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## **Beyond the Revolving Door: Long-Term Lived Experience of Eating Disorders and Specialist Service Provision**

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Running Head: EATING DISORDERS AND SPECIALIST SERVICES

**Article Full Title:**

Beyond the Revolving Door: Long-Term Lived Experience of Eating Disorders and  
Specialist Service Provision

**Short Title:**

Eating Disorders and Specialist Services

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**Abstract**

In this study, we undertook a narrative analysis of participants' long-term lived experience of eating disorders and specialist service provision. Eight participants were recruited with service experience across five National Health Service (NHS) Trusts in the UK. All participants had a minimum of 10 years self-reported experience living with an eating disorder. The data are presented across different temporal stages that demonstrate the development of participants' self-construct in relation to their first contact with specialist services, what had happened in their lives for this to become necessary, and their current relationships with services, before gaining an appreciation for what they need from services to help them feel heard going forward. Findings suggest current methods of service delivery result in delayed and inappropriate supports, and a consequent "battling" against professionals, which can provide an obstacle to compassionate and collaborative working, and promote "revolving door" experiences.

**Keywords**

Qualitative Methods; Narrative Inquiry; Eating Disorders; Long-term experience; SEED; Users' Experiences; Psychology; Social Construction.

7267 + (145 abstract) = 7412 total

## EATING DISORDERS AND SPECIALIST SERVICES

**Introduction**

Historically eating disorders (EDs) have been considered a “nervous disease” (Striegel-Moore & Bulik, 2007, p. 182) located in the feminised individual, where clinical research focused on the isolated measurement of individual factors like body image satisfaction (Malson, Riley, & Markula, 2009). More recently, researchers are drawing attention to how distress that manifests in body concerns is constructed within socio-political, cultural and service contexts (Brooks, 2009; Eivors, Button, Warner, & Turner, 2003; Orbach, 1986; Riley, Rodham, & Gavin, 2009; Wiggins, 2009). Feminist approaches in particular advocate for a more thorough understanding of how cultural practices, gender roles and embodiment inform the experience of living with these diagnoses by highlighting the ways in which dominant psycho-medicalised narratives participate in the sociocultural processes that inform the very development of these presentations (Gelo, Vilei, Maddux, & Gennaro, 2015; Gremillion, 1992; Malson et al., 2009; Orbach, 1986, 2009). Specialist ED services have the potential to create the conditions from which EDs emerge and are exasperated, or provide the safe and nurturing environment necessary for healing, and service-users’ experiences currently shift along this continuum (Eli, 2014; Gremillion, 2003).

Eating disorders predominantly affect well-educated, Caucasian women from middle to upper-class backgrounds living in Western societies (Bruch, 1973). These are the same societies in which psychiatric explanations and treatments for these presentation prevail (Gremillion, 1992). Much research and theoretical debate surround the experience of Anorexia Nervosa (AN), the most salient ED, for which standardised ‘causes’ remain elusive. There have been minimal improvement in treatment outcomes in EDs over the last 50 years (Botha, 2015; Steinhausen, 2002),

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1  
2  
3 high drop-out rates (Fassino, Pierò, Tomba, & Abbate-Daga, 2009) and low levels of  
4  
5 service-user satisfaction (Botha, 2015). By considering AN as an inherently gendered  
6  
7 phenomenon situated within a gendered culture and political system (Orbach, 1986)  
8  
9 we can start to make sense of these outcomes in terms of their relationship to feelings  
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11 of powerlessness and issues of control.  
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14  
15 In a neo-liberal consumer culture, the slender body is heralded as the epitome  
16  
17 of ideal femininity inscribed with culturally esteemed values of self-denial,  
18  
19 achievement, and success (Bordo, 1993). Increasingly, research which has started to  
20  
21 address how EDs are spreading across ethnic, socioeconomic and geographical  
22  
23 boundaries, is finding that the slender body ideal can be viewed as a type of currency  
24  
25 with which individuals attempt to move towards increased social acceptance and  
26  
27 mobility (Becker, 2004; Cheney, 2011). In Westernised cultures, individuals have  
28  
29 been “taught to regard self-denial as a ‘good thing’... a particularly ‘good’ thing for  
30  
31 women, as it is women who are more inherently prone to badness and moral  
32  
33 weakness.” (Lawrence, 1979, p. 95). The control and denial of food thus becomes an  
34  
35 overly conforming reaction to societal controls, and also a resistance to “an  
36  
37 excessively controlling society in which systems and institutions assert organized,  
38  
39 systematized, and collective control over women” (Surgenor, Horn, Plumridge, &  
40  
41 Hudson 2002, p. 92). Through this lens AN is understood as a purposeful attempt to  
42  
43 establish an ownership of the self in an inherently power imbalanced and expectant  
44  
45 world. Paradoxically however, this very attempt to feel more in control results in a  
46  
47 loss of power and agency as individuals’ mental and physical health deteriorates, and  
48  
49 they become dependent on the services around them for their survival (Surgenor et al.  
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51 2002).  
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## EATING DISORDERS AND SPECIALIST SERVICES

**Systemic oppression and dominant models of care**

By the time that individuals with EDs access services, the majority have been taught to view their eating practices, and their inability to loosen their control of these as the ‘illness’ (Lawrence, 1979). Within the psychiatric and medicalised model of care, individuals are not afforded much transformative agency from this viewpoint, but rather their sense of ‘will’ is instead positioned as a problematic source of guilt and remorse (Gremillion, 1992). Psychiatry therefore becomes a cultural practice that unquestioningly supports the status quo that individuals with EDs are simultaneously prescribing to and rebelling against (Gremillion, 1992). In a condition which has developed around issues of self-governance, the possibility of resolving these becomes more challenging, if not impossible, when the dominant regime of care seeks to assume such functions (Lawrence, 1979).

Treating EDs as a problem within an individual is consistent with the prevailing psycho-medical narratives, and neoliberal logic that downplays the importance of the social components of mental health and enforces a cultural imperative around self-management by pathologizing experiences that deviate from what is considered “functional, productive or desirable” to the market economy (Esposito & Perez, 2014, p.414). Treatment ‘resistance’, which is said to accompany the ‘ego-syntonic’ features of EDs (Fassino & Abbate-Daga, 2013) becomes the main culprit in the increasing chronicity of ED presentations (Strober, 2004) and the “revolving door” phenomenon of relapse rates (BEAT, 2015, p. 35). Wider political discourses collude with a diminished sense of social accountability, and place the burden of improvement and compassionate care on overwhelmed services (Cambell, 2015), unsupported staff (Crawford, Gilbert, Gilbert, Gale, & Harvey, 2013) and disenfranchised service-users.

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Correspondingly, growing prevalence and poor outcome rates associated with EDs, and the disproportionate amount of funding allocated to research in this area, reflects how dominant models of understanding and delivery of services are worryingly insufficient (Schmidt et al., 2016). There has been a call for “fresh perspectives” (Botha, 2015, p.328) and “a new paradigm” (Touyz & Hay, 2015, p. 1) in the way we conceptualise, research and develop interventions for EDs. Nevertheless, despite their association with topical discourses around treatment resistance and low ‘recovery’ rates (Botha, 2015; Hay & Touyz, 2015), long-term experiences of EDs have received relatively little attention in research to date (Hay & Touyz, 2015; Hay, Touyz, & Sud, 2012; Schmidt et al., 2016). Recent qualitative research has started to explore the lived experience of those with ‘severe and enduring’ presentations (Robinson, Kukucska, Guidetti, & Leavey, 2015), and is beginning to challenge the dominant more hopeless narratives by finding that full recovery in such presentations is possible where hope, support, motivation and self-efficacy can be nurtured (Dawson, Rhodes, & Touyz, 2014).

The present research explores the following questions:

1. What are people’s experiences of receiving input from services for long term eating disorders?
2. What are the social, political, and cultural narratives which impact on those experiences?

These questions are explored through a Narrative Analytical lens: “The study of narrative is the study of the ways humans experience the world” (Connelly & Clandinin 1990, p. 2), and can be useful in exploring the impact of dominant societal discourses, culture and self (Weatherhead, 2011). A narrative approach was employed in seeking to explore the research question through the lens of participants’

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1  
2  
3 subjective life experiences as they become grounded within a particular time, social  
4 context and perspective (Personal Narratives Group, 1989). By valuing and  
5 understanding the subjective nature of personal experience, we can start to  
6 acknowledge these, and hopefully learn from them.  
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## Method

### Design

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21 Events become meaningful because of their placement in an individual's  
22 narrative, which provide a creatively authored, and socially constructed account  
23 (Riessman, 1993). Narrative inquiry assumes that storied experiences represent our  
24 subjective realities (Connelly & Clandinin, 1990). Narrative research provides  
25 methods for examining and relating meaning across the ideational (content-specific),  
26 interpersonal (relational) and textual (structural) qualities implicit within the stories  
27 people tell about their lives (Riessman, 1993). Narrative analysis preserves accounts  
28 shared by participants within their social and cultural context (Riessman, 2008) and  
29 therefore allows for the exploration of these, with the aim of understanding them  
30 better (Patton, 2002).  
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44 In qualitative research in general, and narrative approaches in particular, the  
45 researcher's professional, personal and epistemological positioning is important<sup>1</sup>. The  
46 researcher is considered a co-creator of meaning (Riessmann, 1993; 2008) where  
47 sharing narratives comprise a social function for both narrator and listener (Squire,  
48 2008). Ethical approval was gained from the NHS Research Ethics Committee and  
49 the Health and Research Authority in England. Participants provided written consent  
50 to be included in the research, and for their data to be published.  
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## EATING DISORDERS AND SPECIALIST SERVICES

### Participants

Participants were invited to take part in the study if they were 18 years or older, had self-reported experience of specialist ED services, and were living with an ED for 10 years or more. This is consistent with Robinson's (2009) description of severe and enduring eating disorders. In keeping with a 'transdiagnostic' approach to EDs, where eating too much or too little are seen as conceptually inseparable ways of managing emotional distress (Fox & Power, 2009), participants were not excluded based on any particular diagnostic category. They were recruited directly through two NHS Trusts. In addition to this, an advertisement was circulated within a special interest group formed to collaboratively develop understanding of EDs from service-user, carer and professional perspectives.

Fifteen people expressed an interest in participation. Five people ceased responding to correspondence, and two people were excluded for not having experience of specialist services. A total of eight participants (seven female), with experience across five NHS Trusts volunteered to take part. Participants' ages ranged from 20-64 years. The average age was 44 years. Length of experience living with an ED ranged from over 10 to over 40 years, and average length of experience receiving input from specialist services was 10 years. Five of the eight participants had experienced multiple inpatient admissions, one had a singular admission and two had none. Six out of eight participants were working or studying at the time of their participation.

### Procedure

Recruitment leaflets and emails were circulated. Participants expressed interest in the project with the researcher directly, or through their service. Participants were invited to bring images or objects that felt meaningful to their

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3 experience to interviews, where photographs of these could be taken with permission  
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5 and included with the analysis. Consent was gained in person before each interview,  
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7 and participants were given the choice of using their own name or a pseudonym for  
8  
9 the purposes of the research. A number participants chose to waive their right to  
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11 anonymity and use their own names, however the guidelines of the current journal did  
12  
13 not permit the use of these. Consequently, all names have been removed from this  
14  
15 article.  
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19 Individual, life history accounts were sought at a variety of locations  
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21 depending on the preference of participants and feasibility for the researcher. All  
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23 interviews began with the same open-ended narrative statement to explain the  
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25 boundaries of the interview and encourage a natural starting point. Clarifying  
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27 questions and additional prompts were included where necessary to facilitate the  
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29 expansion of the narrative (Riessman, 1993). Participants were encouraged to share  
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31 their stories at a comfortable pace, and in a way that facilitated a consideration of how  
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33 they viewed and understood their experiences (Josselson, 2011).  
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38 Interviews lasted 90-180 minutes, and were transcribed verbatim. To enhance  
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40 trustworthiness of the data, the researcher created summary stories, which were  
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42 offered to participants with an option of meeting again to review these. One  
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44 participant declined this offer, three took part in face-to-face conversations, three  
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46 chose to review these by email, and one discussed theirs over the phone.  
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### 50 **Data Analysis**

51  
52 Narrative analysis (NA) is grounded in principles of narrative psychology  
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54 (Howitt, 2010) which aims to explore and understand the narrator's construction of  
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56 self and identity in relation to their cultural contexts (Weatherhead, 2011). There is no  
57  
58 definitive framework for conducting NA which can promote creativity (Crossley,  
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2007). This research was guided by several frameworks including Crossley (2007; 2000), Howitt (2010), Riessman (1993; 2008) and Weatherhead (2011).

Each interview was listened to, transcribed and read through a number of times to enhance engagement with the data (Crossley, 2007). Summary stories were created for each participant by highlighting and reflecting on events that the researchers deemed salient and emotive. Any additional reflections deemed pertinent to the participant or researchers, were incorporated into the final version of these stories. These were then plotted across difference levels of context before being organised into themes based on temporal and contextual qualities. This focus was aided by the use of a visual map to plot the location of themes and images across individual, familial, social, political and societal levels for each participant (Joyce, 2017).

The findings are presented in terms of acts and scenes to respect the fact they represent a narrow subsection of the available data, and that the participants' individual life stories continue behind these scenes. Scenes emerged from the data as a way to unify the diversity of participants' interactions with services and elicit the consequent impact of these on the development of their self-constructs. They are intended to illustrate fluidity across narratives, while maintaining a sense of each participant. To increase the reflexivity and rigour in the analytical process, co-authors were invited to listen to interviews, provide feedback and remain involved in the analytic process throughout.

### **Findings**

Act One introduces the character of specialist ED services. The opening scene depicts the point and context around participants' first contact, and the second scene

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2  
3 explores participants' accounts of what had happened in their lives to get them to that  
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5 point. Act Two scene one captures what services have conveyed to the participants'  
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7 through their interactions, and Act Two scene two depicts the battling nature that  
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9 characterises these interactions. Act Three exposes the 'villains' behind services'  
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11 perceived malice, and explores what participants need from services to feel heard, as  
12  
13 well as their hopes for the future. For a diagrammatical overview of these scenes, and  
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15 the themes and imagery they contain see Figure 1.  
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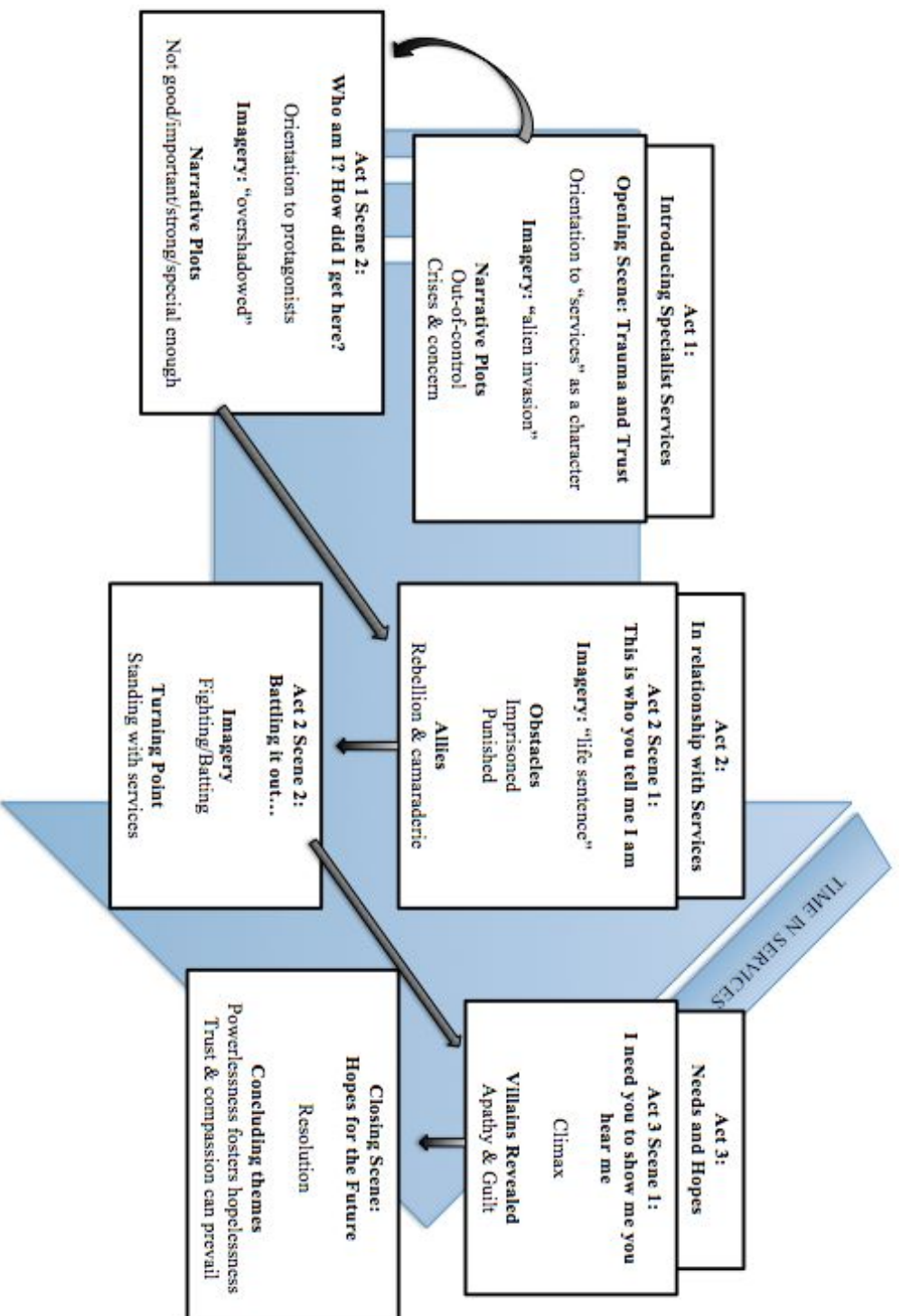


Figure 1. Diagrammatical overview of acts, scenes and the narrative plots and imagery they contain.

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## Act One: Introducing Specialist Services

### Opening Scene: trauma and trust

Picture an old, grand, red-brick building set amongst a mature modest garden and old-fashioned turning circle for cars to pull up and drop people off. It feels quite warm here on a bright sunny day, but as you get closer to the entrance the smell of hospital and the dank, chill of uncirculated air runs out to meet you. Many participants made their initial contact with ED services on inpatient wards like this. They used vivid and emotive language to describe how “horrific”, “dehumanising” and “agonising” it was. One participant’s experience caused them to question her identity, without any therapeutic input to understand why she found eating so difficult, and how she could manage the resulting distress: “I gained weight quite quickly - they really piled it on thick and fast...this sort of alien invasion...my body had just been taken over it was almost like it wasn’t me in the mirror”.

In contrast, another participant found that it was a relief to have the control taken away, even if the involuntary nature of their hospitalisation had come as a surprise:

I was suddenly admitted, and I knew I was in trouble... I didn’t realise it was compulsory until after they showed me around...I said what!? I can’t do that! Which is when I realised yeah they had sectioned me I think.

All but two participants did not choose to engage with services but were strongly encouraged, coerced, or sectioned. Some participants had been already known to mental health (MH) services and found their general practitioner (GP)

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2  
3 responsive to their requests, while others did not. Although one participant had a  
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5 diagnosis of AN on their medical record, their later request for support was declined  
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7 by their GP, who asserted that their weight was not “low enough” to qualify. They  
8  
9 attempted again a couple of years later:  
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14  
15 ...At that point I kind of just thought well there mustn't be anything wrong  
16  
17 with me then because I kind of I was better than I had been at my worst - I  
18  
19 think I kind of thought I must be too well to get help... I had a couple of  
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21 experiences like that with GPs but that was the only time I asked for help until  
22  
23 I took [in] my own referral form.  
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28 Concerned managers, families, partners and professionals featured  
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30 prominently as reasons participants sought help. For one person it was their manager,  
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32 and for another it was their orthopaedic consultant. Having conveyed concerns about  
33  
34 low mood, and an inability to eat to their GPs respectively, these participant's  
35  
36 relationship with food was not explicitly addressed until they were so severely  
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38 underweight it was either affecting their ability to work, or had resulted in severe  
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40 physical health consequences such as osteoporosis.  
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44  
45 Similarly, half of the participants were already known to MH services before  
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47 any concern about an ED was identified. For example, two participants were only  
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49 referred to specialist services after making several attempts to end their life. Thus,  
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51 many participants were in quite a raw, and fragile condition by the time they first  
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53 encountered services, which were then rarely perceived as welcoming places.  
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## EATING DISORDERS AND SPECIALIST SERVICES

**Act One, Scene Two: Who am I? How did I get here?**

All participants expressed feeling *not good enough*, and were able to relate this to early life experiences and relationships. Many shared experiences of trauma and abuse, objectification, exploitation, and struggling to feel safe in the world. For example, one participant grew up “in the shadow” of their brother, and became resigned to her place as a woman and a “second-class citizen” to all of those more deserving. She was “the good girl” that could “never quite fit in”. While trying to ensure the needs of others were always met, hers were silenced, and love and joy remained perpetually out of reach (see Figure 2).

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INSERT FIGURE 2 HERE  
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Similarly, another participant spoke about feeling “unloved” and “unnoticed” all her life and, having been accustomed to a controlling and punitive home environment, restricting their food intake initiated a way to impart some “control” on their newfound independence from an abusive mother. Another participant related the development of their ED to their first memory of feeling “powerful” and “in control” of their father, after feeling overshadowed by his “Victorian” attitude, and the need to always do “the right thing”. In the context of feeling unimportant and not “special enough”, they found a sense of achievement and control in restricting their food intake and exercising excessively.

Another participant’s lifelong on-and-off relationship with services started when they reached puberty, and began to experience depression. Four decades later they remain affected by chronic low mood, and a need to feel empty to be



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1  
2  
3 comfortable. Exercise helped them manage the “tension and anger” of self-hatred that  
4  
5 accompanied the unwanted sexualised attention they received from men growing up,  
6  
7 and restricting helped them “cut off” from the more difficult feelings. Similarly,  
8  
9 another participant described their ED as serving a protective function:  
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14 My dad was an alcoholic ... And my mum didn't cope particularly well, and it  
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16 was in that context that things developed so I think there was a lot of stuff  
17  
18 going on around me that felt very difficult - and emotionally felt very difficult  
19  
20 - to cope. And then when my parents split up, which was a good thing and I  
21  
22 was happy about that, things didn't really settle as you would have - as I  
23  
24 certainly hoped they would. That's when things actually became more difficult  
25  
26 for a while, and that's what was going on really so you know it's not rocket  
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28 science I suppose you know? That was just how I coped.  
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35 Things went “downhill” for this participant after leaving University without a sense of  
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37 direction and purpose, and they described getting “really hooked on the sense of  
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39 achievement - that sense of doing something”.  
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42 Another participant had felt controlled, put down and abused within many of  
43  
44 their early relationships: “it was almost like I wasn't strong enough”. They described  
45  
46 how they “always hated” their body, and “seemed to be always battling and didn't  
47  
48 know how to eat normally”. They experienced being both significantly under, and  
49  
50 over-weight: “it was kind of like me rebelling against myself”. Similarly, for the male  
51  
52 participant, his experience related to demonstrating strength, and a protest against  
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54 internalised gender norms and social expectations. He spent his life doing “more than  
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56 others on less”.  
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## EATING DISORDERS AND SPECIALIST SERVICES

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3 All but two participants spoke about how “food was always an issue”, “from a  
4 young age”. For example, having grown up with stories about how “different” and  
5 “faddy” she was as a child, one participant found it difficult to feel like she was “in a  
6 comfortable skin”. She did not “want to take up space”, and felt trapped in childhood  
7 but also “terrified” of becoming an adult. For many participants EDs became a way of  
8 acknowledging and understanding the consequences of their early life experiences,  
9 but this happened at various stages sometimes with, and sometimes without, the help  
10 of services.  
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21 Overall, all participants’ narratives referred to how their ED developed in the  
22 context of managing unmet need for psychological security and autonomy, self-worth  
23 and purpose in the context of feeling powerless, and overlooked by others. Thus,  
24 while no two stories were the same, there were many overlapping themes and  
25 narrative plots that made sense of the courage, and the vulnerability with which  
26 participants approached services for help.  
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**Act Two: In Relationship with Services****Act Two, Scene One: This is who you tell me I am**

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42 Inpatient services were described as “prison-like”, recreating the critical and  
43 controlling conditions from which EDs emerged, and reinforcing the rigidity that  
44 accompanies them. Seemingly punitive rules and absurd circumstances (see Figure 3),  
45 contributed to a sense of injustice and oppression, where participants felt they were  
46 “being punished for having an illness”. One participant spoke about how such  
47 punitive measures escalated distress, and highlighted staff’s inability to manage this  
48 by imposing their own agenda rather than demonstrating compassion or  
49 understanding: “The worst bit though is explaining and not being listened to... I’m  
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## EATING DISORDERS AND SPECIALIST SERVICES

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3 used to staying in situations where I'm not actually heard, or [I'm] told what I'm  
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5 saying”.

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8 Most participant’s spoke about how critical, malicious and consuming an ED  
9  
10 is, which services can then collude with when they restrict focus to weight  
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12 management, adhering to rigid rules, arbitrary weight thresholds and mealtime  
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14 routines (see Figure 4): “patients are told not to focus on the numbers and weight yet  
15  
16 your progress is judged purely on what you weigh”. Success and worthiness became  
17  
18 explicitly defined in terms of “numbers”, reinforcing a sense of objectification, and  
19  
20 reflecting wider socio-cultural values about there being a “right” weight.  
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22 Consequently, “there probably is an atavistic sense of self-punishment and lack of  
23  
24 worth associated with ED, that the structure and nature of inpatient treatment  
25  
26 exacerbates”.

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44  
45 Many participants felt inpatient experience did them “more harm than good”,  
46  
47 contributing to their “revolving door” admissions where they “came out worse” than  
48  
49 when they went in: “I was not helped I was drugged”. One participant spoke about  
50  
51 losing hope after their first inpatient stay because they had seen the “experts” and  
52  
53 nothing had changed. Similarly, another participant spoke about how AN felt like a  
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55 “life sentence”, providing them with a label that undermined hope and attacked their  
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## EATING DISORDERS AND SPECIALIST SERVICES

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3 sense of self-worth, while simultaneously offering an identity they felt the need to  
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5 defend against losing:  
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10 And when you haven't got the words... I mean you know I really didn't  
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12 understand what was wrong with me so having this label that said I was  
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14 anorexic well you're not going to bloody take that away from me! It's the only  
15  
16 thing I'm good at.  
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21 Participants felt like they were being set up to fail. They spoke about how  
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23 there was little support in preparing for transitioning into the outside world and to  
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25 thinking beyond their ED: "it's like you can be in hospital and fed or then you come  
26  
27 into the community where you get some therapeutic input but you're not getting the  
28  
29 same food support so you're kind of getting one or the other all the time – you're  
30  
31 never getting them kind of hand in hand".  
32  
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34

35 Conversely, many participants who engaged with ED services on an outpatient  
36  
37 basis - described finding their therapists supportive, even if the work itself was  
38  
39 "frustrating", and at times "confusing". They spoke similarly of the benefit, and hope  
40  
41 that could come from working with interested and understanding professionals.  
42  
43 However, for others this compassion, and validation was only found amongst the  
44  
45 other service-users: "you can see in their eyes that they are feeling exactly the same".  
46  
47 The professionals were often less informed, which led to feelings of frustration:  
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52  
53 I started to get a bit indignant then - you know - I thought well why don't they  
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55 understand - they are looking after us - why don't they read up on it you know  
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57 but again there wasn't much understanding of it.  
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## EATING DISORDERS AND SPECIALIST SERVICES

**Act Two, Scene Two: Battling it out**

As individuals begin to experience oppression, they may seek refuge in the support of others. The socio-political context of eating difficulties as expressed through service barriers or limitations, added to stigmatising and criticising social narratives, often creates a context in which people with long term eating difficulties see others with similar experiences as their primary source of support.

Having approached services with a fragile sense of self, and expending the last of their courage exposing their vulnerability in looking for help from others, participants found punishment where they had hoped to find care. This led to indignation and frustration as participants started to use “fighting” language, “battling” metaphors, and descriptive imagery around not receiving any help to “tackle the problem” of eating in the outside world; “the battle I’ve been up against with professionals to get them to stop solely focusing on the physical experience”, and the “struggle” with holding on to hope in this relationship with EDs and services.

As a result, participants described a process of “banding together” with other service-users, sharing stories of camaraderie (Figure 5) and “rebellious” the professionals by hiding on them or refusing to comply with treatment protocols. One participant described how her third inpatient stay had “allowed us to be the children that we’d never been... we laughed we joked we were told off we didn’t care”. Due to the benevolent figures of the ward sister as the fond disciplinarian “she created the boundaries so it was a very safe place”, and the psychiatrist who “was very much like the father that I never had...” this experience of camaraderie had a more healing impact.

## EATING DISORDERS AND SPECIALIST SERVICES

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Compassion featured prominently in the narratives that depicted more positive relationships with services, where participants and services battled together *against the ED* rather than each other. Many participants spoke about turning points in terms of learning that “compassion [for oneself] is the key”, developing “powerful tools” to support this outlook, and shared, credible weight goals with the service that made long-term sense: “the service set target weight at a BMI of 20 [which] is so helpful - it’s difficult but it’s so helpful because there is no way that my natural weight is less than that”.

One participant spoke about the benefits of the service “holding their line”, and giving them “the push” they needed but doing this at a pace that allowed them to develop trust. With weight gain came an increase in distress and anxiety from feeling physically uncomfortable and psychologically out of control. But because of their rapport with their therapist, and the service’s flexibility to offer person-centred therapeutic models, this facilitated “formulating things in that way [which] really helped me to start to put the pieces together a bit more”. Similarly, for another participant, the turning point came when they stopped looking at their life, their MH diagnosis and the ED as *separate* experiences, and found a supportive space within services to help them make sense of this as a whole.

## EATING DISORDERS AND SPECIALIST SERVICES

**Act Three: Climax and Resolution: Needs and Hopes****Act Three, Scene One: I need you to show me you hear me**

Services could be experienced as maliciously indifferent, where “cold”, “clinical” and “corrupt” experiences of professionals reinforced participants’ sense they were worthless, unimportant and *not* good, strong, special, important or low weight *enough*. But services were also depicted in a warmer more compassionate light, when particular staff had been perceived as supportive, encouraging, nurturing, caring, and patient. Participants reflected on how the wider social and healthcare systems’ apparent lack of understanding could promote such indifference, and undermine such compassion:

They see it as an eating problem while that’s the symptom...the person gets forgotten and we sit there and talk collectively about ED or SEED<sup>ii</sup> as opposed to the person who struggles for so many years with this illness and how can we support them to move forward - there’s a kind of an apathy...

Consequences of such perceived apathy were considered in two, seemingly self-serving, threads. One was the limited availability of fit-for-purpose services and the capacity for GPs to appropriately assess and refer into these. The second reflected the participants’ own understanding of EDs, which, similarly to the unhelpful professionals they encountered, were based on very “stereotypical” media portrayals. Consequentially, participants did not consider themselves “bad”, “young” or, in the male participant’s case, female “enough” to be legitimately considered as experiencing an ED, which resulted in delayed opportunities to receive specialist input.

## EATING DISORDERS AND SPECIALIST SERVICES

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6 Once somebody says 'it's that' I can go and fuel myself, and I can educate  
7 myself on what that is. I'm not saying I can get myself out of it but I can  
8 understand it better ... it's an eating disorder it's a label and I didn't ask to  
9 have this. It makes it better - a lot better - because you feel like you're not the  
10 only one, you're not a freak... knowledge is power really.  
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19 However, even when participants had been signposted in the right direction,  
20 some ended up avoiding services due to frightening first experiences of the  
21 professionals involved:  
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28 ...she showed me one of the patient bedrooms and she was talking about the  
29 spy hole in the bedroom... and supervision after meals... and I remember  
30 saying something about 'Oh well I don't do that I don't make myself sick I  
31 just restrict' and she said well 'by the time we are finished feeding you you  
32 might start!' and I drove off like a scene out of the dukes of hazard - there was  
33 like dust coming out of from behind (laughs. pauses)...Needless to say I didn't  
34 get admitted, I didn't go for a voluntary admission because I was absolutely  
35 petrified.  
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49 Similarly, another participant spoke to how their experiences had made them  
50 "suspicious" and untrusting of professional support. They were no longer in direct  
51 contact with these having experienced a number of inappropriate interactions with  
52 staff, which were triggering in terms of early life experiences of powerlessness and  
53 objectification: "the male doctors they've been very abusive and you know in a sexual  
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## EATING DISORDERS AND SPECIALIST SERVICES

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3 way and that doesn't help...they've let me down"<sup>iii</sup>. Such direct accounts of malice  
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5 were thought about in terms of how certain professionals could be drawn into these  
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7 positions of power, with opportunities to "exploit the vulnerable", or "get away with"  
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9 indifference.  
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12 Correspondingly, it was believed that from a political and economic  
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14 standpoint there is a vested interest in maintaining the status quo in a culture of  
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16 "stretched" NHS resources when services are put out to tender "under pressure" there  
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18 is no safeguard against the prioritising of "profits over people". Participants argued  
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20 that it would be more cost effective to invest more in services:  
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26 Yet because it [the current system] guarantees repeat income and if you invest  
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28 in what people need...it costs money and I'm not saying an NHS funded  
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30 option would have a bottomless pit of money but at least it's not for profit -  
31  
32 it's about meeting patient need and it's a huge frustration to me because I'm a  
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34 taxpayer at the end of the day.  
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41 One participant spoke about the consequent "guilt" associated with receiving  
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43 on-going support from community services when "everyone" is aware of the lack of  
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45 funding, and the blaming social narratives around ED "being a choice" not an illness.  
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47 Another spoke about feeling others were more worthy of services' limited resources.  
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49 This sense of "judgement" and "stigma" was found in the social narratives that  
50  
51 participants reflected on, such as those surrounding employment benefit and social  
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53 media. Participants felt vilified, leaving them vulnerable to internalising the blame  
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55 they heard about in their wider social contexts.  
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## EATING DISORDERS AND SPECIALIST SERVICES

**Closing Scene: Hopes for the future**

All participants shared concern about how a “one size fits all” approach promotes a sense of disempowerment, and undermines trust, compassion and hope, which were considered fundamental to living beyond this diagnosis (see Figure 6). Participants reflected how the high turnover rate of inpatient staff, particularly in the private services they had attended most commonly, acted as a barrier to consistency and compassionate understanding, as staff were not provided with necessary training.

Two in particular described their hopes that regardless of what someone’s first contact with services looks like it can be meaningful and considerate, where trust can be fostered, unlike their own experiences. Participants believe this will depend on changing attitudes in service delivery, which currently maintain an “us and them” culture, where rigidity and powerlessness promotes dependency and hopelessness:

You’re not treating them and giving them a packet of pills and saying take these and you will be better or take food six times a day and you will be better. They have to want to do it, but they need motivation and they need emotional support...even those of us who don’t want to recover...It’s not that I’m being treated, it’s that I’m being allowed to reflect and be guided to solve things my own way (pause) and it’s not a cure because it’s not making me better in that sense of the word but it’s allowing me to keep living.

Participants emphasised how they wanted to share their experiences in the hope it would help others receive timelier, or more appropriate support. Through art and online blogs; sharing their stories with advocacy initiatives and NHS representatives; becoming involved in service development and clinical practice “one day”; or being

## EATING DISORDERS AND SPECIALIST SERVICES

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3 involved in this research; all participants wanted to play their part in promoting better  
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5 understanding of EDs and encourage a more compassionate consideration of this  
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8 experience.  
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14 INSERT FIGURE 6 HERE  
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20  
21 Figure 7 contains a visual representation of the hypothesised relationships  
22  
23 between political ideology, stigmatising social narratives, and service-level apathy in  
24  
25 staff and service-users that was described by the participants. These relationships are  
26  
27 conveyed as taking place within a triad of vilification (consistent with current political  
28  
29 ideologies, and participants' perception of stigmatising social discourses),  
30  
31 vulnerability (consistent with themes from participants' life experiences) and violence  
32  
33 (consistent with the "battling" language and imagery participants used when  
34  
35 describing their relationship with services). Such a process likely undermines hope in  
36  
37 those who work in mental health settings, as it does with those who experience EDs.  
38  
39 It perpetuates a "them and us" culture between practitioners and service-users  
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41 (Richards, 2010, p.40), which reinforces the "us and them" experience the participants  
42  
43 described in this study.  
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## EATING DISORDERS AND SPECIALIST SERVICES

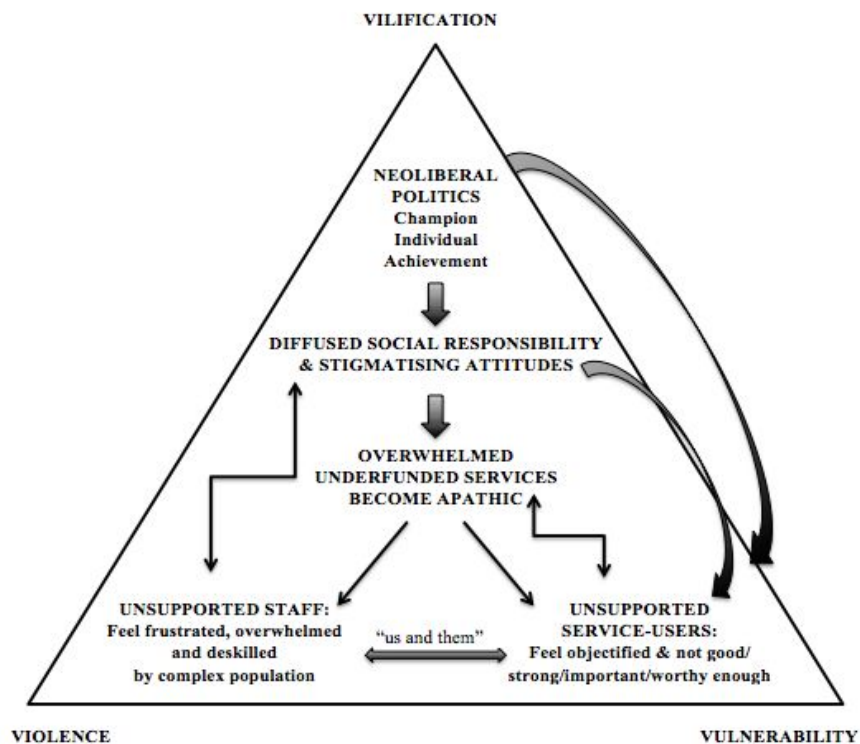


Figure 7: Triad of vilification, vulnerability and violence.

## Discussion

In analysing the narratives of eight individuals with long-term lived experience of EDs and specialist service provision, the findings presented here offer much to consider for professionals, service commissioners, and the public alike. Act One conveys an understanding of the courage and the vulnerability with which participants first encountered services. In Act Two, however, we learn that instead of finding the support they needed, a majority found punishment, and violent assault on their already tenuous identities. This led to indignation, and frustration, which fuelled a battle between participants and professionals.

## EATING DISORDERS AND SPECIALIST SERVICES

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3 In keeping with previous qualitative research, this finding highlights the  
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5 determination with which individuals with EDs seek out a sense of community to  
6  
7 protect and preserve their identities (Bates, 2015), and the role that social power and  
8  
9 belonging plays in mitigating feelings of exclusion (Cheney, 2011). Individuals who  
10  
11 have experienced ED inpatient services report the need for well-being orientated care  
12  
13 environments, and empathic staff who connect with patients as people rather than  
14  
15 sources of pathology (Sheridan & McArdle 2016). As evidenced here, the absence of  
16  
17 such conditions creates anxiety and distrust, which serves as a barrier in the first  
18  
19 instance to engagement. Thus, while psychiatric informed environments are  
20  
21 experienced as oppressive, controlling and illness-focused by many with experience  
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23 of ED (Eivors et al., 2003; Sheridan & McArdle, 2016) few of the participants here  
24  
25 described finding themselves on services' more benevolent side.  
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30 We witness a climactic Act Three where participants described the  
31  
32 dichotomised aspect of services. They were all consuming, malicious and indifferent  
33  
34 to some, while others found allies within this structure who held them in a more  
35  
36 considerate and encouraging place. This polarisation was understood in terms of  
37  
38 systemic apathy and social stereotyping, which limited understanding, and increased  
39  
40 the likelihood of delayed access to appropriate care. Stereotypical representations in  
41  
42 the mainstream and social medias reflect and perpetuate oversimplified, stigmatising  
43  
44 attitudes, and egocentric discourse around EDs being "a choice" (Bannatyne & Abel,  
45  
46 2015), which is consistent with demonising and commercially profitable political  
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48 ideologies (Esposito & Perez, 2014; Ramon, 2008). This led to a fear and avoidance  
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50 of services by the participants, which was acknowledged in the context of socio-  
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52 political vested interest in generating repeat income for private inpatient services, and  
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54 venerating the power of individualised guilt and self-blame to assure this.  
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## EATING DISORDERS AND SPECIALIST SERVICES

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3 Barriers to participants receiving supportive care were experienced at a  
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5 political, social, service and individual level (see Figure 7). In the community context  
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7 participants described missed opportunities, and examples of inadequate care that  
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9 delayed people's access to appropriate supports, reinforcing the sense that they were  
10  
11 not yet "worthy" of care. Such findings are echoed by others who report feeling like  
12  
13 they were "not good enough", and needing to "get better at [their ED]" in order to be  
14  
15 worthy of care and support (McCubbin, 2016). Thus, when services are not supported  
16  
17 with the necessary funding, training and insight to provide an appropriate level of  
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19 care, these findings demonstrate how they begin to play an active role in creating  
20  
21 "revolving door" cases (BEAT, 2015, p.35).  
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26 Similar to findings from previous qualitative research in EDs, these  
27  
28 participants shared a strong sense of unworthiness and self-hatred at various points in  
29  
30 their narratives (Godier & Park, 2014; Robinson et al., 2015; Thiel, Brooks,  
31  
32 Ohlmeier, Jacoby, & Schussler, 1995). Expanding on this literature, these findings  
33  
34 were able to root this sense of "not good enough" in the context of participants' life  
35  
36 stories, and with an understanding of the impact of abuse, trauma and feeling  
37  
38 overshadowed by the "more worthy other". Moreover, there was recognition of how  
39  
40 these feelings were reinforced in early, and some on-going, interactions with services  
41  
42 and the role that professionals can play in maintenance of participants' negative self-  
43  
44 image. In line with other research, notions of rigidity and inflexibility were discussed  
45  
46 in terms of the unhelpful aspects of a "one size fits all" approach (Turton et al., 2011),  
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48 and the need to foster hope above all other treatment outcomes (Dawson et al., 2014).  
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## EATING DISORDERS AND SPECIALIST SERVICES

**Attending to issues of power and control in clinical practice**

“The big issue” in ED literature has been portrayed as disproportionate funding compared to the seriousness of the presentations, prevalence rates and poor treatment outcomes (Schmidt et al., 2016). However, this research contests this assertion by highlighting the active role of services in shaping the experience of those who live with long-term EDs. A blind injection of funds, without a radical rethinking of how they should be employed, could cause more harm than good. Increasing detection rates, while continuing to promote medicalised, hopeless and excluding practices which don't attend to issues of power and control is not the way forward. In feminist approaches therapeutic interventions seek to model ways of managing power differentials at the political level by challenging societies' control of those affected, and at a personal level by discouraging acquiescence to social norms and encouraging a sense of legitimate agency (Surgenor et al. 2002).

Austerity measures create cultures of threat where employees do not feel secure or valued in their own roles which can promote compassion fatigue (Bhutani, Bhutani, Balhara, & Kalra, 2012; Rothschild, 2006) and increase the likelihood of staff being experienced less positively by patients. Compassion requires motivation and ability to engage with, understand and alleviate suffering, and it can rarely be born from a “doing more for less” culture (Crawford et al., 2013, p. 719), which has become the norm in UK healthcare services (Seddon, 2008). Nevertheless, it is the individuals within the system that continue to be vilified instead of the Government and organisations responsible for promoting such cultures (Crawford, 2012). Specialist ED services have a long way yet to go in providing equitable, and timely, care and support (BEAT, 2015; HM Government, 2014).

## EATING DISORDERS AND SPECIALIST SERVICES

Services should be encouraged by research which has found some evidence of effectiveness in intensive psychological interventions for long-term experience of EDs (Touyz et al., 2013) and in the consistent application of compassionate, psychosocial principles (Dawson et al., 2014; Gale, Gilbert, Read & Goss, 2014). However, this research highlights concern about the feasibility of compassionate ED service delivery in the current socio-political context. Table 2 outlines some suggestions about how we can use this information in practice to ensure these findings are responded to.

**Conclusion**

Findings presented here paint a timely revision to the picture of the wilful, defiant ED patient 'resisting' the benefits of effective treatment approaches (Eli, 2014; Fassino & Abbate-Daga, 2013; Hebebrand & Bulik, 2011). Instead they support the depiction of a healthcare system unable to connect and collaborate with the patients it ultimately seeks to serve. Similar to findings in Robinson et al.'s (2015) thematic analysis of people with experience of enduring EDs, the findings from this study suggest that individuals with long-term experience of ED are ready to work alongside services to optimise care for themselves, and for others. The question remains: are the professionals willing to acknowledge their failings and build on their strengths in a meaningful collaboration with service-users, and with the necessary awareness of the role political and organisational contexts have played in the harm that has already been caused.



## EATING DISORDERS AND SPECIALIST SERVICES

Table 1. MAKE A CHANGE: What we need to do to show we are listening

At an individual level:	At a service level:
<b>Maintain</b> an awareness about the understandable influence of eating disorder stereotypes on prejudicial attitudes	<b>Challenge</b> current practice when we know it is no longer fulfilling the role it was designed to undertake
<b>Ask</b> rather than assume how to behave and communicate with someone in distress to ensure we empower rather than offend	<b>Have</b> recruitment, training and supervision processes in place that can foster compassionate approaches to service delivery
<b>Kindly</b> report practices where we are not adequately supported or trained to work in a way that respects the people we work for	<b>Acknowledge</b> the role that services can play in the maintenance of psychological distress & the promotion of safe, therapeutic spaces
<b>Educate</b> ourselves in an understanding of eating difficulties from service-user perspectives	<b>Negotiate</b> intervention outcomes in meaningful collaboration with service-users
<b>Act</b> with compassion towards ourselves and others; it is a difficult job we do	<b>Generate</b> quality benchmarks with service-user guidance
	<b>Evaluate</b> service delivery with these in mind to ensure long term cost-effective care is fairly assessed

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<sup>i</sup> The primary author completed this research as part of her doctoral training in clinical psychology. She had no personal experience with EDs prior to spending 6 months working in a community based ED service in the North West of England. Here she was struck by the power of the stories she heard to

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make sense of seemingly inexplicable symptoms, and she developed an interest in systemic, narrative and compassion-focused approaches to understanding these experiences.

<sup>ii</sup> Severe and Enduring Eating Disorders as described in Robinson (2009).

<sup>iii</sup> The allegations of abuse referred to here were historical and had been reported and investigated at the time.

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## EATING DISORDERS AND SPECIALIST SERVICES

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Figure 2. A participant's chosen image at interview.

The Commandments

*(Mass Exodus? 2, Verse 1)*

Thou shalt be assumed to be stereotypical.  
Thou shalt eat a yoghurt with a dessert spoon, not a tea spoon, even though it is too big to fit in the pot!  
Thou shalt only eat Bran Flakes on Tuesdays & Fridays.  
Thou shalt walk, at a snail's pace, the same route at the same time every single day.  
Thou shalt not go for a walk if it is windy.  
Thou shalt be treated like a five year old at all times.  
Thou shalt be reminded to wear a coat whenever you venture out.  
Thou shalt have nobody to talk to even if you are crying your heart out.  
Thou shalt receive no TLC however bad a day you are having.  
Thou shalt not have a serviette, even if you have food round your mouth & all over your hands.  
Thou shalt not have a caffeinated cup of tea or coffee.  
Thou shalt only have one sachet of source, salt & pepper.  
Thou shalt ask permission to use the laundry (lest you should set the place on fire).  
Thou shalt be regularly woken in the middle of the night & forced to stand out in the cold, due to false fire alarms.  
Thou shalt never receive an apology if the staff make a mistake.  
Thou shalt be woken up by strangers staring at you in bed in the middle of the night (supposedly checking you are still breathing).  
Thou shalt do the same routine seven days a week, no matter how mundane & bad for your well being.  
Thou shalt not be trusted to take so much as a vitamin tablet without supervision.  
Thou shalt not be trusted with nail clippers or tweezers, let alone a pair of scissors.  
Thou shalt spread marmalade on toast with a spoon.  
Thou shalt display notices on the notice board with Sellotape, not drawing pins.  
Thou shalt eat all the food on the plate, even if the quantity is completely abnormal.  
Thou shalt eat cold custard & porridge, lest you should burn yourself.  
Thou shalt be surrounded by obese staff at all times.  
Thou shalt have all aspects of your personality attributed to your condition, to further boost your self esteem.  
Thou shalt not be deemed capable of using a hole punch or stapler without supervision.  
Thou shalt eat in silence, regardless of how hard you try to spark conversation.  
Thou shalt have your yoghurt lid removed by staff, as if you were a toddler & incapable of doing this for yourself.  
Thou shalt begin to smoke like a chimney in order to cope with the anxiety & insanity of all of the above!

The "professionals" say I am mentally ill??????????? Is it any wonder???????????

Figure 3. "The commandments" a poem written by one of the participants.

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Figure 4. Image from “Newspaper Piece”, artwork created by one of the participants. Bottom left writing reads: “NO patients allowed in this dining room at all except at mealtimes” Caption on the bottom of image on the right reads “Yay! Getting out for the weekend and party!”



Figure 5. Image from “Newspaper Piece”, artwork created by one of the participants. Caption reads: “Hey, How are you doing? xxx They don’t like us happy in here do they? x bye bye! Not normal, but fuck ‘em! xxx”



Figure 6. Image from “Newspaper Piece”, artwork created by one of the participants. Sign reads: “I’m not telling you it’s going to be easy, I’m telling you it’s going to be worth it”.

For Peer Review

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