight. However, after being introduced to an understanding of anorexia as a 'mental thing' during treatment, she began to experience it as such:

> [At first] it was very much kind of body image. Whereas now it's a definite coping mechanism kind of feelings […] It was a Dr who said to me, it's actually nothing to do with the food, that's not the problem […] I was sat next to him and was like 'oh my God. What?'. I always thought it was about food and that I didn't want that because it had so many calories in […] not that I was actually maybe feeling nervous about something and that I was then choosing to use that as a tangible object of control. So that was the doctor who changed my perception on it, and then the second time round of relapse it became control, a thing I could just control.

Mia therefore directly attributed her understanding of what anorexia is 'about', and her lived, internal experience of self-starvation, to the understanding that was offered to her by a doctor. I further examine Mia's ideas about 'control' later in relation to interpretive identity-work.

Some participants spoke explicitly about the positive value of coming to identify with the diagnosis of anorexia for their recovery. Looking again at Anna, diagnostic framing had felt relieving to her, because understanding her struggles as belonging to anorexia reduced the shame she sometimes felt, and provided a potential way forward:

> Sometimes I think that particular things are personal failings I have that I have to keep secret […] there is kind of a relief when something would be like well OK that's part of the condition and the condition as a whole can be managed.

Interpreting her struggles in terms of a clinical category felt to Anna as though it validated her experiences and allowed them to be taken seriously:

> [The diagnosis] was a lens through which we [Anna and therapist] could take things seriously. The things that upset me weren't just ridiculous things I had to never tell anyone about, so we actually needed to pause and discuss them thoroughly […] and in so many ways I found that useful.

Her therapist's ability to personalise treatment meant that, in addition to being understood as someone who belonged to the general category of anorexia, she also felt recognised as a person with her own unique experiences. She explained that her therapist both "made it feel as though it was a thing that could be treated, and that he knew about", but also recognised that "everybody is different".

Anna also saw the diagnosis as having acted as a 'stepping stone' to addressing broader struggles, and something that she and her therapist "left behind and moved beyond", to focus more on experiences such as anxiety, abuse, and stress.

An identification with anorexia also remained valuable to Anna post-treatment. In continuing to make her struggles tangible, it reminded her that she needed to continue to look after herself, and not expect herself to be 'well' simply because she has regained weight:

> I think in some ways I find it [identifying with the diagnosis] useful, because I do struggle with my mental health and I think those things can slip under the radar […] it's this thing that it's like, tangibly, I actually really do need to be careful […] I think in many ways it's like identifying myself with anorexia is a way of reminding people that this isn't just something that is gone the minute my BMI is restored […] or even the fact that I can't tell them that but I can reassure myself that this will be a longer process.

Lisa also explained how coming to identify with the diagnosis, and in particular its related 'illness' framing, was helpful in terms of managing her wellness:

> Seeing it as an illness […] and something that I am going to have to guard against […] I think its understanding that actually, once you have that kind of restrictive illness perhaps, perhaps you've got to accept that even when you don't want it anymore it's going to, it's probably going to be something that you've got to fight. Being able to see it in that way has helped me a lot.

She explained how she retrospectively understands that she had indeed "needed" the diagnosis of anorexia, and that she has come to identify with it in a "healthy" way that has ultimately allowed her to begin to move beyond it.

Interpretive identity-work

Karp (1992) explains how, once an individual has come to develop an identity as a depressed person, they then search for the meaning of that identity (see chapter two). This entails the reconstruction and reinterpretation of past events, a search for the cause(s) of one's current situation, the construction of new theories about the nature of depression, and the establishment of modes of coping. Participants' interviews suggested similar interpretive processes in relation to anorexia. I understand these as a form of interpretive identity-work. I defined this as the processes of interpretation and meaning-making that individuals partake in as they make sense of their identity. Having come to identify with anorexia, participants then sought to account for their belonging to this category. This interpretive identity-work is closely related to diagnostic framing, because the diagnostic understanding this imposes informs one's personal sense-making. Interpretive identity-work may be integral to the therapeutic work and 'self-discovery' that occurs during eating disorder treatment (Scott, 2011).

In the interviews, interpretive identity-work was reflected in the ways that participants framed their biography in terms of anorexia. Earlier experiences were understood through the lens of the diagnosis. Life events were narrated as contextualising and causal factors for developing anorexia, and previous behaviours retrospectively understood as symptoms. Further, specific occasions took on new meanings as key 'turning points', as they were framed as moments of significant change (Strauss, 1959). A major aspect of interpretive identity-work which I focus on here is the identification of reasons for having developed anorexia. Participants typically offered rich, multiply-informed accounts. They amalgamated a range of different understandings as they pieced together various aspects of their experiences and narrated these into an explanation. These explanations came across as well-versed and were suggestive of ongoing identity-work over time. It seemed that

exposure to new ideas (especially in treatment) and active attempts to better understand one's situation (such as through 'personal research') had shaped these personal understandings.

Participants' explanations were often informed by common clinical understandings of anorexia, such as ideas about 'control', 'coping mechanisms', and 'perfectionism'. Indeed, over time and through engagement with treatment, individuals may become 'schooled' in describing their experiences through a particular model, and in using clinical concepts to account for their anorexia (Dignon, 2007). Here we can see a direct link to diagnostic framing, as this can be considered a mechanism through which 'schooling' occurs.

An example of a frequently drawn on clinical idea was 'control'. This was a part of the causal narrative given by seven participants. For three of these (Jack, Mia, and Amelia), it was central to their descriptions of how and why they developed anorexia. The idea that anorexia manifests as a desire to control one's eating and weight in response to a lack of control in other areas of one's life is a common clinical and lay understanding of anorexia. Dignon (2007) argues that clinical knowledge of anorexia has served to construct a template of typical traits and manifestations of the condition. This template includes the characteristic of control, as well as fat phobia, fear of maturity, obsessionalism and perfectionism. Psychoanalyst Bruch (1978) was the first clinician to write about control in anorexia (see chapter two). She understood anorexia to be an attempt to establish a sense of identity and control whereby the individuals body becomes an "arena for their only exercise of control" (1978: 59). Feminist psychoanalytic therapists such as Orbach and Lawrence who were writing around a similar time also adopted ideas about control. Lawrence (1979) argued that a 'control paradox' is at the centre of anorexia. This refers to the anorexic's rigid control in terms of self-denial and in relation to food and weight which is directly contrastable to their experience of themselves as 'out of control' and 'greedy'. Later clinicians (e.g. Palmer, 1989)

also drew on ideas about control to explain anorexia, and clinical conceptualisations now frequently present anorexia as a control strategy, whereby self-starvation is a means for establishing a sense of control that is lacking in other areas of one's life (Dignon, 2007). Indeed, 'control' is now generally acknowledged by clinicians as a key paradigm in anorexia (Nunn, 2001), and recent NICE guidelines reinforce this notion by referring to individuals with eating disorders as having 'control issues' (NICE 2017b: 24).

Jack, Mia and Maisy all understood their eating disorder as 'really' being about control (as opposed to weight). As Jack explained: "It's never been 'I want to be a certain weight' […] I'd say it's more been a control thing over just like food and exercise rather than being like a weight thing 100%".

A control-based causal narrative was most strongly evident in Mia's account, and we have already seen how she had initially been introduced to ideas about control by a doctor. She identified difficulties among friends and family which led to her feeling 'out of control' as a reason for her having first relapsed. She then explained that she had turned to weight loss to resolve this, stating "I needed some control back. So I just started to look again at food". Furthermore, when describing her conceptualisation of anorexia, she stated that it involves her mind attempting to generate feelings of being in control, and that her 'wasting' body is an unintentional outcome of these attempts. She also explained that she had identified herself as currently having six specific behaviours that she habitually engages in and that she uses these "as a form of control". Control, then, appeared as a central concept in Mia's (and others) identity-work.

For some participants, explaining their anorexia meant also making sense of simultaneous physical health problems or other psychiatric diagnoses. In these cases, participants' narratives tended to account for both; the stories for both of their diagnoses intertwined

into one, and the explanation for each condition also accounted for the other. Jack's narrative of the development of his eating disorder, and his ongoing management of his struggles, was inseparably bound with his experiences of bowel problems:

> The bowel symptoms definitely kicked off the being aware of what I was eating etc, which then you know sort of spiralled into the controlling nature which you know went into the eating disorder bit.

The same was true for Michael. Since identifying with the diagnosis of anorexia, he retrospectively understood his bowel problems differently from how he had previously. He explained how the development of his anorexia and his bowel problems sustained each other:

> *I now can see* that it was because of that, because I wasn't eating enough and losing weight [I developed bowel problems…] *I can now look back* and say, before I was in my mid 20s I never had a problem with my bowels, it only came about as I started to lose weight […] the gastroparesis, and because it slowed down, that led to constipation and this twisting […] that just added the fuel to the fire of the eating disorder, the twisting my stomach hurts I'd then be careful about what I eat, in being careful about what I eat I slim down even more which makes it [my eating disorder] worse (My emphasis).

Retrospectively understanding the relationship between anorexia and the serious medical problems he had experienced was an important aspect of his interpretive identity-work. This work was also informed by information gleaned from the internet about anorexia and biological processes relating to weight loss and gain. Unlike others who had been formally diagnosed, Michael did not acquire information about anorexia from being directly immersed in clinical discourse of eating disorders during treatment. Rather, he actively sought out information online, the impact of which he understood as 'formalising':

> Since the beginning of the year my understanding of being somebody who is anorexic has become a lot more formalised […] My understanding of what eating disorders are, what anorexia is, how it affects you, how it affects your psychology as well as your physiology.

Naomi had a diagnosis of autism in addition to anorexia, and her understanding of each of

these conditions merged such that they were both prominent in explaining her experiences:

> I can look back at my history now and see eating disorder traits back into my really
> early childhood, I think some of that probably comes from texture aversion with
> autism and sensory things.

In addition to autism and anorexia, she also made reference to depression and anxiety, and

linked these various conditions together:

> It wasn't until actually my first admission and being in hospital that I realised how
> depressed I was and how it was that that was underlying the eating disorder and the
> anxieties around that and my mood and how I talked to myself […] through therapy
> I've discovered that it wasn't just the depression, it's an anxiety, and that underlying
> that is probably autism.

Clinical and 'critical' anorexic identities

Shohet (2007) differentiates between 'full' and 'partial' narratives of recovery from anorexia,

and in doing so identifies different degrees of affiliation with institutional master narratives.

Her participants engaged differently with clinical and feminist narratives of how anorexia

comes about, and what recovery involves. While a 'full' narrative of recovery involves

embracing institutional narratives, partial narratives involve adopting only select aspects and

actively subverting others. That there are different degrees of affiliation with dominant

clinical ideas also resonates in this research. As might be expected, the three participants

who tended not to align themselves with the diagnosis and were critical of it, tended also

not to have incorporated clinical narratives into their self-understandings (I discuss this

later). However, even among those who did identify with the diagnosis, while they may have

embraced some aspects of clinical ideas, they were sometimes also critical of others. Across

the whole sample, individuals self-understandings ranged from those with a strong 'clinical'

feel (an example being Mia in her incorporation of ideas about control) through to those

that were more critical and clinically distanced (the three participants discussed later), with

participants between these two extremes incorporating elements of both.

An example of a participant who incorporated both is Kelly, whose descriptions of how she

would (hypothetically) explain anorexia to others intertwined a range of different

explanations, drawing on clinically informed ideas about phobias, control, 'methods of

coping', and self-punishment:

> [Anorexia is] a bit like a phobia […] I think I would probably explain it as a bit of a
> phobia. I would relate the fear of food and gaining weight […] it's about really being
> scared and I think I'd probably explain it as well as a way, as a method of coping […]
> in a lot of cases it gives you somewhat of a release and a way of coping with bad
> things that have happened […] food is something that it literally sustains your life and
> you can deny yourself the absolute, if you can't control anything else in your life, and
> you want to find a way to I guess punish yourself in some way.

However, Kelly was also critical of the explanations of anorexia that she engaged with

during treatment. She had experienced trauma and understood this as a reason for her

developing an eating disorder. She found that this trauma was not accounted for in the

discourse that was offered during treatment, leading her to feel "misunderstood". She was

also critical of the focus on "cultural norms of beauty" that had been an assumed causal

factor during treatment, as this did not resonate with her experiences and she found this

conceptualisation problematic. Accordingly, while she identified with the diagnosis of

anorexia, she also did not feel that it fully represented her experiences:

> I felt like nobody really understood and I kind of wanted to say well yeah I do have
> this diagnosis, but that's not going to tell you anything about what's going on […] I
> didn't ever see anorexia spoken about as a response to trauma that often […] as
> opposed to just kind of like you are losing weight to appear more beautiful.

In the quote above, Kelly critiques the diagnosis and the clinical narratives that surround it.

For three participants – Natalie, Ben, and Sarah – a critical understanding of the diagnosis

was more prominent. For a range of different reasons and in different ways, they did not readily identify as 'having anorexia'.

Sarah believed herself to have an eating disorder, but actively avoided saying 'anorexia'. She explained that this word (which she did not use during the interview) made her very uncomfortable, although on some level she recognised it as 'correct':

> I'm still not comfortable with that word as you see I don't like using it. That has been given to me, that diagnosis, by lots of different people […] and it's in my medical records and everything but it's not a word that I can really use […] I feel quite comfortable saying I had an eating disorder and when I say that I mean I had that [anorexia], I just can't say the word very easily […] I can go on the internet and I can find out what that diagnosis means, and I can associate with everything in it, so I suppose I know that that it is what it is.

Sarah struggled to explain why the word anorexia makes her uncomfortable, but identified two possible reasons. The first relates to an aspect of her experience that has been described in chapter five in relation to the meaning of being diagnosed. That is, prior to her 'recovery', she was wary of claiming anorexia for fear that this would offer others a route to 'fix' her. The second reason was because of the difficult memories the word invoked:

> Thinking about that time in my life was so upsetting and I don't ever want to go back there […] I'm so much happier and I just I guess I just want to not use that word, it just makes me think about it and it makes me feel scared I think.

Sarah's most significant experience of professional input was with a psychologist she saw at an eating disorder clinic at her university. She explained that he had not based her treatment around a diagnosis, and that he "never used that label and made a point of never using that label. [He said] 'I'm not going to diagnose you or anything'". Accordingly, despite believing herself to have (or have had) anorexia, her interview narrative was distanced from the idea of anorexia as a diagnostic concept. She did not describe her experiences in

diagnostic terms and there was also an absence of a clinical 'feel' to the descriptions and explanations that she offered.

Natalie, who described having identified with anorexia after having left inpatient treatment, had since developed a more critical understanding of the diagnosis. She recognised that this had (at least in part) come from her experience of academia (she was currently studying for a social science PhD), where she had developed critical views:

> I'm quite anti-diagnosis about most things and I'm quite into not removing a disorder from yourself as a way of understanding it. Because I think actually, for me anyway, it's a part of myself and that's how I'll understand most mental health issues […] I know that I'm a critical person about that so it comes from there too, but it's really difficult (the idea that) it's a disease, it's not your choice […] because then it completely takes away autonomy.

Natalie's critical views extended beyond the concept of a diagnosis and its associated 'illness' framing, and also led to her critically questioning the 'causal narratives' that are associated with the diagnosis. For example, she tentatively invoked the possibility that her eating disorder had developed for reasons relating to (lack of) control, while also doubting this idea:

> A lot of people say 'oh, eating disorders are all about control'. Maybe they are, maybe they are not, I don't know, I mean if I look at what's happened over the past six months of my life, everything has happened which has not been in my control, and now I'm really not having an easy time with food and my weight so I'm like OK, maybe it is a little bit about when things are not in your control. But it's not that simple, I think it's just so many things.

Natalie did not identify with the diagnosis at the time of the interview, because she was critical of the associated illness framing. However, she still referred to herself as 'having anorexia', and still used the word to refer to her ongoing experiences of food and weight related distress. What we see here in relation to both Sarah and Natalie is an identification with anorexia in a 'non-diagnostic' manner. This suggests that 'anorexia' might be

understood as something of a variable term, that was invoked differently by different participants; while for some, it meant adopting a diagnostically and clinically-informed construction of anorexia, for others it incorporated at least some element of distancing from this dominant construction.

Ben described having never fully internalised the idea that he has anorexia. He did not understand the diagnosis as adequately accounting for his experiences, due to these being more complex and broad than a diagnosis of anorexia suggests. Ben had gone on to experience further struggles after inpatient treatment that were unrelated to food and weight and explained:

> While anorexia is what we are talking about here today […] I don't think it was the be-all and end–all of what was going on or still what then was to happen […] I still don't think it explains for me this sort of, the complexity of the feelings.

While he had ambivalently 'taken on' the suggestion of having anorexia during treatment, he still saw this as other people's understanding, and never fully internalised it, even while he 'recovered':

> I still don't think I was saying right, I have this diagnosis and I'm going to work against it. It was just me achieving tasks and just doing stuff […] I never ever once thought to beat anorexia nervosa this is what I have got to do.

He also described resisting the idea of being 'categorised':

> I didn't join together the dots; heart rate, bad skin, you meet the criteria, because it was just all about me, I don't meet a criteria and maybe that's part of who I was you know […] I can't be categorised because it's just the way I am […] it's like you don't want to be, don't want to fit the bill out […] maybe you know I just I'm so stubborn […] like I am Ben, I do not fit.

In addition, Ben described the gendered construction of anorexia as an influence on him not relating to the diagnosis, as he struggled to make sense of his own experiences through

available discourse. Reflecting on the gendered nature of information in media about body image, he stated that: "I think it was it was definitely sort of the reason why I didn't want to position myself as that was because I didn't have a gendered dialogue to be able to sort of articulate it".

That the diagnosis is predominantly associated with females contributed to Ben's 'self-stigma'. The 'stigmatisation of himself' (as he described it) was an additional facet of his lack of identification with the diagnosis, and is discussed further in chapter seven. For now however, it is noteworthy that his concerns that others would view or treat him in problematic ways if they knew about his (past) diagnosis led him not to publicly identify with it, and thus contributed to him distancing himself from anorexia.

Ben felt that perhaps it would have been helpful in the past to have identified with the diagnosis, because this would have led him to blame himself less, recognise commonality with others, and find a way of moving forwards. He explained "to have also maybe met with other people in a similar situation may have sort of helped, just to have like collectively worked towards something".

Valuing 'being anorexic'

This section is concerned with participants' valuing of an anorexic identity. It is well recognised that individuals attribute 'psychological benefits' to the experience of anorexia, such as feeling safe, special, and 'in control', and that anorexia is sometimes viewed as a protective friend whom it is difficult to leave (Serpell et al, 1999; Espindola and Blay, 2009; Warin, 2010; Lavis, 2011). Indeed, anorexia can become the object of desire (Lavis, 2016). Here, my focus is specifically on participants valuing of an anorexic identity; that is, their valuing of being recognised (by themselves or by others) as belonging to the diagnosis. This might be understood as distinct from a focus on participants valuing of the practice of

weight loss and/or restricted eating, as the concern is with wanting to be positioned as 'anorexic', rather than valuing the behaviours and physical manifestations that are understood as symptoms of the diagnosis. However, these two facets overlap. For example, low weight may be valued precisely because it is indicative of one's 'anorexic status' (Lavis, 2011; Fox and Diab, 2015). Accordingly, a focus on the latter also addresses the former.

Almost all participants described some aspect and extent of valuing 'being anorexic', in terms of either a private recognition of themselves as belonging to the diagnosis, or being socially recognised as 'very sick' with anorexia (with these processes being intertwined).

Maddie spoke about this directly and explicitly

> I suppose I still want to keep hold of it [anorexia…] It feels like I kind of want to wear it and say 'look, this is what I'm fighting, this is what I have done and got through' […] I will never be that person I was before […] I don't think people fully understand that the darkness you feel, and how you continuously remind yourself of what you've been through […] it's almost a pride and it's a shame at the same time.

That anorexia can be a source of both shame and pride has been recognised elsewhere (Rance et al, 2017b; Skårderud, 2007). The pride aspect of anorexia is thought to be partly related to an association between anorexia and self-control (Rance et al, 2017b; Skårderud, 2007). Anna alluded to this idea, as well as explaining that the weight loss involved in her anorexia carried tones of achievement and success:

> I hate this part but sometimes there is satisfaction [in knowing I had it] because at one stage I did have that capacity of control […] When I secretly had anorexia, like no one knew that I had it, it was like achieving - I was managing to lose weight really, really rapidly, and that is hard […] you can't help but attribute some kind of success to it.

An association between anorexia and success, achievement and feelings of satisfaction has also been shown above in relation to the meanings that individuals attributed to initially

being diagnosed. These feelings may be understood as linked to anorexia's imbuement with ideas about heroism, strength, and discipline (Lavis, 2011: 78).

Sarah described valuing anorexia for the social role it offered her. Despite her discomfort with using the diagnostic term, it had been important to her that she was known as someone who underate. Around the time that she initially began to restrict her food intake, another student at her school was recognised by her friends as having difficulties with food. Sarah stated "I remember hating her and thinking no, that's going to be my role". As she became increasingly known by friends and family as someone with an eating disorder, this positioning became very important to her:

> That was who I am and in my friendship group you know, one friend is quite loud and funny and another friend is really good at music and I'm the person who doesn't eat and that's what I do, and there can't be anyone else who does that.

It was clear that Sarah valued not only being known to have an eating disorder, but also her being *different* in this respect. Furthermore, it had been important to Sarah to uphold this social identity (I examine the ways in which she did this in chapter seven):

> My identity was my eating disorder, without that I was a nobody, I was nothing, not pretty, not clever, just nothing. My eating disorder was my everything and it for me was the reason anyone would ever find me interesting or appealing in anyway.

Since the time she described above, Sarah considered herself to be largely recovered. While she was happy about this, to some extent she continued to value her eating disorder, stating "I don't want it to ever go completely because it's part of me".

Mia and Amelia described how being known as 'anorexic' altered the expectations others had of them. Mia felt that when she was diagnosed, the label of anorexia instantly 'stuck' and affected others' interpretations of her actions:

> That label had been branched on me so I couldn't do things, anything I did do was just always assumed that was the eating disorder speaking […] instantly that became who I was.

Amelia identified benefits of others' labelling and altered expectations, while also understanding these as ultimately detrimental. Being known as 'anorexic' led to a feeling that she was 'important' and 'had been recognised'. She worried about losing this positioning, and in particular the inability to use the diagnosis as an 'excuse'

> I feel like it [anorexia being part of my identity] almost gave the anorexia a strong hold like, you are now important. You've been recognised and then it's like that fear […] well, what happens when you don't have it, when you can't say that you are anorexic anymore, what is going to be your excuse? For doing things that aren't right, you can't just blame it on something else […] I know I can say, I can't do this because I'm anorexic.

This idea of the diagnosis acting as an 'excuse' is identified by Brinkmann (2016), who describes how it can act as an exemption from responsibility. In relation to ADHD, he states that "responsibility is often transferred from the person as a volitional subject onto the "ADHD entity" (2016: 71). Here, we can see a link to entification, and in particular, the ways in which 'undesirable' and 'abnormal' characteristics are located within the separate entity of anorexia, rather than within oneself.

The valuing of an anorexic identity was tied up with a wish to be positioned as good at anorexia and recognised as 'very sick'. Even when participants did not explicitly describe valuing an anorexic identity, they none the less often alluded to there having been something desirable about the idea of being someone who was very unwell with an eating disorder. Participants spoke of wanting to do anorexia well, and having desired to be 'the best anorexic'. For example, Anna referred to the 'mental picture' she had of the 'very low weight anorexic' as having at one point been 'aspirational'. We also saw in chapter four that a desire to do anorexia well was also something that I experienced.

Medical markers of anorexia come into play here. These were often experienced positively for two overlapping reasons. Firstly, they acted as proof of one's diagnosis (that they were valued for this reason further suggests that an 'anorexic' positioning was desirable), and secondly, they suggested that one was doing anorexia well. Subjective meanings of medical markers and the ways in which they inform how individuals 'do' anorexia are discussed in detail in chapter seven. Here I give examples of the meaning of medical markers to illustrate the current points. Regarding proof of diagnosis, Anna described having appreciated being prescribed calcium for the fact that it acted as confirmation that "I definitely have this", and similarly, Jack explained: "When you see the blood test results it's almost like, it's not a good thing but […] that's confirming me to that I've got it and it's there".

Medical markers were therefore valued for materialising the diagnosis. In relation to doing anorexia well, Claire described how at one point, she had valued the affirming effect of having been in hospital in terms of proving that she had been good at anorexia:

> For a couple of years after I got discharged from hospital, it became more important that I could be like yes I had this, I was really good at having it, I ended up in hospital because of it […] it was like a kind of a positive, not a positive thing, but that affirmation that I needed to be like actually I was really unwell, I needed that support.

The following quote from Hannah demonstrates the desirable qualities that were sometimes attributed to the idea of being extremely unwell:

> There was a girl when I was inpatient […] I think she was the worst person I have ever in my life seen […] she'd had two cardiac arrests, liver failure, kidney failure, everything failure. Even though all of us girls apart from her talked about it saying […] "we'd never want to be like her", I think there was a part of everyone that was like 'how did she get that far, how did she manage that?'

Even though Natalie described having not identified with anorexia during inpatient treatment, much of her experience none the less involved concerns over the extent to which she was appearing 'sick enough'. Describing her conflicted desire to be unwell, she

explained how she felt when seeing others who were ill: "I'm so weirdly jealous of you that is so poorly and gets to stay in bed but I shouldn't be because that not, that's not right like, I should want to be well and healthy".

Like others, she described the validating impact of medical markers that confirmed her sickness.

> If your bloods came back and they were dodgy […] if you'd passed out […] that was evidence that you were unwell […] there was a part that was like 'yes', I must really be, I must really be unwell then.

These meanings of medical markers resonate with findings from Riley et al's (2009) research into 'body talk' in 'pro-anorexia' and 'recovery' websites. They found that in 'pro-anorexia' websites, concerns about health and appearance were reframed as 'markers of success'. The findings also accord with Eli's (2014a) research into amenorrhea[62]. She found that this is experienced as a key marker of recognised illness and is "loaded with serious implications for identity validation, clinical recognition, and status hierarchy" (2014a: 54). The latter point about status hierarchy and role of medical markers and clinical interventions within this is further explored in the next chapter.

I have described various ways in which participants valued being understood as 'anorexic'. However, it is crucial to highlight the double-edged nature of this. Individuals with anorexia are ambivalent regarding the condition and about recovery and treatment (Norbo, 2006; Williams and Reid, 2010; Eli, 2014b; Boughtwood and Halse, 2010), and anorexia is often both intimately cherished and experienced as intensely limiting and problematic (Fox and Diab, 2015; Warin, 2010). Even while most participants in some ways valued being positioned as anorexic and ill, they also simultaneously wanted to *not* be anorexic and

---

[62] This was previously a criterion for anorexia, but it was removed in the ICD – 11 and DSM – 5.

indeed sometimes worked to avoid being positioned in this way. Again, this is a facet of participant's experiences that resonates with my own. Identification with anorexia thus appears to be simultaneously desirable and undesirable.

As has been alluded to previously in the discussion of entification, some participants understood this 'split desire' (both wanting and not wanting to identify with anorexia) in terms of a break between themselves and 'the anorexia'. As the following quote from Jack suggests, an enjoyment of being unwell was often attributed to the pathology of anorexia:

> It's almost like the eating disorder part of you is saying 'yes I've beaten it', or 'I'm winning'. It's almost like that little bit of your brain which is, the irrational bit, is almost celebrating it.

Similarly, when Hannah described how she appreciated having 'bad blood results' for its confirmation of her eating disorder, she stated "I know that's pretty unwell thinking (…) that is the illness", and Amelia described the appreciation of the recognition of her 'sickness' as directly belonging to anorexia:

> When I was threatened with hospital it really pushed me to get better, like I didn't want to go to hospital. However […] anorexia is satisfied that you are at a low weight so that could potentially happen […] that's not the forefront of it but I know that […] is a factor […] I know I've got low vitamin D and there is part of the anorexia that loves that.

The valuing of being positioned as a 'successful anorexic' and legitimately sick resonates strongly with the anthropological literature reviewed in chapter two (Rich, 2006; Warin, 2010; Lavis, 2011; Eli, 2014b). This includes Lavis' (2011) research which shows how individuals undertake deliberate practices to align themselves with the construct of a 'good anorexic', including for example the effortful, daily enactment of self-surveillance over one's thinness. It also includes Warin (2010) and Rich (2006), who suggest that being a 'successful

anorexic' is a valued status position that offers a sense of distinction and empowerment, and that can be made more credible by medical complications.

Anorexia, then, appears to be a sometimes-valued illness identity in which signs of illness and medicalised markers can become entwined. Anorexia is somewhat unique in the extent to, and ways in which, it offers a valued identity. However, historically, there are overlaps with other conditions. Sontag (2002) describes the romanticising of tuberculosis (TB) during the 18th and 19th century, noting its associations with upward social mobility and its perception as an attractive mark of distinction and breeding. She also describes how visible aspects of TB became an ideal feminine look, and how "a person dying young of TB really was perceived as a romantic personality" (1991: 31). Lavis (2011) draws similarities between the romanticising of TB death and death in anorexia. She suggests that Sontag's claims create "a potent image of the wasting away of pure young bones", and that this image is also evident in the construct of a 'good anorexic' (2011: 82). Warin (2010) draws similarities between HIV and anorexia in respect to desired identity. She argues that both conditions have their own powerful sense of connection and relationships as a shared identity, and that they both entail "a puzzling desire to belong" (2010: 77). However, despite these overlaps and similarities with other conditions, I suggest that anorexia is somewhat unique in the extent to which individuals often seek to become 'better' at their condition.

Chapter Six summary

This chapter has addressed how individuals develop different diagnostic self-understandings, or 'anorexic identities'. They varied in terms of the extent to which they incorporated, or were critical of, dominant clinical understandings. It has also showed how these diagnostic self-understandings develop through interpretive processes such as diagnostic framing and interpretive identity-work. In addition, for those who think of themselves as 'anorexic', this

is sometimes fluctuating and / or fragile, in that they experience doubts about the 'realness' of their anorexia, or feel that they are not unwell 'enough'. Related to this, being recognised (by oneself or others) as legitimately 'anorexic', and successfully embodying an anorexic identity, is sometimes valued by individuals. In the next chapter, I show how this valuing of an anorexic positioning can influence individuals efforts in terms of the ways that they 'do' their diagnosis.

Chapter Seven

Doing anorexia

This chapter addresses how the diagnosis of anorexia is 'done' or performed. Participants were self-consciously aware of their own behaviours and private experiences, and other's perceptions of these, in terms of the extent to which they were indicative of them doing the diagnosis 'well'. Sometimes there was a desire to fulfil expectations of the diagnosis and be recognised as legitimately 'anorexic' and 'sick'. At others, individuals attempted to distance themselves from the diagnosis, to free themselves from associated behavioural expectations or as a way of managing perceived stigma and problematic misunderstandings of the condition. My focus, then, is on how participants performed both towards and away from anorexia (Warin, 2010). I begin by returning to the notion of anorexic scripts that I introduced in chapter four. I detail a core feature of anorexic scripts - low weight and weight loss - and explain the centrality of this to performing anorexia. I then discuss the various ways in which participants sought to live up to the diagnosis, and their reasons for doing so. I also address ways of doing anorexia in treatment, including via the adherence to specific anorexic scripts, and via hunger, eating, and medical markers and clinical interventions. Following this, I consider how individuals performed anorexia in relation to other patients, and the between-persons performative identity-work this involves. Lastly, I look at the ways and circumstances in which participants sought to distance themselves from the diagnosis, rather than align themselves with it.

Diagnostic scripts

The clinically-informed anorexic scripts I describe throughout this chapter are based on what emerged in participants accounts, and I describe them with reference to literature and clinical discourse. This adds breadth and depth to the previous discussion of anorexic

scripts, which related to my own experiences (see chapter four). It includes a return to serious and bad patient scripts, and the introduction of two additional scripts - chronic anorexia and good anorexic patient.

Low body weight and/or ongoing weight loss are core features of anorexic scripts. By this I mean that they are common features that constantly reoccur across different anorexic scripts, are central to them, and are privileged in clinical settings. A low body weight has been a criterion for diagnosing anorexia since the DSM III (APA, 1980)[63]. Losing weight is therefore considered a primary 'anorexic behaviour'; one does anorexia by losing weight. There is also an association between the extent of weight loss and the severity of one's anorexia, whereby being a very low weight is indicative of 'strong' illness. This association is written into the DSM - 5 criteria for anorexia, which uses BMI to categorise severity[64]. Anorexia is considered mild for a BMI greater than 17, moderate for 16 – 16.99, severe for 15 – 15.99, and extreme for below 15. As discussed in chapter two, treatment practices reinforce an association between weight and severity by equating anorexia with bodily thinness and 'more thin' with 'more anorexic' (Lavis, 2011). This equation was recognised by Natalie in her description of inpatient treatment:

> [There was concern with] what your bloods are and what you weigh and that that is a marker of how well you are, or that's a marker of recovery […] it almost takes over everything else […] if all these people around me are focusing on my weight, then that must mean something so I should focus on that.

Other participants also explained how their concern with weight was exacerbated by treatment, or even that it was learned through treatment in the first place. For example, Maddie explained that being weighed further increased her "obsession" with weight and

---

[63] Prior to the DSM III, DSM publications did not include specific diagnostic criteria.
[64] Severity can also be adjusted based on other 'clinical symptoms', such as the degree of functional disability, but BMI is the primary means for classification.

desire to control it. Amelia did not initially experience her eating disorder as a "weight thing" (as described in chapter five), but noted that weighing became a feature of her anorexia after she began treatment and was weighed weekly:

> I didn't weigh myself, I don't weigh myself. That never really became a control element of it until I went to [eating disorder clinic], and then […] it definitely became a big thing.

Existing literature also suggests that concerns about food and weight are perpetuated when these are the focus of treatment (Eivors et al, 2003; Rance et al, 2017a). I suggest that treatment discourse privileges weight loss as indicative of the condition, and thus centralises its place and importance in anorexic scripts. With this being the case, low weight and weight loss are vital ways in which one performs the condition. This is highlighted in a quote from Claire:

> I wanted people to know that actually I'd been really good at having this eating disorder and that it was something that I was like the best at having […] I guess *the way to show that* back then, and even probably validates it to some extent, is the whole weight thing and you think that you're not going to be taken seriously unless you're really underweight (emphasis added).

In the following section, I examine how the centrality of weight loss to performing anorexia played out in individual's attempts to live up to the diagnosis.

Living up to anorexia

Reasons for living up to anorexia

Some participants spoke explicitly about their wish to 'live up' to their diagnosis of anorexia. They identified a range of reasons for this, including access to treatment, adhering to an assigned social role, and securing the valued aspects of one's anorexic identity. Related to these reasons, living up to anorexia was part of a wish to be positioned as genuinely 'sick'. However, this aspect of living up to the diagnosis was expressed subtly and was alluded to

indirectly in discussions of treatment experiences. I therefore address it later in a discussion of medical markers and clinical interventions and focus initially on the participants explicitly described reasons for living up to the diagnosis.

Accessing and navigating treatment

Kelly, Anna and Lisa all spoke about living up to their diagnosis in order to access treatment. A major way in which they sought to do this was via ongoing weight loss, witnessed by the professionals involved in their care. In chapter five, I addressed how Anna felt that she needed to be seen to be doing anorexia in order to retain access to the treatment that she desperately wanted, and that she understood this to result partly from the 'irrationality' of her anorexia, and partly from the scarcity of treatment. Also relevant here, is Anna's recall of her initial assessment at the EDS. She described how the picture of anorexia that she already held in mind and was further explicated within the assessment process formed part of an 'aspiration':

> When I mentioned in my assessment that I was afraid if I didn't keep losing weight I wouldn't get treated, the clinical psychologist emphasised several times that they treat people with many body types and weights […] I had this slightly 'aspirational' picture in my mind of the very low weight anorexic that I was measuring myself against […] and [she] was obviously consciously trying to make sure I didn't think that she was also measuring me against it? Though assessment does implicitly measure you against an 'ideal' anorexic template because there are 'target' weight ranges? The [BMI] 17.5, and 0.5kg weight loss per week[65] etc (email).

We can see how Anna related herself to a particular image of anorexia and that this informed her self-understanding. This idea of having in mind an image of anorexia prior to engaging with treatment has also been addressed in chapter five. I showed how Claire and

---

[65] Here, Anna referred to BMI and weight loss 'markers' that are used in clinical practices to assess the severity of, or risks associated with, an eating disorder, and to make treatment decisions. NHS guidelines (2017a) include BMI and speed of weight loss as factors to be considered when assessing for an eating disorder, and they are treated as indicative of medical risk (Treasure, 2009). A BMI 17.5 is significant in clinical discourse, because being below this was a criterion for diagnosing anorexia in the ICD – 10 and DSM – IV.

Hannah did not initially identify with anorexia because they did not see themselves 'matching up' to their ideas of what this 'looks like', and how Kelly's decision to seek help was influenced by her recognition that she had started to resemble this 'image'. With Anna however, she also recognised that this image was reproduced by the clinical standards in which she was immersed (I discuss this further below).

Kelly and Lisa also both described actively seeking to continue weight loss in the lead up to starting treatment or in order to access further help. Like Anna, both attributed the 'need' to do this partly to the pathology of anorexia (or to 'just how things are' because of anorexia), and partly to clinical practices. For Kelly, the clinical practices in question were the BMI restrictions used to make decisions about admission to treatment[66]:

> One of the things that did spur me on to lose weight or just like another driving factor was probably so I could get the treatment and be taken seriously. I think that a lot of it was probably down to myself being unwell, but I think it was kind of driven a little bit by hospital guidelines.

Lisa described how during her most recent relapse, she had asked for additional support from services when things were 'slipping'. After some weeks of feeling that the extent of her struggles was not being recognised, she felt she needed to prove this by losing more weight:

> I've always left [treatment] feeling that I want […] to continue with recovery, but then its fallen away quite quickly and then I've been desperate to lose weight because, partly because I'm just desperate to lose weight, there doesn't have to be reason, that's just the way it is, the status quo […] but I also want to lose weight because I'm desperate for help and I'm desperate for somebody to notice.

Kelly, Anna and Lisa all made explicit reference to the role of clinical discourse in informing their desire to lose weight. The 'standards' for anorexia portrayed in clinical practice

---

[66] This reflects Kelly's perceptions of the NHS treatment that she received, and may not accurately represent the way clinical decisions were 'really' made. However, NICE (2017b) do recognise that admission decisions are sometimes made on the basis of BMI, especially in areas where funding is limited.

suggested that rate and extent of weight loss matter in determining severity of eating disorder and need for treatment. Thus, these standards appear to have reinforced to them the centrality of weight loss to anorexic scripts.

As addressed in chapter two, existing literature recognises that BMI contingent admission to services within NHS treatment systems can incentivise weight loss (Treasure et al, 2011; Rance et al, 2017a). Ringer and Holen (2016) describe how, in their ethnography of outpatient and inpatient mental health services in Denmark, potential patients being assessed for admission had sensed that they had the responsibility to 'prove' the existence of their illness by presenting symptoms in a recognisable way, in order to access care. With available anorexic scripts detailing ongoing weight loss as a core feature of anorexia, participants took this up as a way of making 'the illness within' visible to professionals to prove their need for treatment.

Participants also spoke about their wish to be seen losing weight (or maintaining a low weight) at other stages of clinical monitoring (and not only when seeking treatment). They described using strategies such as not eating or drinking the day of being weighed (Natalie, Maddie, Lisa, Sarah), using laxatives (Anna) and wearing the lightest clothes possible (Maddie). Maddie, for example, had been concerned that professionals may interpret any weight gain as a sign that she was no longer anorexic, stating "I almost thought that if I gained weight it was 'oh you're getting better, right off you go'".

In addition to describing her felt need to live up to the diagnosis while waiting for treatment, Kelly also described attempting to 'fit' the diagnosis during treatment. She stated that she felt the need to "fit the perfect bill of what other people thought an anorexic was". As an inpatient, she sought to live up two conflicting roles simultaneously. Privately, she wanted to understand herself as 'good at anorexia', but she also sought to publicly perform being a

'good patient' who was 'good at recovery'. I address these roles, which I understand as anorexic scripts, in detail later in this chapter. However it is relevant to the current discussion to address Kelly's reasons for seeking to live up to these roles. She identified 'perfectionism' and a desire to 'perfectly' fulfil the social positions she took up, as key reasons:

> Perfectionism was definitely like, is, a massive part of my life, and when speaking to other people that have had anorexia a lot of it was like you want to be the best at anorexia but then it gets to a point where you want to be the best at recovery […] so I did feel like I had to live up to this standard of the best person in recovery. But that also was really difficult to do when you were trying to fit the stereotype of the anorexic as well, so it's like you are trying to fit into both roles at the same time and obviously they are completely different.

Responding to labels: living up to chronic anorexia

Mia described how, a few weeks prior to the interview, a professional had referred to her as having 'chronic anorexia'. Her immediate response was to reject this suggestion, because she did not see herself as fitting her idea of how someone with chronic anorexia looks, as reflected in her saying "my legs aren't like those stick things that somehow people get to". However, this initial response was followed by a wish to inhabit the suggestion. She explained this using a metaphor of performing a role and character:

> If you are going to describe me as that I am going to do it […] it feels sort of like a role in a play. I didn't feel as though I was that character in that performance, I had wrongly been given it, then I was like you know what I am going to play the role, and just almost hit all the specifications for it […] they were putting me in that lead role, I just felt fine, I am going to have to live up to the description of that character, if you are going to put me in that role then I'm going to be in the limelight and people are going to see me.

Mia described wishing to act in ways that were congruent with professional's expectations of her, and she expressed defiance in her wish to do this. She appeared to perceive the role of chronic anorexia as particularly visible and important, as reflected in her phrasing such as 'lead role' and 'in the limelight', and this perception seemed to contribute to her felt need to

live up to the role. I suggest that 'chronic anorexia' can be understood as an anorexic script to which, once it had been suggested, she was motivated to adhere.

I questioned Mia about the 'specifications' for chronic anorexia that she had referred to. She explained that they emerged from what she had 'researched', which she considered to be like a 'checklist' of chronic anorexia:

> All the bulletins, when it's like 'you are like this' […] like baggy clothing and all that, that to me was like your specification. Like restricting, missing [food], so I just wanted to tick all of them.

Chronicity is a clinical term which refers to conditions that persist for a long time. 'Chronic anorexia' refers to the individual with anorexia "who is continuously ill over many years and "fearful" of change" (Strober, 2004: 247). It is believed in part to result from the "recalcitrant psychopathology of anorexia" (Lacey and Sly, 2016), and is associated with low levels of recovery and 'treatment resistance' (Strober, 2004; Vitoesk and Watson, 1997). Chronic anorexia is identified as a challenging presentation to clinicians (Strober, 2004), who tend to be pessimistic about the likelihood of recovery (or are perceived by patients to hold this attitude) (Fox and Diab, 2015; Lacey and Sly, 2016).

Mia's description of chronic anorexia seems to allude to ideas about 'seriousness' more so than chronicity, as seen her references to behaviours and an emaciated body, rather than length of time of the condition. This perhaps indicates how chronicity is associated with severity, and how chronic and serious anorexic scripts overlap. Tierney and Fox (2008) identified four features of practitioners' views of what constitutes chronic anorexia, and these suggest that it is understood as being about more than only length of illness. The features they described are entrenched patterns of food restriction, entrenched "anorexic"

cognitions, an identity intertwined with anorexia, and the maintenance of a BMI under 17.5[67].

Despite its limitations, the labelling theory of mental illness (Scheff, 1966) provides a broad frame for understanding Mia's responses to the label of chronic anorexia. When described in this way by another person, she used the associated script to guide her behaviour and sought to 'live up' to that role. Moreover, it appears to be a role that she subsequently internalised and personally identified with, as reflected in her use of the phrase chronic anorexia to describe her current relationship with anorexia at the start of her interview. This accords with Scheff's contention that individuals come to fulfil and internalise the deviant role (of mentally ill) that others place them in through social interaction.

Anorexia as social reputation

Sarah described her desire to live up to her eating disorder in terms of having a 'reputation' (that she valued) to uphold. As explained in chapter six, she valued being known in her friendship group as "the person who doesn't eat" for the distinct social role it offered her, and because she felt that having an eating disorder was the only appealing aspect of her. Living up to the reputation of her eating disorder was about wanting to hold on to a valuable social positioning. However, while mostly speaking about living up to her 'reputation' in terms of an agentic wish to retain this positioning, she also made reference to having been given the role of 'eating disordered' by others and stated: "I had a reputation to uphold, like everyone labelled me with an eating disorder so I had to live up to my reputation so people would always believe me".

---

[67] This is a generalisation, as individual clinicians often specified a much lower BMI.

For Sarah, 'upholding her reputation' meant that in the food diary she kept for her dietician, she claimed to have eaten less than she had. She also avoided being seen by others buying food because she imagined that this would affect how they judged her eating disorder status:

> I'm just lying and making it up or I'm letting down my reputation like you know, I've got this reputation of being somebody who doesn't eat and then people will just think 'oh she hasn't got that reputation anymore.'

Despite considering herself to be much better at the time of the interview, she still sometimes tried to retain aspects of the reputation, although only within her own family:

> I still now sometimes feel the need to keep up that reputation so if we have a big family gathering […] I will not have as much as I would eat normally […] because I don't want people to think that its totally OK, I want them to still question it a little bit.

For Sarah, the ways in which she sought to live up to anorexia and her reasons for doing so appeared less clinically informed than for others. She seemed to not so much want clinical recognition or a medicalised, diagnostic identity, but more to be known among groups of friends and family as someone who under-eats. This accords with Sarah's experiences and identity more broadly, as has been described previously. She had not had intensive or extended periods of treatment in a clinical setting, and while she believed herself to have (or have had) anorexia, she was somewhat distanced from a clinically defined diagnostic concept of it.

Falling short of anorexia

Participants recounted occasions when they had not 'lived up' to anorexia, and the distress this caused. Anna recalled explaining to a counsellor (whom she saw prior to beginning treatment at an EDS) that she was soon to attend a family event but was "really scared" due to not being able to count the calories in food. Initially, the counsellor advised her to "eat what everyone else is eating", and when Anna explained that she was unable to, the

counsellor responded by stating "well you're anorexic, so just go and don't eat anything."

Anna experienced this comment as a suggestion that by intending to eat at the event, she

was not being 'properly' anorexic, and she found this upsetting:

> It was like a knife in my heart to hear that. Because she didn't understand that as hard as it was to eat, it was just as hard not to eat […] it is excruciatingly painful and to be told that this is what an anorexic is and you are now failing at it, I've never felt so upset.

A situation described by Mia can be similarly understood. She had found it difficult to

independently attend an outpatient appointment after transitioning to adult services, rather

than being taken by her grandparents as she had been as an adolescent. She described

"hating" doing it, "because it's almost me like trying to fight it [anorexia]". I suggest that Mia

independently attending an appointment was difficult because it meant she was not acting in

accordance with the expectation that 'doing anorexia' involves *not* 'fighting it'. Being taken to

appointments by her grandparents had been a compromise that allowed her to attend

without undoing her sense of self as anorexic (Lavis, 2011).

I have addressed various ways in which participants sought to live up to the diagnosis of

anorexia, and their reasons for doing so. This included Kelly's description of feeling she

needed to live up to two contrasting roles – the good and the bad anorexic patient - while

in treatment. I examine these roles further in the following section, and suggest that they

are examples of anorexic scripts.

The 'good' and 'bad' anorexic patient: doing anorexia and recovery in treatment

Good and bad patient scripts

The 'good anorexic patient' script denotes someone who complies with treatment, eats and

gains weight as required, is honest, and has a 'good attitude'. In contrast, the 'bad anorexic

patient' script, which I illustrated in chapter four, denotes someone who is 'non-compliant' in treatment, deceives staff so that they are able to prevent weight gain and/or avoid eating, is dishonest, and has a 'bad attitude'. Here, I explore how 'good' and 'bad' patient scripts emerged in participants accounts.

Mia's doing of anorexia was partly informed by her contrast with another patient, whom she described as a 'bad patient'. This patient was the only other individual diagnosed with anorexia with whom Mia experienced inpatient treatment[68]. She described her discomfort with this person, noting the ways in which she acted 'badly', and her own reasons for *not* acting this way:

> She was very much rebellious, I have always been well-behaved at school and in the presence of strangers, so although I did sort of like miss stuff [food], I wasn't rude about it or a badly behaved patient, but she was just vile and aggressive […] with her knife and fork just scraping stuff across the plate like 'I'm not having this' […] When she was on the phone, once I can remember she just kept walking around and around the pool table […] it just made me mad. I didn't want to be like that because I would say I was quite a well-behaved patient and that the staff were happy to work with me.

Mia's description of the 'bad patient' focuses on attitude (vile, aggressive and rude) and behaviour (refusing food and exercising). Her 'othering' of this patient strengthened her own positioning in line with an opposing 'good patient' script. We can also begin to see here how comparisons with other patients played a role in the doing of one's anorexia, an idea which I address in detail later.

Ben also put forward ideas about differences between 'good' and 'bad' patients. When directly asked about this, his response reinforced the association between being tube fed and being a 'bad patient' that I described in chapter four.

---

[68] Mia was an inpatient in a child and adolescent psychiatric unit, where most other patients were diagnosed with psychiatric conditions other than eating disorders.

> I can relate to that [the notion of a bad patient] in some of the experiences I've had […] you know in those that had to be sort of like fed through a tube, I categorise them, they are a bad patient but you know, their struggle was different.

We can also see that he understood himself as different to 'bad patients', something that he had also alluded to at an earlier point of the interview when he was discussing his lack of identification with the diagnosis of anorexia:

> When I was in there [treatment] I wasn't sort of kicking and screaming you know, people that sort of came into the inpatient […] had to be fed through a tube, I never had to do that. I was obligatory, you know I was decent, I was an obliging citizen of the inpatient community […] compliant is the word.

The implication here was that the category of bad patient was more relevant to the 'other' patients than to him, and that his ready compliance marked his experience as different to those to whom the category belonged.

Kelly described how the patients she was with in inpatient treatment had been known, by both staff and other patients, as 'good' or 'bad', and how staff had seen her as 'good':

> [Other patients] would talk about people like 'oh, they are a good person to be around' or 'don't go near them because we know that they do this' [for example water loading] they were made out to be like a really bad person as opposed to somebody that is unwell [staff would say] 'it's nice to have you because you're like one of the ones that wants to get better' […] it was spoken in terms of there are good patients and there are bad patients […] instead of it just being like there are patients that are a little bit further along in their recovery.

Kelly was therefore critical of the moral judgements implicit within the notions of good and bad patients, suggesting instead that different behaviours and ways of engaging in treatment were related to the extent of 'unwellness' or 'recovery'. I previously described above how Kelly had felt conflicted in treatment due to her wish to perfectly fulfil being "the best at recovery" and also "fit the stereotype of the anorexic". In her descriptions of this, she equated 'the good patient role' with 'being good at recovery' (see page 240). At a later point

in the interview, she further implied this equation, and also significantly equated being a bad

patient with being good at anorexia. The alignments Kelly made between these two sets of

roles (the 'good patient' is 'good at recovery', and 'the bad patient' is 'good at anorexia')

can be understood further with reference to clinical discourse, and it is useful to do this

here before attending in more detail to Kelly's descriptions of how she aligned herself with

these different scripts.

Patient scripts, pathology, and recovery

The bad patient script overlaps with being 'good at anorexia' because clinical discourse 'ties

up' acting badly in treatment with the pathology of anorexia. As has been addressed in

chapter two, anorexia is clinically recognised to involve an 'egosyntonic' valuing of

symptoms, denial of illness, resistance to change, and a 'lack of insight' (Garner, 1985;

Vitousek et al, 1998; Konstantakopoulos, 2011). Accordingly, anorexic patients are

perceived to be potentially manipulative, devious, resistant to therapy, 'non-compliant' and

'difficult to treat' (Bruch, 1988; Gremillion, 2003; Darmon, 2017; Vitousek et al, 1998), and

anorexia is:

> […] unpopular with clinicians because of the perception that clients habitually deny,
> deceive, and rationalise to protect their symptomatology (…) anorexics become
> adept at manipulating their apparent weight, disposing of food surreptitiously, and
> distracting professional attention from their physical status (Vitoesk et al, 1998: 392).

This suggests that 'being anorexic' typically entails being a bad patient, because in the

apparently desperate attempt to pursue one's symptoms, one acts 'badly'. Such a view can

also be understood in terms of the entification of anorexia (see chapter six), which is

embedded in some clinical approaches. This involves positioning anorexia as an external

entity, and in terms of the 'bad patient', invokes an image of an individual who is

overwhelmed by an external force to the extent that they are unable to control their 'true

self' and will 'do anything' to maintain a low weight. Such a view of the potency of anorexia,

and its ability to interfere with treatment, was held by participants such as Naomi, who

stated:

> When you're being that controlled by these compulsions that you need to do you
> will do anything to be able to do them, even if you know really that you shouldn't,
> you will still do that so you might lie about eating or you might find a way to slip
> your butter into your pocket.

I asked most participants about their views on perceptions of individuals with anorexia as

difficult to treat, manipulative, and deceitful. All recognised this as a commonly held view.

Some 'agreed' with the perception and related their own and/or others' experiences to it.

Some were more critical of this as a stereotype and misplaced moral judgement. None the

less, all recognised the existence of this perception.

An example of a 'deceitful' behaviour that accords with a 'bad patient' script is water

loading[69]. This behaviour is widely recognised among clinicians and is understood to result

from an "intense fear of weight gain or a desire to please" (Martin et al, 2009). With regard

to the former, an individual may seek to appear heavier than they 'really' are, so that they

can avoid 'actual' weight gain. Thus, making oneself appear heavier is a way of doing

anorexia. However, as described earlier in this chapter, many participants spoke about a

desire to distort their weight the other way (i.e. to be lighter). While an 'opposite'

behaviour, this too can be understood as a way of doing anorexia, because it involves

performing a core feature of anorexic scripts – low weight and weight loss.

I suggest that, while the 'bad patient' is linked to being 'good at anorexia', the 'good

anorexic patient' script reflects a clinical version of 'recovery'. In previous chapters, I have

addressed how in treatment, recovery from anorexia involves (what I have called) diagnostic

---

[69] Water loading refers to the practice of distorting one's weight so that it appears higher, by consuming large
volumes of liquid prior to being weighed.

framing, and the patient internalising the institutions views and personally committing to recovery (Darmon, 2017). When learning to play the role of the patient in recovery, the individual adopts the expected, required attitudes and becomes an active participant in the government of the self (Carney et al, 2008). I suggest that in acting in accordance with the institution's views, displaying the required attitudes, and actively governing the self, one becomes a 'good patient'. Scott's (2011) work on RIs (see chapter two) also sheds light on good patient scripts. She argues that while total institutions (Goffman, 1961a) involved overt authoritative control of inmates, in RIs there is a form of disciplinary power in peers' monitoring each others' conduct. This 'performative regulation' includes the 'performance of conformity', and the mutual surveillance of this by peers. In these performances, inmates perform as 'rule followers' and play the 'good inmate' role. Playing the good inmate role might also be conceived as adherence to the script of the 'good anorexic patient'. This idea of the mutual surveillance of peers is reflected in Kelly and Mia's accounts which show how peers recognised each other as 'good' or bad'.

Performing conflicting scripts

Kelly described the different ways that she performed being both 'good at anorexia' and 'good at recovery'. She explained that the former performance was mostly private, and the latter was public and relational.

> Being the good anorexic, it was a lot more private [it] went on in my own mind. I almost policed my own thoughts, so I kind of felt like 'oh you shouldn't be thinking like this'. You know how we spoke about being hungry, it was like 'well, people with anorexia don't feel like that, so therefore you are not a good anorexic' […] as if some kind of external force could understand what I was thinking at all times so I must kind of stick to this role.

This alludes to Kelly's self-conscious monitoring of the extent to which her internal experiences accorded with the script of a good anorexic. The performance was largely 'internal', in that she seemed to perform in this way for herself. However, she did also

describe public aspects to her performance of anorexia when she described how the behavioural expectations in the inpatient environment influenced her:

> When I was around other people, other patients, I felt like I should be perhaps conforming to the norms that we had within the service […] like the dining room […] being the correct amount of frightened of food.
> .

In contrast to her privately performed 'good at anorexia', Kelly understood her performance of 'good at recovery' as being public and performed for others:

> Mostly when I was talking to healthcare professionals […] my parents, my partner, all the people who wanted to see me get better […] in the phrases that I would use when I was talking to them, I would say 'oh I really want to recover' and 'I really want to do this with my life' […] in the back of my mind I was thinking, and I suppose this plays into the conflict, 'oh do I really want that, because I want to be the good anorexic'.

Having described performative pressures to eat as an anorexic should while an inpatient, Kelly also described similar concerns in terms of trying to get 'recovery' right. She stated "I'd go out for dinner when I got a bit better […] and I was like 'how do I do this, how do I look like somebody that's recovering from anorexia?'". This suggests that performing a recovering script is different from simply 'being anorexic' (and 'frightened of food'), but is also not straight forwardly being 'well' and 'normal'. Rather it is something of a balancing act, in which one is both 'anorexic', but also working not to be.

Kelly's descriptions show how performances were relational and shifting across different contexts. This was also highlighted by Lisa, when she described wishing she were able to turn her anorexia 'on' and 'off' depending on who she was with and where she was:

> I've often wanted to be able to switch on and off […] in different contexts. You know, present at work and be totally fine, present at an appointment with services really desperate for help and be able to kind of switch it back on […] alter your weight at the flick of a switch almost […] even when you feel that you've come to a kind of peace with where you are with it, it can still change in those different contexts.

Eating and hunger in treatment

Restricted eating is important to diagnostic scripts in that it is a means through which individuals achieve weight loss or maintain a low body weight. As inpatients, participants were required to be eating, and were (more or less voluntarily) following a 'meal plan' as part of their treatment. In these circumstances, the *ways* in which they ate, and their apparent desire for food, were important to how they 'did' anorexia.

During Natalie's interview, we had a collaborative discussion about the experience of hunger and enjoyment of food during inpatient treatment. Within this emerged our shared sense that a desire to eat had been something to keep to ourselves or only share with certain other patients. Natalie described having felt that she should not have been wanting food by mimicking a caricatured, imagined staff position: "You want food? You shouldn't want food and enjoy it!" She also described the feeling of hunger as "unspeakable […] because it doesn't conform to that view of what you should be". Here, she positioned hunger as outside of a clinically-assumed anorexic script.

In the above quote (see page 249) we saw how Kelly, in her self-monitoring of her adherence to a 'good anorexic' script, experienced her hunger as a sign that she was 'falling short'. Kelly also spoke about performing both being 'good at anorexia' and 'good at recovery' through the ways she ate, as she sought to align her own eating behaviour with that of other patients, and seek the correct 'balance' in her approach to eating as someone who was recovering. In addition, she described how in the lead up to her admission, she had had concerns about whether she appeared anorexic 'enough':

> What if they didn't think that I was sick enough if I wasn't like visibly struggling with every meal? […] the main problem with it was the feeling that somebody else was watching you eat all the time or would think that you were, you looked like you were just scoffing the food down, that you looked really fat, or that yeah they'd think you weren't sick enough.

The concern with 'looking fat' when eating was also expressed by Mia. She described an occasion when a member of bank staff had forgotten to give her the snack she was meant to eat, and how she did not want to let them know. She explained: "I easily could have communicated that but I still just, I didn't want to come across as fat, for like actually wanting the stuff". The concern with looking fat reflects a wish not to appear to be desiring food. Desiring food does not fit anorexic scripts, and positions one outside of anorexia.

During inpatient treatment, I was self-conscious regarding how my eating appeared to others, and sensed that my eating behaviour was viewed as indicative of anorexia. This sense was perpetuated by the treatment programme, in that eating increasingly 'normally' (e.g. completing meals at a 'normal' speed and appearing relaxed when eating) was treated as a sign of 'progress' and suggested that one was being 'less anorexic'. A specific example of a performative aspect of mealtimes relates to my use of 'staff support'. This involved inciting continuous verbal encouragement from staff during meals and an outward demonstration of my distress at having to eat, expressed verbally and in my body language. Enacting meals in this manner can be understood as me performing a rejection of food, and as a way of doing anorexia in circumstances in which I had to eat. It allowed me to be positioned me as someone who did not want to eat, despite eating.

Medical markers, clinical interventions, and serious anorexia

I have argued that low body weight and weight loss are core features of anorexic scripts. Low body weight is a key medical marker of anorexia, and is central to performances of anorexia. In addition, other medical markers were understood by participants as key indicators of extent and 'realness' of illness, either by being directly perceived as such, or by a recognition that others (patients and clinical staff) treated them in this way. These markers included for example 'negative' blood and ECG tests, and DEXA (bone) scans. Moreover,

clinical interventions such as being hospitalised, sectioned, tube fed, and prescribed

medication, were also attributed this meaning. Because of these meanings, medical markers

and clinical interventions were intertwined in performances of illness, and influenced how

participants perceived anorexia in (and positioned themselves in relation to) others.

The backdrop against which one's 'doing' of anorexia occurred was often one in which

there was concern about the fraudulence of one's anorexia, that it was not serious enough,

or that it did not warrant the treatment one was receiving. This was addressed in chapter

six, when I explained how participants sometimes doubted their diagnosis. It is also reflected

in the following quotes:

> Natalie: When I was admitted that time I was thinking […] 'oh, I must be really sick now then'. Not actually believing it, but 'Oh I am pulling off this false façade thing that *I am a proper [anorexic]*', like I still don't feel, *I still feel like a fraud, still felt like a fraud, that I should not be there* (emphasis added).

> Lisa: I feel like I've never been as low BMI as other people are, I've either gone in voluntarily as well, you feel that you're being greedy and asking for help, and *if you have real anorexia* then you should be kind of forced into it (emphasis added).

> Kelly: I kind of walked in [to inpatient treatment] and everybody says the same thing that goes in […] 'I'm the biggest one here', '*I don't deserve to be here*' […] so that was a really big thing at the start (emphasis added).

In chapter six, I recognised how participants sometimes valued being recognised as 'truly'

anorexic and/or 'very sick'. Concerns about fraudulence and being undeserving are

dynamically related to this position of 'true' anorexia in the sense that they often strove

towards or valued the latter, in order to move away from the former. However, in

experiencing situations and encounters that left their anorexia 'wanting' (such as an in

comparison to other patients), their status as 'sick' was undermined and they felt fraudulent

or undeserving. As reflected in the above quotes from Natalie, Lisa, and Kelly, these

dynamics were tied up with medical markers and clinical interventions. We can understand

these as informing the script of 'serious anorexia' (or serious *enough* anorexia). This is an idea that I introduced in relation to my own experiences in chapter four, where I indicated that clinical recognition of physical illness is a crucial feature of a 'serious anorexia' script.

Also in chapter six, I described how the valuing of an 'anorexic identity' was indicated in the ways that medical markers and clinical interventions were imbued with desirability and valued as proof of one's diagnosis and/or signs that one was doing anorexia 'well'. This desirability is also seen in the language that some participants used. Medical markers and clinical interventions were referred to as 'status symbols' and 'badges', and attributed meanings of success and achievement. For example, Anna described the experience of medical complications as having a 'badge-collecting aspect', and Natalie referred to tube feeding as a 'badge of honour'. Kelly described medical problems in a similar way:

> I had the ECG […] they checked my pulse and stuff and that was really low and again it, I kind of want to get back to that feeling of like reinforcement […] it was almost a bit of a badge […] there was like OK, so you are having physical symptoms […] its reinforced the fact you do have an eating disorder […] I knew that my heart wasn't good and I wasn't scared. I didn't feel like 'oh no, it's such a shame or, or 'I should be terrified' or 'this is really bad', I just kind of felt a bit, almost happy.

The apparent reassuring and confirming effect of medical markers and clinical interventions can be understood in terms of them acting as confirmation that one is properly performing a serious anorexic script and negating concerns about not being good enough.

For some participants, there were further (related) implications of these meanings of medical markers. Lisa spoke about how she previously saw the proof of her anorexia afforded by medical markers as allowing her to ask for help, accept her 'problem', and make strides towards recovery:

> I know I was always looking for some kind of external 'proof' of the reality of my illness […] I used to feel that UNLESS there was some kind of physical sign (an objective sign rather than subjective feelings such as tiredness/dizziness etc) then I had no 'excuse' to ask for help […] or to accept I 'really' had a problem with eating. I think I was always also hoping for some kind of marker that would allow me to stop what I was doing (email).

For Anna, having medical complications recognised by clinicians created a 'medical feel' to her weight restoration that she found comforting and reassuring:

> One of the health complications I used to get was hypoglycaemia […] they'd urgently ring me because my blood sugar level was like coma whatever level […] on the one hand I was worried […] but on the other it was kind of like 'this should be happening because I've lost a lot of weight'. So it confirms, 'yes I really have lost lots of weight' […] there was that sense that when you are restoring weight, like that notion is almost like a comforting thing because it has a sort of medical feel to it.

During the final stages of her weight restoration, when she was no longer 'recovering' out of medical necessity, Anna had to 'let go' of this medical feel:

> I had to make the conscious decision to let go of, 'I'm doing this because I'm being told to and because it's a medical necessity', to 'I have decided to do this because I prefer life at a higher BMI' […] it was breaking through that frame of the anorexia, like consciously stepping outside of it […] while it's all done on those medical terms, when it's like 'your weight is very low' […] there's some kind of comfort in that, it's a medical need, it's because I'm anorexic.

In the above quote, Anna ties together anorexia with its medicalisation, such that the medical markers and 'need' informing her recovery felt like an 'anorexic frame'. Thus, in finally moving away from anorexia, she also had to move on from being medicalised.

In both this and the previous chapter, I have shown how medical markers and clinical interventions were valued as signs that one 'really' had anorexia and that it was sufficiently serious. At this point it is worth reflecting back on Michael's case study. Like others, Michael described valuing his thinness and, related to this, his low blood pressure and slow pulse for the feeling of achievement that it brought him (see case study, chapter five). However,

unlike for others, this valuing was not linked to the diagnosis of anorexia. At the time he was referring to when describing how he felt about his blood pressure, he did not yet identify with the diagnosis. Rather, the achievement seemed to be about his success in 'pushing boundaries' with his cycling and body, more so than inhabiting a diagnosis.

Related to medical markers and clinical interventions being valued as proof of anorexia, a *lack* of these signs – including as compared to others - induced a sense that one was *not* doing anorexia properly. Lisa described how she had previously had a bone scan which 'only' showed osteopenia (as opposed to osteoporosis)[70] and that this led her to feel "like a bit of a failure", especially because younger patients seemed to have "the full-blown diagnosis" (osteoporosis). She also described a feeling of fraudulence linked to blood test results:

> I have sometimes felt that 'I can't really be unwell/have a 'serious' problem if all my bloods are fine' […] I still feel a bit of a fraud somehow for never having experienced problems with potassium since it's such a key marker (email).

Natalie described how having shorter periods of bed rest than other patients led her to feel she was 'too fat' and should not be in treatment. Medical markers and clinical interventions in others thus had implications for the 'realness' of her own anorexia.

It is important to note however that a few participants (Naomi and Ben) did not describe having experienced medical markers and clinical interventions as signs of the extent of illness, or as having valued them or found them reassuring. When discussing her experience of being tube fed, Naomi explained:

---

[70] Osteoporosis is a condition of low bone density which results in a higher risk of fractures (Kanis et al, 1994). It is common in anorexia nervosa (Mehler et al, 2011) because starvation induces hormonal adaptations which contribute to lowered bone mass (Kanis et al, 1994). Osteopenia, also common among individuals with anorexia (Bachrach et al, 1991), is the stage before osteoporosis. It indicates that one has low bone density, but not low enough to be classed as osteoporosis (NHS, 2019).

> I didn't think it means that I was any more unwell than someone who manages to eat the food because, it's the same […] I needed it to be able to see that well, those calories are equal to those calories […] to make those steps, whereas other people actually having what goes down the tube is worse than eating, they'd rather eat it. Everyone's different and I accept that.

A few participants who referred to tube feeding had described how in treatment these were seen as 'status symbols' (Lisa) or a 'badge of honour' (Natalie). In my own experiences, I had valued being tube fed for its confirming effect on my identity as a 'serious anorexic', despite it being distressing. For Naomi however, the only way she described having valued being tube fed was in seeing it as a needed intervention that allowed her to progress:

> I know I needed it and I know that I wouldn't have managed to go from having nothing to food […] when it happened it was needed and there was no other way that I'd have been able to move forward without it.

That there are varying meanings attributed to tube feeding accords with findings from Halse et al (2005) that adolescent female patients receiving treatment for anorexia attributed meanings to being tube fed that fit into four categories: an unpleasant physical experience, a necessary or helpful intervention, a physical or psychological signifier of anorexia, and a focus in a struggle for control. The view of tube feeding as a 'signifier of anorexia' accords with my own experiences and the meanings described by Lisa and Natalie. In contrast, the former two categories of meaning are relevant to Naomi.

Performing anorexia in relation to other 'patients'

Patient dynamics: comparing and 'competing'

Literature suggests that being in treatment with others with a diagnosis of anorexia is experienced as simultaneously helpful and problematic. This is because, for example, support, understanding and friendships arise from shared experiences, but exposure to others' 'eating disordered behaviours' can worsen one's own and increase distress (Colton

and Pistrang, 2004; Offord et al, 2006; Rich, 2006; Warin, 2010; Smith et al, 2014; Eli, 2014b; Rance et al, 2017b).

As was shown in chapter two, anthropological research into eating disorders has addressed ways in which this worsening of one's anorexia can occur. To recap some key points, Eli (2014b) describes how, while valuing being a part of a community of patients and building friendships, her participants also felt endangered living alongside others with eating disorders because it could trigger "disorder-supportive desires" (2014b: 6). Living closely alongside other patients led to embodying their eating disorder logic and practices. Rich (2006) and Warin (2010) address competitiveness among individuals diagnosed with anorexia, whereby individuals strive to be recognised as the 'best anorexic' and the most sick, because being positioned in this way offers a sense of empowerment and distinction and legitimises ones diagnosis. It is useful to note here that when the idea of competition is used in relation to comparisons, this usually alludes to a desire or active seeking to be 'more anorexic' or 'more ill' than others.

In accordance with existing literature, participants in this study who had undergone treatment alongside others with anorexia tended to experience this as both helpful and unhelpful. They described pleasant and meaningful relationships with other patients and also identified problematic aspects of living closely alongside them. In this section, I focus on between-patient comparisons and mainly highlight 'difficult' aspects of relationships with other patients. However, it is important to recognise that comparisons occurred among or within valued friendships.

Almost all participants spoke about making comparisons with other patients (or others with an eating disorder more generally), in terms of weight, body size and eating behaviour, and often framed this as a known and expected part of anorexia. In addition to self-consciously

monitoring their own performance of anorexia, participants monitored others' performances. Others' 'doing' of anorexia had implications for one's own, as they made sense of their own behaviours and symptoms in relation to others. As Naomi succinctly stated when describing her experience of comparing herself to others: "That person is doing that so I should do that, or I shouldn't be doing that because that person is doing that".

Mia's description of how she compared herself to the 'bad patient' whose behaviour she found difficult suggests that sharing a diagnosis with another invites comparisons:

> I just hated it instantly [when admitted]. I was just in comparisons, with her shape and me, what she was eating and what I was eating and I didn't like it […] it was like I'm in here for the same reason as her, but she is not eating and almost again, conforming to that character, that role in the play, and I'm also that character but I'm being different and yet we still fall under the same category.

Being in the 'same category' suggested that they should be acting in accordance with the same script, but the differences between them demonstrated they were not. For Mia, this realisation seemed to be uncomfortable.

Comparing was an active process. It was not only about being aware of how one was similar/different to others, but also involved actively making meaning of those similarities/differences to reflect on one's own positioning. The ways and extent to which comparing occurred varied partly in accordance with type of treatment, because different treatment arrangements involved different extents of contact with others with an eating disorder. Generally, it was the case that of those who had had more extensive contact with others (Amelia, who was in outpatient treatment, and all of those who had experienced inpatient treatment, apart from Ben) described being impacted by comparisons with other patients. In addition, comparisons with others were also a particularly important aspect of Sarah's experiences (even though she had not had intensive treatment). Most of this

discussion therefore focuses on a treatment context, although I also address experiences

outside of treatment when relevant.

Participants tended to describe the comparisons that occurred in treatment settings as

problematic and as having occured in a context of unhelpful competition. This accords with

existing research whereby comparisons (and related competing) between patients are

recognised as the source of much distress and as hindering 'recovery' (Colton and Pistrang,

2004; Offord et al, 2006). Hannah described the inpatient setting as "toxic" because of

comparing:

> At times it was quite toxic. It sort of always depended on the patients and who was
> there […] it was always quite a bitchy environment, and yeah there was quite a lot
> of comparing. That was what was difficult about inpatient is - you do compare.

While participants often used the word 'competing' when discussing comparisons, Natalie

and Kelly were critical of this term. Natalie, for example, felt that it simplified what is

actually a very complex process. None the less, both still recognised the problematic

interpersonal processes to which it refers; they still recognised that they, or other patients,

at times felt a desire to do anorexia 'better' than (or as well as) those around them.

Despite comparing and competition being problematic, there was sometimes an element of

wanting to compare oneself with others. This seemed to be the case for Natalie (who also

experienced comparisons as unhelpful). She described using bodily comparisons to make

relative sense of her own body:

> I don't have a clue what my body looks like if I don't have anything to compare it to
> […] if I know 'OK this is my height, this is my weight, this is kind of what I look like',
> I don't know where that sits, unless I compare.

Outside of a treatment context, Sarah deliberately sought to compare herself to others as a

way of worsening her anorexia. In a context in which she valued her social identity as

someone with an eating disorder, it was important to her to be the 'smallest', and to be

recognised as eating less than others. She described how, when another family member of a

similar age developed an eating disorder and her family expressed their concern about this,

her own positioning was threatened:

> I was so annoyed that I have always been the person with that in my family, nobody
> else has any problems with food, this is not fair and I found it really difficult and still
> to this day I just don't like her […] I think well you know that's my thing, that's mine
> not hers. I'm the one with [an eating disorder].

Regarding deliberately seeking comparisons, Sarah described how conversing with someone

with an eating disorder would invoke 'competition' and a drive to restrict her eating further,

and sometimes revealed new 'tips' for doing so. Describing an occasion when she was

'unwell' and met with an acquaintance who had recently lost weight, she explained:

> I could hear the sensible side of me going 'don't talk to her, you know that's a really
> bad idea' […] and then her [anorexia] saying […] 'we need to go and see if she can
> give us any tips and this could be really good like we need to try and talk to her' […]
> 'also we need to be better than her' and it was almost like the beginning of a race, in
> like an athletics championship.

Sarah also explained that if she had had the opportunity to take part in this research when

she was "really ill", she would have been motivated to do so in order to make comparisons

with me (knowing I had previously had a diagnosis of anorexia):

> I'd have read that you'd had a problem then I'd be like this is a good opportunity to
> meet someone else who's got a problem and like you know, this will make me worse
> and this will help me eat less so this is a good thing to do. But also I would have felt
> really, really competitive and I would have sort of, no offense but I would have hated
> you.

Participants in Lavis' (2011) research similarly described attempts to "deliberately cause a

'rising up' of anorexia" and "agentially self-trigger the illness" (2016: 461). Her participants

did this by bringing themselves 'too close' to food and thus inciting fear, through practices

such as thinking about food intensely and counting calories. Lavis understands this desire to incite anorexia as a part of the continuous work that it takes to maintain the condition and hold on to the safety that it offers. It seems, then, that for many, comparing oneself to others was experienced as difficult, unwanted, and uncomfortable, but may have sometimes been purposefully sought.

There were particular circumstances in inpatient treatment that especially engendered comparing. One such circumstance was the arrival of new patients into treatment. I have shown in chapter two how I found this distressing, because new patients seemed to successfully embody anorexia, whereas I did not. Participants had similar experiences. Natalie described how the arrival of a new patient on the unit led her to feel confused and to question herself:

> They'd come in and be admitted and you'd just be like 'what does that say about me?', like 'how what do I do, how do I understand, how do I deal with all of this stuff that is going on inside of me?'

Claire described how a new patient's apparently more successful anorexia – as indicated in the severity of their weight loss – led her to be critical of her own weight loss and suggested that she could have done it 'better':

> The hardest thing was when you had people who came in who were sicker […] if they'd been at a lower weight than I was when I got admitted I'd feel guilty because it would be like I could have got a bit lower, I could have got better [at losing weight] they'd be really, really stick thin and I was like why weren't they stopped sooner […] I felt like I could have probably gone on a little bit further and done a bit better to actually get a bit thinner.

Eating was another circumstance which engendered comparing. I have argued that one's approach to food in treatment was important to performances of anorexia. This is further demonstrated in the ways that participants concerned themselves with others' behaviours around food. Natalie described comparing her eating with others':

> [I would compare] how I behave with food, how I respond to food, to someone else. So I would watch them and think like 'oh, you're really struggling eating this banana or whatever and I'm not like, oh, maybe I should be struggling eating this banana, but I'm not bothered about the banana, I'm bothered about the other thing'. Or like 'oh you're doing this thing where you are separating out everything, yet I kind of like not doing that […] does that mean that I'm not sick enough? Maybe I should do this too?'

Viewing others 'doing' anorexia in the ways they ate led Natalie to doubt whether her own eating was correct - whether she was acting in accordance with anorexic scripts. This doubting led her to question whether she was sick enough, therefore highlighting the relevance of food performances to demonstrating 'sickness'. These dynamics can also be inferred from Long et al's (2011) research, which shows how 'rivalry' concerning who appears the most distressed can occur at meal times. Of particular relevance here, is a participant in their study who described comparing her eating with others' and, when noticing something different about their behaviour, thinking "if I don't do that, surely I'm not anorexic" (2011: 423).

For Claire, others' 'anorexic' eating behaviour induced frustration. She described how other patients used various tactics to minimise their food intake, such as choosing lower calorie options when these were not allowed. Observing this made Claire feel 'annoyed': "I was frustrated I guess at myself because I hadn't kind of done it […] it was like the principle of the whole thing and then you'd feel guilty that you hadn't done it as well".

Other patients' behaviour highlighted what she 'should' also be doing, leading her to feel 'guilt' and frustration. That comparing oneself with others in treatment, and a related sense of not being 'bad enough', can lead to feelings of guilt and shame is recognised in existing research (Offord et al, 2006; Rance et al, 2017b). I also personally experienced this, both in comparisons generally and specifically in relation to eating behaviour. I compared my eating

with others right from the outset of inpatient treatment. In the diary entry for my first day of treatment, I wrote:

> Every patient is naturally judging those around them – what are they eating? How fast are they eating it? […] When I was eating I was worried that I was eating too fast and that everyone else would think I was greedy (Diary, 9th October 2006).

3 months later, I wrote about observing newly admitted patients during a meal time:

> I could see the table with the new admissions […] [She] looked completely distressed about having to eat. I hate to see it because it makes me feel bad that I am not like that with food anymore (was I ever like that?).

Like Claire, a feeling of guilt emerged when I found myself not being as 'anorexic' as I once was or could have been. For me, this guilt incited a longing to return to food restriction.

Hierarchies of anorexia

As I have begun to show in relation to food performances, comparisons with other patients were an impactful aspect of Natalie's treatment. She also said "I compared my body and weight constantly to every single person in there, and that was kind of like the benchmark for who is the poorliest person here". I have also shown how Natalie had undergone inpatient treatment feeling 'fraudulent' and that seeing other patients with more significant clinical interventions – such as longer periods of bed rest – led her to doubt her own 'sickness'. Considering these aspects of Natalie's experiences, it seems that key indicators of anorexia relating to the body, weight, and clinical interventions, informed a 'hierarchy of anorexia' (Warin, 2011) whereby Natalie was sensitive to finding herself positioned lower than others.

Lisa alluded to this idea of a hierarchy when she described medical markers as 'status symbols':

I've noticed there's almost something of a 'competitive' element in terms of 'who has to take the most Sando K'[71] in treatment [...] Mind you – re the 'competitive' stakes and low K, it's still a far lower anorexic 'status symbol' (you know what I mean) than low BMI and NG tubes[72] (email).

Lisa, like Natalie, as a result of feeling less ill than other patients doubted her anorexia. At times, feeling less ill, thin, and distressed than others – in other words, being lower in the hierarchy – meant she felt less deserving of having her needs met.

The tendency to find oneself 'less anorexic' than others was recognised as common. When Lisa described understanding herself as 'less unwell', she stated:

I'm almost always the most physically 'well' person in treatment (and that's not just my anorexic goggles talking – I really HAVE been lucky to have escaped a lot of the physical issues other people experience, and have […] usually been admitted at a higher BMI than the trend seems to be in most inpatient settings) (email).

In referencing 'anorexic goggles', she invoked a shared understanding that individuals with anorexia tend to inaccurately find themselves 'falling short' of others. Similarly, Kelly stated: "I think it's bizarre how it operates that everyone else thinks that, in an inpatient situation, that everybody else is thinner than them".

Amelia also alluded to a hierarchy, and spoke directly about desiring to be the most ill. When explaining her experiences of being in a therapeutic group, she said:

It's almost elements of it become a competition with others, to who can be the best, I don't even know what that means […] But that's how your brain works, it's like that competition of who is the ill-est. And it's horrible.

She also recalled recently attending a therapy group with four other young women with eating disorders, and appreciating having been there (in treatment) longer than them. This

---

[71] Sando K is a medication used to treat low potassium.
[72] 'NG tube' refers to nasogastric tube.

was seemingly because needing to be in treatment a long time suggested that she had 'done' anorexia better than those who did not.

Comparative strategies and performative identity-work

Participants sometimes engaged in, or were aware of others engaging in, active comparisons with each other which drew on personal experiences of medical markers, clinical interventions, and other indicators of 'successful anorexia'. I understand these active comparisons as a form of performative identity-work, in which individuals 'work up' and perform an alignment with anorexia. The indicators of 'successful anorexia' that are drawn on act as identity markers, because they are used to communicate one's anorexic positioning to others.

Sometimes, this performative identity-work seemed to occur in a 'one way' process, as a way of demonstrating the extent of one's sickness to someone else who did not have anorexia. More often however, it was described as occurring between patients, in a relational, comparative context.

Lisa described the 'one way' process:

> I hear myself slipping it into conversation […] I've noticed that I'm most prone to doing it when I don't feel someone really grasps the impact of this illness on me […] or if I feel somehow insecure about if they see it as 'real' or 'serious' [I'm] always mentioning how tired I am, and mentioning being anaemic or something! (email).

This reinforces our understanding of medical markers as indicative of illness, as Lisa describes drawing on these in such a way as to perform her illness as 'real'. Kelly also described her understanding of the 'use' of medical markers and clinical interventions in this way:

> In the context of mental distress not really being taken seriously and physical distress being considered, probably being taken more seriously [...] I think like it's a very easy way to demonstrate to somebody this happened, this is how poorly I was and to be honest how would you know unless I told you that this had happened to me.

The revealing of indicators of anorexia that occurred between patients and included a comparative dimension were usually described as unhelpful, and were recognised as part of the competition that occurs between patients. Lisa felt frustrated by other patients revealing such information:

> I HATE it when I have heard other patients 'drop into conversation' how sick they've been - but I also recognise it as stemming from their own insecurity/vulnerability [...] it's frustrating! I always try not to be 'triggering' in any way if talking about my problems in groups (weight/medical issues/restriction etc) (email).

The situation she describes is comparative in the sense that those revealing the information about their anorexia did so while aware that others with the diagnosis were present. Participants also described how the revealing of information occurred in processes of mutual sharing. This is noted by Warin (2010), who describes how "beyond the obvious markers of weight loss in anorexia there are the invisible indicators of metabolic imbalances and cessation of bodily processes (such as menstruation), results and effects that are compared among those diagnosed to reveal the seriousness of their disorder" (2010: 77). Kelly described this:

> It's like anecdotal kind of like 'yeah, I fainted here and here' [...] like various like physical things of like you know [...] 'I didn't eat anything for like a month' [...] you start getting a bit of back and forth [...] it's not a positive conversation to have.

I partook in these conversations in treatment, and sometimes initiated them. In a diary entry during my second admission, I describe walking away from a conversation with another patient feeling angry with myself, because I sensed that she did not like me for talking about how physically unwell I had been – something I had done in order to communicate the

'strength' of my anorexia. However, I also became frustrated with others if they seemed to be speaking about their own experiences for this purpose, especially if they did so too 'obviously'. Describing an encounter with a particular patient during my second admission, I wrote:

> She's just so competitive, I can't stand it! She asked me if it had just all gone wrong pretty much straight away when [last] discharged, I said that it had, and started to explain my situation […] she was like "oh I was losing more each week". What do you want, a medal?! (Diary, 2nd August 2007).

Participants' awareness of comparative dynamics and their potential problematic impact were often revealed when they responded to the post – interview question. They expressed how they had been concerned with the potential for such processes to occur during the interview. Claire explained she had been concerned prior to the interview that she may have felt the need to "show off" to my "anorexic side". Relatedly, to restate a quotation from Anna (originally presented in chapter three):

> When you […] mentioned you'd had anorexia [I worried] that us talking about our anorexia could be too complicated. Sort of blurring the lines between empathising, comparing, competing, and that sort of complaining 'oh isn't it awful when…' that also ends up celebrating something.

Anna's use of the phrase 'celebrating something' alludes to the valuing of being positioned as 'ill' and the ways this can be iteratively 'worked up' in interaction.

Naomi described how her concerns about comparative processes during the interview led her to be conscious of what she said to me:

> There were times I was conscious about giving certain information that might be typically triggering or used by some sufferers as part of competitive comparisons. I know that you consider yourself recovered, but I found it hard to judge how much information might be too much information.

These examples show how the interviews unintentionally functioned like an experimental situation in that they shed light on comparative dynamics in anorexia. Literature suggests that insider research and interviewer self-disclosure can lead to a sense of comparison and competition (Abell et al, 2006; Berger, 2015). Due to the comparative dynamics that occur in relation to the diagnosis of anorexia, this was a particularly relevant in the interviews in this research.

Concluding points: anorexic scripts in others

The above analysis of between-patient comparing suggests that others' performances of anorexia had implications for how participants understood their own. In seeing other patients apparently 'do' anorexia more successfully, participants' understanding of themselves as 'truly' or 'seriously' anorexic was undermined. This was an uncomfortable process which induced shame, guilt and a feeling of fraudulence, perhaps because it undermined the sense of empowerment and distinctiveness associated with being a 'successful anorexic' (Rich, 2006; Warin, 2010). The flipside to this is that finding themselves more successful in comparison to others, positioned them as 'higher' in an anorexia hierarchy, and this experience felt validating and rewarding. Perhaps for this reason, individuals sometimes tried to (re)align themselves with anorexia during performative identity-work. This involved 'displaying' their anorexia by demonstrating how well they had embodied anorexic scripts, and working to position themselves as 'successfully' anorexic in relation to others. Eli (2014b) suggests that, in the context of inpatient treatment, one's eating disorder identity is 'slippery' and requires constant negotiation and work. We can understand this performative identity-work as part of this broader identity-work that occurs in treatment.

However, it is noteworthy that Ben and Jack did not engage in these comparative processes. For Ben, this was perhaps due to him not being invested in a diagnostic identity based on

anorexia. Jack had only had limited contact with others with an eating disorder, and this was in online support groups or 'chat rooms'. He compared himself with others, but did so in order to learn better ways of coping with his eating disorder.

Distancing anorexia

Avoiding others' expectations

Coinciding with others' attempts to live up to their diagnosis and adhere to anorexic scripts, participants also sometimes worked to disavow their diagnosis or reshape other people's expectations of it. This was in order to manage behavioural expectations and stigmatising and problematic understandings of the diagnosis.

Participants who wanted to avoid the behavioural expectations associated with anorexia did this by not revealing their diagnosis to others. Sarah described an occasion when she first met the new girlfriend of a long-term friend, whom she assumed had heard about her eating disorder. She had felt awkward eating in front of her, because she felt she needed to live up to the expectations that she imagined the new girlfriend had, to prevent her from wrongly concluding that she had never had an eating disorder. Sarah then described how she sometimes chooses not to reveal her eating disorder to new friends, in order to avoid these sorts of concerns. Having others not expect that she will restrict her eating allows her eat 'freely' with them.

Natalie did not inform others of her diagnosis for similar reasons. At the time of the interview, she did not have many others in her daily life who knew about her ongoing struggles with under-eating. She explained that having others know would lead her to feel restricted and unable to change, and as though she needed to continue losing weight and restricting her food intake. Like Sarah, others not knowing induced a sense of freedom:

> It's so nice having nobody know, because you can go out for dinner and just eat whatever you want and no one is thinking anything. Whereas if I go out for dinner with anyone that knows, the only thing I can order is a salad, because I know I think that they are judging or watching or expecting that that's what I'll have. […] With most of them not knowing I can just, it is freer […] if I want not a soup or salad, it's OK.

Amelia also felt that others knowing about her diagnosis restricted her ability to change. She described how this led them to pre-determine her to act in a certain way, and explained this as them thinking "Amelia has got anorexia, and so she is like this". She implied that this makes it more difficult for her to act outside of their pre-determined ideas and limits her ability to recover, citing a recent example of a family member finding it "weird" when she chose to sit down and relax in front of the TV (because this does not fit with her usual 'anorexic' behaviour). Amelia explained that she had asked her family not to think of her as having anorexia or to make assumptions about how she will behave:

> I've now tried to say to my family can you please try to treat me as not anorexic […] I now try to see myself as an underweight person that needs to put weight on, not as anorexic.

The experiences of these participants can be understood in terms of them attempting to free themselves from anorexic scripts, because these invoked unwanted and restrictive behavioural expectations. For Sarah and Natalie, this was about not bringing these into play by avoiding revealing their diagnosis. For Amelia, it involved differentiating between a 'label-free' description of her need to gain weight and a diagnostic one.

Managing problematic perceptions

Participants spoke about lay perceptions, stereotypes, and/or cultural and media portrayals of anorexia being problematic and inaccurate. Aspects of these that were considered to be especially problematic included the idea that individuals with anorexia are motivated by a desire to be skinny and become more attractive, that they are influenced by media images

and/or are overly concerned with their appearance, that anorexia involves not wanting to eat, having no appetite, never eating certain foods, and finding self-starvation effortless, and that it is only a female condition. Some of these aspects of imputed misunderstandings resonate with findings from Dimitropoulos et al (2016). In their study exploring how individuals with anorexia believe the general public perceive the condition, participants felt that the public understood their struggles as a desire to emulate celebrities and models and that this trivialized their experiences. As was also the case for participants in this research, the framing of anorexia as volitional and socio-culturally influenced was understood as problematic. For some in this research, perceptions of how others envisage anorexia led them to hide their diagnosis, and/or be strategic in the ways in which, and to whom, they revealed it. These strategies speak to the impression management that Goffman (1963) describes in relation to managing stigma.

Mia felt "scared" to publicly identify with the diagnosis due to others' misunderstanding of what it involves. She felt that the general perception of anorexia is stereotypical and depicts someone who does not eat because they think they are fat and want to lose weight. This perception did not resonate with her current experience:

> You say that word, people just instantly think that you're not eating because you think you're fat and you want to lose weight. I don't want to lose weight any more […] I hate how I look, I just know no different and as I say it becomes like an outcome of what's happening in here [in my mind].

Mia's family and a few close friends were aware of her diagnosis, but she did not tell additional people in order to not invoke the stereotype. Her perceptions of how others understand anorexia impacts on the language she uses in conversation with them. She explained that she will use the word anorexia when talking to someone who understands that she is not simply motivated by a desire to be skinny (such as a mental health professional). However, in conversation with friends, she will say "illness" or "eating

disorder", as she imagines the word anorexia will lead them to "jump to a conclusion" (they will make incorrect assumptions about the nature of her experience).

Prior to beginning treatment, Kelly had also found it problematic to be known as someone with anorexia. She linked this to the portrayal of anorexia in media, which she felt did not represent her experiences. She explained that anorexia is portrayed as involving wanting to lose weight to appear more attractive and never eating, whereas her own experiences are (partly) about responding to trauma, and behaviourally involve elements of what she referred to as bulimia (making herself vomit). Having others identify her as someone with anorexia therefore led her to feel that misconceptions about the diagnosis would be placed on her:

> I just don't think that a label can sum up your experience [...] I kind of wanted to say well yeah, I do have this diagnosis, but that's not going to tell you anything about what's going on.

Having others know about her diagnosis also led her to worry that they would consider her "not skinny enough", implying that she understood herself not to 'match up' to the physical appearance that others assume anorexia entails. Kelly described feeling pressured to 'fit' how she imagined others saw anorexia, and stated "I felt like I had to fit the bill of the diagnosis, as opposed to it fitting me".

Anna described having deliberately 'cultivated' her anorexia in a way that went against how it is typically portrayed in media. Rather than being understood as experiencing something "illogical" or "superficial", she wanted to be recognised as having a "serious mental illness":

> My doctor would ask if I purged and I'd say 'of course not, I know it isn't effective and can only empty a tiny proportion of what I consume' […]. It was like I wanted to appear totally rational and reasonable. And I'd be careful to avoid any suggestion that I was doing it out of appearance […] it was like I really wanted to have a form of anorexia that couldn't be explained away as a fad, or illogical, or superficial, like it often is in the media. Like I was frightened that people would say there was nothing really wrong, I was determined to make sure my anorexia was unquestionably a serious mental illness (email).

Ben perceived anorexia as a potentially stigmatising diagnosis. I described in the previous chapter how he had never fully internalised the idea that he was 'anorexic', and had only ever vaguely and ambivalently identified with the diagnosis. In part this was because he felt it did not fully account for his experience, and because he personally resisted 'being categorised'. Also relevant to his lack of identification with anorexia was what he described as his 'own stigmatisation' of the diagnosis and his related hiding of it from others:

> I can't easily say anorexia, like I really rarely say that […] I think because of the stigmatising element as well, of not wanting to say […] not wanting to communicate to others that this is something that I have had in the past

In part, Ben attributed his perceived stigmatisation of the diagnosis to gender. He explained: "So few people know it about me. [After treatment] I wanted to sort of redefine myself as not the guy, the *boy* that was admitted to inpatient".

However, he sensed that he is likely misplaced in his concerns about how others would react if they knew:

> I don't think I give people enough credit for actually […] being helpful as opposed to judgemental […] people don't often go 'so you don't eat food?' People don't do that, but maybe that's what I was scared of […] every time people see me they are not going to go […] 'Ben, anorexic.' […] they'll listen to the story and then they'll get a new Snapchat notification and they'll soon move on. I stigmatise myself which is so bad.

Participants also spoke about managing the ways in which they revealed their diagnosis for other reasons. Anna explained that she sometimes reveals her experience with anorexia to

others, and sometimes does not. When she does discuss her experiences, she, like Mia, is careful in the language she uses. She explained that she often chooses to use the phrase 'eating disorder' as opposed to 'anorexia', due to the use of the latter leading to 'mythologising' and 'gossiping':

> Even the 'oh I'm so sorry, that's awful, it's so hard to recover from' that comes out in reference to anorexia is a kind of mythologising and that sort of gossip where people relish the worst - that wouldn't happen if it were binge-eating disorder.

Regarding 'mythologizing', Anna seemed to be suggesting that discussions about anorexia being difficult to recover from can take on an exaggerated and unhelpful form. In describing how conversations about anorexia can 'relish the worst', she refers to the performative identity-work described above, whereby indicators of 'successful' anorexia are communicated. Naomi discussed her concerns about revealing her diagnosis in the context of newly developing relationships, particularly when 'dating'. Her worry was that anorexia would be perceived as a burden.

Most participants, then, spoke about perceived problematic and stigmatising perceptions of anorexia as factors which restricted their revealing of the diagnosis and led them to be strategic in terms of to whom and how they positioned themselves as anorexic. On the other hand, a few described their attempts to 'be open' about their experiences with anorexia precisely because they wished to challenge problematic views. Amelia explained she had told more people about her diagnosis and become increasingly 'open' over time, due to her belief that "it needs to be spoken about more". Maddie described becoming "obsessed" with "raising awareness" of anorexia because "people need to understand it". This had involved her reading, writing and talking to others about anorexia and various organised 'awareness raising' activities.

Chapter seven summary

In this chapter, I have shown how the anorexic scripts – or 'ways of doing' anorexia – that

individuals encounter in clinical contexts inform how they position themselves in relation to

the diagnosis, and how they perform their diagnosis. This includes in relation to weight,

hunger and eating, and clinical interventions and medical markers. I have also shown how

individuals make sense of the ways in which they 'do' their diagnosis in relation to others,

and how others' performances of anorexia influence their own. Moreover, while the valuing

of an anorexic positioning can influence individuals to perform towards the diagnosis, such a

positioning is also sometimes problematic. This is due to perceived stereotyping and

misinformation, and individuals adopt strategies to manage this in interaction with others.

Chapter Eight

Conclusion

The aim of this research has been to explore the experience and impact of 'having' a diagnosis of anorexia. I have addressed this through an exploration of my own experiences of being diagnosed with the condition and undergoing inpatient treatment, along with the experiences of 14 others who have also been diagnosed (or self-diagnosed) and had treatment. I have sought to understand how individuals experience being diagnosed, what this event means to them, and how the diagnosis informs their self-understanding, performance of symptoms, and interaction with others.

In this concluding chapter, I outline the overall contributions of the research. I begin by summarising key insights relating to each research objective, and considering their sociological and clinical implications. I then summarise what this research has found in relation to male experiences of the diagnosis in particular. In doing so, I draw together facets relating to the gendered construction of the diagnosis which have thus far been addressed in a dispersed manner, across different chapters. Following this, I comment on a methodological insight regarding reflexive strategies and insider interviewing. I then identify possible areas for future research. Finally, I draw some overall conclusions about the diagnosis of anorexia and its functions.

The experience of being diagnosed

The first research objective was *to explore how individuals come to be diagnosed with anorexia and what meanings they attach to this event.* I have examined the interpretive processes that lead individuals to be diagnosed with anorexia, and the lived experience of being diagnosed in terms of what the event means to them at that time. This is an aspect of experience that

has not previously been an explicit or substantial focus of social science research into anorexia.

I identified three different routes to being diagnosed: self-directed, other-directed, and mixed. These routes highlight the various interpretive processes, engaged in by both self and others, involved in identifying a problem and initiating help-seeking, as well as the pathway to receiving a diagnosis after having sought help. I pointed to the influence of lay understandings of what it means to 'be anorexic', in terms of aspects such as gender and how anorexia 'looks', on these routes. I have highlighted the role of personal meanings and ambiguity in the help-seeking process, and the ways in which individuals engage with their own and others' understandings of their 'symptoms'. These findings offer a sociological, rich understanding of help-seeking, which is an aspect of anorexia that has, in contrast, previously tended to be explored from a clinical, service-focused or psychological perspective. The findings are relevant to those seeking to improve services for anorexia, given that research commissioned by Beat has suggested that there is a "clear pattern of delay in seeking help for eating disorders" (Beat, 2015: 24) and that longer time to treatment following the onset of 'symptoms' is associated with poor treatment outcomes (Beat, 2015; Treasure and Russell, 2011).

This research has shown that being diagnosed with anorexia holds various meanings. Participants either did not identify with the diagnosis, understood it as a 'useful way forward', or experienced it as a marker of success and recognition of suffering. This concurs with existing critical psychology literature which addresses the lived experience of receiving other psychiatric diagnoses (Horn et al, 2007; Hansson-Halleröd et al, 2015), in that the diagnosis holds a range of both 'positive' and 'negative' meanings. This finding has relevance to clinicians involved in diagnosing anorexia, and supports the assertion that they should employ discernment regarding the functions of a diagnosis and its meaning to the person

being diagnosed (Hayne, 2003; Horn et al, 2007). That said, the meaning of the diagnosis as a 'marker of success' appears to be somewhat unique to anorexia. This meaning is also reflected in anthropological research which suggests that anorexia is experienced as an 'earned status' (Warin, 2010, Eli, 2014b), and is important in understanding performative aspects of the diagnosis (see below). I also found that the route through which a person reaches diagnosis is related to the subjective meaning it is afforded at the time it is 'given' (for example, those for whom help seeking was other-directed tended not to identify with the diagnosis). This has relevance to the sociology of diagnosis, because it suggests that in order to fully illuminate the process of diagnosis (Jutel, 2011), one needs to examine proceeding events and circumstances.

An additional key finding is that the occasion of diagnosis may not in itself instigate or represent biographical disruption (Bury, 1982). While being diagnosed is both meaningful and impactful, it is not necessarily a pivotal moment in terms of changing a person's understanding of themselves or interpretation of their experiences. This research suggests that personal identification with the diagnosis, and an 'acceptance' of it as the proper explanation of one's struggles, occurs gradually over time, sometimes prior to being diagnosed (whereby receiving the diagnosis is confirmation of one's existing understanding), or after being diagnosed. In the case of the latter, an identification with the diagnosis is learned through what I have conceptualised as 'diagnostic framing' and 'interpretive identity-work'. It seems then, that for anorexia, while the act of being diagnosed is meaningful for self-understanding and identity, it is not necessarily a discretely transformative event.

Anorexia and identity

An additional objective was *to explore how individuals relate to the diagnosis of anorexia and how it informs their self-understanding and identity, and how these facets are influenced by the*

experience of treatment. I explored how individuals develop an identification with the diagnosis of anorexia, and how the diagnosis informs their self-understanding and personal sense making. Using notions of 'diagnostic framing' and 'interpretive identity-work', I have shown how individuals learn an 'anorexic identity' in treatment contexts. These findings support existing research which suggests that individuals are socialised into clinical understandings of their anorexia diagnosis in the hospital institutions in which they are treated (Carney et al, 2008; Darmon, 2016). However, I have also highlighted how diagnostic understandings are not necessarily wholly accepted or internalised. Rather, they are critically engaged with, such that individuals may reject aspects of the diagnosis and associated clinical understandings, deeming them irrelevant to their experiences, insufficient for explaining them, or as not helpful to their 'recovery'. This supports Brinkmann's (2016) suggestion that a diagnosis is an interpretive resource drawn on by reflexive, self-conscious individuals. That said, it is necessary to recognise the relative dominance of diagnostic, clinical explanations in present-day western societies and the ways in which these constrain and direct the self-understandings available; there are limits on the extent to which the diagnosis can be freely 'rejected'.

I have also offered insights into the value and meaning of an anorexic identity, particularly in terms of how clinical recognition of illness can be drawn into this. That individuals may value being positioned as 'successfully anorexic' is recognised elsewhere (Rich, 2006; Warin, 2010; Lavis, 2011; Eli, 2014b). A contribution of this research has been to illuminate how medical markers of illness can inform and materialise this 'success', and be experienced positively as proof of one's diagnosis and as suggestive that one is doing anorexia 'well' (see also Warin, 2010). I reflect on this point further below when considering the performance of anorexia.

Performing and managing anorexia

The final objective was *to explore how individuals manage and perform the diagnosis, both in and outside of treatment contexts.* I examined how and why individuals seek to 'live up' to their diagnosis of anorexia, and described how this involved adhering to clinically based 'anorexic scripts'. I have argued that anorexic scripts significantly inform how individuals relate to and 'do' their diagnosis. In addition, individuals sometimes seek to avoid being positioned as 'anorexic', or work at managing the impressions they give others of their diagnosis, due to perceived stigma and misunderstanding.

Brinkmann's (2016) notion of diagnostic scripts has shed light on how individuals make sense of themselves as patients with anorexia, and how they reflexively interpret, monitor, and perform their symptoms. This aspect of the research has highlighted participant's self-awareness in terms of how 'successful' they are at anorexia. I stated above that this success is partly informed by clinical recognition of illness. It is also informed by comparisons with others. In exploring this aspect of performing anorexia, I have offered a new way of understanding 'competition' between patients. While typically interpreted using a pathological frame, whereby the 'drive' to compare oneself to others is understood as symptomatic of an illness, this research has approached comparisons in terms of personal sense-making and performative identity-work. Individuals perform their identity as 'an anorexic' in relation to others, 'working up' their anorexia in interaction with them and reading their performances and using them to make sense of their own. It is important for clinicians to be aware of performative and inter relational dynamics in anorexia, given that they add a 'hidden layer' to the experience of treatment, which complicates a person's engagement with it. Moreover, given the ways in which clinical recognition of illness can inform performances of 'successful anorexia', it is important that clinicians are sensitive to the complex and conflicting meanings and significance of experiencing health related

complications in eating disorder treatment. In a similar vein, the notion of diagnostic scripts has illuminated potentially iatrogenic aspects of treatment. Clinical settings and procedures can inadvertently reinforce aspects of anorexic scripts relating to low weight and weight loss, and thus individuals may seek to continue to lose weight in order to adhere to this diagnostic expectation. Similar to Lavis (2011), I have shown how for those admitted to treatment, "many learn how to 'do' and 'be' the clinic's anorexia" (2011: 279). However, I have also nuanced this suggestion by identifying multiple anorexic scripts and recognising that there is more than one version of 'the clinic's anorexia'.

Gender and anorexia - male experiences

This research suggests that the construction of anorexia as a 'female condition' has implications for how males relate to the diagnosis and for their identity as someone with anorexia. For the three male participants in this research, these implications were varied and they were not all impacted by the gendered nature of the diagnosis in the same way. For Ben, we have seen that the gendered construction of anorexia contributed to his lack of identification with the diagnosis. He distanced himself from it, in part because he did not wish to be known as a *male* who had been treated for anorexia. Moreover, he understood the female-specific information about anorexia that he had encountered in clinical contexts to have constrained his ability to relate himself to the diagnosis. In contrast, gendered understandings of anorexia did not seem to lessen Michael's identification with the diagnosis, but they did have implications for what being anorexic meant to him. He understood that being a 50 year-old male anorexic made him different to most others with the diagnosis, and this affected how he related to the information he read about anorexia (in that he felt that he was being informed about something that was 'removed from who he was'). However, gender did not feature as a major understanding in how he made sense of his lack of a formal diagnosis. This was unlike Jack, who also identified as having an eating disorder, but

understood gender to have impacted on how professionals interpreted his situation and to be a reason for his initial 'missed diagnosis'. Thus, while gendered constructions of anorexia influence those who are diagnosed, the impacts are not homogenous.

Methodological insight

In this research, I adopted various reflexive strategies, including a novel approach of asking interviewees questions about their experience of undertaking an interview with a self-identified 'insider'. This proved effective, as participants' responses to these questions offered valuable insight into the ways in which my insider positioning and self-disclosure impacted the interviews. Unexpectedly, the post-interview question also offered insight into the very interpersonal dynamics I was exploring in the substantive content of my research. I addressed this in chapter seven when I described how participants had reflected on their initial concerns about how comparative dynamics would potentially play out during the interview. These reflections offered valuable insight because they indicated the scope and weight of such concerns. My use of these post-interview questions is of relevance to future insider researchers who may also benefit from adopting this reflexive strategy.

Recommendations for future research

Clinicians' perceptions and experiences of 'anorexic scripts': In order to elaborate the understanding of 'anorexic scripts' offered in this thesis, it would be beneficial to explore these from the perspective of clinicians working with individuals diagnosed with anorexia. This could include an examination of the anorexic scripts that clinicians encounter, and how they may perpetuate, reinforce or engage with these when treating patients. It could also assess how clinicians interpret the behaviours and presentation of individuals diagnosed with anorexia that do not 'fit' the scripts. This could be in terms of whether or not this is interpreted as evidence 'against' the diagnosis or whether it is subsumed into it. This relates

to Brinkmann's (2016) discussion of diagnostic self-affirmation, in which he notes that a whole range of 'symptoms', including those that are not ordinarily associated with a particular diagnosis, can come to be interpreted as belonging to it.

Male anorexia: This research has begun to explore issues relating to gender and the lived experience of a diagnosis of anorexia. Further research incorporating a wider breadth of male experiences would be beneficial for enhancing the tentative insights here. I have suggested that the three male participants in this research were all affected by the gendered construction of anorexia, but in different ways. It may be that common features of their experience would emerge in research pertaining to the experiences of a wider sample of males.

The experience of an anorexia diagnosis: doing *to* and doing *for*

When a medical professional diagnoses someone with anorexia, the intention is to help. The diagnosis can assist in better understanding the nature of the individual's struggles and in providing access to treatment. It can therefore feel like a relief to the person who receives it, as it seems to offer a way forward, and validates and legitimises suffering. However, being diagnosed with anorexia can also have hidden or unintended consequences. For example, individuals may try to 'live up to' their diagnosis through continued weight loss and restricted eating, in order to not lose access to treatment or in hope of retaining the private sense of achievement that the diagnosis can provide.

The diagnostic explanation of self-starvation – that it is a key manifestation of a condition known as anorexia nervosa – is culturally and clinically dominant in contemporary western societies. As a recipient of this label begins and moves through treatment, they are expected to accept, internalise, and 'work with' the understanding that they are anorexic. In this way, the diagnosis is imposed onto them. Once labelled as anorexic, they may struggle to be

understood by others – including friends, family, and clinicians - outside of the parameters of
anorexia pathology, and an identity as someone who is 'anorexic' is difficult for them to
reject legitimately. In treatment settings, they may also be understood as a certain 'type' of
anorexic – as chronic or difficult, for example. This is an understanding which they may then
(however passively or actively) come to adopt. Individuals may also encounter certain
expectations of how they should behave, or misunderstandings of their experiences, which
they must negotiate and work to avoid. In these respects, we can understand the diagnosis
as doing *to* the individual.

In other respects, the diagnosis does *for* the individual. Individuals use clinical understandings
of anorexia resourcefully to make sense of their past and current experiences. They are
reflexive and self-conscious regarding their diagnosis, rather than simply passively accepting
the definitions and explanations of anorexia they encounter. They *work* at understanding the
relevance of such explanations to their personal experiences, 'drawing in' those that
resonate and are most personally helpful. Some largely reject the diagnostic definitions of
their struggles, and do not personally or socially align themselves with anorexia. For others,
the diagnosis offers a useful framework for their recovery, and for others still (or indeed,
simultaneously), it offers them a desirable positioning and social role. In seeking to press
themselves into this role, individuals reflexively draw on the anorexic scripts they
encounter.

Notions of identity, identity-work, and 'having' and 'being' a diagnosis have been valuable in
illuminating the dynamics of the diagnosis as doing *to* and *for* those who are diagnosed. By
using these concepts as analytic frames, I hope I have contributed to a more detailed
understanding of the experience of anorexia, and that I have highlighted the complexities
underlying processes of seeking help, being diagnosed, and undergoing treatment. In relation
to clinical diagnoses more generally, the findings from my research suggest that it is

important to recognise the ways in which cultural, clinical, and personal meanings of

diagnostic categories interact, and how diagnoses intersect in individuals' lives in varied

ways. They also highlight the importance of sociology (and 'critical' social sciences more

generally) in shedding light on the hidden and unintended consequences of clinical activity.

References

Abbate-Daga G, Amianto F, Delsedime N, De-Bacco C and Fassino S (2013) Resistance to treatment and change in anorexia nervosa: A clinical overview. *BMC Psychiatry.* 13(1).

Abell J, Locke A, Condor S, Gibson S and Stevenson C (2006) Trying similarity, doing difference: The role of interviewer self-disclosure in interview talk with young people. *Qualitative Research.* 6(2): 221-244.

Adams T, Holman Jones S and Ellis C (2015) *Autoethnography.* Oxford: Oxford University Press.

Adler P and Adler P (1987) *Membership Roles in Field Research.* Newbury Park: Sage.

Akey J, Rintamaki L and Kane T (2013) Health Belief Model deterrents of social support seeking among people coping with eating disorders. *Journal of Affective Disorders.* 145(2): 246-252.

American Psychiatric Association (1980) *Diagnostic and Statistical Manual of Mental Disorders. Third Edition: III.* Arlington, VA: American Psychiatric Association.

American Psychiatric Association (1994) *Diagnostic and Statistical Manual of Mental Disorders. Fourth Edition: IV.* Arlington, VA: American Psychiatric Association.

American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders Fifth Edition: 5.* Arlington, VA: American Psychiatric Association.

Anderson L (2006a) Analytic autoethnography. *Journal of Contemporary Ethnography.* 35(4): 373-395.

Anderson L (2006b) On apples, oranges, and autopsies: A response to commentators. *Journal of Contemporary Ethnography.* 35(4): 450-465.

Andrés-Pepiñá S, Plana M, Flamarique I, Romero S, Borràs R, Julià L, Gárriz M, and Castro-Fornieles J (2020) Long-term outcome and psychiatric comorbidity of adolescent-onset anorexia nervosa. *Clinical Child Psychology and Psychiatry.* 25(1): 33-44.

Aneshensel C (1999) Mental illness as a career: Sociological perspectives. In Aneshensel and J Phelan (eds) *Handbook of the Sociology of Mental Health.* New York: Springer, 585-603.

Arcelus J, Mitchell A, Wales J and Nielsen S (2011) Mortality rates in patients with anorexia nervosa and other eating disorders: A meta-analysis of 36 studies. *Archives of General Psychiatry.* 68(7): 724-731.

Arnold, B and Hagan, J (1992) Careers of misconduct: The structure of prosecuted professional deviance among lawyers. *American Sociological Review.* 57(6): 771-780.

Athens L (1994) The Self as a Soliloquy. *The Sociological Quarterly.* 35(3): 521-532.

Atkinson P (2006) Rescuing autoethnography. *Journal of Contemporary Ethnography.* 35(4): 400-404.

Atkinson P (2015) *For Ethnography.* Los Angeles: Sage.

Atkinson P and Housley W (2003) *Interactionism.* London: Sage.

Atkinson P, Coffey A and Delamont S (2003) *Key Themes in Qualitative Research: Continuities and changes.* California, AltaMira Press.

Bachrach, L, Katzman, D, Litt I, Guido D and Marcus R (1991) Recovery from osteopenia in adolescent girls with anorexia nervosa. *The Journal of Clinical Endocrinology & Metabolism.* 72(3): 602-606.

Barley S (1989) Careers, identities and institutions: The legacy of the Chicago School of sociology. In M Arthur, D Hall and B Lawrence (eds) *Handbook of Career Theory.* Cambridge: Cambridge University Press, 41-65.

Barlow C (2016) Documents as 'risky' sources of data: A reflection on social and emotional positioning – a research note. *International Journal of Social Research Methodology.* 19(3): 377-384.

Beat (2015) *The Costs of Eating Disorders: Social, health and economic impacts.* Report, PriceWaterhouseCoopers (PWC). beateatingdisorders.org.uk/uploads/documents/2017/10/the-costs-of-eating-disorders-final-original.pdf. Accessed 12 February 2017.

Becker A, Thomas J and Pike K (2009) Should non-fat-phobic anorexia nervosa be included in DSM-V? *International Journal of Eating Disorders.* 42(7): 620-635.

Becker, S (1963) *Outsiders: Studies in the sociology of deviance.* London: Free Press of Glencoe.

Becker H (1991[1963]) *Outsiders: Studies in the sociology of deviance.* New York: Free Press.

Bell K and McNaughton D (2007) Feminism and the invisible fat man. *Body & Society.* 13(1): 107-131.

Belsey C (2002) *Post-Structuralism: A Very Short Introduction.* Oxford: Oxford University Press.

Beresford P (2003) *It's Our Lives. A short theory of knowledge, distance and experience.* Shaping Our Lives National User Network. Citizen Press, London.

Berg B (2004) *Qualitative Research Methods for the Social Sciences.* 5th edn. Boston: Pearson.

Berger R (2015) Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research.* 15(2): 219-234.

Berkman ND, Lohr KN and Bulik CM (2007) Outcomes of eating disorders: A systematic review of the literature. *International Journal of Eating Disorders.* 40(4): 293-309.

Biddle L, Donovan J, Sharp D and Gunnel D (2007) Explaining non-help-seeking amongst young adults with mental distress: A dynamic interpretive model of illness behaviour. *Sociology of Health & Illness.* 29(7): 983-1002.

Birch M and Miller T (2000) Inviting intimacy: The interview as therapeutic opportunity. *International Journal of Social Research Methodology.* 3(3): 189-202.

Blaxter M (1978) Diagnosis as category and process: The case of alcoholism. *Social Science & Medicine.* 12(1-A): 9-17.

Blaxter M (2009) The case of the vanishing patient? Image and experience. *Sociology of Health & Illness.* 31(5): 762-778.

Bloor M, Fincham B and Sampson H (2007) *Qualiti (NCRM) Commissioned Inquiry into the Risk to Well-Being of Researchers in Qualitative Research.* Cardiff: ESRC National Centre for Research Methods.

Bonner A and Tolhurst G (2002) Insider-outsider perspectives of participant observation. *Nurse Researcher.* 9(4): 7-19.

Bordo S (1993) *Unbearable Weight: Feminism, western culture, and the body.* Berkeley, California: University of California Press.

Bordo S (2009) Not just 'a white girl's thing': The changing face of food and body image problems. In H Malson M Burns (eds) (2009) Critical Feminist Approaches to Eating Dis/Orders. London: Routledge, 46-60.

Bordua, D (1967) Supplement: Recent trends: Deviant behavior and social control. *The Annals of the American Academy of Political and Social Science.* 369: 149-163.

Boughtwood D and Halse C (2008) Ambivalent appetites: Dissonances in social and medical constructions of anorexia nervosa. *Journal of Community & Applied Social Psychology.* 18(4): 269-281.

Boughtwood D and Halse C (2010) Other than obedient: Girls' constructions of doctors and treatment regimes for anorexia nervosa. *Journal of Community & Applied Social Psychology.* 20(2): 83-94.

Branaman, A (2009) The protean Goffman: Erving Goffman and the new individualism. In M Jacobsen (ed) *The Contemporary Goffman.* New York: Routledge, 232 – 255.

Brinkmann S (2013) *Qualitative Interviewing.* Oxford: Oxford University Press.

Brinkmann S (2016) *Diagnostic Cultures: A cultural approach to the pathologization of modern life.* London: Routledge.

British Sociological Association (2017) Statement of Ethical Practice. BSA publications. https://www.britsoc.co.uk/media/24310/bsa_statement_of_ethical_practice.pdf Accessed 13th November 2017.

Brook B (1999) *Feminist Perspectives on the Body.* London: Longman.

Brossard B and Carpentier N (2017) To what extent does diagnosis matter? Dementia diagnosis, trouble interpretation and caregiving network dynamics. *Sociology of Health & Illness.* 39(4): 566-580.

Brown P (1990) The name game: Toward a sociology of diagnosis. *The Journal of Mind and Behavior.* 11(3/4): 385-406.

Brown P (1995) Naming and framing: The social construction of diagnosis and illness. *Journal of Health and Social Behavior.* 34-52.

Bruch H (1974) *Eating Disorders: Obesity, anorexia nervosa, and the person within.* London: Routledge and Kegan Paul.

Bruch H (1978) *The Golden Cage: The enigma of anorexia nervosa.* London: Open Books.

Bruch H (1988) *Conversations with Anorexics.* New York: Basic Books.

Brumberg J (1988) *Fasting Girls: The history of anorexia nervosa.* Massachusetts: Harvard University Press.

Bryman A (1988) *Quantity and Quality in Social Research.* London: Unwin Hyman.

Bulik C, Reba L, Siega-Riz A and Reichborn-Kjennerud T (2005) Anorexia nervosa: Definition, epidemiology, and cycle of risk. *International Journal of Eating Disorders.* 37(S1): S2-S9.

Burke P and Reitzes D (1981) The link between identity and role performance. *Social Psychology Quarterly.* 44(2): 83-92.

Burnham J (2014) Why sociologists abandoned the sick role concept. *History of the Human Sciences.* 27(1): 70-87.

Burnier D (2006) Encounters with the self in social science research: A political scientist looks at autoethnography. *Journal of Contemporary Ethnography.* 35(4): 410-418.

Bury M (1982) Chronic illness as biographical disruption. *Sociology of Health & Illness.* 4(2): 167-182.

Busfield J (1996) *Men, Women and Madness: Understanding gender and mental disorder.* Basingstoke: Macmillan.

Busfield J (2017) The concept of medicalisation reassessed. *Sociology of Health & Illness.* 39(5): 759-774.

Button E and Warren R (2001) Living with anorexia nervosa: The experience of a cohort of sufferers from anorexia nervosa 7.5 years after initial presentation to a specialized eating disorders service. *European Eating Disorders Review.* 9(2): 74-96.

Button E, Chadalavada B and Palmer R (2010) Mortality and predictors of death in a cohort of patients presenting to an eating disorders service. *International Journal of Eating Disorders.* 43(5): 387-92.

Cain C (1991) Personal stories: Identity acquisition and self-understanding in Alcoholics Anonymous. *Ethos.* 19(2): 210-253.

Carney T, Ingvarson M and Tait D (2008) *Experiences of 'Control' in Anorexia Nervosa Treatment: Delayed coercion, shadow of law, or disseminated power and control?* Legal studies research paper no 08/07. Sydney Law School, The University of Sydney.

Casilli A Tubaro P and Araya P (2012) Ten years of ana: Lessons from a transdisciplinary body of literature on online pro-eating disorder websites. *Social Science Information.* 51(1): 120-139.

Chandler A (2016) *Self-Injury, Medicine and Society: Authentic bodies.* London: Palgrave Macmillan.

Chang H (2008) *Autoethnography as Method.* California, Left Coast Press.

Chang H (2016) Autoethnography in health research: Growing pains? *Qualitative Health Research.* 26(4): 443-451.

Charmaz K (2006) The power of names. *Journal of Contemporary Ethnography.* 35(4): 396-399.

Chatham-Carpenter A (2010) 'Do thyself no harm': Protecting ourselves as autoethnographers. *Journal of Research Practice.* 6(1): 1-13.

Chavez C (2008) Conceptualizing from the inside: Advantages, complications, and demands on insider positionality. *Qualitative Report.* 13(3): 474-494.

Chernin K (1984) *The Hungry Self: Women, eating and identity.* New York: HarperPerennial.

Chrisp T, Tabberer S and Thomas B (2013) Bounded autonomy in deciding to seek medical help: Carer role, the sick role and the case of dementia. *Journal of Health Psychology.* 18(2): 272-281.

Chu S (2016) Special observations in the care of psychiatric inpatients: A review of the literature and developments in practice. *ARC Journal of Psychiatry.* 1(1): 21-23.

Clarke A, Shim J, Mamo L, Fosket J and Fishman J (2003) Biomedicalization: Technoscientific transformations of health, illness, and U.S. biomedicine. *American Sociological Review.* 68(2): 161-194.

Cockell S, Geller J and Linden W (2003) Decisional balance in anorexia nervosa: Capitalizing on ambivalence. *European Eating Disorders Review.* 11(2): 75-89.

Coffey A (1999) The Ethnographic Self: Fieldwork and the representation of identity. London: Sage.

Collin A and Young R (eds) (2000) *The Future of Career.* New York: Cambridge University Press.

Colton A and Pistrang N (2004) Adolescents' experiences of inpatient treatment for anorexia nervosa. *European Eating Disorders Review.* 12(5): 307-316.

Conrad P (1975) The discovery of hyperkinesis: Notes on the medicalization of deviant behavior. *Social Problems.* 23(1): 12-21.

Conrad P (1992) Medicalization and social control. *Annual Review of Sociology.* 18: 209-232.

Coomber R and Letherby G (2010) *Are the 'Hard-to-reach' Really Hard-to-reach, and are Sensitive Topics Sensitive?* The Australian Sociological Association annual conference - Social Causes, Private Lives. Macquarie University, 6 December 2010.

Court A, Cooke A and Scrivener A (2017) They're NICE and neat, but are they useful? A grounded theory of clinical psychologists' beliefs about and use of NICE guidelines. *Clinical Psychology & Psychotherapy.* 24(4): 899-910.

Couture A, Zaidi A and Maticka-Tyndale E (2012) Reflexive accounts: An intersectional approach to exploring the fluidity of insider/outsider status and the researcher's impact on culturally sensitive post-positivist qualitative research. *Qualitative Sociology Review.* 8(1): 86-105.

Crisp A (2006) Death, survival and recovery in anorexia nervosa: A thirty-five year study. *European Eating Disorders Review.* 14(3): 168-175.

Crisp A, Palmer R and Kalucy R (1976) How common is anorexia nervosa? A prevalence study. *British Journal of Psychiatry.* 128: 549-554.

Currin L, Schmidt U and Waller G (2007) Variables that influence diagnosis and treatment of the eating disorders within primary care settings: A vignette study. *International Journal of Eating Disorders.* 40(3): 257-262.

Currin L, Schmidt U, Treasure J and Jick H (2005) Time trends in eating disorder incidence. *The British Journal of Psychiatry.* 186(2): 132-135.

Currin L, Waller G and Schmidt U (2009) Primary care physicians' knowledge of and attitudes toward the eating disorders: Do they affect clinical actions? *The International Journal of Eating Disorders.* 42(5): 453-458.

Daly K (1992a) The fit between qualitative research and characteristics of families. In Gilgun J, Daly K and Handel G (eds) *Qualitative Methods in Family Research.* California: Sage, 3-11.

Daly K (1992b) Parenthood and problematic: Insider interviews with couples seeking to adopt. In: J Gilgun, K Daly and G Handel (eds) *Qualitative Methods in Family Research.* California: Sage, 103-125.

Dare C, Eisler I, Russell G, Treasure J and Dodge L (2001) Psychological therapies for adults with anorexia nervosa: Randomised controlled trial of out-patient treatments. *The British Journal of Psychiatry.* 178: 216-221.

Darmon M (2017) *Becoming Anorexic: A sociological study.* London, Routledge.

Dashper K (2015) Revise, resubmit and reveal? An autoethnographer's story of facing the challenges of revealing the self through publication. *Current Sociology.* 63(4): 511-527.

Davies C (1999) *Reflexive Ethnography: A guide to researching selves and others.* London: Routledge.

Davis, N (1972) Labeling theory in deviance research: A critique and reconsideration. *The Sociological Quarterly.* 13(4): 447-474.

Dawson L, Rhodes P and Touyz S (2014) 'Doing the impossible': The process of recovery from chronic anorexia nervosa. *Qualitative Health Research.* 24(4): 494-505.

De Tona C (2006) 'But what is interesting is the story of why and how migration happened'. *Forum: Qualitative Social Research.* 7(3): Art 3.

Deakin H and Wakefield K (2014) Skype interviewing: Reflections of two PhD researchers. *Qualitative Research.* 14(5): 603-616.

Delamont S (2009) The only honest thing: Autoethnography, reflexivity and small crises in fieldwork. *Ethnography and Education.* 4(1): 51-63.

Dell'Osso L, Abelli M, Carpita B, Pini S, Castellini G, Carmassi C and Ricca V. (2016) Historical evolution of the concept of anorexia nervosa and relationships with orthorexia

nervosa, autism, and obsessive-compulsive spectrum. *Neuropsychiatric Disease and Treatment.* 12: 1651-1660.

Denzin N (2006) Analytic autoethnography, or déjà vu all over again. *Journal of Contemporary Ethnography.* 35(4): 419-428.

Dignon A (2007) *All of Me: A fuller picture of anorexia.* Oxford: Peter Lang.

Dignon A, Beardsmore A, Spain S and Kuan A (2006) 'Why I won't eat': Patient testimony from 15 anorexics concerning the causes of their disorder. *Journal of Health Psychology.* 11(6): 942-956.

Dimitropoulos G, Freeman V, Muskat S, Domingo A and McCallum L (2016) "You don't have anorexia, you just want to look like a celebrity": Perceived stigma in individuals with anorexia nervosa. *Journal of Mental Health.* 25(1): 47-54.

Dwyer S and Buckle J (2009) The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Methods.* 8(1): 54-63.

Eivors A, Button E, Warner S and Turner K (2003) Understanding the experience of drop-out from treatment for anorexia nervosa. *European Eating Disorders Review.* 11(2): 90-107.

Eli K (2014a) An embodied belonging: Amenorrhea and anorexic subjectivities. *Medicine Anthropology Theory.* 1(1): 53-80.

Eli K (2014b) Between difference and belonging: Configuring self and others in inpatient treatment for Eating Disorders. *PLoS ONE.* 9(9) https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0105452.

Eli K (2018) Distinct and untamed: Articulating bulimic identities. *Culture, Medicine, and Psychiatry.* 42(1): 159-179.

Eli K and Warin M (2018) Anthropological perspectives on eating disorders: Deciphering cultural logics. *Transcultural Psychiatry.* 55(4): 443-453.

Ellis C (1995) *Final Negotiations: A story of love, loss, and chronic illness.* Philadelphia: Temple University Press.

Ellis C (2004) *The Ethnographic I: A methodological novel about autoethnography.* California: AltaMira Press.

Ellis C (2007) Telling secrets, revealing lives: Relational ethics in research with intimate others. *Qualitative Inquiry.* 13(1): 3-29.

Ellis C and Bochner A (2000) Autoethnography, personal narrative, reflexivity: Researcher as subject. In N Denzin and Y Lincoln (eds) *The Handbook of Qualitative Research.* 2nd edn. Sage. 733-768.

Ellis C and Bochner A (2006) Analyzing analytic autoethnography: An autopsy. *Journal of Contemporary Ethnography.* 35(4): 429-449.

Ellis C, Adams T and Bochner A (2011) Autoethnography: An overview. *Forum: Qualitative Social Research.* 12(1): Art 10.

Ellis C, Kiesinger C and Tillmann-Healy L (1997) Interactive interviewing: Talking about emotional experience. In R Hertz (ed) *Reflexivity and Voice.* California: Sage Publications, 119-149.

Elzakkers I, Danner U, Hoek H, Schmidt U and van Elburg A (2014) Compulsory treatment in anorexia nervosa: A review. *International Journal of Eating Disorders.* 47(8): 845-852.

Eppley K (2006) Defying insider-outsider categorization: One researcher's fluid and complicated positioning on the insider-outsider continuum. Review essay. *Forum: Qualitative Social Research.* 7(3).

Escobar-Koch T, Banker JD, Crow S, Cullis J, Ringwood S, Smith G, van Furth E, Westin K and Schmidt U (2010) Service users' views of eating disorder services: An international comparison. *International Journal of Eating Disorders.* 43(6): 549-559.

Espindola C and Blay S (2009) Anorexia nervosa's meaning to patients: A qualitative synthesis. *Psychopathology.* 42(2): 69-80.

Estroff S, Lachicotte W, Illingworth L and Johnstone A (1991) Everybody's got a little mental illness: Accounts of illness and self among people with severe, persistent mental illnesses. *Medical Anthropology Quarterly.* 5(4): 331-369.

Fairburn C (2005) Evidence-based treatment of anorexia nervosa. *International Journal of Eating Disorders.* 37: S26-S30.

Fairburn C and Cooper Z (2011) Eating disorders, DSM–5 and clinical reality. *British Journal of Psychiatry.* 198(1): 8-10.

Fakhoury W and Priebe S (2002) The process of deinstitutionalization: An international overview. *Current Opinion in Psychiatry.* 15(2): 187-192.

Farnsworth E (1996) Reflexivity and qualitative family research: Insider's perspectives in bereaving the loss of a child. *Marriage & Family Review.* 24(3–4): 399-415.

Fazeli P, Calder G, Miller K, Misra M, Lawson E, Meenaghan E, Lee H, Herzog D and Klibanski A (2012) Psychotropic medication use in anorexia nervosa between 1997 and 2009. *The International Journal of Eating Disorders.* 45(8): 970-976.

Feeney E, Noble H and Waller G (2007) Referral patterns to a specialist eating disorder service: The impact of the referrer's gender. *European Eating Disorders Review.* 15(1): 45-49.

Fine G (2003) Towards a peopled ethnography: Developing theory from group life. *Ethnography.* 4(1): 41-60.

Finlay L (2002a) 'Outing' the researcher: The provenance, process and practice of reflexivity. *Qualitative Health Research.* 12(4): 531-545.

Finlay L (2002b) Negotiating the swamp: The opportunity and challenge of reflexivity in research practice. *Qualitative Research.* 2(2): 209-230.

Finlay L (2003) The reflexive journey: Mapping multiple routes. In L Finlay and B Gough (eds) *Reflexivity: A Practical Guide for Researchers in Health and Social Sciences.* Oxford: Blackwell, 3-20.

Fisher B and Strauss A (1978) The Chicago tradition and social change: Thomas, Park And their successors. *Symbolic Interaction.* 1(2): 5-23.

Fisher B and Strauss A (1979) George Herbert Mead and the Chicago tradition of sociology (part two). *Symbolic Interaction.* 2(2): 9-20.

Fox J and Diab P (2015) An exploration of the perceptions and experiences of living with chronic anorexia nervosa while an inpatient on an Eating Disorders Unit: An Interpretative Phenomenological Analysis (IPA) study. *Journal of Health Psychology.* 20(1): 27-36.

Frey I (2019) Anorexia's failed little sisters: Reflections on researching bulimia as a former bulimic. *Social Theory & Health.* [online] https://link.springer.com/article/10.1057/s41285-019-00100-5

Friedson E (1970) *The Profession of Medicine.* New York: Dodd, Mead.

Gans H (1999) Participant observation in the era of `ethnography'. *Journal of Contemporary Ethnography.* 28(5): 540-548.

Gard M and Freeman C (1996) The dismantling of a myth: A review of eating disorders and socioeconomic status. *International Journal of Eating Disorders.* 20(1): 1-12.

Garfinkel H (1967) *Studies in Ethnomethodology.* New Jersey: Prentice Hill.

Garner D (1985) Iatrogenesis in anorexia nervosa and bulimia nervosa. *International Journal of Eating Disorders.* 4(4): 701-726.

Garrett C (1998) *Beyond Anorexia: Narrative, Spirituality, and Recovery.* Cambridge: Cambridge University Press.

Gibbs J (1966) Conceptions of deviant behavior: The old and the new. *The Pacific Sociological Review.* 9(1): 9-14.

Giddens A (1991) *Modernity and Self-Identity: Self and Society in the Late Modern Age.* Cambridge: Polity Press.

Giles D and Newbold J (2011) Self-and other-diagnosis in user-led mental health online communities. *Qualitative Health Research.* 21(3): 419-428.

Giorgi A (1975) An application of phenomonological method in psychology. In A Giorgi, C Fischer and Murray E (eds) *Duquesne Studies in Phenomonological Psychology.* Vol 2. Pittsburgh: Duquesne University Press, 82-103.

Goddard E, Hibbs R, Raenker S, Salerno L, Arcelus J, Boughton N, Connan F, Goss K, Laszlo B, Morgan J, Moore K, Robertson D, Saeidi S, Schreiber-Kounine C, Sharma S, Whitehead L Schmidt U and Treasure J (2013) A multi-centre cohort study of short term outcomes of hospital treatment for anorexia nervosa in the UK. *BMC Psychiatry.* 13(287).

Goffman E (1959) *The Presentation of Self in Everyday Life.* London: Penguin Books.

Goffman E (1961) *Asylums.* London: Penguin Books.

Goffman E (1963) *Stigma.* London: Penguin Books.

Goode E (1975) On behalf of labeling theory. *Social Problems.* 22(5): 570-583.

Goodson I and Gill S (2011) The narrative turn in social research. *Counterpoints.* 386: 17-33.

Gough B (2002) Introducing reflexivity. In: L Finlay and B Gough (eds) *Reflexivity: A practical guide for researchers in health and social sciences.* Oxford: Blackwell, 1-2.

Gouldner A (1968) The sociologist as partisan: Sociology and the welfare state. *The American Sociologist.* 3(2): 103-116.

Gouldner A (1971) *The Coming Crisis of Western Sociology.* London: Heinemann.

Gove W (1970) Societal reaction as an explanation of mental illness: An evaluation. *American Sociological Review.* 35(5): 873-884.

Gove W (1975) The labelling theory of mental illness: A reply to Scheff. *American Sociological Review.* 40(2): 242-248.

Gowers S and McMahon J (1989) Social class and prognosis in anorexia nervosa. *International Journal of Eating Disorders.* 8(1): 105-109.

Gowers S, Weetman J, Shore A, Hossain F and Elvins R (2000) Impact of hospitalisation on the outcome of adolescent anorexia nervosa. *The British Journal of Psychiatry.* 176(2): 138-141.

Grace D, Steinberg M, Chown S, Jollimore J, Parry R and Gilbert M (2016) " … it's almost therapeutic, right? Because it's almost like that session that I never had": Gay men's accounts of being a participant in HIV research. *AIDS Care.* 28(10): 1306-1311.

Greenberg S and Schoen E (2008) Males and eating disorders: Gender-based therapy for eating disorder recovery. *Professional Psychology: Research and Practice.* 39(4): 464-471.

Greene M (2014) On the inside looking in: Methodological insights and challenges in conducting qualitative insider research. *The Qualitative Report.* 19(29): 1-13.

Greenhalgh S (2001) *Under the Medical Gaze: Facts and Fictions of Chronic Pain.* Berkeley: University of California Press.

Greenley J (1979) Familial expectations, posthospital adjustment, and the societal reaction perspective on mental illness. *Journal of Health and Social Behavior.* 20(3): 217-227.

Gregertsen E, Mandy W and Serpell L (2017) The egosyntonic nature of anorexia: An impediment to recovery in anorexia nervosa treatment. *Frontiers in Psychology.* 8: Art 2273.

Gremillion H (2003) *Feeding Anorexia: Gender and Power at a Treatment Center.* Durham: Duke University Press.

Gueguen J, Godart N, Chambry J, Brun-Eberentz A, Foulon C, Divac S, Guelfi J, Rouillon F, Falissard B and Huas C. (2012) Severe anorexia nervosa in men: Comparison with severe AN in women and analysis of mortality. *The International Journal of Eating Disorders. 45*(4): 537-545.

Gulliksen K, Nordbø R, Espeset E, Skårderud, F and Holt A (2015) The process of help-seeking in anorexia nervosa: Patients' perspective of first contact with health services. *Eating Disorders.* 23(3): 206-222.

Halse C, Boughtwood D, Clarke S, Honey A, Kohn M and Madden S (2005) Illuminating multiple perspectives: Meanings of nasogastric feeding in anorexia nervosa. *European Eating Disorders Review.* 13(4): 264-272.

Hammersley M (2011) *Methodology - Who Needs It?* Los Angeles: Sage.

Hammersley M and Atkinson P (2007) *Ethnography: Principles in Practice.* 3rd edn. London: Routledge.

Hanna P (2012) Using internet technologies (such as Skype) as a research medium: A research note. *Qualitative Research.* 12(2): 239-242.

Hannon J, Eunson L and Munro C (2017) The patient experience of illness, treatment, and change, during intensive community treatment for severe anorexia nervosa. *Eating Disorders.* 25(4): 279-296.

Hansson Halleröd SL, Anckarsäter H, Råstam M and Hansson Scherman M (2015) Experienced consequences of being diagnosed with ADHD as an adult – a qualitative study. *BMC Psychiatry.* 15(1).

Hay P, Touyz S, Claudino A, Lujic S, Smith C and Madden S (2019) Inpatient versus outpatient care, partial hospitalisation and waiting list for people with eating disorders. *Cochrane Database of Systematic Reviews 2019*. Issue 1. Art. CD010827. Retrieved from https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD010827.pub2/abstract Accessed 14th November 2019.

Hayano D (1979) Auto-ethnography: Paradigms, problems, and prospects. *Human Organization.* 38(1): 99-104.

Hayne Y (2003) Experiencing psychiatric diagnosis: Client perspectives on being named mentally ill. *Journal of Psychiatric and Mental Health Nursing.* 10(6): 722-729.

Hepworth J (1999) The *Social Construction of Anorexia Nervosa. Inquiries in social construction.* London: Sage.

Hewitt J and Shulman D (2011) *Self and Society: A symbolic interactionist social psychology.* 11th Edn. Boston: Allyn & Bacon.

Higgins A, Porter S and O'Halloran P (2014) General practitioners' management of the long-term sick role. *Social Science & Medicine.* 1982(107): 52-60.

Hodkinson P (2005) 'Insider Research' in the study of youth cultures. *Journal of Youth Studies.* 8(2): 131-149.

Hoek H (2014) Epidemiology of eating disorders in persons other than the high-risk group of young Western females. *Current Opinion in Psychiatry.* 27(6): 423-425.

Hoek H and van Hoeken D (2003) Review of the prevalence and incidence of eating disorders. *International Journal of Eating Disorders.* 34(4): 383-396.

Holland J, Hall N, Yeates D and Goldacre M (2016) Trends in hospital admission rates for anorexia nervosa in Oxford (1968–2011) and England (1990–2011): database studies. *Journal of the Royal Society of Medicine.* 109(2): 59-66.

Holmes S (2016) 'Blindness to the obvious'? Treatment experiences and feminist approaches to eating disorders. *Feminism & Psychology.* 26(4): 464-486.

Holt N (2003) Representation, legitimation, and autoethnography: An autoethnographic writing story. *International Journal of Qualitative Methods.* 2(1): 18-28.

Horn N, Johnstone L and Brooke S (2007) Some service user perspectives on the diagnosis of borderline personality disorder. *Journal of Mental Health.* 16(2): 255-269.

House J, Schmidt U, Craig M, Landau S, Simic M, Nicholls D, Hugo P, Berelowitz M and Eisler I (2012) Comparison of specialist and nonspecialist care pathways for adolescents with anorexia nervosa and related eating disorders. *The International Journal of Eating Disorders.* 45(8): 949-956.

Hubert T, Pioggiosi P, Huas C, Wallier J, Maria A, Apfel A, Curt F, Falissard B and Godart N (2013) Drop-out from adolescent and young adult inpatient treatment for anorexia nervosa. *Psychiatry Research.* 209(3): 632-637.

Hudson J, Hiripi E, Pope H and Kessler R (2007) The Prevalence and correlates of eating disorders in the National Comorbidity Survey replication. *Biological Psychiatry.* 61(3): 348-358.

Hughes S and Pennington J (2017) *Autoethnography : Process, Product, and Possibility for Critical Social Research.* Thousand Oaks: Sage.

Hugo P, Kendrick T, Reid F and Lacey H (2000) GP referral to an eating disorder service: Why the wide variation? *British Journal of General Practice.* 50(454): 380-383.

Illich I (1975) *Medical Nemesis.* London: Marian Boyers.

Jago B (2002) Chronicling an academic depression. *Journal of Contemporary Ethnography.* 31(6): 729-757.

Jago B (2011) Shacking up: An autoethnographic tale of cohabitation. *Qualitative Inquiry.* 17(2): 204-219.

Jellinkek E (1952) Phases of alcohol addiction. *Quarterly Journal of Studies on Alcohol.* 13(4): 673-684.

Jenkins J and Ogden J (2012) Becoming 'whole' again: A qualitative study of women's views of recovering from anorexia nervosa. *European Eating Disorders Review.* 20(1): 23-31.

Jenkins R (2014) *Social Identity.* 4th edn. New York: Routledge.

Johnstone L (2014) *Straight Talking Introduction to Psychiatric Diagnosis.* Monmouth, PCCS Books.

Jutel A (2009) Sociology of diagnosis: A preliminary review. *Sociology of Health & Illness.* 31(2): 278-299.

Jutel A (2011) *Putting a Name on It Diagnosis in Contemporary Society.* Baltimore, John Hopkins University Press.

Jutel A (2015) Beyond the sociology of diagnosis: Beyond the sociology of diagnosis. *Sociology Compass.* 9(9): 841-852.

Jutel A and Nettleton S (2011) Towards a sociology of diagnosis: Reflections and opportunities. *Social Science & Medicine.* 73(6): 793-800.

Kanis J, Melton L, Christiansen C, Johnston C and Khaltaev N (1994) The diagnosis of osteoporosis. *Journal of Bone and Mineral Research.* 9(8): 1137-1141.

Karp D (1996) *Speaking of Sadness: Depression, disconnection, and the meanings of Illness.* New York: Oxford University Press.

Keel P and Brown T (2010) Update on course and outcome in eating disorders. *International Journal of Eating Disorders.* 43(3): 195-204.

Keel P and Klump K (2003) Are eating disorders culture-bound syndromes? Implications for conceptualizing their etiology. *Psychological Bulletin.* 129(5): 747-769.

Keel P, Brown T, Holm-Denoma J and Bodell L (2011) Comparison of DSM-IV versus proposed DSM-5 diagnostic criteria for eating disorders: Reduction of eating disorder not otherwise specified and validity. *The International Journal of Eating Disorders.* 44(6): 553-560.

Kells M and Kelly-Weeder S (2016) Nasogastric tube feeding for individuals with anorexia nervosa: An integrative review. *Journal of the American Psychiatric Nurses Association.* 22(6): 449-468.

Keski-Rahkonen A and Mustelin L (2016) Epidemiology of eating disorders in Europe: Prevalence, incidence, comorbidity, course, consequences, and risk factors. *Current Opinion in Psychiatry.* 29(6): 340-345.

Keys A, Brozek J and Henschel A (1950) *The Biology of Human Starvation.* Volume one. Minnesota: University of Minnesota Press.

Khalsa S, Portnoff L, McCurdy-McKinnon D and Feusner J (2017) What happens after treatment? A systematic review of relapse, remission, and recovery in anorexia nervosa. *Journal of Eating Disorders.* 5(1): Art. 20.

Kinderman P, Allsopp K and Cooke A (2017) Responses to the publication of the American Psychiatric Association's DSM-5. *Journal of Humanistic Psychology.* 57(6): 625-649.

Kirpitchenko L and Voloder L (2014) Insider Research Method: The significance of identities in the field. *SAGE Research Methods Cases.* Retrieved from https://methods.sagepub.com/case/insider-research-method-the-significance-of-identities-in-the-field Accessed 20th March 2019.

Konstantakopoulos G, Tchanturia K, Surguladze S and David A (2011) Insight in eating disorders: Clinical and cognitive correlates. *Psychological Medicine.* 41(9): 1951-1961.

Kralik D, Brown M and Koch T (2001) Women's experiences of 'being diagnosed' with a long-term illness. *Journal of Advanced Nursing.* 33(5): 594-602.

Kvale S and Brinkmann S (2015) *InterViews: Learning the craft of qualitative research interviewing.* 3rd edn. Los Angeles: Sage Publications.

Lacey H and Sly R (2016) Severe and enduring anorexia nervosa: A new approach to its diagnosis, features, and treatment. In Touyz S, Le Grange D, Lacey J and Hay P (eds) Managing Severe and Enduring Anorexia Nervosa: A Clinician's Guide. New York: Routledge, 202-222.

Laségue E (1873[2016]) On hysterical anorexia. *Dialogues in Philosophy, Mental & Neuro Sciences.* 9(1): 24-31.

Lavis A (2011) *The Boundaries of a Good Anorexic: Exploring pro-anorexia on the internet and in the clinic.* Doctoral Thesis. Goldsmiths, University of London.

Lawler S (2008) *Identity: Sociological perspectives.* Cambridge: Polity Press.

Lawrence M (1979) Anorexia nervosa: The control paradox. *Women's Studies International Quarterly.* 2(1): 93-101.

Lawrence M (1984) *The Anorexic Experience.* London: Women's Press.

Le Grange D (2016) Anorexia nervosa in adults: The urgent need for novel outpatient treatments that work. *Psychotherapy.* 53(2): 251-254.

Le Roux C (2017) Exploring rigour in autoethnographic research. *International Journal of Social Research Methodology.* 20(2): 195-207.

Lee R (1993) *Doing Research on Sensitive Topics.* London: Sage.

Leighton K and Millar H (1985) Anorexia nervosa in Glasgow. *Journal of Psychiatric Research. 19*(2–3): 167-170.

Lemert E (1951) *Social Pathology: Systematic approaches to the study of sociopathic behavior.* New York: McGraw-Hill.

Letherby G (2013) Theorised subjectivity. In G Letherby, J Scott an M Williams (Eds) *Objectivity and Subjectivity in Social Research.* London: Sage, 79-102.

Liazos A (1972) The poverty of the sociology of deviance: Nuts, sluts, and perverts. *Social Problems.* 20(1): 103-120.

Link B, Cullen F, Struening E, Shrout P and Dohrenwend, B (1989) A modified labeling theory approach to mental disorders: An empirical assessment. *American Sociological Review.* 54(3): 400-423.

Lionnet F (1989) Autoethnography: The an-archic style of dust tracks on a road. In F Lionnet (ed) *Autobiographical Voices: Race, Gender, Self-Portraiture.* New York: Cornell University Press, 97-129.

Lo Iacono V, Symonds P and Brown D (2016) Skype as a tool for qualitative research interviews. *Sociological Research Online.* 21(2): 103-117.

Lock J (2015) An update on evidence-based psychosocial treatments for eating disorders in children and adolescents. *Journal of Clinical Child and Adolescent Psychology.* 44(5): 707-721.

Lofland J (1995) Analytic ethnography. *Journal of Contemporary Ethnography.* 24(1): 30-67.

Long S, Wallis D, Leung N and Meyer C (2011) "All eyes are on you": Anorexia nervosa patient perspectives of in-patient mealtimes. *Journal of Health Psychology.* 17(3): 419-428.

Lynch M (2000) Against reflexivity as an academic virtue and source of privileged knowledge. *Theory, Culture & Society.* 17(3): 26-54.

Lyotard J (1984) *The Postmodern Condition: A Report on knowledge* (Transl. by G. Bennington & B. Massumi). Minneapolis: University of Minnesota Press.

MacLean A, Sweeting H, Walker L, Patterson C Räisänen U, Hunt K (2015) "It's not healthy and it's decidedly not masculine": A media analysis of UK newspaper representations of eating disorders in males. *BMJ Open.* 5(5): e007468.

MacSween M (1993) *Anorexic Bodies: A feminist and sociological perspective on anorexia nervosa.* London: New York: Routledge.

Madden S (2004) 'Anorexia nervosa' — still relevant in the twenty-first century? A review of William Gull's anorexia nervosa. *Clinical Child Psychology & Psychiatry.* 9(1): 149-154.

Madison S (2006) The dialogic performative in critical ethnography. *Text and Performance Quarterly.* 26(4): 320-324.

Maj M (2005) The aftermath of the concept of 'psychiatric comorbidity'. *Psychotherapy and Psychosomatics.* 74(2): 67-68.

Malson H (1998) *The Thin Woman: Feminism, post-structuralism, and the social psychology of anorexia nervosa.* New York: Routledge.

Malson H and Burns M (2009) Re-theorising the slash of dis/order: An introduction to critical feminist approaches to eating dis/orders. In H Maslon and M Burns (eds) *Critical Feminist Approaches to Eating Dis/Orders.* London: Routledge, 1-6.

Malson H, Finn D, Treasure J, Clarke S and Anderson G (2004) Constructing 'the eating disordered patient': A discourse analysis of accounts of treatment experiences. *Journal of Community and Applied Social Psychology.* 14(6): 473-489.

Mankoff M (1971) Societal reaction and career deviance: A critical analysis. *The Sociological Quarterly.* 12(2): 204-218.

Marchesi C, Ampollini P, DePanfilis C and Maggini C (2008) Temperament features in adolescents with ego-syntonic or ego-dystonic obsessive-compulsive symptoms. *European Child & Adolescent Psychiatry.* 17(6): 392-396.

Martin A, Pascoe E and Forbes D (2009) Monitoring nutritional status accurately and reliably in adolescents with anorexia nervosa. *Journal of Paediatrics and Child Health.* 45(1–2): 53-57.

Martinussen M, Friborg O, Schmierer P, Kaiser S, Øvergård K, Neunhoeffer A, Martinsen E and Rosenvinge J (2017) The comorbidity of personality disorders in eating disorders: A meta-analysis. *Eating and Weight Disorders - Studies on Anorexia, Bulimia and Obesity.* 22(2): 201-209.

Maruna S and Copes H (2005) What have we learned from five decades of neutralization research? *Crime and Justice.* 32: 221-320.

May T (2001) *Social Research: Issues, methods and process.* 3rd ed. Buckingham: Open University Press.

McCall G and Simmons J (1978) *Identities and Interactions: An examination of human associations in everyday life.* New York: Free Press.

McClelland L and Crisp A (2001) Anorexia nervosa and social class. *The International Journal of Eating Disorders.* 29(2): 150-156.

McLorg P and Taub D (1987) Anorexia nervosa and bulimia: The development of deviant identities. *Deviant Behavior.* 8(2): 177-189.

Mead G (1934) *Mind, Self and Society.* London: The Chicago Press.

Medford K (2006) Caught with a fake ID: Ethical questions about slippage in autoethnography. *Qualitative Inquiry.* 12(5): 853-864.

Mehler P and Brown C (2015) Anorexia nervosa – medical complications. *Journal of Eating Disorders.* 3(1): Art. 11.

Mehler P, Cleary B and Gaudiani J (2011) Osteoporosis in anorexia nervosa. *Eating Disorders.* 19(2): 194-202.

Micali N and Hebebrand J (2015) Anorexia nervosa through the looking glass of the draft ICD-11 diagnostic criteria: A disorder in transition. International Classification of Diseases. *European Child & Adolescent Psychiatry.* 24(10): 1149-1152.

Micali N, Hagberg K, Petersen I and Treasure J (2013) The incidence of eating disorders in the UK in 2000-2009: Findings from the General Practice Research Database. *BMJ Open.* 3(5): e002646.

Micali N, Martini M, Thomas J, Eddy K, Kothari R, Russell E, Bulik C and Treasure J (2017) Lifetime and 12-month prevalence of eating disorders amongst women in mid-life: A population-based study of diagnoses and risk factors. *BMC Medicine.* 15: 1-10.

Miller M and Pumariega A (2001) Culture and eating disorders: A historical and cross-cultural review. *Psychiatry: Interpersonal and Biological Processes.* 64(2): 93-110.

Mogalakwe M (2006) The use of documentary research methods in social research. *African Sociological Review.* 10(1): 221-230.

Morgan H and Russell G (1975) Value of family background and clinical features as predictors of long-term outcome in anorexia nervosa: Four-year follow-up study of 41 patients. *Psychological Medicine.* 5(4): 355-371.

Morse J (2002) Writing my own experience. *Qualitative Health Research.* 12(9): 1159-1160.

Muncey T (2010) *Creating Autoethnographies.* Los Angeles: Sage.

Myint A, Rieders B, Tashkandi M, Borum M, Koh J, Stephen S and Doman D (2018) Current and emerging therapeutic options for gastroparesis. *Gastroenterology & Hepatology.* 14(11): 639-645.

NHS (2019) *Osteoporosis.* Retrieved from https://www.nhs.uk/conditions/osteoporosis/ Accessed 5th July 2019.

NHS Digital (2018) *Admissions for Eating Disorders by Sex and Ethnic Category, England.* https://digital.nhs.uk/data-and-information/find-data-and-publications/supplementary-information/2018-supplementary-information-files/admissions-for-eating-disorders-by-sex-and-ethnic-category-england. Accessed January 2019.

NHS Digital (2019) *Hospital Admissions for Eating Disorders.* digital.nhs.uk/data-and-information/find-data-and-publications/supplementary-information/2019-supplementary-information-files/hospital-admissions-for-eating-disorders. Accessed November 2019.

NICE (National Institute for Clinical Evidence) (2004) *Eating Disorders: Core Interventions in the Treatment and Management of Anorexia Nervosa, Bulimia Nervosa and Related Eating Disorders.* Leicester: British Psychological Society.

NICE (National Institute for Health and Care Excellence) (2017a) *Eating Disorders: Recognition and Treatment (NG69).* National Institute for Health and Care Excellence.

NICE (National Institute for Health and Care Excellence) (2017b) *Eating Disorders: Recognition and Treatment. Full Guidance.* National Institute for Health and Care Excellence.

Nicholls D and Arcelus J (2010) Making eating disorders classification work in ICD-11. *European Eating Disorders Review.* 18(4): 247-250.

Nordbø R, Espeset E, Gulliksen K, Psychol C, Skårderud F and Holte A (2006) The meaning of self-starvation: Qualitative study of patients' perception of anorexia nervosa. *International Journal of Eating Disorders.* 39(7): 556-564.

Norris M, Apsimon M, Harrison M, Obeid N, Buchholz A, Henderson K, Spettigue W (2012) An examination of medical and psychological morbidity in adolescent males with eating disorders. *Eating Disorders.* 20(5): 405-415.

Núñez-Navarro A, Agüera Z, Krug I, Jiménez-Murcia S, Sánchez I, Araguz N, Gorwood P, Granero R, Penelo E, Karwautz A, Moragas L, Saldaña S, Treasure J, Menchón J, Fernández-Aranda F (2012) Do men with eating disorders differ from women in clinics, psychopathology and personality? *European Eating Disorders Review*. 20(1): 23-31.

Nunkoosing K (2005) The problems with interviews. *Qualitative Health Research*. 15(5): 698-706.

Nunn K (2001) 'In search of new wineskins': The phenomenology of anorexia nervosa not covered in DSM or ICD. *Clinical Child Psychology & Psychiatry*. 6(4): 489-503.

Oakley A (1981) Interviewing women: A contradiction in terms. In H Roberts (ed) *Doing Feminist Research*. London: Routledge, 30-61.

O'Connell L (2020) Being 'recovered' and doing research: The challenges and complexities of using autoethnography to conduct doctoral research into anorexia nervosa. In I. Boncori and T. Loughran (eds) *Health and Wellbeing - the University of Essex Reader*. Napoli: Editoriale Scientifica, 63-80.

Offord A, Turner H and Cooper M (2006) Adolescent inpatient treatment for anorexia nervosa: A qualitative study exploring young adults' retrospective views of treatment and discharge. *European Eating Disorders Review*. 14(6): 377-387.

Ojermark A (2007) *Presenting life histories: A literature review and annotated bibliography.* Chronic Poverty Research Centre Working Paper No. 101. Retrieved from https://papers.ssrn.com/sol3/papers.cfm?abstract_id=1629210 Accessed July 2017.

ONS (Office of National Statistics) (2020) *Sexual Orientation, UK: 2018*. Retrieved from https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/sexuality/bulletins/sexualidentityuk/2018 Accessed 3rd February 2020.

Orbach S (1986) *Hunger Strike: An anorectic's struggle as a metaphor for our age.* London: Faber and Faber.

Orimoto L and Vitousek K (1992) Anorexia nervosa and bulimia nervosa. In P Wilson (ed.) *Principles and Practice of Relapse Prevention.* New York: Guilford Press, 85-127.

Palmer R (1988) *Anorexia Nervosa: A guide for sufferers and their families.* 2nd edn. London, Penguin.

Panchenko A and Arnfred S (2015) Anorexia nervosa is frequently associated with psychiatric co-morbidity. *Ugeskrift For Laeger.* 177(39): V11140598.

Parsons T (1951a) *The Social System.* London: Routledge.

Parsons, T. (1951b) Illness and the role of the physician: A sociological perspective. *American Journal of Orthopsychiatry.* 21: 452-60.

Patching J and Lawler J (2009) Understanding women's experiences of developing an eating disorder and recovering: A life-history approach. *Nursing Inquiry.* 16(1): 10-21.

Pavalko E, Harding C and Pescosolido B (2007) Mental illness careers in an era of change. *Social Problems.* 54(4): 504-522.

Pearce C (2010) The crises and freedoms of researching your own life. *Journal of Research Practice.* 6(1): 1-15.

Perry B (2011) The labeling paradox: stigma, the sick role, and social networks in mental illness. *Journal of Health and Social Behavior.* 52(4): 460-477.

Pescosolido B, Gardner C and Lubell K (1998) How people get into mental health services: Stories of choice, coercion and 'muddling through' from 'first-timers'. *Social Science & Medicine.* (2): 275-286.

Peters N (1995) The ascectic anorexic. *Social Analysis.* 37: 44-66.

Pillow W (2003) Confession, catharsis, or cure? Rethinking the uses of reflexivity as methodological power in qualitative research. *International Journal of Qualitative Studies in Education.* 16(2): 175-196.

Plummer K (1979) Misunderstanding labeling perspectives. In: D Downes and P Rock (eds) *Deviant Interpretations.* Oxford: Martin Robertson and son, 85-121.

Plummer K (2012) My multiple sick bodies: Symbolic interactionism, autoethnography and embodiment. In B Turner (ed) *Routledge Handbook of Body Studies.* Oxon: Routledge: 75-93.

Prior L (2003) *Using Documents in Social Research.* London: Sage.

Pugh M and Waller G (2017) Understanding the 'anorexic voice' in anorexia nervosa. *Clinical Psychology & Psychotherapy.* 24(3): 670-676.

Quadagno JS and Antonio RJ (1975) Labeling theory as an oversocialized conception of man: The case of mental illness. *Sociology & Social Research.* 60(1): 33-45.

Raisanen U and Hunt K (2014) The role of gendered constructions of eating disorders in delayed help-seeking in men: A qualitative interview study. *BMJ Open.* 4(4): e004342

Rance N, Clarke V and Moller N (2017a) 'Eating disorders are not about food, they're about life': Client perspectives on anorexia nervosa treatment. *Journal of Health Psychology.* 22(5): 582-594.

Rance N, Clarke V and Moller N (2017b) The anorexia nervosa experience: Shame, solitude and salvation. *Counselling and Psychotherapy Research.* 17(2): 127-136.

Rapley T (2001) The art(fulness) of open-ended interviewing: Some considerations on analysing interviews. *Qualitative Research.* 1(3): 303-323.

Reed-Danahay D (1997) *Auto/Ethnography: Rewriting the self and the social.* Oxford: Berg.

Regan P, Cachelin F and Minnick A (2017) Initial treatment seeking from professional health care providers for eating disorders: A review and synthesis of potential barriers to and facilitators of "first contact". *International Journal of Eating Disorders.* 50(3): 190-209.

Reger J, Myers D and Einwohner R (eds) (2008) *Identity Work in Social Movements. Social movements, protest, and contention.* Minneapolis: University of Minnesota Press.

Reinharz S and Chase S (2003) Interviewing women. In J Holstein and J Gubrium (eds) *Inside Interviewing: New Lenses, New Concerns.* California: Sage, 73-90.

Rich E (2006) Anorexic dis(connection): Managing anorexia as an illness and an identity. *Sociology of Health & Illness.* 28(3): 284-305.

Richards R (2008) Writing the othered self: Autoethnography and the problem of objectification in writing about illness and disability. *Qualitative Health Research.* 18(12): 1717-1728.

Richardson L (2000) New writing practices in qualitative research. *Sociology of Sport Journal.* 17(1): 5-20.

Rier D (2000) The missing voice of the critically ill: A medical sociologist's first-person account. *Sociology of Health & Illness.* 22(1): 68-93.

Riessman C (2015) Ruptures and sutures: Time, audience and identity in an illness narrative. *Sociology of Health & Illness.* 37(7): 1055-1071.

Riley S, Rodham K and Gavin J (2009) Doing weight: Pro-ana and recovery identities in cyberspace. *Journal of Community and Applied Social Psychology.* 19(5): 348-359.

Ringer A and Holen M (2016) "Hell no, they'll think you're mad as a hatter": Illness discourses and their implications for patients in mental health practice. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine.* 20(2): 161-175.

Risjord M (2014) *Philosophy of Social Science: A contemporary introduction.* New York: Routledge.

Robinson K, Sperlinger D and Mountford V (2013) Being men with eating disorders: Perspectives of male eating disorder service-users. *Journal of Health Psychology.* 18(2): 176-186.

Ronai C (1995) Multiple reflections of child sex abuse: An argument for a layered account. *Journal of Contemporary Ethnography.* 23(4): 395-426.

Roncero M, Belloch A, Perpiñá C, et al. (2013) Ego-syntonicity and ego-dystonicity of eating-related intrusive thoughts in patients with eating disorders. *Psychiatry Research.* 208(1): 67-73.

Root T, Poyastro Pinheiro A, Thornton L, Strober M, Fernandez-Aranda F, Brandt H, Crawford S, Fichter M, Halmi K, Johnson C, Kaplan A, Klump K, La Via M, Mitchell J, Woodside D, Rotondo A, Berrettini W, Kaye W, Bulik C (2010) Substance use disorders in women with anorexia nervosa. *International Journal of Eating Disorders.* 43: 14-21.

Rose N (2007) Beyond medicalisation. *The Lancet.* 369(9562): 700-702.

Ross L (2017) An account from the inside: Examining the emotional impact of qualitative research through the lens of "insider" research. *Qualitative Psychology.* 4(3): 326-337.

Rossetto K (2014) Qualitative research interviews: Assessing the therapeutic value and challenges. *Journal of Social and Personal Relationships.* 31(4): 482-489.

Roth W-M (2009) Auto/Ethnography and the question of ethics. *Forum: Qualitative Social Research.* 10(1): Art. 38.

Roux H, Chapelon E and Godart N (2013) Epidemiology of anorexia nervosa: A review. *L'Encephale*. 39(2): 85-93.

Rubin H and Rubin I (1995) *Qualitative Interviewing: The art of hearing data*. Thousand Oaks: Sage.

Russell C and Keel P (2002) Homosexuality as a specific risk factor for eating disorders in men. *International Journal of Eating Disorders*. 31(3): 300-306.

Russell G, Kelly S, Ford T, Steer C (2012) Diagnosis as a social determinant: The development of prosocial behaviour before and after an autism spectrum diagnosis. *Social Science & Medicine*. 75: 1642-1649.

Sabel A, Rosen E and Mehler P (2014) Severe anorexia nervosa in males: Clinical presentations and medical treatment. *Eating Disorders*. 22(3): 209-220.

Saukko P (2008) *The Anorexic Self: A personal, political Analysis of a diagnostic discourse*. Albany: State University of New York Press.

Scheff T (1966) *Being Mentally Ill: A sociological Theory*. Chicago: Aldine.

Scheff, T (1984) *Being Mentally Ill: A sociological theory*. 2nd edn. Chicago: Aldine.

Scheff T (1999) *Being Mentally Ill: A sociological Theory*. 3rd edn. London: Transaction Publishers.

Schervish P (1973) The labeling perspective: Its bias and potential in the study of political deviance. *The American Sociologist*. 8(2): 45-57.

Schmidt U and Treasure J (2006) Anorexia nervosa: Valued and visible. A cognitive-interpersonal maintenance model and its implications for research and practice. *British Journal of Clinical Psychology*. 45: 343-366.

Schmidt U, Currin L, Yeomans M, Ellis G, Nodder J, Stone C, Treasure J and Waller G (2006) *Entry Into Specialist Services For The Eating Disorders: Audit of Clinical Pathways Through Primary and Secondary Care*. Report from the Specialist Clinical Audit Programme for South London, Kent, Surry and Sussex. Bexley: NHS Specialist Clinical Audit Office.

Schoen E, Lee S, Skow C, Greenberg S, Bell A, Wiese J and Martens J (2012) A retrospective look at the internal help-seeking process in young women with eating disorders. *Eating Disorders*. 20(1): 14-30.

Schur E (1971) *Labeling Deviant Behaviour*. New York: Harpaer and Row.

Scott J (1990) *A Matter of Record: Documentary sources in social research*. Cambridge: Polity Press.

Scott N, Hanstock T and Patterson-Kane L (2013) Using narrative therapy to treat eating disorder not otherwise specified. *Clinical Case Studies*. 12(4): 307-321.

Scott S (2007) *Shyness and Society: The illusion of competence*. Basingstoke: Palgrave Macmillan.

Scott S (2011) *Total Institutions and Reinvented Identities*. New York: Palgrave Macmillan.

Scott S (2015) *Negotiating Identity: Symbolic interactionist approaches to social identity*. Cambridge: Polity Press.

Seale C (1998) Qualitative interviewing. In Seale C (ed.) *Researching Society and Culture*. London: Sage, 202-216.

Seed T, Fox J and Berry K (2016) Experiences of detention under the mental health act for adults with anorexia nervosa. *Clinical Psychology & Psychotherapy*. 23(4): 352-362.

Segall A (1976) The sick role concept: Understanding illness behavior. *Journal of Health and Social Behavior*. 17(2): 162-169.

Serpell L, Treasure J, Teasdale J and Sullivan V (1999) Anorexia nervosa: Friend or foe? *International Journal of Eating Disorders*. 25(2): 177-186.

Shohet M (2007) Narrating anorexia: 'Full' and 'struggling' genres of recovery. *Ethos*. 35(3): 344-382.

Shooter M (2010) What my diagnosis means to me. *Journal of Mental Health*. 19(4): 366-368.

Simmons A, Milnes S and Anderson D (2008) Factors influencing the utilization of empirically supported treatments for eating disorders. *Eating Disorders*. 16(4): 342-354.

Simonovic V, Gross D, Ernst J (2015) The historical discourse on the etiology of anorexia nervosa results of a literature analysis. *Sudhoffs Archiv*. 99(1): 31-43.

Skårderud F (2007) Shame and pride in anorexia nervosa: A qualitative descriptive study. *European Eating Disorders Review*. 15(2): 81-97.

Smink F, van Hoeken D and Hoek H (2012) Epidemiology of Eating Disorders: Incidence, prevalence and mortality rates. *Current Psychiatry Reports*. 14(4): 406-414.

Smink FRE, van Hoeken D and Hoek HW (2013) Epidemiology, course, and outcome of eating disorders. *Current Opinion in Psychiatry.* 26(6): 543-548.

Smith V, Chouliara Z, Morris P, et al. (2014) The experience of specialist inpatient treatment for anorexia nervosa: A qualitative study from adult patients' perspectives. *Journal of Health Psychology.* 21(1): 16-27.

Snow, D and Anderson, L (1987) Identity work among the homeless: The verbal construction and avowal of personal identities. *American Journal of Sociology.* 92(6): 1336-1371.

Sontag S (2002) *Illness as Metaphor and AIDS and Its Metaphors.* London: Penguin Classics.

Sparkes AC (2000) Autoethnography and Narratives of Self: Reflections on Criteria in Action. *Sociology of Sport Journal.* 17(1): 21–43.

Squire S (2003) The personal and the political: Writing the theorist's body. *Australian Feminist Studies.* 17(37): 55–64.

Stebbins R (1970) Career: The subjective approach. *The Sociological Quarterly.* 11(1): 32-49.

Steinhausen H (2002) The outcome of anorexia nervosa in the 20th century. *The American Journal of Psychiatry.* 159(8): 1284-1293.

Stone (1962) Appearance and the self. In: A Rose (ed) *Human Behaviour and Social Processes.* London: Routledge and Keegan-Paul, 86-118.

Stone B (2009) Running man. *Qualitative Research in Sport and Exercise.* 1(1): 67-71.

Strauss A (1959) *Mirrors and Masks: The search for identity.* New York: Free Press.

Strober M (2004) Managing the chronic, treatment-resistant patient with anorexia nervosa. *The International Journal of Eating Disorders.* 36(3): 245-255.

Strother E, Lemberg R, Stanford SC, et al. (2012) Eating Disorders in men: Underdiagnosed, undertreated, and misunderstood. *Eating Disorders.* 20(5): 346-355.

Stryker S (1968) Identity salience and role performance: The relevance of symbolic interaction theory for family research. *Journal of Marriage and Family.* 30(4): 558-564.

Surgenor L, Maguire S and Beumont P (2004) Drop-out from inpatient treatment for anorexia nervosa: Can risk factors be identified at point of admission? *European Eating Disorders Review.* 12(2): 94-100.

Swartz L (1985) Anorexia nervosa as a culture-bound syndrome. *Social Science & Medicine.* 20(7): 725-730.

Sweeting H, Walker L, Maclean A, Patterson C, Räisänen U and Hunt K (2015) Prevalence of eating disorders in males: A review of rates reported in academic research and UK mass media. *International Journal of Men's Health.* 14(2): 86-112.

Swinbourne J and Touyz S (2007) The co-morbidity of eating disorders and anxiety disorders: A review. *European Eating Disorders Review.* 15(4): 253-274.

Sword W (1999) Accounting for presence of self: Reflections on doing qualitative research. *Qualitative Health Research.* 9(2): 270-278.

Sykes G and Matza D (1957) Techniques of neutralization: A theory of delinquency. *American Sociological Review.* 22(6): 664-670.

Szmukler G, McCance C, McCrone L and Hunter, D (1986) Anorexia nervosa: A psychiatric case register study from Aberdeen. *Psychological Medicine.* 16(1): 49-58.

Talmy S (2010) Qualitative interviews in applied linguistics: From research instrument to social practice. *Annual Review of Applied Linguistics.* 30: 128-148.

Tamas S (2009) Writing and righting trauma: Troubling the autoethnographic voice. *Forum: Qualitative Social Research.* 10(1): Art. 22.

Tamas S (2011) Autoethnography, ethics, and making your baby cry. *Cultural Studies Critical Methodologies.* 11(3): 258-264.

Taylor J, Murray M and Lamont A (2017) Talking about sunbed tanning: Social representations and identity-work. *Social Science & Medicine.* 184: 161-168.

Taylor S and Bogdan R (1998) *Introduction to Qualitative Research Methods: A guidebook and resource.* 3rd edn. Hoboken: John Wiley & Sons.

Thoits P (1985) Self-labeling processes in mental illness: The role of emotional deviance. *American Journal of Sociology.* 91(2): 221-249.

Thoits P and Evenson R (2008) Differential labeling of mental illness revisited: Patterns before and after the rise of managed care. *Sociological Forum.* 23(1): 28-52.

Thoits, P (1999) Self, identity, stress, and mental health. In C Aneshensel and J Phelan (eds) *Handbook of the Sociology of Mental Health.* New York: Kluwer Academic Publishers, 345-368.

Tierney S and Fox J (2008) Chronic anorexia nervosa: A Delphi study to explore practitioners' views. *International Journal of Eating Disorders.* 42(1): 62-67.

Tierney S and Fox J (2010) Living with the anorexic voice: A thematic analysis. *Psychology and Psychotherapy: Theory, Research and Practice.* 83(3): 243-254.

Till C (2011) The quantification of gender: Anorexia nervosa and femininity. *Health Sociology Review.* 20(4): 437-449.

Tolich M (2004) Internal confidentiality: When confidentiality assurances fail relational informants. *Qualitative Sociology.* 27(1): 101-106.

Tolich M (2010) A critique of current practice: Ten foundational guidelines for autoethnographers. *Qualitative Health Research.* 20(12): 1599-1610.

Treasure J (2009) *A Guide to the Medical Risk Assessment for Eating Disorder.* Section for Eating Disorders, Institute of Psychiatry and the Eating Disorders Unit at South London and Maudsely Trust. Kings College London. Retrieved from: https://www.kcl.ac.uk/ioppn/depts/pm/research/eatingdisorders/resources/GUIDETOMEDIC ALRISKASSESSMENT.pdf Accessed 10th May 2018.

Treasure J and Cardi V (2017) Anorexia nervosa, theory and treatment: Where are we 35 years on from Hilde Bruch's foundation lecture? *European Eating Disorders Review. 25*(3): 139-147.

Treasure J and Russell G (2011) The case for early intervention in anorexia nervosa: Theoretical exploration of maintaining factors. *British Journal of Psychiatry.* 199(1): 5-7.

Treasure J, Crane A, McKnight R, et al. (2011) First do no harm: Iatrogenic maintaining factors in anorexia nervosa. *European Eating Disorders Review.* 19(4): 296-302.

Treasure J, Schmidt U and Hugo P (2005) Mind the gap: Service transition and interface problems for patients with eating disorders. *The British Journal of Psychiatry.* 187(5): 398-400.

Treasure J, Zipfel S, Micali N, Wade T, Stice E, Claudino A, Schmidt U, Frank G, Bulik C and Wentz E (2015) Anorexia nervosa. *Nature Reviews Disease Primers.* 1(15074).

Turnbull S, Ward A, Treasure J, Jick H and Derby L. (1996) The demand for eating disorder care: An epidemiological study using the General Practice Research Database. *The British Journal of Psychiatry.* 169(6): 705-712.

Turner R (1962) Role-taking: Process versus conformity. In: Rose, A (ed) *Human Behaviour and Social Processes.* London: Routeledge and Keegan-Paul: 20-40.

Twaddle, A (1969) Health decisions and sick role variations: An exploration. *Journal of Health and Social Behavior.* 10(2): 105-115.

Uher R and Rutter M (2012) Classification of feeding and eating disorders: Review of evidence and proposals for ICD-11. *World Psychiatry.* 11(2): 80-92.

Valentine C (2007) Methodological reflections: Attending and tending to the role of the researcher in the construction of bereavement narratives. *Qualitative Social Work: Research and Practice.* 6(2): 159-176.

Van Loo H and Romeijn J-W (2015) Psychiatric comorbidity: Fact or artifact? *Theoretical Medicine and Bioethics: Philosophy of Medical Research and Practice.* 36(1): 41-60.

Vitousek K, Watson S and Wilson G (1998) Enhancing motivation for change in treatment-resistant eating disorders. *Clinical Psychology Review.* 18(4): 391-420.

Vo M, Le Grange D, Accurso EC, Goldsmidt A and Le Grange D (2016) The impact of DSM-5 on eating disorder diagnoses. *International Journal of Eating Disorders.* 50(5): 578-581.

Von Ranson KM, Wallace LM and Stevenson A (2013) Psychotherapies provided for eating disorders by community clinicians: Infrequent use of evidence-based treatment. *Psychotherapy Research.* 23(3): 333-343.

Wagner J, Hamilton D, Anderson T and Rempusheski V (2017) Identity work, techniques of neutralization, and deviance: Exploring the relationship among older adult gamblers. *Symbolic Interaction.* 40(3): 352-377.

Walford G (2009) For ethnography. *Ethnography and Education.* 4(3): 271-282.

Wall S (2008) Easier said than done: Writing an autoethnography. *International Journal of Qualitative Methods.* 7(1): 38-53.

Wall S (2016) Toward a moderate autoethnography. *International Journal of Qualitative Methods.* 15(1): 1-9.

Waller G and Turner H (2016) Therapist drift redux: Why well-meaning clinicians fail to deliver evidence-based therapy, and how to get back on track. *Behaviour Research and Therapy.* 77: 129-137.

Waller G, Mountford VA, Tatham M, Turner H, Gabriel C and Webber R (2013) Attitudes towards psychotherapy manuals among clinicians treating eating disorders. *Behaviour Research and Therapy.* 51(12): 840-844.

Waller G, Schmidt U, Treasure J, Murray K, Aleyna J, Emanuelli F, Crockett J and Maria Yeomans (2009) Problems across care pathways in specialist adult eating disorder services. *Psychiatric Bulletin.* 33(1): 26-29.

Waller G, Stringer H and Meyer C (2012) What cognitive behavioral techniques do therapists report using when delivering cognitive behavioral therapy for the eating disorders? *Journal of Consulting and Clinical Psychology.* 80(1): 171-175.

Wallier J, Vibert S, Berthoz S, Huas C, Hubert T and Godart N (2009) Dropout from inpatient treatment for anorexia nervosa: Critical review of the literature. *International Journal of Eating Disorders.* 42(7): 636-647.

Walsh B (2013) The enigmatic persistence of anorexia nervosa. *The American Journal of Psychiatry.* 170(5): 477-484.

Warin M (2010) *Abject Relations: Everyday worlds of anorexia.* New Brunswick: Rutgers University Press.

Weber M, Davis K and McPhie L (2006) Narrative therapy, eating disorders and groups: Enhancing outcomes in rural NSW. *Australian Social Work.* 59(4): 391-405.

Weinstein R (1983) Labeling Theory and the attitudes of mental patients: A review. *Journal of Health and Social Behavior.* 24(1): 70-84.

Weltzin T, Cornella-Carlson T, Fitzpatrick M, Kennington B, Bean P and Jefferies C (2012) Treatment issues and outcomes for males with eating disorders. *Eating Disorders.* 20(5): 444-459.

Whitaker A, Davies M, Shaffer D, Johnson J, Abrams S, Walsh B and Kalikow K (1989) The struggle to be thin: A survey of anorexic and bulimic symptoms in a non-referred adolescent population. *Psychological Medicine.* 19(1): 143-163.

Wiles R (2013) *What Are Qualitative Research Ethics?* London: Bloomsbury.

Williams J and Jauhari bin Zaini M (2016) Rude boy subculture, critical pedagogy, and the collaborative construction of an analytic and evocative autoethnography. *Journal of Contemporary Ethnography.* 45(1): 34-59.

Williams S and Reid M (2010) Understanding the experience of ambivalence in anorexia nervosa: The maintainer's perspective. *Psychology & Health.* 25(5): 551-567.

Winston A, Paul M and Juanola-Borrat Y (2012) The same but different? Treatment of anorexia nervosa in adolescents and adults. *European Eating Disorders Review.* 20(2): 89-93.

World Health Organization (1992) *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines.* Geneva: World Health Organisation.

World Health Organization (2018) *International classification of diseases (11th Revision) – 6B80 Anorexia Nervosa.* Retrieved from: https://icd.who.int/browse11/l-m/en#/http://id.who.int/icd/entity/263852475 Accessed 23rd January 2019.

Zipfel S, Giel K, Bulik C, Hay P and Schmidt U (2015) Anorexia nervosa: Aetiology, assessment, and treatment. *The Lancet Psychiatry.* 2(12): 1099-1111.

Zola I (1972) Medicine as an institution of social control. *The Sociological Review.* 20(4): 487-504.

Zola I (1973) Pathways to the doctor-from person to patient. *Social Science & Medicine.* 7(9): 677-689.

Appendices

Appendix One

Information sheet for participants

Experiences of being diagnosed with and treated for anorexia

I would like to invite you to take part in my research project concerning the diagnosis and treatment of anorexia nervosa. Participation in the project is entirely up to you. Before you decide whether or not to take part, it is important that you understand what this would involve. Please read through this sheet carefully.

About the research team

My name is Lauren O'Connell. I am a postgraduate researcher in the sociology department at the University of Essex, and this research is part of my PhD. I am the sole researcher on the project, which is also overseen by an experienced supervisor - professor Joan Busfield (University of Essex). My PhD is funded by the Economic and Social Research Council.

I am keen to understand people's personal experiences of being diagnosed with anorexia and receiving treatment. My interest in this topic partly stems from my own experience of an eating disorder. I was diagnosed with anorexia in 2006 and have been recovered for about seven years.

About the research

The aim of the research is to explore the experience of being diagnosed with and treated for anorexia, and how these events affect the individual. The research will address questions such as: What does having a diagnosis and receiving treatment mean to the individual? How do these events affect the individual's identity and their understanding of anorexia? In addition to conducting interviews, I will also investigate and reflect on my own experiences.

Inclusion in the research

To participate in this research, the following should apply to you:

- Age 18yrs or above and living in the southern or midland regions of England
- Have been diagnosed with anorexia by a health professional (you may or may not still have this diagnosis).
- Have received, or are currently receiving, treatment for anorexia. 'Treatment' includes any regular input from a health professional(s), for example: seeing your GP to be physically monitored, attending an outpatient or inpatient eating disorder service, appointments with a home treatment team, or time spent on a hospital ward.
- Not be feeling especially unwell or have very serious health complications.

I am interested in speaking to a range of people, including individuals who consider themselves to currently have anorexia, those who are in recovery and those who are recovered.

Participation in the research

If you choose to participate then you will be invited to take part in an interview with me at some time from January 2018 onwards .We will arrange a time and place for the interview that is convenient for you. Before the interview begins, we will talk through this information sheet and I will answer any questions that you may have. If you still wish to participate, I will ask you to sign a consent form, and we will then begin the interview. The interview will cover topics such as your experiences of anorexia, being diagnosed and receiving treatment. There will not be a strict set of questions to follow, so we will be free to talk about those aspects of these experiences that are relevant and meaningful to you. The interview will likely last

between one and two hours, and will be recorded on a digital voice recorder. I will type up the voice recording into a word document at a later date. At your request, I will send this document to you, so that you are able to alter the content and/or provide additional information and comments (if you choose). After you have participated in an interview, I may also invite you to participate in a second interview – but there would be no obligation to agree to this. The second interview would cover the same topics as the first but would be an opportunity to go into more detail.

You will be free to leave the research at *any* time, without having to give a reason, and without disadvantaging you in any way – even if you have previously agreed to take part. You can do this by informing me in person or via the contact details below. If you wish, any information that you have already provided will be destroyed. This research is not linked to any treatment that you may currently be receiving, and so whether you participate will not affect your treatment in any way.

Taking part in the interview will involve talking about your experiences of anorexia and treatment and this may be difficult for you. **You should only take part in the study if you are content to discuss these topics in the context of a research interview.** Your wellbeing is of upmost importance. Please do not take part if you expect that sharing your experiences will be stressful or that it will have a negative impact on your physical or mental wellbeing.

Anonymity and confidentiality

The researcher and supervisor will follow ethical and legal practice. Your participation in the study and your personal information will remain confidential. You will not be made identifiable to others at any stage during the research process or in the publication of findings. This means that your name and any other identifying information will not be used in publications.

During the course of this research, the information you provide will be stored securely and anonymously and will only be accessed by the research team. The information will be destroyed after the research has been completed.

Research publication

The research will be published as a PhD thesis and also in academic journals and conferences. I will be happy to provide you with information regarding any publications relating to this research.

Ethical review

This research has been agreed by the research ethics committee at the University of Essex

Contact details

Lead researcher - Lauren O'Connell (BSc, MSc, PGCE).

Email: lauren.oconnell@essex.ac.uk.   Phone or text: 07702864499

Project supervisor - Professor Joan Busfield

Email: busfj@essex.ac.uk

Ethics officer (Sociology department, University of Essex) – Professor Nigel South - Please use this contact for further information should you wish to speak to someone outside of the research team

Email: n.south@essex.ac.uk

Appendix Two

Interview processes for each participant

Partici-pant	Interview mode	Interview processes	Post-interview questions	Transcript / summary
One Mia	Skype	• Interview one - 1 hr and 15 mins • Interview two – 1 hour	Responded	Sent to participant No comments returned
Two Anna	In person	• Interview one - 2 hrs and 20 mins • Follow-up interview questions and conversation by email	Responded	Sent to participant Comments added to summary
Three Natalie	In person	• Interview one - 2 hours • Follow – up conversation by email	Responded	Sent to participant No comments returned
Four Kelly	Skype	• Interview one - 1 hr 45 mins • Interview two - 15 mins	Responded	Sent to participant No comments returned
Five Sarah	In person	• Interview one - 2 hours 45 mins • Follow-up interview questions by email	Responded	Sent to participant No comments returned
Six Claire	Skype	• Interview one - 1 hour)	Responded	Participant did not wish to see
Seven Ben	In person	• Interview one - 2 hours	Responded	Sent to participant No comments returned

Eight Naomi	In person	• Interview one - 1 hr 35 mins	Responded	Participant did not wish to see
Nine Michael	Skype	• Interview one - 1 hour 45 mins	Did not ask (already addressed matter during the interview)	Sent to participant No comments returned
Ten Amelia	Skype	• Interview one - 1 hour 20 mins	Responded	Sent to participant No comments returned
Eleven Jack	Skype	• Interview one - 1 hour	Responded	Sent to participant No comments returned
Twelve Maddie	In person	• Interview one – 1 hour and 5 mins	Responded	Sent to participant No comments returned
Thirteen Lisa	In person	• Interview one - 1 hour and 45 mins Further interview questions by email	Responded	Participant did not wish to see
Fourteen Hannah	In person	• Interview one - 1 hour	Responded	Sent to participant No comments returned

Appendix Three

Brinkmann and Kvale (2015) Validity as quality of craftmanship: Validation at seven stages

1. Thematizing. Validity relates to the soundness of the study's theoretical presuppositions of the study and on the logic of the translation from theory to research questions.

2. Designing. Validity relates to the adequacy of the design and methods used for the aims of the research. Ethically, validity relates to beneficence; valid knowledge is beneficial with minimized harmful consequences.

3. Interviewing. Validity relates to "the trustworthiness of the subject's reports and the quality of interviewing". Interviewing should involve careful questioning and checking of the meaning of what is said.

4. Transcribing. Validity relates to translation from oral to written language and is affected by the linguistic style of the transcript.

5. Analysing. Validity relates to whether the questions put to a transcript, and the logic of interpretations, are sound.

6. Validating. Involves reflective judgement on the forms of, and procedures for, validation, as relevant to a specific study.

7. Reporting. Concerns the validity of the account of the main findings in the research report. Readers may also play a role in validating the results.

Adapted from Brinkmann and Kvale (2015: 283 – 284)

Appendix Four

Tolich (2010) Foundational guidelines for autoethnographers

Consent

1. Respect participants' autonomy and the voluntary nature of participation. Document informed consent processes.

2. Practice "process consent". This involves checking at intervals that participants want to remain in the research.

3. Recognize the coercion involved in gaining informed consent after writing a manuscript.

Consultation

4. Consult with relevant others.

5. Do not publish anything that one would not show the persons mentioned in the autoethnography.

Vulnerability

6. Consider internal confidentiality: the possibility of 'insiders' identifying each other in the text.

7. Consider ones' future vulnerability as the author of the autoethnography.

8. No story should harm others, and potential harm should be minimised.

9. A nom de plume should be used to minimise risk, when relevant.

10. Assume all people mentioned in the autoethnography will read it.

Adapted from Tolich (2010: 1607 - 1608).