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Journal of Health Psychology

**‘Eating disorders are not about food, they’re about life:’ Client perspectives on
anorexia nervosa treatment**

Nicola M. Rance, University of the West of England, Bristol

Naomi Moller, The Open University

Victoria Clarke, University of the West of England, Bristol

Abstract

Poor success rates and high levels of dropout are common features in the treatment of anorexia nervosa. Using semi-structured interviews this study elicited the views of 12 women who were recovered, or in recovery, for anorexia nervosa and had received treatment. Results derived from a thematic analysis revealed the women’s high degree of dissatisfaction with treatment and their perception that the treatment system is overly focused on, and driven by, food and weight. In contrast, what the women really wanted was to be seen and treated as a ‘whole person’ and to have a ‘real’ relationship with their therapist.

Keywords

Anorexia nervosa, treatment, therapeutic relationship, qualitative research, thematic analysis

Introduction

Anorexia nervosa (AN) is a debilitating mental illness which impacts on both the physical and psychological health of sufferers (Bulik, Reba, Siega-Riz & Reichborn-Kjennerud, 2005; Crisp, 2006). Despite the development of multiple treatment approaches, dropout rates are high (e.g., Surgenor, Maguire & Beumont, 2004; Wallier et al., 2009) and treatment success rates are poor (e.g., Bulik, Berkman, Brownley,

Sedway & Lohr, 2007; Keel & Brown, 2010). Recovery, if it occurs, tends to be a protracted process with high levels of relapse and the likelihood of traversing from one eating disorder (ED) to another (e.g., from restricting AN to purging AN or bulimia nervosa [BN]) (Berkman, Lohr & Bulik, 2007; Eddy et al., 2008; Steinhausen, 2002).

The current disappointing outcomes for clients diagnosed with AN has promoted debate over the evidence base for treatment approaches (e.g. Bulik et al., 2007; Fairburn, 2005). Despite this there are National Institute of Clinical Excellence (NICE 2004) treatment recommendations for AN. Key among these are that most people with anorexia nervosa: 'should be managed on an outpatient basis with psychological treatment' (p.64) and that such psychological treatment: 'should normally be of at least six months' duration' (p.64). In addition it is recommended that inpatient care, when it is required, should include psychological treatment: 'which has a focus both on eating behaviour and attitudes to weight and shape, and wider psychosocial issues with the expectation of weight gain' (p.65); and that, following inpatient weight restoration: 'people with anorexia nervosa should be offered outpatient psychological treatment that focuses both on eating behaviour and attitudes to weight and shape, and wider psychosocial issues with regular monitoring of both physical and psychological risk' (p.65).

NICE recommendations provide an expectation about best care for AN patients but they may not always be implemented. Treatment across the UK is very variable (Royal College of Psychiatrists, 2007) and treatments identified as effective in the guidelines may not be routinely available (NHS Wales, 2012). Additionally, GPs are the current gatekeepers to outpatient treatment in the secondary care sector (Nice, 2004)

and in 2009 the UK eating disorders charity 'beat' surveyed 1,500 people affected by an ED about their experiences of visiting their GP. The charity concluded that: "Far too many people encounter a GP who is not up to date about eating disorders The majority of people told us their GP was unable to help them – GPs didn't know about available treatment or how they could access it" ('beat', 2009, p.3).

In order to better understand service users' experiences of treatment some researchers have explored the experiences of sufferers themselves. This body of research is relatively small and has focused primarily on sufferers' experiences of inpatient treatment (e.g., Colton & Pistrang, 2004; Fox & Diab, 2015; Gremillion, 2002; Offord, Turner & Cooper, 2006; [Smith et al., 2014](#)). These studies have contributed to the debate by highlighting patients' perceptions of various elements of hospital treatment (e.g., finding peer relationships both helpful and unhelpful; welcoming and resenting control being taken away), but they examine only a part of the ED treatment system.

The only studies found by the authors that did not focus solely on inpatient treatment were those by Button and Warren (2001) and Eivors, Button, Warner and Turner (2003). Button and Warren's (2001) study explored treatment experiences as part of a broader investigation of sufferers' experiences of living with AN and suggested that not only do sufferers view individual psychotherapy/counselling as important, but also that they view the quality of relationship with a therapist as especially so. Unfortunately, however, it was impossible in this study to determine which participants had had inpatient treatment and which had had outpatient treatment. In contrast, the study by Eivors et al. (2003) did look specifically at

treatment experiences but its focus was on the experience of dropout in particular. As such, it only canvassed the views of patients who had prematurely ended their treatment. That notwithstanding, the study highlighted participants' view that a lack of negotiation regarding treatment, and a focus on symptoms (rather than underlying causes) was especially unhelpful. Indeed, the authors suggested that the latter in particular could sometimes facilitate sufferers' 'strategy of focusing life around food as a means of coping with stress and other life issues, possibly inadvertently reinforcing the eating disorder' (p.98). Thus, although Button and Warren's (2001) and Eivors et al.'s (2003) studies have been provided insights into sufferers' experiences of outpatient treatment, it remains the case that knowledge about outpatient and private psychotherapy in general is scant. This is problematic given the recommendations within the NICE guidelines that most adults with AN: 'should be managed on an outpatient basis with psychological treatment' (p.60). It is also somewhat surprising given the potential wealth of insights that sufferers - – in terms of both accessing it and being a part of it - might have to offer based on their first-hand knowledge of the system.

The current study thus aimed to begin the process of eliciting clients' views by giving AN sufferers the opportunity to talk about their experiences of being treated for their eating disorder. Study participation was restricted to women because approximately 90% of individuals with an ED are female (Hoek & van Hoeken, 2003; Kjelsås, Bjørnstrøm & Götestam, 2009). In addition, both theory (e.g. Malson & Burns, 2009) and research (e.g. Dignon, 2007; McVittie, Cavers, & Hepworth, 2005) suggest that gender critically shapes how participants with AN are understood and understand

themselves, which implied that the experiences of men and women in AN treatment might be quite different.

Method

Participants

The study ~~focuses~~ focused on the treatment experiences of women with a formal or self-diagnosed history of AN. It was decided to recruit participants both with and without formal diagnoses of AN because only a small percentage of people with an ED actually receive a formal diagnosis ('beat', 2009) thus it seemed important not to exclude the population with a self-diagnosis of AN. In addition, for ethical reasons, participants had to self-identify as recovered or 'on the road to recovery.' Lastly it was decided to recruit participants who had at least some history of therapy with a female practitioner; this was because it was assumed that because of the gendered nature of AN (Malson & Burns, 2009), treatment experiences might be different with male and female therapists. Within these constraints the aim was to recruit a diverse sample to generate a broad understanding of treatment experiences. Thus a maximum variation (Sandelowski, 1995) or maximum heterogeneity (Fassinger, 2005) sampling strategy was used. This meant using a variety of recruitment strategies: internet-based advertisements for the study on the 'beat' website as well as notices in the waiting room of a number of eating disorder counselling services and support groups in the South-West of England.

Following receipt of ethical approval from the faculty research committee, 12 women were recruited. Eleven of the women had received both a diagnosis and treatment

from the NHS while one had a long-standing history of restriction but no formal diagnosis (due to not having sought help through the NHS). Participants' ages ranged from 18 to 50 years (mean 31.5) and the duration of their EDs ranged from two to 28 (mean 13.3). When asked to rate how recovered they saw themselves on a scale from 0 to 100% the participants' responses ranged from 40 to 100%. All participants had a history of restricting food and had received counselling from at least one female therapist. See Table 1 for further details about participants.

[Insert Table 1 about here]

The women had received treatment in both inpatient and outpatient settings as well as within the NHS, school/university counselling services, charity counselling services and private practice. They had experienced a variety of therapeutic approaches including CBT, Cognitive Analytic Therapy, Psychodynamic therapy and Integrative therapy. In general, it appeared that their experiences of CBT had been within the NHS and that their experiences of more integrative, psychodynamic approaches had been within the private or school/university counselling systems. As can be seen in Table 1, they received treatment from a range of practitioners, including psychiatrists, consultants, psychologists, nurses, CPNs, therapists, counsellors and support workers. The variety of professional designations implies a broad range of types of training both in terms of type and length. It should be noted that the diversity of treatment experienced by the participants is not untypical; those with AN may receive treatment in CAMHS, paediatric or adult psychiatric services or in student services, and 20% are treated exclusively in primary care (Treasure, Schmidt & Hugo, 2005).

Data Collection

A semi-structured interview schedule was developed to capture the unique experiences and beliefs of the participants whilst simultaneously ensuring that the core areas of interest in the study were covered. The interviews explored the participants' experiences of living with, and receiving treatment for, AN and lasted between 59 and 103 minutes. The first author (a trainee counselling psychologist with a history of AN working in the ED field) conducted all interviews.

Potential participants were provided with written information about the study upon initial contact with the first author and were encouraged to ask questions before agreeing to take part. Prior to the interview commencing they were given a further opportunity to ask questions before being asked to read and sign a consent form. After the interview they were reminded of the sources of support listed on the information sheet they had received upon enquiring about the study. Approximately half of the interviewees asked about the interviewer's interest in the topic and she responded by disclosing her ED history – most made their enquiry after the interview although one made it before. The interviews were tape-recorded and 'orthographic' transcripts (Braun & Clarke, 2006, p.88), which provided the appropriate level of detail for the analytical method being used, were produced.

Data Analysis

Thematic Analysis (TA) was used to analyse the interview transcripts; TA was chosen because it is a theoretically flexible method of analysis (Braun & Clarke, 2013) which allowed the study to utilise a critical realist epistemology and to focus on the identification of broad themes in the participants' experience of treatment. The

analysis followed Braun and Clarke's (2006) six-phase approach which involves following the phases of: familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing the report. The first author led the analysis and discussed each stage in the process with the second and third authors (a counselling psychologist with a history of BN, and a qualitative psychologist with a history of compulsive overeating respectively) who also read and familiarised themselves with all 12 manuscripts. As such, the authors encouraged one another to develop, clarify and refine their thinking, thus optimising the rigour and quality of the analytical process. Three superordinate themes were identified; participants' experience of anorexia (Rance, Clarke & Moller, 2015); participants' perceptions of their therapist's body (Rance, Clarke & Moller, 2014) and participants' views of their treatment experience, which is discussed in the current paper.

Reflexivity and quality of the analysis

There are a range of approaches to judging the quality of a qualitative analysis (e.g. Yardley, 2008; Morrow, 2005). Braun & Clarke (2006)'s 15-point checklist for assessing whether a piece thematic analysis is 'good' has been followed for the current study. In addition the researchers engaged in a careful process of reflexivity, as "owning one's perspective" (Elliott, Fischer & Rennie, 1999) is another key quality criteria. All the authors have some history of eating difficulties with two having received treatment for such (one inpatient); being to some extent 'insiders' (Labaree, 2002) to the phenomenon under investigation was managed in various ways, including keeping a

research journal, the systematic and collaborative process of analysis, and the attempt to bracket off personal experiences and perceptions during the analysis.

Results

The women's narratives revealed a high degree of dissatisfaction with the treatment(s) they had experienced. Although some might argue that this is to be expected from a client group who are known to be ambivalent about recovery (Cockell, Geller & Linden; Williams & Reid, 2010), the women presented their complaints in a constructive manner, which suggested that they not only wanted help, but also had ideas about what might be beneficial. In short, the women – who were assigned pseudonyms to maintain their anonymity - perceived the treatment system as overly focused on food and weight. In contrast, they felt that 'eating disorders are not about food, they're about life' (Megan) and that a key part of treatment is being seen, and treated, as a 'whole person' (Amy).

While many of the women's criticisms were based upon the treatment(s) they had received in the NHS, their belief in the unhelpfulness of treatment which focused primarily on food and weight applied to all treatment settings. What follows is an account of both the women's perceptions of this focus in relation to three aspects of their treatment in particular (treatment access, treatment structure and treatment providers), and their desire for treatment that focuses on them as a 'whole person'. Extracts from the interview transcripts are used to give voice to the participants and demonstrate the interpretative adequacy of the analysis.

Access to treatment

Difficulties obtaining NHS treatment was a common theme in the women's narratives. As Katie explained: 'It's so hard to get help in the NHS for eating disorders ... everybody almost that I hear of or meet is "Unless I'm a BMI of 10 I'm not going to get any help".' Sarah too spoke of the way in which her own hospital admission had been repeatedly delayed as people with a lower Body Mass Index (BMI; a heuristic proxy for human body fat based on an individual's weight and height) had taken 'priority' over her. For a population known to be competitive (e.g., Colton & Pistrang, 2004; Rich, 2006) and highly motivated to lose weight (e.g., Dignon, Beardsmore, Spain & Kuan, 2006), treatment systems influenced by weight could clearly have serious consequences. Indeed, it appeared that such systems had the potential to push someone who wanted help into losing yet more weight. As Claire explained:

I feel that I'm forced to be manipulative sometimes to get the help that I need ... when it's kind of focused on "Well if you lose another kilo then we'll, then we'll escalate you up the waiting list" ... you [are] kind of almost forced to play that game.

Thus it seemed that the systems described by the women incentivised weight loss – a finding which is worrying given that a very low BMI is a known predictor of increased mortality risk (Button, Chadalavada & Palmer, 2010).

The women's narratives also suggested that even when access to a service had been achieved there was no guarantee of on-going help. Claire, for example, described how her fellow day-patients feared that if they gained too much weight they would be 'kicked off the day programme.' Furthermore, it seemed that their fears were not unfounded as Katie explained how: 'As soon as my weight became normal in the

hospital they discharged me and I came home, it was very BMI dependent.’ Hence it appeared that both admission and discharge decisions were perceived by the women as being contingent upon BMI.

Although many of the participants spoke about their struggles to get treatment, there were exceptions. Megan, for example, described how she had received ‘really joined up care’ and had had to ‘beat them off with a stick, you know, “go away, leave me alone”.’ This was, however, not the norm described by the participants.

Treatment structure

Based on their experiences, the women felt several features of AN treatment had the potential to impede recovery. These included: therapy that focused narrowly on food/weight, inpatient treatment that did not include therapy, out-patient therapy that was short-term, and overly rigid CBT.

Therapy that focused on food/weight. It appeared that therapy which focused narrowly on food and weight had the potential to encourage the women to remain in, rather than relinquish, their ED. For example Lucy, who felt her food manipulation had been an expression of her inner battle with being lesbian, believed that therapy had led her to develop new ED behaviours: ‘Then I start[ed] developing an issue with weight because the weight that wasn’t even a problem before now becomes a problem because I’m trying to keep myself in counselling to be able to talk about my psychological issues.’ And Megan found that:

[I] spent two years with them [local ED service] to get to the point where I realised that focusing on food and maintaining restoring weight doesn’t work

for me, because all it does is push me further into depression which I don't handle very well it makes me suicidal.

It was with relief that Megan explained how, after much fighting and being a 'mouthy cow', she had managed to get treatment from her community mental health team which focused not on her eating but on her depression. Echoing the sentiments of many of the women, Megan said that she believed 'eating disorders are not about food, they're about life [but] a lot of people want them to be about food.'

Inpatient treatment that did not include therapy. Megan's assertion that a lot of people want EDs to be about food and (implicitly) weight – as opposed to life – was supported by a number of the women who spoke about not having received therapy during their inpatient stay. As Sam explained:

Their [inpatient unit's] sole purpose really [was] to get me back to a healthier weight they didn't provide anything else so you then came out and it got transferred as so often happens from one form of eating issue to another.

Nina also discussed the absence of therapy during her stay in hospital and said it was the 'worst point' about inpatient treatment and: 'a waste ... because obviously you're going through huge changes in a really intense environment and there wasn't any outlet for your feelings.' Thus it seemed that despite their apparent desire for some form of psychological therapy, for some of the women at least, only weight restoration was addressed.

Out-patient therapy that was short-term. A further issue discussed by the women was that of time constraints on out-patient therapy. Sarah said that this made her laugh: 'because we used to get limited to like eight sessions or, you know, 10 sessions, it's like

it must take you about six to actually start talking.’ Megan too said she had needed time to become accustomed to talking about her ED because: ‘I don’t talk to anybody about it, you know, it’s the way I do things is to hide it.’

Amy also explained that you need time to build trust in your therapist. In discussing how she had done this with her current therapist she said: ‘I found that relatively easy to do, it was within probably a six months or a year I was able to feel that.’ Services that offer only short-term therapy are thus potentially inhibiting (or even preventing) the development of a trusting therapeutic relationship, a factor which is known to have an impact upon therapy outcome (Lambert & Barley, 2001; Norcross, 2002).

Overly rigid CBT. Although not all of the women had received CBT for their AN, those who had done so consistently described it in unfavourable terms. Sophie, for example, said she had felt like she was ‘being pushed through a machine’ and Claire said ‘it made me feel like I was banging my head against a brick wall.’ In particular, it appeared that the women saw CBT as too rigid and circumscribed in approach, preventing them from being able to explore the causes rather than the symptoms of their ED. As Sam explained: ‘CBT never looked beyond the food aspect which was quite frustrating when I had a hundred and one things kind of tangled up that I thought might have been the cause.’ An additional problem with CBT, as perceived by Claire, was the implicit message underlying the treatment:

It felt quite rigid and it was like “If you understand you have your thoughts and your feelings are reflecting [them] and challenging your negative thoughts

then you will get better, and if you're not getting better you're just not trying hard enough".

The women clearly felt frustrated by what they saw as the formulaic nature of CBT and seemed to view it as not helpful in facilitating recovery.

Treatment providers

The women's belief that the AN treatment system is overly focused on food and weight was also apparent in their descriptions of the institutions and individuals who provide help. Hayley, for example, spoke of the way in which her local ED service seemed to base treatment interventions on the belief that no 'cure' was possible: 'I very much got the message from the eating disorder service that an eating disorder was something I managed for the rest of my life and I didn't even know like you could ever get fully better.' If symptom 'management' is believed to be the best a sufferer can hope for then it makes sense that treatment would (and even should) focus on such issues as restoring weight and establishing a healthy eating regime. Unfortunately, however, not only does such a belief lead to a focus on symptoms rather than causes, but it also removes hope from anyone who has the illness.

Individual practitioners were also, at times, described as appearing to hold beliefs about EDs (and those who suffer with them) which influenced the way in which they treated their clients. Sarah, for example, said that her therapist was: 'Complete textbook case if he hadn't read it in the book then whatever I said was wrong.' The impact of this for her was extreme:

He was like "Oh you can't be that bad because you're not throwing up in bags, you're not hiding it", it's like "I live on my own" when I started seeing him I

was bingeing and being sick about twice a week by the time I finished with him I was throwing up all day every day.

Amy also described her therapist as judging what she said according to whether or not it fitted in with a typical anorexic's profile – and when it didn't, she said it got dismissed with a simple: 'no, because anorexics don't do that'. The perception that certain treatment providers had rigid, limited, 'textbook' beliefs is clearly unhelpful and was associated with participants' perception that they were not able to address the real, idiosyncratic issues underlying their illness.

The women's narratives also revealed their perception that some treatment providers knew almost nothing (stereotypical or otherwise) about EDs. Claire, for example, explained how she had sometimes left sessions with her therapist thinking: 'Maybe I just wasted that whole 40 pounds worth of session or whatever explaining something to him which he didn't know and I've spent forty minutes and it was complete waste of time.' For Katie, however, it was not just frustration that arose from her community psychiatric nurse's lack of understanding:

Her saying "I'm sorry I just don't get it" kind of feels like she's dismissing it and it's not really a problem and I don't have a problem and there's nothing wrong with my weight and there's nothing wrong with my eating so why should I try and get better.

Hence it was clear from the women's narratives that treatment providers' beliefs, knowledge and preconceptions had the potential to leave them feeling misunderstood, frustrated and unconnected.

In conclusion, it appeared that the treatment systems experienced by the women were potentially iatrogenic at a number of levels. From incentivising weight loss (in order to gain access to treatment), compounding their obsession with weight and food, and limiting their opportunities to explore the causes of their illness, to leaving them feeling misunderstood, frustrated and unconnected, it appeared that both their personhood and needs were being lost in the system. This was an unhelpful and ironic situation given that a fundamental part of the intra- and interpersonal experience of those with an ED is that of feeling invisible, unheard and worthless (Reindl, 2001; Shelley, 1997).

Being treated as a 'whole person' and having a 'real' relationship

The women were clear that what they really wanted was to be seen and treated as a 'whole person' (Amy, Katie) rather than a 'diagnostic tick box', a 'thing with problems' (Katie) or an 'object' (Sophie). As Amy explained, her therapist's ongoing ability to help her was due to the fact that: 'She doesn't want to work on the eating disorder she wants to work on me she sees me as a whole person.'

Additionally, the women seemed to want a 'real' relationship with their therapist, one in which their therapist was authentic and expressed herself not just as a professional providing a service, but as someone who cared and 'seemed genuinely interested' (Sophie). To this end, many of the women felt a therapist's willingness to talk about herself was especially important as it helped to 'round' her out 'as a person' (Claire) and showed that she trusted them with personal information about herself. Although the women varied in terms of the amount and type of information they wanted their therapist to disclose (some wanted a lot and others wanted very little), with the

exception of Nina and Katie (whose preferences are discussed below) they all felt that personal disclosures were beneficial. Indeed, a therapist not talking about herself was often presented as potentially problematic. Lucy, for example, spoke about the fact that she had found it 'hard to open up to somebody and talk to somebody and trust somebody who you don't know anything about' and Sam said that it had always 'got to [her]' that 'you're supposed to build that relationship with someone but they don't tell you anything about [themselves].'

In contrast, both Nina and Katie said they preferred a therapist who did not disclose anything about herself. As Katie explained: 'I'm the kind of person that if somebody else starts talking about them then I shut off completely, and I just want to listen [to] them and I can't bring myself into it because I feel selfish.' Similarly, Nina explained that: 'Once you know stuff [about them] it's, don't know, it's somehow *wrong* to offload all your stuff because they're then a person, not just your therapist.' Interestingly, although Nina clearly stated that she did not want her therapist to be 'a person', like the other women she nonetheless believed that the relationship between client and therapist was paramount: 'It's just about your relationship with them isn't it, and whether you get on rather than anything else.' Thus, irrespective of their views on therapist self-disclosure, the women were united in their belief that the therapeutic relationship was crucial to the therapy process and, ultimately, to their recovery.

Discussion

The results presented above offer an insider's view of ED treatment systems and suggest a number of areas that might usefully be explored by those seeking to both

improve treatment success rates and lower levels of drop out. This is especially the case for the women's belief that inpatient admission and discharge decisions were overly influenced by weight and BMI which echoes the finding in Escobar-Koch et al.'s (2010) large-scale qualitative study whose British participants described weight-based treatment criteria as a 'barrier' for those seeking help. Weight-base treatment criteria suggest that treatment providers are failing to follow NICE's (2004) recommendation that: 'In anorexia nervosa, although weight and body mass index (BMI) are important indicators of physical risk they should not be considered the sole indicators' (p.64). This is a cause for concern as it means that sufferers who are at high levels of risk despite having a seemingly low risk BMI may miss out on treatment.

Some commentators (e.g. Lee, Lee, Ngai, Lee, & Wing, 2001) have critiqued dominant conceptualizations of AN in terms of weight phobia and previous studies have identified sufferers' belief that treatment systems (especially inpatient ones) are overly focused on weight (e.g., Colton and Pistrang, 2004; Dignon, 2007; Eivors et al., 2003; Escobar-Koch et al. 2010; Offord et al., 2006). However, the finding that treatment systems and therapy which focus almost exclusively on weight and food might have negative behavioural side-effects (e.g., increase suicidality (Megan), provoke restriction (Nina) and encourage ED behaviours (Lucy)) is important, and corroborates other research (e.g. Gowers, Weetman, Shore, Hossain, & Elvins, 2000) about the potentially negative impacts of AN treatment.

The women's experience of inpatient treatment which lacked or had minimal psychological therapy – a finding also mentioned by both Colton and Pistrang (2004) and Offord et al's (2006) studies – is concerning given that NICE (2004) recommends

that inpatient care should not only provide psychological treatment but also that this treatment should: 'Focus both on eating behaviour and attitudes to weight and shape, and wider psychosocial issues' (p. 65). Treatment dissatisfaction offers a possible explanation for the poor treatment success rates and high levels of dropout common in AN treatment and is important to investigate.

The finding that the women frequently experienced outpatient therapy as too short was also noteworthy given NICE's (2004) recommendation that: 'Outpatient psychological treatment and physical monitoring for anorexia nervosa should normally be of at least six months' duration' (p. 64). The women were clear in their belief that the short timescale of therapy could impact upon the development of both trust in their therapist and the therapeutic relationship. Thus, it is possible that the poor treatment success rates and high dropout levels might also be in some way influenced by therapy that is too short.

The final element of treatment described in negative terms by the women was that of CBT (one of the psychological treatments endorsed by the NICE Guidelines, 2004). In the women's view it was rigid and overly focussed on food/weight. As with their objections to the short-term nature of outpatient therapy, to inpatient treatment that had no therapeutic component, and to treatment that focused solely upon weight and food, the women's objection to CBT appeared to be linked to their desire to explore the factors underlying their illness.

The study finding that participants experienced treatment as overly focused upon weight and food, adds to an increasing body of research that patients with AN prefer a holistic approach to their treatment [\(e.g. Smith et al., 2014\)](#). For example in

their review of qualitative studies examining the views of adolescent clients towards AN treatment, Westwood and Kendal (2012) found a clear preference for treatment: “which considers their psychological and social needs, rather than a sole focus upon physical concerns.” It is noted however that NICE guidelines still require a focus on weight/food, as critical for effective treatment for AN (Nice, 2004); it is also worth noting that AN sufferers, particularly when in the grip of the condition, are often reluctant to talk about their food/eating practices.

In relation to treatment providers themselves, the women seemed to find limited knowledge and stereotypical assumptions particularly problematic but also talked about experiencing a lack of hope from treatment providers. This is a finding that was echoed in Offord et al. (2006) as well as Fox & Diab (2015) whose in-patient participants similarly described how some treatment providers appeared ignorant about AN and others came across as pessimistic about the efficacy of AN treatment. Prior research on patient preferences (e.g. Gulliksen et al., 2012) has found a clear preference for practitioners to have expertise in treating AN. Offord et al.’s (2006) study also gave voice to a desire in their participants to be ‘seen as an individual in their own right’ as opposed to being simply ‘another anorexic.’ This clearly echoes the finding in this study that the women wanted to be seen and treated as a ‘whole person.’

Similarly, the finding that the women wanted a ‘real’ relationship with their therapist was akin to Wright and Hacking’s (2012) finding (in their study of relationships between women with anorexia and healthcare professionals) that: ‘Both staff members and patients expressed the need to be “genuine”, even “transparent” in

order to establish an authentic and therapeutic relationship' (p.110). It also echoes prior research on patient preferences about the importance of the therapeutic relationships in AN treatment (e.g. Tierney, 2008; Westwood & Kendall, 2011).

The results of this study thus both extend and add depth to current evidence regarding the treatment experiences and desires of sufferers of anorexia. In so doing it is hoped that they will encourage further debate about ways in which current treatment practices might be enhanced in order to facilitate improvements in treatment success rates and reductions in dropout levels.

When interpreting the findings of this study it should be noted that the participants were a self-selected group and may therefore have had their own agenda (e.g. wanting to talk about their negative experiences of treatment) when agreeing to take part. It is also important to note that, when discussing treatment (for AN or any other issue), if it has not been successful there might be a tendency to blame others rather than to take responsibility for one's own role in it. That said, a number of the women remarked on how hard it must be for practitioners to work with a client group who are ambivalent about recovery and thus not always willing to engage, which suggests that they were not wholly blaming the system for their own difficulties. Furthermore, it is recognised that the women's perceptions of the flaws in the AN treatment system are based upon their own unique experiences (which may or may not reflect the treatment system as a whole). That notwithstanding, it nevertheless feels vital that their viewpoints be heard as they have the potential to shed some light upon the poor outcome levels and high rates of drop out.

There are a number of issues that future research might usefully focus on in order to develop and extend the findings of this study. In particular, it could explore the experiences of male clients, often side-lined in the research literature (Strother, Lemberg, Stanford, & Turberville, 2012), as well as those who self-identify as having had positive experiences of treatment in order to try and establish the types of intervention and treatment ethos that were helpful. Additionally, it would be beneficial if direct comparisons could be made between treatment systems which focus primarily on food and weight and those which have a broader remit so that treatment outcomes (in both the short- and long-term) can be contrasted and the more optimal of the two approaches established. Additionally, given that the treatment experiences described by a number of the women differed from what would be expected if the NICE (2004) guidelines were being followed, it would be useful if a formal audit could be undertaken to ascertain what forms of treatment are in fact being delivered. Finally, it would be helpful if future research could investigate clients' experiences of therapeutic approaches in which they feel they were seen and treated as a 'whole person' and able to have a 'real' relationship with their therapist, to establish whether or not, in practice, this is actually beneficial to recovery.

The results presented above clearly have implications for both treatment systems as a whole, and individual practitioners within them and it is hoped that they will add to the imperative to continue researching and developing new treatments for AN. It is also hoped that they will encourage the development of a middle ground position whereby weight is a part, but not the foundation, of treatment focus and that through developing more holistic approaches success rates will rise and dropout levels

will fall. Finally, it is hoped that, in light of all that has been said above, treatment 'resistance' in AN contexts might be considered as a sign that something in the current system is not working rather than a simple rebellion against being asked to gain weight.

References

- 'beat'. (2009). *Choice or chance – Ending the information lottery*. Norwich: 'beat'.
- Berkman, N. D., Lohr, K. N. & Bulik, C. M. (2007). Outcomes of eating disorders: A systematic review of the literature. *International Journal of Eating Disorders*, 40, 293-309.
- Braun, V. and Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. London: Sage.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Bruen, J. (2011). *Problems with BMI*. Retrieved on 27 June 2012 from <http://www.livestrong.com/article/93472-problems-bmi/>.
- Bulik, C. M., Berkman, N. D., Brownley, K. A., Sedway, J. A. & Lohr, K. N. (2007). Anorexia nervosa treatment: A systematic review of randomized controlled trials. *International Journal of Eating Disorders*, 40, 310-320.
- Bulik, C. M., Reba, L., Siega-Riz, A-M. & Reichborn-Kjennerud, T. (2005). Anorexia nervosa: Definition, epidemiology and cycle of risk. *International Journal of Eating Disorders*, 37, S2-S9.
- Button, E. J. & Warren, R. L. (2001). Living with anorexia nervosa: The experience of a cohort of sufferers from anorexia nervosa 7.5 years after initial presentation to a specialist eating disorders service. *European Eating Disorders Review*, 9, 74-96.

Button, E. J., Chadalavada, B. & Palmer, R. L. (2010). Mortality and predictors of death in a cohort of patients presenting to an eating disorders service. *International Journal of Eating disorders*, 43(5), 387-392.

Cockell, S. J., Geller, J. & Linden, W. (2003). Decisional balance in anorexia nervosa: Capitalizing on ambivalence. *European Eating Disorders Review*, 11, 75-89.

Colton, A. & Pistrang, N. (2004). Adolescents' experiences of inpatient treatment for anorexia nervosa. *European Eating Disorders Review*, 12, 307-316.

Costin, C. (2009). The embodied therapist. Perspectives on treatment, personal growth, and supervision related to body image. In M. Maine, W. N. Davis & J. Shure (Eds.), *Effective clinical practice in the treatment of eating disorders* (pp.179-192). New York, NY: Routledge.

Crisp, A. (2006). Death, survival and recovery in anorexia nervosa: A thirty five year study. *European Eating Disorders Review*, 14, 168-175.

Dignon, A. (2007). *All of me: A fuller picture of anorexia*. Peter Lang: Berne, Switzerland.

Dignon, A., Beardsmore, A., Spain, S. & Kuan, A. (2000). Patient testimony from 15 anorexics concerning the causes of their disorder. *Journal of Health Psychology*, 11(6), 942-956.

Eddy, K. T., Dorer, D. J., Franko, D. L, Tahilani, K., Thompson-Brenner, H. & Herzog, D. B. (2008). Diagnostic crossover in anorexia nervosa and bulimia nervosa. *American Journal of Psychiatry*, 165(2), 245-250.

- Eivors, A., Button, E., Warner, S. & Turner, K. (2003). Understanding the experience of drop-out from treatment for anorexia nervosa. *European Eating Disorders Review, 11*, 90-107.
- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, 38*, 215–299.
- Escobar-Koch, T., Banker, J. D., Crow, S., Cullis, J., Ringwood, S., Smith, G., van Furth, E., Westin, K. and Schmidt, U. (2010), Service users' views of eating disorder services: An international comparison. *International Journal of Eating Disorders, 43(6)*, 549–559.
- Fairburn, C. G. (2005). Evidence-based treatment of anorexia nervosa. *International Journal of Eating Disorders, 37*, S26-S30.
- Fassinger, R. E. (2005). Paradigms, praxis, problems, and promise: Grounded theory in counseling psychology research. *Journal of Counseling Psychology, 52(2)*, 156-166.
- Fox, J. R. E. & Diab, P. (2015). An exploration of the perceptions and experiences of living with chronic anorexia nervosa while an inpatient on an Eating Disorders Unit: An Interpretative Phenomenological Analysis (IPA) study. *Journal of Health Psychology, 20 (1)*, 27-36.
- Gowers, S. G., Weetman, J., Shore, A., Hossain, F., & Elvins, R. (2000). Impact of hospitalisation on the outcome of adolescent anorexia nervosa. *The British Journal of Psychiatry, 176(2)* 138-141
- Gremillion, H. (2002). In fitness and in health: Crafting bodies in the treatment of anorexia nervosa. *Signs, 27(2)*, 381-414.

Gulliksen, K. S., Espeset, E. M.S., Nordbø, R. H.S., Skårderud, F., Geller, J. and Holte, A.

(2012), Preferred therapist characteristics in treatment of anorexia nervosa: The patient's perspective. *International Journal of Eating Disorders*, 45(8), 932–941.

Hoek, H. W. & van Hoecken, D. (2003). Review of the prevalence and incidence of eating disorders. *International Journal of Eating Disorders*, 34, 383-396.

Keel, P. K. & Brown, T. A. (2010). Update on course and outcome in eating disorders. *International Journal of Eating Disorders*, 43, 195-204.

Kjelsås, E., Bjørnstrøm, C. & Gøtestam, K. G. (2009). Prevalence of eating disorders in female and male adolescents (14-15 years). *Eating Behaviors*, 5, 13-25.

Labaree, R. V. (2002). The risk of 'going observationalist': Negotiating the hidden dilemmas of being an insider participant observer. *Qualitative Research*, 2(1), 97-122.

Lambert, M.J. & Barley, D. E. (2001). Research summary on the therapeutic relationship and psychotherapy outcome. *Psychotherapy*, 38(4).

Lee, S., Lee, A. M., Ngai, E., Lee, D. T. S. and Wing, Y. K. (2001), Rationales for food refusal in Chinese patients with anorexia nervosa. *International Journal of Eating Disorders*, 29(2), 224–229.

McVittie, C., Cavers, D. & Hepworth, J. (2005). Femininity, Mental Weakness, and Difference: Male Students Account for Anorexia Nervosa in Men. *Sex Roles*, 53(5-6), 413-418

Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology*, 52 (2), 250-260.

National Institute for Clinical Excellence (2004). *Eating disorders: Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders. Clinical Guideline 9*. London: NICE.

NHS Wales (2012). Improving treatments for eating Disorders: How to Guide 20.

Available at: <http://www.1000livesplus.wales.nhs.uk> [Accessed 30 July 2015]

Norcross, J. C. (2002) (Ed.). *Psychotherapy relationships that work*. New York, NY: OUP.

Offord, A., Turner, H. & Cooper, M. (2006). Adolescent inpatient treatment for anorexia nervosa: A qualitative study exploring young adults' retrospective views of treatment and discharge. *European Eating Disorders Review*, 14, 377-387.

Rance, N. M., Clarke, V. & Moller, N. P. (2014). "If I See Somebody Therapist or Anything, I'll Immediately Scope Them Out": Anorexia Nervosa Clients' Perceptions of Their Therapist's Body. *Eating Disorders: The Journal of Treatment and Prevention*, 22 (2), 111-120.

Rance, N. M., Clarke, V. & Moller, N. P. (2015). The Anorexia Nervosa Experience: Shame, Solitude and Salvation.

Reindl, S. M. (2001). *Sensing the Self*. Cambridge, Massachusetts: Harvard University Press.

Rich, E. (2006). Anorexic (dis)connection: Managing anorexia as an illness and an identity. *Sociology of Health and Illness*, 28(3), 284-305. Royal College of

Psychiatrists (2007). Eating disorders in the UK. Policies for service development and training. CR87. London: RCP. Available at:

<http://www.rcpsych.ac.uk/files/pdfversion/cr87.pdf> [Accessed 30 July 2015]

- Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing & Health, 18*, 179-183.
- Shelley, R. (1997). *Anorexics on anorexia*. London: Jessica Kingsley Publishers Ltd.
- Smith, V., Chouliara, Z., Morris, P. G., Collin, P., Power, K., Yellowlees, A., Grierson, D., Papageorgiou, E., & Cook, M. (2014). The experience of specialist inpatient treatment for anorexia nervosa: A qualitative study from adult patients' perspectives. *Journal of Health Psychology, 0*, 1-12.
- Steinhausen, H. C. (2002). The outcome of anorexia nervosa in the 20th century. *American Journal of Psychiatry, 159*(8), 1284-93.
- Strother, E., Lemberg, R., Stanford, S. C., & Turberville, D. (2012). Eating Disorders in Men: Underdiagnosed, Undertreated, and Misunderstood. *Eating Disorders, 20*(5), 346–355.
- Surgenor, L. J., Maguire, S. & Beumont, P. J. V. (2004). Drop-out from inpatient treatment for anorexia nervosa: Can risk factors be identified at point of admission? *European Eating Disorders Review, 12*, 94-100.
- Tierney S. (2008). The individual within a condition: a qualitative study of young people's reflections on being treated for anorexia nervosa. *Journal of the American Psychiatric Nurses Association, 13*, 368–375
- Treasure, J., Schmidt, U. & Hugo, P. (2005). Mind the gap: service transition and interface problems for patients with eating disorders. *The British Journal of Psychiatry, 187*(5), 398-400.

- Wallier, J., Vibert, S., Berthoz, S., Huas, C., Hubert, T. & Godart, M. (2009). Dropout from inpatient treatment for anorexia nervosa. *International Journal of Eating Disorders, 42*, 636-647.
- Westwood, L. M. and Kendal, S. E. (2012), Adolescent client views towards the treatment of anorexia nervosa: a review of the literature. *Journal of Psychiatric and Mental Health Nursing, 19(6)*, 500–508.
- Williams, S. & Reid, M. (2010). Understanding the experience of ambivalence in anorexia nervosa: The maintainer's perspective. *Psychology and Health, 25(5)*, 551-567.
- Wright, K. M. & Hacking, S. (2012). An angel on my shoulder: A study of the relationships between women with anorexia and healthcare professionals. *Journal of Psychiatric and Mental Health Nursing, 19*, 107-115.
- Yardley, L. (2008). Demonstrating validity in qualitative psychology, In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (2nd ed., pp. 235-251. London: Sage.

Table 1. Age, illness and recovery details for interviewees

Name	Age	Age at onset of illness	Self-reported % recovered	Duration of illness	Food-related ED behaviours	Therapist history
Katie	26	11	no data	15	Food restriction, binge-purging	Four female therapists; Three female CPNs; Two female psychologists; Female nurses and therapists on inpatient ward; One male therapist
Sarah	32	16	<50	16	Food restriction, binge-purging	Three female therapists; One female psychologist; One male therapist; One male psychologist
Alice	50	22	60	28	Food restriction, purging	Three female therapists
Megan	41	14	60	27	Food restriction, binge-purging	Three female therapists; Female nurses and therapists on inpatient ward; One male psychiatrist
Sophie	19	13	60	6	Food restriction only	Female therapists and CPNs running contemplation programme; One male therapist; One male psychiatrist
Claire	33	12	50-80	21	Food restriction, binge-purging	Four female therapists; One female CPN; One male psychiatrist
Nina	34	30	70	4	Food restriction, binge-purging	Female nurses and therapists on outpatient day-programme; One male therapist
Sam	18	12.5	95	5.5	Food restriction only	Female nurses and therapists on inpatient ward; One female consultant; One female

Amy	42	19	95	16	Food restriction, binge-purging	therapist; One female support worker Female nurses and therapists on outpatient day-programme; Two female therapists
Hayley	25	10	100	12	Food restriction only	Nurses (one male, others female) and therapists on inpatient ward; Four female therapists; One male therapist
Susie	23	16	40-50	7	Food restriction, binge-purging	One female support worker; Female nurses and therapists on inpatient ward; Female therapist
Lucy	25	16	100	2	Food restriction, purging	Three female counsellors
