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Lavis, Anna

Transcultural Psychiatry

Not Eating or Tasting Other Ways to Live: A Qualitative Analysis of Living Through and Desiring to Maintain Anorexia

Abstract

Whilst recent discussions of anorexia have recognised key aspects of the illness experience, such as control and emotional regulation, there remains a cross-disciplinary emphasis on body image concerns as central to anorexia. In dialogue with clinical, psychological and social analyses, this paper draws on ethnography and qualitative interviews with individuals diagnosed with anorexia to offer an alternative perspective.

Focusing on individuals' engagements with food and (not) eating suggests that material moments of starving, calorie counting and thinking about food offer a critical lens onto what anorexia does *for*, as well as *to*, individuals living with the illness. Participants' narratives show that anorexia can make it possible to retreat into a numb and protective 'bubble.' The illness thereby offers a way to be in the world that both responds to and ameliorates distress; some individuals describe the ambivalent 'safety' of living *through* their anorexia. Food practices thereby offer a distraction from distress whilst also being the modality of 'holding onto' anorexia's safety.

By outlining the relationship between food and (not) eating practices, and the desire amongst some individuals to maintain their illness, this paper contributes to discussions of treatment resistance. Intersecting with wider reflections on 'recovery' and 'harm minimisation' in mental health, it asks how this desire might be approached ethically in both analysis and therapeutic practice. Individuals' narratives suggest the need to reposition attention away from anorexia itself to the distress and life events that may underlie both the illness and the desire to maintain it.

Keywords: Anorexia; Desire; Distress; Eating; Food; Recovery; Treatment Resistance.

Introduction

Self-starvation is a core diagnostic tenet of anorexia nervosa. Although changes followed publication of the DSM-5, diagnosis remains characterised by body image concerns and excessive dieting. That this nosology positions the latter as only the process by which emaciation is achieved has been further cemented by one of the changes in DSM-5: a fear of weight gain/fat no longer needs to be verbalised if behaviours interfering with weight gain are observable (American Psychiatric Association 2013). As such, an individual's supposed concern with body image can now be *inferred* from their food-related practices, such as self-starvation.

Inferring the meaning of self-starvation, and interpreting this through the body, also has a history in the social sciences. Discussions of culture and gender in eating disorders have tended to see self-starvation as a process towards an end goal, albeit a culturally-shaped one (Bordo 1993; Hepworth 1999; Malson 1997). Anorexia, in particular, has been argued to be a quest for thinness that sits at the extreme of a 'continuum that begins with normal dieting' (Garrett 1998: 23). Whilst highlighting these meeting points between culture and anorexia is important, there is a temporality to this framing of self-starvation as 'about the body,' which is less recognised, and requires consideration. It interprets anorexia as *reactive* - produced by external forces on a passive body – and imputes meaning retrospectively from the thin body, thereby assuming a particular teleology that dualistically privileges body over voice.

In contrast, discussions of anorexia, particularly in psychology, have explored relationships between the illness and affect. Bruch (1973) suggested that difficulty in identifying and describing feelings is common to individuals with eating disorders. Difficulties in emotional regulation have long been described in relation to bulimia nervosa (See Cooper et al. 1988) and more recently there has been a renewed interest in emotional regulation in anorexia. This has explored alexithymia and also engaged with self-starvation

as a way of regulating one's feelings (Brockmeyer et al. 2012; Fox 2009; Gilboa-Schechtman et al. 2006; Harrison et al. 2009; Kyriacou et al. 2009). Moreover, emotional regulation has been identified as a maintenance factor (Serpell et al. 1999).

Echoing these discussions of affect, a recent focus on interpersonal functioning has explored experiential aspects of anorexia. Avoiding expressing feelings, and giving priority to others' feeling over one's own, has been identified (Arcelus et al. 2013; Cervera et al. 2003), as has low existential well-being Fox and Leung (2009). This resonates with anthropological analyses which have argued that 'existential angst is a core feature of eating disorders that is often overlooked in approaches that focus on cultural pressures about weight and body image' (Lester 2014: 249).

What is 'overlooked' in experiences of anorexia is a focus of various recent ethnographic explorations. The illness has been discussed as a modality of care for self and others (Lavis 2015 a) and a way of being in the world that is felt to leave no trace and not to harm others (Lavis 2014). These can underpin an ambivalent desire to maintain the illness (Lavis 2011; 2016 a). Also reflecting on ambivalence, Eli employs the concept of liminality to explore the in-betweenness of anorexia (2014) and interrogate embodied social being with the illness (podcast 2014). Exploring 'everyday worlds of anorexia' (Warin 2010) offered Warin a way to address the 'embodied sentience' (2003: 78) of the illness, focusing on the senses rather than bodily emaciation. Reflecting on intimacies of cleanliness and abjection, she argues that anorexia has a 'logic of practice (2010: 177). Gooldin also engages with embodied processes of 'being anorexic' (2008). Charting ways in which 'hunger plays a crucial role and in which everyday (mundane) practices acquire out-of-the-ordinary meanings' (ibid. 275), she explores how cultural templates of morality become present in illness subjectivities and practices. Lester too has highlighted how anorexic bodily practices become moralised (1995). Intersecting with her wider work on eating disorders treatment (2009), she highlights the 'moral imperative extending well beyond issues related to body weight and shape' (2014: 241). Echoing this focus on morality, O'Connor and Van Esterik (2008) argue that 'anorexics [are] misguided moralists, not cognitive cripples' (ibid. 7. Also Giordano 2005).

These discussions show anorexia to be more complex than a focus on bodily emaciation, or even on emotional regulation, allows. A shared anthropological interest in

embodied practices casts light on complex meanings of the illness. These have been accompanied by analyses (Cheney 2013; Lavis 2013, 2016 b; Warin 2003) that explore culturally-situated meanings of food refusal in anorexia. Yet, to date little attention has been paid to the material intimacies of individuals' engagements with food and the ways in which these cohere around a central pivot of desire. Therefore, this paper approaches food as a continually navigated *presence*, rather than simply an absence in anorexia. It thinks through the meanings and functions of what we might term 'food related not eating practices.' Individuals' accounts illustrate that not eating can be as much about engaging with food as avoiding it, and that both are key to relationships with anorexia.

As such, food and (not) eating practices offer a novel pathway into the value that anorexia may have for some individuals diagnosed with it. In dialogue with discussions of the impact of self-starvation on emotion, noted above, these visceral practices illustrate what anorexia does for, participants. Focusing on this aspect of the illness's meaning is not an attempt to dislocate anorexia from cultural context, or disregard the attention to cultural triggers present in body-focused analyses. Rather, it allows a tracing of how anorexia and culture touch edges in more intricately embodied ways, as anorexia can come to be desired for its function.

This paper will show that the illness may be experienced as simultaneously a cause of, and yet solution to, 'biographical disruption' (Bury 1982). Anorexia offers a way of getting by day-by-day as participants live *through* the illness, feeling that it 'looks after' them. As such, self-starvation emerges as a fragile way to maintain anorexia and its 'safety'. Not eating is thus a paradoxical mode of self-care in a world of potentially painful interpersonal relationships and emotional pain (see also Lavis 2015a). This recognition problematises any assumption that a desire to maintain anorexia articulated by some participants is primarily about being or becoming thin. Instead, self-starvation emerges as an attempt to live through the present moment. The illness is described as offering a way of being in the world that both responds to and ameliorates distress.

Yet, this linearity of cause and effect in the relationship between a desire to maintain anorexia and not eating is also not the end of the story. Self-starvation, anorexia, and desire all produce one another in ways felt sometimes to be agential and wanted and, at other times, painfully out of control. Participants' agency may be simultaneously shared with

anorexia and also lost to the illness. Interrogating this requires a topological rather than linear way of approaching the illness in analysis.

I have previously argued (Lavis 2011) for a topological approach when exploring individuals' desire to maintain their anorexia. This approach comes to the fore here, as we access desire through the critical lens of not eating. For this, 'we need to think and write in topological ways, discovering methods for laying out a space, for laying out spaces, and for defining paths to walk through these' (Mol and Law 2002: 8); topology 'doesn't localise objects in terms of a given set of coordinates' (Mol and Law 1994: 643) and it is also, to borrow from Serres, 'tactile' (2008: 81). As both eating (Abbots and Lavis 2013; Probyn 2000) and desire (Grosz 1994) have been argued to forge connections, a topological approach engages with the space *inside* the illness that is apparent in participants' narratives. Many participants describe this space as numb and also as a 'protective' 'bubble'. It is a space made through the tangle of threads that connect anorexia, not eating, and desire.

Although my use of 'desire' to conceptualise a valuing of anorexia comes from participants' narratives, I do not assume this term to be unproblematic. The paper pays attention to ambiguity and multiplicity not only in individuals' relationships with anorexia, but also contained within desire itself. It would be unethical to assume that desire for anorexia is either fully agential or just 'the anorexia talking' (Tan 2003). Recognising that both may be true at once illustrates that desiring to keep anorexia is not necessarily a choice as the illness may attenuate *and* compound distress. Exploring not eating, thus, attends to desire whilst also recognising that this may be wanted, held on to and actively worked upon, but also unwanted and even painful (see also Lavis 2011: 225). It also does not ignore participants' suffering.

The paper acknowledges the clinical realities of anorexia, and recognises that many individuals with anorexia do not feel desire to maintain their illness. Anorexia has 'one of the highest mortality rates of all psychiatric illnesses' (Bogle 2000: 2). It has been suggested that 'in the long run subjects with anorexia nervosa have an almost four-fold risk of dying compared to healthy people the same age and sex' (Van Hoeken et al. 2005: 18). Yet it is perhaps because, not in spite, of anorexia's dangers that it is important to listen to individuals' voices, in all their depth of desire and suffering. Intersecting with wider

discussions of 'recovery' and 'harm minimisation' in mental health, this paper therefore asks how the tangle of desire and distress may be approached ethically in both ethnographic analysis and therapeutic practice.

Studies and Methodology

The paper draws on two qualitative studies.

Study One

This was undertaken for an anthropology PhD (2006-2011) and it comprised participant observation and interviews with service users and staff in an English National Health Service (NHS) eating disorders inpatient unit (EDU), and on pro-anorexia websites. It was funded through an Economic and Social Research Council studentship and received university ethics approval. The year of ethnography in the EDU (2007-2008) also received ethical approval from the NHS and informed written consent to 'hang around' as an ethnographer was gained from all inpatients and staff. The total number of EDU service user participants was 45. 40 staff members also took part, but the staff interviews are not referred to here. The number of online interview participants was 15.

In the EDU interview recruitment was carried out by the author. After checking capacity to consent and any potential for distress with the nursing team, I approached service users with a participant information sheet and invited them to take part in an interview. If they refused, they were not asked again. Informed written consent was obtained from all interview participants in addition to the observation consent form already signed. Unstructured interviews took place on the EDU in spaces chosen by participants. Interviews lasted between one hour and seven hours, sometimes split over different occasions, all at the direction of the participant. If the interview was divided over more than one occasion, informed written consent was taken on each occasion and re-confirmed verbally afterwards. Interviews were transcribed by the author and their own transcript was shared with each participant for member checking (Koelsch 2013) and the opportunity for comment or discussion.

Recruitment for the online interviews with pro-anorexia website participants was undertaken in two ways: I approached some participants through existing pro-anorexia spaces that I had consent from the website creator to 'hang out' in as an ethnographer. Each time I entered a 'live space' of a site, such as a chat room, this permission was resought from all participants present at the time. I also set up a 'Pro-Anorexia Research Group' on *Facebook*, which people asked to join, with some participants also inviting others (see Lavis 2011 for more details). When individuals joined the group during the study period I invited them to take part in an online interview. If an individual refused to take part in an interview, they were not asked again. Interviews were conducted as a series of *Facebook* messages or email exchanges with the author. Informed consent was continually reconfirmed in writing throughout.

Interviews in both field sites focused on participants' feelings towards their eating disorder. They all began with the question 'if I say anorexia/bulimia/EDNOS [as appropriate], what do you think of?' From there, I followed the discursive and analytic emphases of participants themselves.

Study Two

This comprised interviews with service users of English NHS eating disorders outpatient, daypatient and inpatient services (2013-2015). It was funded by the Collaboration for Leadership in Applied Health Research and Care and received ethical approval from the NHS. The total number of service users interviewed was 30. 15 carers (relation/friend) also took part in an interview, but these are not referred to here.

Recruitment was two-staged: A study PI who is also a clinician in the NHS service in which the research was set identified service users according to the inclusion criteria. Individuals were then approached by a member of the study team (author, another PI, or one of two RFs). They were given information about the study and asked if they would like to take part. If an individual refused, they were not asked again.

Each participant took part in a semi-structured interview with a member of the study team. These were conducted in clinical settings or in a participant's home, at the participant's choice, and lasted approximately an hour, also at the participant's direction.

Informed written consent was taken prior to the interview and reconfirmed verbally afterwards.

The focus of this study was to explore risk factors for eating disorders. Although the majority of questions focused on participants' recollections of the events and feelings leading up to development of the illness, some questions asked about participants' feelings towards this now. . Topic guides were flexible; although all written questions were posed to all participants, we also invited participants to talk about any other aspects of experience they felt it important to highlight to the researcher. Interviews were transcribed by a professional transcribing company and quality checked by the author. All names in the paper are pseudonyms.

Analysis

In both studies, interviews engendered a process of co-examination between participant and researcher of the meanings of their eating disorder. Transcripts were analysed by the author using iterative thematic analysis (see Braun and Clarke 2006). Conducting the analysis concurrent with data collection in each study ensured iterative interaction between data and analysis to enhance reliability (Morse et al. 2002). Overall reliability was established through a further analytic process in which the transcripts of each study were compared to those of the other.

Although both studies were participated in by individuals with various eating disorders diagnoses, and I acknowledge the diagnostic fluidity of eating disorders and overlapping experiences among these, comparing transcripts across the two studies identified subjectivities and experiences distinct to the participants diagnosed with anorexia nervosa. Their narratives share an emphasis on connections between suffering, agency, and desire, and relationships between these and self-starvation. Therefore, this paper only includes accounts of individuals with anorexia. Drawing out their specificities and commonalities is intended to offer clinically-applicable insights into complexities of living with and *through* anorexia.

'A Safe Space:' Living Through Anorexia

Not Eating as Self-Anaesthetisation

During his interview in the EDU Laurie reflected on his anorexia; although calling it his ‘dirty illness,’ Laurie described resisting attempts by staff to increase his diet, and hiding and throwing away food to avoid eating. Arguing that he wanted to ‘keep [his] anorexia for now’ and that eating would ‘take it away,’ Laurie explained, ‘it’s a friend, definitely a friend. It keeps me company and it helps me.’ Laurie’s mother had recently been diagnosed with a terminal illness. Relating his pain and prospective grief, he said of anorexia, ‘it’s a way that I cope.’ In explaining that anorexia’s ‘help’ lay in its attenuation of distress, Laurie echoed many other participants. Elle said, ‘it sort of helps to relieve feelings and stuff. It does its stuff so I don’t have to feel them.’

These accounts support analyses of anorexia as ‘a functional coping strategy in which control of eating serve[s] as a means of coping with ongoing stress and exerting control’ (Eivors et al. 2003: 96. Also Treasure and Schmidt 2008; Williams and Reid 2009; Zanker 2009). Whilst these discussions often portray the body as the locus of that control, they also highlight cognitive processes through which self-starvation regulates affect. Described as allowing individuals to ‘avoid dealing with other problems’ (Cockell et al. 2002: 77), anorexia is recognised to produce emotional numbness. This is illustrated by Elisa, who developed anorexia after her sister became ill:

I became quite depressed and quite anxious. It relieved that to an extent and made me kind of be able to be numb. I felt completely... it’s hard to put into words really but it’s almost like everything became a bit of a blur and like I was living in this kind of cloud where I didn’t really feel anything at all because I was so nutritionally deprived. I just couldn’t feel anything about...that’s something that I think I felt I needed.

Abigail likened being in treatment to ‘having an anaesthetised limb cut off.’ She said, ‘it’s better to keep it anaesthetised so it doesn’t hurt. That’s why people continue to be anorexic, so they can remain anaesthetised.’ Abigail’s simile questions an assumption of numbness as *only* a by-product of nutritional deprivation.. Whilst participants widely recognised the physiology of this numbness - as engendered by the neurological effects of starvation – many also described actively working to (re-)produce and maintain it. This was done not only by starving but also engaging mentally with food. Laurie said:

I was never getting upset about mum's illness and stuff like that, I was just blanking the fact that she was ill. Erm, so I'd keep myself occupied with food issues. [...] while you are actually paying attention to food, your brain doesn't... it thinks consistently on one item, it doesn't usually go back to: oh you're upset. It's just literally food, food, food.

Laurie's words – 'I kept myself occupied with' - echo those of other participants who described agentially undertaking self-anaesthetisation through a dual process of not eating and continually thinking about food. Lacey, who recounted a difficult relationship with an alcoholic father, described how this worked:

I think it occupies so much of your mind as well that you can't really think about all the shit stuff, like I remember sitting on the bus on the way back from school and it was a Friday so my dad... dad would be home, 'cos he worked away in the week and then he came back on Friday. And I got off the bus and I realised that I'd spent the entire bus journey counting the calories that I'd eaten that day, and that I was gonna have to eat when I got home. [...] Like looking back on that, it was just like I was thinking about probably so I don't have to think about everything else.

Likewise, Emma, who related her pain at a friend's suicide, said, 'I spent like a lot of time like calorie counting. That was like a coping mechanism. Like people self-harm like so they don't commit suicide, so I started doing it so I didn't like feel down.' Although on the one hand, this doubling of not eating and calorie counting supports discussions of 'a simultaneous refusal to eat and incessant preoccupation with food' (Heywood 1996: 17) unagentially set in motion by nutritional deprivation, it also emerges as a process with an, albeit painful, logic and agency. These visceral practices signify the continual effort to reproduce anorexia, and thus the protective numbness it offers. It is through this recognition that anorexia as a very visceral modality of coping becomes clear.

Many participants describe food as 'scary' and explain this fear to be underpinned by the threat eating poses to anorexia. Yet, some individuals also elucidate that calorie counting and allowing food to fill their heads can be a deliberate mechanism to incite this fear. It draws *too close* to food to be comfortable. Participants describe using this discomfort to engender a 'rising up' of anorexia; they agentially self-trigger the illness (see

also Lavis 2011). Although, as discussed later, this upsurge of anorexia can feel frightening and out of control, here triggering is employed to '(re-)bring on' the numbness that anorexia offers.

The visceral not eating practices traced so far in this paper thereby emerge as a painful and multi-layered work of self-care through which pain is attenuated as the illness is reproduced and strengthened. Such descriptions of strengthening anorexia to (re-)gain its anaesthetisation importantly highlight that anorexia is not only a response to prior or ongoing distress; to participants it also offers an, albeit precarious, solution. Numbness is not merely a secondary effect of self-starvation practices that are aimed at bodily emaciation or control. It is a central way to make it through the present moment, which may continue to pose otherwise unbearable pain. Or, as Lacey put it, 'I'm doing this to make me feel happy.' In indicating how anorexia may become valuable, her words suggest that the numbness it offers is more than a simple absence of pain.

Numbness Spatialised: Absence, Presence and Connection

Overlaying physiological effects of self-starvation with a constant mental engagement with food transforms the numbness offered by anorexia into something more tangible and tactile than a mere absence of feeling. In a different context Oakley has argued that numbness equates not to a loss of feeling but to a 'buzz of diffuse sensations' (2007: 76). Following this, we might say that the numbness in participants' accounts comprises the potential for a different sort of feeling. Claudine said of her anorexia:

You just sit there and sometimes it manifests itself in a sort of numbness and I'll just lie on my bed, stare into space and I'll sleep a lot or something like that. I just want to stop thinking and you do almost, zone out as it were.

There is stasis and retreat to Claudine's words as anorexia's numbness is felt to create a space in which to 'sit', 'rest,' and 'stay,' as other participants put it. Showing this spatialised numbness to be key to the value of anorexia, Esther described the illness as having been 'a safe place for years.'

Emilia said, 'I think it [anorexia] becomes a bit of like a friend, like it's a, it's almost like it's a world that you live in that's separate from everybody else.' The spatiality to such

descriptions of the illness as a separate 'world' elucidates how the dual processes of engaging with food but not eating described above forge the space of the present moment for and around participants. Through these, anorexia mediates how individuals live through, and move beyond, the present moment, and may be the only way in which they are able to do this. Beginning this analysis within this space offered by *existing* illness has thereby offered a critical entryway into how not eating is circular and processual rather than aimed at a teleological end-point. Through it, , distress is soothed, numbness is created and relationships with anorexia are played out day-by-day. Importantly, these processes also show anorexia's spatiality to be a mode of connection as well as disconnection. In her interview, Nita said:

It's that safety from other people, really. protection from life in general [...] it just kind of felt like I was being protected and in this little bubble of anorexia that er, those worries kind of, you know, couldn't get in. [...] There's a real safety there, that erm, anything I can't deal with in life, any worry, anything that's difficult, either the, you know, the eating disorder or the anorexia's there to protect you from it.

Whilst a sense of anorexia offering 'a space apart,' particularly from other people, does resonate through Nita's narrative, her words also suggest that the numbness of anorexia is not only about disconnection. In demarcating a 'protective' space, 'cloud' or 'bubble,' anorexia offers a safe way to be *in* as well as *apart from* the world. It signifies a protected way to navigate the world from *inside* the illness. Cally described retreating *into* anorexia in situations she finds too difficult so that the illness can be 'out in the world,' as she put it, 'instead of [her].' This suggests that whilst allowing her to appear and feel absent, anorexia actually enables her to be present in situations that might otherwise be unliveable. Cally suggest that part of the value of the illness to her is that agency can be shared with, or handed to, anorexia when needed. Likewise, Jumela described anorexia with the words 'it holds my hand' and Leila said, simply, 'it looks after you.' These statements offer up to analysis a sense of anorexia as not only acting *on* participants, but also *for* them; they show the valued numbness to be intrinsically tied to a sense of relationality between participants and their illness. Taking up these dual threads of agency and relationality, the next section will engage with the desire to hold onto the illness that is underpinned by the functions it comes to have for participants, as charted in this section. It will show how 'desires and

subjectivities are not given, but rather arise in specific material and corporeal relations' (Law and Moser 1999: 249) of not eating, as anorexia both makes the space of the present and (re-)emerges through it.

Entanglements of Not Eating and Desire

Desire to Maintain Anorexia

Describing anorexia as the only thing that allowed her 'to exist', Elle said of her illness, 'I just don't want to be without it. It's as simple as that really.' Likewise, Milla described anorexia as 'something you feel quite protective of; you don't want anybody to sort of rip it away from you.' She described the threat of this 'ripping' as something that would leave her 'raw', 'alone' and 'unsafe'. The desire to maintain anorexia that these statements evince has been recognised. It is acknowledged that 'core features of eating disorders can be highly valued' (NICE 2004: 6.5.5). This has been put forward as a 'maintenance factor' (ibid. 354) that influences drop-out from (Eivors et al. 2003), and poor response to (Löwe et al. 2001), treatment. Or, as Lacey put it, 'it [anorexia] was something to be, like, defended then, 'cos there were people attacking it and I didn't want them to.' Warin has suggested that a desire to be anorexic can be 'an important dimension of [individuals'] lives' (2010: 82). and Girard (2013) has reflected on desire for the illness as 'mimetic,' thereby framing anorexia as contagious. Yet, such a focus on the desire to *become* rather than *remain* anorexic arguably positions the object of desire as bodily thinness (see also Bruch 2001). This conceptualises desire as prior to anorexia, rather than arising within it, and intersects with a wider imagining of desire-as-lack common to psychoanalysis (eg. Lacan 2001). It also envisions the illness as primarily a teleological 'relentless pursuit of thinness' (Yin Lim and Agnew 1994: 309) as future goal.

In contrast, the voices in this paper have offered a different portrait. I argued earlier for numbness to be re-sited from the peripheries to the centre of analysis in line with participants' accounts of its centrality to living through anorexia. In turn, participants' narratives of living through this spatialised numbness shift bodily emaciation from the centre to the peripheries, but they do not efface it. Instead they proffer alternative understandings of desire for anorexia, seeing it as arising from *within* the illness. Indira said,

‘You get caught up in shape and weight, but for a whole load of other reasons’. When asked how she felt about her anorexia, she said, ‘I think it’s serving a function because it helps me. [...] It does still numb me from other things.’ Indira then explained the relationship between her anorexia and emaciation with the words, ‘so if I can get my fingers around the top of my arm then I feel safe.’ That this statement echoes the ‘safe space’ of anorexia earlier is not a coincidence. It illustrates how, although not a central goal of not eating, bodily thinness becomes caught up in the (re-)production of anorexia’s safety.

Milla described continually circling her arms with her hands to check for weight gain. Yet, she did not express a wish to become thin or, even, become thinner. Instead, Milla explained that emaciation had *become* important to her *after* developing anorexia. This is because, if the dual processes around food and (not) eating described above re-produce and strengthen anorexia, thinness offers a visual marker of this reproduction. It reassuringly indexes the continuing presence of the illness, attesting that you have not eaten too much and thereby threatened it. This recognition shifts our understanding of statements such as Yvette’s; she said, ‘If like I ate something that was, sort of, not what I would normally eat, then, like, I was worried that I would put on weight and sort of lose control.’ Her words evince how the body is drafted into the day-to-day process of maintaining anorexia to cope with day-to-day life. In highlighting the temporality through which thinness becomes important to participants as a measure of its numbness and safety, these narratives suggest that anorexia is enacted *with* the body but never simply *about* the body. This necessitates a reconsideration of the desire for the illness. Repositioning bodily emaciation to the peripheries and articulations of living *through* anorexia to the centre shifts the illness from a *means to a desired end* in the future to *the object of desire itself*.

Connections and Spirals

The visceral not eating practices described earlier as key to holding onto anorexia day-by-day therefore suggest the need for a conceptualisation of desire in line with that proposed by Deleuze (2007), extended and challenged by Grosz (1994. See Lavis 2011). Grosz writes, ‘desire can instead be seen as what produces, what connects’ (1994: 165. See Warin 2010). This imagining of desire allows us to recognise that the space inside anorexia is (re-)produced and textured by the ways in which the illness, not eating, and bodily emaciation

are continually connected and reconnected by participants. This echoes Probyn's discussion of desire, informed by Deleuze and Grosz. She says that desire 'produces the pleats and folds which constitute the social surfaces we live' (1996: 13). As we have seen, in participants' narratives those social surfaces are folded into anorexia; it is through the tangible numbness and the presence of the illness that individuals describe being able to move through – survive - the world; anorexia offers them a way to attenuate distress and beyond the present moment. Yet, this is also not all there is to say; whilst narratives of living through anorexia unsettle the, perhaps seemingly axiomatic, relationships among desire, anorexia and emaciation, they also invite their own reflections.

In her interview Libby said, 'it's not so much a competition with the other girls but a competition within myself as well, to stay as anorexic as possible.' Alongside the perpetual bodily checking above, Libby's words confirm the earlier accounts of maintaining anorexia as a process that takes continual work. This shifts our perspective on statements such as Leila's that anorexia 'helps you so you help it.' Although it was clear from her interview that this sense of reciprocity is key to Leila's conceptualisation of anorexia as a 'friend', her words also suggest that maintaining the illness requires individuals to always eat a little less than before. As such, not eating, and agentially triggering anorexia to (re-)produce numbness as described earlier, risk reproducing anorexia *too much*.

In her interview Miriam said, 'sometimes I could sit and talk to someone perfectly rationally about food ... but put me in front of it ... phewf, that's bad!' Like other informants, Miriam attributed this profound fear of food not only to how it threatened anorexia but also to how it might trigger the illness in a way that was unagential. On the flipside of the agential inciting of anorexia to strengthen its protective numbness, discussed above, Miriam described how she might suddenly feel herself to have 'too much anorexia.' Then, she said, 'there's too much of it and then there's less me'. Through this process anorexia's space transforms from 'safe' to entrapping as safety and an ability to function in the everyday are no longer maintained through anorexia, but lost to it.

Describing this as 'like rolling down a slope,' Lacey evinced the loss of agency by describing anorexia as 'something I did and just couldn't stop doing.' Likewise, Jane recounted how anorexia 'got a tighter and tighter hold on me' and Zahara said, 'I felt like I wasn't existing.' Illustrating the stark inverse of the valued numbness, Zahara's words illustrate that desire for anorexia is, following Berlant (2010), invested with 'cruel

optimism.’ She suggests that when describing something we desire, ‘we are really talking about a cluster of promises we want someone or something to make to us and make possible for us’ (2010: 93). Borrowing from Berlant, we could say that anorexia as an object of desire ‘provides something of the continuity of the subject’s sense of what it means to keep on living on and to look forward to being in the world’ (ibid. 94). Yet it also shows how relations of attachment can be ‘too possible, and toxic’ (ibid. 94); practices of not eating that hold onto anorexia are precarious.

Circularities and Entrapment

Yet, whilst demonstrating that living through anorexia may perhaps inevitably have extremely painful limits, this spiralling also does not necessarily signify the end of desire. Elisa described wanting to recover ‘but at the same time not really wanting things to get any better, um, because there's still all those positive things that it gives me.’ It has been suggested that ambivalence ‘is part of eating disordered behaviour’ (Treasure et al. 2007: 86) and that ‘at the same time as receiving positive, egosyntonic effects from the behaviours those with anorexia may also acknowledge the negative effects, causing strong feelings of ambivalence’ (Williams and Reid 2009: 1). Elucidating this simultaneity Tanya said, ‘people don’t seem to understand that eating disorders really are Hell,’ whilst also describing visiting pro-anorexia websites every day to help her ‘stay anorexic.’ Dawn pointed out that such ambivalence ‘is just conflicting thoughts.’ As her words suggest, the desire to hold on to anorexia may be fractured or fluid, as hatred and longing for anorexia are often juxtaposed within the same sentence.

In the introduction I argued for a topological approach to analysis and the simultaneity rather than linearity this allows has been key to understanding participants’ narratives throughout this paper. To return more explicitly to this now, drawing on Grosz’s use of a Möbius strip as a way of thinking through subjectivity, we might say that participants’ accounts illustrate ‘the inflection’ (see Grosz 1994: xii) of desire in ambivalence and ambivalence in desire. Importantly, feeling lost within anorexia may reinvigorate a desire for the illness. Some participants describe how it provokes a longing for the safety that anorexia offered *before*. This in itself may incite a renewed effort at the food centred practices described above, in order - to trigger, reclaim and strengthen one’s ‘friend’ anorexia.

Thus, if as Deleuze argues, ‘desire assembles the social field’ (2007: 129), perhaps it is the particular shape, as well as dynamic, of desire that we need to recognise in individuals’ narratives of anorexia. Ambivalence and need may become part of desire itself, as living *through* anorexia both attenuates and compounds distress in increasingly small circles; as a solution to distress, anorexia perhaps ultimately only soothes the pain that it causes even though it may offer the only way of getting by ‘for now’ as Laurie put it. This elucidates that desire for anorexia and the practices of (not) eating and engaging with food that are entangled in it do not necessarily imply choice or even agency. Maintaining the illness may be about finding ways of living within increasingly compromised conditions of possibility, some of which ensue from the illness itself.

Reflections and Clinical Implications: Finding Meaning *Within* Anorexia or ‘Starting to Taste Other Way of Living’?

Engaging with Lacey’s statement that ‘people don’t see sort of, what’s underneath [anorexia],’ this paper has sought to explore experiences of eating disorders beyond the lens of emaciation (See also Eli 2014; Fox and Leung 2009; Gooldin 2008; Lask and Frampton 2009; Zanker 2009). Through ‘roaming and meanders,’ which Coles (2013: 256. Also Geertz 2010) has argued are ‘implicit in any consideration of topology,’ it has traced the multi-directionality of relationships among food practices, emaciation and desire. This has offered a way to explore what anorexia does *for*, as well as *to*, individuals, and has elucidated its complex relationship with distress. The illness may simultaneously feel profoundly painful and yet also be integral to getting through, and remaining in, the world- to ‘existing’ as Elle put it. ; or as Emma said earlier, anorexia may be equated to how people may ‘self-harm like so they don’t commit suicide.’

Tracking back and forth across the numb, ‘safe,’ space inside the illness has thereby offered a ‘micro-analysis’ (Deleuze 2007) which has brought into view ‘the immanent fields that people, in all their ambiguity, invent and live by’ (Biehl and Locke 2010: 317). This has not only allowed recognition of desire, which Deleuze argues to be ‘the element of a micro-analysis’ (Deleuze 2007: 125), but also of suffering and loss of agency. Without assuming participants’ agency to be unaffected by the illness, it has argued for the need to listen to individuals’ articulations of desire for anorexia, recognising the complex but ordinary functions that the illness may have. Yet, in the lives lived beyond the paper’s margins, it is

perhaps suffering that most evokes the limits of such an engagement. A palpable conjoining of desire and suffering invites consideration of how it is possible to respond to a call for clinically-useful qualitative findings (See Bezance and Holliday 2013) whilst remaining multi-dimensionally ethical to the individuals whose narratives are replete with such layering and complexity.

Focusing on not eating as a way to access the entanglements of desire and anorexia has offered insights into high rates of treatment resistance in anorexia. As Tan argues, 'on the one hand, psychiatrists risk dereliction of duty of care by allowing patients to come to harm; on the other, they risk medical paternalism by overriding patients' choices' (2003: 1246). It has been suggested that it can be ethical to accept treatment refusal, especially against a background of prior treatment failure (See Draper 2000; Matusek and Wright 2010). Yet it has also been argued that 'anorexia nervosa is not inevitably a progressive terminal illness' (Melamed et al. 2003: 62) and it is therefore 'preferable that treating physicians focus on the preservation of life' (ibid. 62). Self-starvation as a modality of self-care through anaesthetisation casts a different light on how 'the removal of ingrained anorexic behaviours leaves the patient feeling desperately out of control' (Zanker 2009: 329); it shows quite how tactile that feeling is. If not eating maintains anorexia, and emaciation allows it to be reassuringly measured through the body, the weight gain of treatment potentially demonstrates a profound loss. This is made more acute as recovery so often entails confronting the painful life experiences that initially necessitated anorexia's 'helpful' numbness. As Brockmeyer et al. have argued, 'an exclusive focus on feeding and weight restoration in the treatment of AN may deprive the patient of an extremely important coping mechanism without providing a more functional one' (2012: 500).

Against this background, we might suggest that if it is progression of illness – and thus preservation of life - that requires clinical intervention there is a case for reflecting on anorexia in relation to wider discussions of, and practices around, recovery (Deegan 1988; Adame and Knudson 2008; Hall et al. 2013; Leamy et al. 2011) in mental health. Although the increasing application of recovery discourses to clinical practice in the UK has been contested for what has been seen as a neoliberal and outcome-based takeover of its original rights-based definition (see Harper and Speed 2012), a core emphasis on recovery as a process of moving towards 'a new and valued sense of self and purpose' (Deegan 1988: 11) is useful here. This focuses on living well with illness rather than the removal of clinical

symptoms (see Slade and Longden 2015). Certainly some research participants explicitly argued for treatment to include the possibility of aiding an individual to remain anorexic and retain, or find, meaning within this process. In her interview, Charlene said, 'I still feel whatever people's problems or illnesses or whatever, if they make a decision and it's their life, it should be respected.' Such a call to be left alone, or aided to continue, one's 'quiet starving,' as Chloe put it, can be compared to the discussions of how to maintain a 'healthy anorexia' on pro-anorexia websites. There, 'healthy anorexia' is defined as one that successfully negotiates not eating and yet not dying on a day-to-day basis (see Lavis 2011). This, therefore, allows the perpetuation of certain food-centred practices, and may be enough to stay alive whilst maintaining anorexia's numbness if that is desired, or needed perhaps.

Yet, this bleak binary of not eating and not dying also confronts us with the fact that anorexia's numbness may be comforting but it is also perhaps ultimately a state of painful limbo; one that takes a huge and painful effort to maintain. Therefore, to leave individuals within, or help to perpetuate, this limbo would perhaps be unethical. It may not embody the central tenets of the recovery movement noted above as it could perhaps rarely aid a living well with anorexia. Instead, it may risk a return to a therapeutic pathway of chronicity and hopelessness, deterioration and damage limitation, so critiqued in relation to 20th century psychiatry (see Johnstone 2000) and its management of 'schizophrenia' in particular.

Moreover, the option of leaving individuals shut inside a potentially increasingly cramped and unagential space of anorexia is also not necessarily supported by participants' narratives. This paper opened with Laurie wanting to keep 'anorexia *for now*.' Like many other participants, he saw it both as part of him and also as his way of coping. He felt that it had come out when he needed it to during a particularly difficult time in his life and he hoped that it was a temporary solution to distress. As such, although treatment is often described as terrifying, it does also sometimes signal a change of texture to participants' accounts as they look back on their erstwhile friend, anorexia. Lacey, whose voice we have listened to throughout this paper, said, 'I think I'm...I'm too awake to it now for it to be as good as it was.' As her ties to anorexia loosened she said, 'I feel like I'm starting to taste other ways to live.'

Thus, perhaps what is needed in both analysis and treatment is a thoughtful engagement with the nuance of what 'tasting other ways to live' could or might mean for an

individual whose anorexia offers a way of living through or getting by. Such a reflection would need to step between the symptom removal of much current clinical treatment, and the 'quiet starving' of holding onto anorexia, to focus on the present moment – the space inside the illness – as this paper has attempted to do. Aiding individuals to maintain and live through their anorexia in a safe way *for now*, and avoid the descent into a loss of agency or life-threatening emaciation, would echo a harm minimisation approach. This first emerged in discussions around substance misuse (Newcombe 1987) but has more recently been called for in relation to self-harm (Holley et al. 2012; NICE 2011). Whilst not necessarily suggesting that a 'living well' with illness can ultimately ever be found in anorexia, this approach would, importantly, not take away the meanings and function that the illness holds for individuals now, as they live through distress in the present moment.

Arguing that anorexia may be a response and painful solution to past or ongoing distress also, importantly, suggests that key to understanding and aiding those with anorexia is the reintegration of the illness into contemporary discussions of the relationships between traumatic life events and mental ill-health (see Romme and Escher 2012; Tew 2011). Arguably a pervasive focus on anorexia as *about* the body has served to disconnect the illness, and its treatment, from such a recognition. By reinstating these intersections, this paper has called for a topological and situated approach to the myriad contact points among anorexia and individuals' lives, bodies and emotions. Only through this, perhaps, might we begin the task of forging forms of support that replace those offered by anorexia itself. Overall, this illustrates that listening to individuals' voices is key to forming empathetic understandings of anorexia and ways to approach it in therapeutic practice.

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