

Eating Disorders Patients' Views on Their Disorders and on an Outpatient Service

A Qualitative Study

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Abstract

The objective of the study was to determine sufferers' views of outpatient treatment for eating disorders and provide practical recommendations for treatment practice. Twenty NHS outpatients participated in semi-structured interviews, which were subjected to thematic analysis. Respondents expressed ambivalence about whether their eating disorder is a way of exerting control or a disorder that controls them and this leads to them seeking treatment. Sufferers preferred a practical and sensitive approach and began to rely on treatment for recovery. Treatment needs to facilitate sufferers' need for control by striking a balance between practical and empathetic approaches that both involve patients in treatment decisions and give authoritative guidance.

Keywords

- *ambivalence*
- *anorexia nervosa*
- *bulimia nervosa*
- *control*
- *eating disorder services*

Introduction

QUALITATIVE research into service users' perspectives of treatment of eating disorders 'could inform the therapeutic process and provide a greater understanding of recovery' (Le Grange & Gelman, 1998) as it can reveal participants' meanings and experiences of treatment (Bell, 2003; Hepworth, 1994). Current qualitative studies looking at the perspectives of those who have experienced an eating disorder have identified five common themes pertaining to the treatment of eating disorders. First, supportive, understanding relationships both during treatment and outside treatment (with family and friends) are important (Bell, 2003; Cockell, Zaitsoff, & Geller, 2004; Le Grange & Gelman, 1998; Matoff & Matoff, 2001; Tozzi, Sullivan, Fear, McKenzie, & Bulik, 2003). In particular, being able to talk openly about issues was felt to be an alternative coping mechanism in place of previously used eating disorder behaviours (Cockell et al., 2004; Le Grange & Gelman, 1998).

Second, interventions that addressed psychological issues were preferred over more medicalized treatments focused on food and weight (Bell, 2003). Sufferers rated techniques such as those learnt through cognitive behavioural therapy and used them once formal treatment had ceased but felt that treatments that focused too heavily on issues around eating, such as food monitoring, were unhelpful (Cockell et al., 2004; Le Grange & Gelman, 1998).

Third, sufferers felt that experiences outside the treatment setting played an important role in their recovery (Bell, 2003) as spending time with others can become an alternative to the isolation of experiencing an eating disorder and act as a coping strategy (Cockell et al., 2004; Matoff & Matoff, 2001).

Fourth, Control is an important factor for many individuals with eating disorders (e.g. Malson, 1998) therefore sufferers need a modicum of control in their treatment. Without this, treatment can diminish perceived control and exacerbate the disorder (Bell, 2003; Eivors, Button, Warner, & Turner, 2003). Eivors et al. (2003) developed the 'Interactional Model of Control' whereby control is re-exerted when the individual is confronted with treatment requirements as interference from others can trigger 'out of control' feelings. Re-exerting control includes non-compliance and drop-out from treatment. However, after drop-out, left unsupported, sufferers can feel so out of control of the disorder that they re-seek help.

Finally, the concept of ambivalence has been found to play a role in sufferers' perspectives of treatment where the sufferer is unsure about whether their

eating disorder is a 'friend' or 'enemy' (Colton & Pistrang, 2004) or whether or not it is a problem that needs to be treated (Colton & Pistrang, 2004; Malson, Finn, Treasure, Clarke, & Anderson, 2004). The concept of ambivalence is further explored in this study, which aimed to describe sufferers' perspectives of their eating disorders and their experiences of an outpatient service and provide related practical recommendations for treatment.

Method

Participants

Twenty respondents (age range 17–41, one male) referred from primary care and diagnosed with anorexia nervosa and/or bulimia nervosa were recruited while being treated at an NHS outpatient eating disorder service. The service had multi-professional staffing including psychiatrists, clinical psychologists and nurses.

Procedure

The study was approved by the NHS research ethics committees. Therapists in the service administered information sheets to patients, excluding individuals considered too vulnerable to participate. The purpose of the study was stated as being to 'investigate sufferers' perspectives of eating disorders and service provision'. If individuals were interested and willing, contact details were passed to the researcher who interviewed patients at the clinic having obtained informed consent for the interview, and for tape-recording and transcribing.

An open-ended, semi-structured interview asked respondents to provide accounts of how their eating disorder had affected them, experiences of treatment and perceptions of the strengths and weaknesses of the service. Using existing literature, the research team devised a list of open questions, some 13 about life history salient to eating disorders and treatment and 13 about experiences of services.

Data analysis

A semantic approach to thematic analysis was used to analyse the data, using the six phase process outlined by Braun and Clarke (2006). The inductive approach of identifying themes was partly formed by the interview questions. Initial analysis was conducted by JB, further analysis by SW and it was reviewed in depth by MR and RH. In brief, analysis involved re-reading the interview transcripts, identifying and labelling codes in each of the transcripts,

organizing the codes into themes, then finalizing the themes and ensuring they worked with the original transcripts. To protect anonymity of participants quotations are attributed to pseudonyms.

Results

Ambivalence about control and its role in treatment seeking

Sufferers consistently described a facet of their eating disorder being a need to feel in control of some aspect of their life. Eating disordered behaviour could inculcate feelings of control and power and serve as a coping mechanism for stress. Eating was often controlled when external circumstances resulted in sufferers feeling that they had no control over their life: 'If I'm not controlling other things in my life, [food] is something that I have got control over' (Susan). For some, eating was felt to be the only thing in their life that they did have control over, as expressed by Caroline: 'Everybody else, like my parents or whoever, control everything ... right down to what I should or shouldn't be thinking, ... I feel ... the eating is the only thing that I control.'

Ambivalently, the restrained behaviours, which were initially positive and used as a way of feeling in control, became all absorbing: 'It just takes over your whole life, you know it is your life. There is nothing else that you can concentrate on. It just, it swallows you really' (Helen). Sufferers could no longer cope with what once was a coping strategy and the control once exerted by sufferers over food and their bodies in turn became controlling:

The reason that you do it in the first place is to have some bit of control. But then you realize when you do try and eat you can't. You start getting real problems in your head when you realize you've got to stop doing it and you can't stop. (Julia)

The struggle to retain control resulted in some feeling desperate and suicidal, leading them to seek treatment. For Julia, this desperation manifested as an overdose attempt: 'I took an overdose the week before I come in here because I'd just had enough ... I just couldn't cope with it anymore. I couldn't get out of it.' Similarly, Helen described how: 'I thought "if this is all my life is going to be like then I don't want it quite honestly".' Sufferers were concerned, however, that by receiving treatment control would be completely removed. As Sally describes: 'My first impressions were that they were out there against me and they were going to make me do something I didn't want to do.'

Moreover, fear was also manifest in how treatment would centre upon weight gain: 'I was upset because, petrified at putting weight on and I thought that would be what it (treatment) would be like' (Christina).

Given the importance ascribed to control by sufferers, an essential component of the eating disorder service was that control was not removed. As part of the process of maintaining a sense of autonomy it was evident that staff at the clinic took a consultative approach with their clients that was viewed positively. However, it was also evident that complete control over treatment by sufferers was undesirable and that a combination of autonomy and direction was the balance that constituted a successful approach: 'But here I'm in control of what I want ... I feel as though I'm in control of my treatment but I feel as though I'm steered in the right path and motivated to do certain things' (Melanie).

The following extract from Christina also suggests how involvement in treatment decisions is helpful, as opposed to other approaches, which can, as Eivors et al. (2003) show, exacerbate the disorder: 'But there was obviously that choice there which is good. I mean if you start to feel too pressured you can go the other way.'

A practical and caring approach

The service was praised for its practicality and focus on managing the disorder. One might say its broadly cognitive behavioural approach, although respondents did not mention CBT by name. For example, as one sufferer describes, the adoption of coping strategies was an important component of successful treatment identified by sufferers:

Say like I thought I was going to have a binge and then we've got to think of something that might distract you so if it's something like having a walk or it's just doing a bit of gardening or something like that. (Miranda)

However, effective communication was paramount as listening to the sufferers' problems aided the therapist to recognize their needs successfully and suggest replacement coping strategies.

You get a chance to talk about what you are going through, to be really open and you're given different ways of looking at things ... you're told you could do it this way or you could do it that way and if that doesn't work you're given ... another mechanism of coping. (Elly)

... it's actually having someone who's listening to what I say and suggesting different ways. I think that's the best form of support. (Rachel)

Being able to talk to staff was undoubtedly facilitated by the understanding and supportive relationships participants shared with them. This was defined as a sense that sufferers generally felt cared for by staff:

Just the love and support and that they care about you. (Sally)

A feeling that they actually want to see you get better and that they will stick with you. (Helen)

As found in previous research (Bell, 2003; Cockell et al., 2004), from sufferers' perspective the therapeutic agenda should not primarily emphasize the body, body weight and eating. Treatment needs to embrace wider psychological issues that are important to the individual. As the sole male respondent described this involves seeing past the eating disorder and developing ways to 'live in the world':

I don't mean so much putting weight on. I mean psychiatric, psychological problems, you know, sorting what problems you've got out ... And I think, putting the eating disorder aside there should be more social skills and you know, working things out that way, in living, living in the world and independence (Robert).

It was important that staff had the right levels of expertise, not because experts were expected to have the solution or cure, but because they knew enough to be sensitive about the concerns of eating disorder patients: 'You need somebody who knows what to say and what not to say because your progress can be put back so far by just a single remark ... like "You're looking well", which you translate as "You're looking fat"' (Melanie).

Reliance on treatment

Although respondents were initially fearful of treatment, they came to rely on it as a safety net. Some expressed fear at the thought of treatment being prematurely withdrawn, which could result in exacerbating the eating disorder. For Caroline the only coping mechanism she felt she could resort to was losing weight and self-destruction in order to gain control over her treatment: 'I'm nearly at the end. And I'm scared shitless about it. ... There's only one thing for it, start losing weight ...' However, inconsistent with the Interactional Model of Control (Eivors et al., 2003) control is not re-exerted by dropping out of treatment, rather it is used to continue it.

It is evident that quality treatment needs to provide a sense of safety and commitment not just through therapeutic relationships but through a long term commitment. Respondents felt that they required more regular contact with the clinic and found it difficult when they needed to contact the service

between appointments: 'I know it's money, but more input rather than just seeing somebody once a week 'cos once a week isn't enough' (Robert).

Long referral times were another concern especially as help-seeking often occurs through desperation:

It was like 12 weeks and it was ... a long time and I was getting really, I can't believe this. (Helen)

I wasn't entirely happy to begin with ... she mentioned the group [bulimia group], which wasn't going to start until next term [six months]. (Helen)

Discussion

Expanding on the important concept of control from existing literature, participants expressed ambivalence about control; the problem is a form of coping and feeling safe, by controlling something, and a disorder that controls them and makes them afraid. These mixed emotions can precipitate crisis and help-seeking. Treatment is required rapidly, before sufferers further escalate restraint or bingeing to cope. Service limitations such as long referral times and limited contact are problematic. Respondents' concerns about control reflect the ideas of Bell (2003) and Eivors et al. (2003) in that interventions need to address control in treatment so that the cycle of control can be broken.

Respondents were fearful of attending treatment; afraid that they would be forced to gain weight or otherwise have control removed. They were appreciative of treatment that offered them practical help to change, rather than imposing change upon them. However, they also desired clear guidance and goal setting because they felt that empathy alone would not redress their problems. Nonetheless, consistent with previous research (Bell, 2003) empathy with the therapist was important and was characterized here by feelings of caring and security. Respondents also appreciated staff's expertise on eating disorders in the service.

Authoritative treatment, such as CBT, can provide patients with the mental tools to manage their own lives, including: help managing feelings and emotions; work on unrealistic beliefs about diet and restraint; practical suggestions for managing 'high risk' situations without resorting to the problematic behaviours; building self-esteem and self-worth; and reviewing and managing social relationships. This ideal, which confirms existing, recommended good practice (e.g. Fairburn & Brownell, 2002) involves the therapist facilitating and empowering the patient to change their thought patterns.

However, sensitivity, ambivalence and conflict also appear to be part of the experience of suffering

from an eating disorder. Staff lacking the specialist expertise to appreciate this may alienate sufferers, even with slight and passing remarks or behaviours. Sufferers are uncertain about being patients and recovery is not about a 'cure' in traditional terms but empowering sufferers to change themselves.

The study is limited in that it only takes into account patients' perspectives of one eating disorder service, but in addressing sufferers' ambivalence about their disorders and their treatment, it raises two questions for clinical work and future research. First, is controlling restraint an acceptable treatment goal? For example, do ex-anorexics have a right to be unusually, but not life-threateningly, thin? And second, is it possible to control control itself? That is, are people realistically capable of managing the amount of control they exert, particularly under pressure, and countering the tendency for control to become more extreme? Or, is this tantamount to learning to be less controlling and focusing less on diet and body shape? There is a continuum between excessive restraint and the restraint required in an affluent society to eat a healthy diet and not become overweight. Learning to exercise healthy levels of dietary restraint may be a useful addition to treatment (Reid, Hammersley, & Rance, 2005). Treatment that focuses heavily on acquiring a correct, healthy body weight may inadvertently help perpetuate sufferers' control issues.

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