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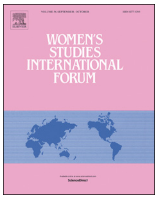

Severe and Enduring Anorexia Nervosa: The personal meaning of symptoms and treatment[☆]

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ABSTRACT

The current study aims to explore the experiences of women with severe and enduring anorexia nervosa (SE-AN). Six women with recurring difficulties of AN for over a decade were interviewed regarding their experiences of their eating disorder and of their treatment. The interviews were transcribed and analysed using Interpretative Phenomenological Analysis. The results identified the functional role of AN to resolve complex underlying psychological difficulties (in particular a diminished sense of self and search for identity) and the role of unhelpful treatment experiences and negative relationships with staff in the maintenance of AN. The themes provide an insight into the problems of women who struggle with their eating disorder for many years. The clinical implications of the findings are discussed in the context of the need for services to move away from focussing on weight and eating, towards facilitating clients to address the underlying psychological issues of the disorder.

Introduction

Anorexia Nervosa (AN) is a serious mental health condition characterised by significant reduction in food intake, resulting in severe weight loss in relation to age and height. Weight gain is feared and avoided and perceptions of body weight and shape are disturbed (American Psychiatric Association, 2013). Long-term outcome studies of AN have shown that a significant proportion of individuals do not fully recover from their anorectic symptoms and up to 20% develop chronic symptoms (Steinhausen, 2002). Predictors of outcome have been inconsistently identified in the literature (for a review see Wallier et al., 2009). There is some evidence to suggest that relapse is more likely to occur in those patients who purge, present with a lower body weight, have a longer duration of AN, early age of onset, dysfunctional family environments and significant co-morbidity (Noordenbos, Oldenhave, Muschter, & Terpstra, 2002; Steinhausen, 2002). Nevertheless, the roles played by such factors in determining the course and chronicity of AN remain unclear.

In recognition of the proportion of individuals who do not recover from their anorectic symptoms, a number of terms have appeared in the literature over recent years e.g. chronic AN and SE-AN (Geller, Williams, & Srikameswaran, 2001; Noordenbos et al., 2002; Strober, 2004). However, attempts to delineate such cases have lacked definition with length of illness and number of unsuccessful treatment attempts being used as inclusion criteria (Noordenbos et al., 2002; Noordenbos, Jacobs, & Hertzberger, 1998; Strober, 2004; Treasure, Stein, & Maguire, 2015). Broomfield, Stedal, Touyz, and Rhodes's (2017) systematic review found that the terms chronic, severe and enduring were the most frequently used terms and that illness duration and number of failed treatment attempts were the most common defining criteria within the research literature. Previously, Tierney and Fox (2009) conducted a study to explore healthcare practitioners' views of what constitutes a chronic case of AN. They identified a lack of readiness to change, maintenance of a low Body Mass Index (BMI) (17.5 kg/m^2 or under), and a firm interconnection of AN with identity as criteria for chronic AN. However, the usefulness of such a label has been debated with SE-AN being preferred (Noordenbos et al., 1998; Theander, 1992; Tierney & Fox, 2009). For the purpose of this study the term SE-AN will be used for sufferers with recurring difficulties for over a decade, onset of AN in adolescence to early 20s and who are now over the age of 30 years.

The adverse effects of having AN for a long period of time are multiple and severe and include physical, psychological and social problems (Noordenbos et al., 2002) yet, despite recent qualitative studies that address underlying causes (e.g. Fox & Diab, 2015; Hannon, Eunson, & Munro, 2017; Robinson, Kukucska, Guidetti, & Leavey, 2015), an understanding of the meaning attributed to symptoms by clients with SE-AN has not as yet been explored (Conti,

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Rhodes, & Adams, 2016).

A number of qualitative studies have explored the meaning of anorectic symptoms with an aim of understanding the maintenance of AN (e.g. Fox, Larkin, & Leung, 2011; Nordbo, Espeset, Gulliksen, Skarderud, & Holte, 2006; Serpell, Treasure, Teasdale, & Sullivan, 1999; Williams, King, & Fox, 2015). Restrictive symptoms have been found to have a powerful personal significance and value. For example, Serpell et al. (1999), using a grounded theory analysis of letters written by patients to their anorexia as a friend and enemy, concluded that the illness can provide protection, control and structure, a sense of specialness and achievement, and allows for communication of emotions but that the costs of the disorder may include damage to personal relationships, constant thoughts about food and feeling taken over. Nordbo et al. (2006) identified eight constructs regarding the psychological meaning of anorexic symptoms; 1) stability and security; 2) avoiding negative experiences; 3) demonstrating mental strength; 4) deriving a source of worth; 5) creating an identity; 6) eliciting care; 7) communication; 8) to die. All of these constructs indicate that anorexic behaviour is purposeful and functional to the individual.

Whilst the restrictive behaviours may provide positive ego-syntonic effects, the negative effects of the disorder (upon self and others) are also acknowledged by patients, resulting in strong feelings of ambivalence. The ambivalence experienced by those with AN has been consistently identified in the research literature (e.g. Colton & Pistrang, 2004; Dawson, Mullan, & Sainsbury, 2015; Fox et al., 2011; Reid, Burr, Williams, & Hammersley, 2008; Williams & Reid, 2010). Williams and Reid (2010) found that participants felt ambivalent about whether AN gave them control or controlled them, and whether it played a positive or negative role. The feeling of losing control may lead the individual to seek treatment (Reid et al., 2008).

There have been a number of studies that have explored AN (not specific to SE-AN) and its treatment from the patient's perspective, the majority focussing on the recovery process (e.g. Darcy et al., 2010; Federici & Kaplan, 2008; Tozzi, Sullivan, Fear, McKenzie, & Bulik, 2003). Recovery appears to depend on social support, motivation and treatment specific factors. In a meta-ethnographic analysis of qualitative studies about the treatment of AN published up to 2005, a number of second and third order themes were identified by Espíndola and Blay (2009). In particular, professionals' 'rigidity and lack of sympathy' limited positive change for patients. In addition, the theme 'perception of treatment modalities' suggests that AN needs to be understood in a broad manner, considering the individual as a whole including biological, psychological and social aspects, with patients showing a preference for psychosocial interventions. Approaches focussed on nutrition and weight gain were perceived to ignore the central psychological aspects of AN. The authors postulate that the difficulty in treating patients with AN is due to the complex psychological mechanisms involved, especially an impaired sense of identity, with subsequent reviews of AN literature arriving at similar conclusions (Duncan, Sebar, & Lee, 2015; Williams, 2014).

Explanations for limited treatment efficacy and poor outcome have largely focussed on factors relevant to the patient. Thus, patients have been characterised as being in denial of their illness, 'difficult to treat', 'uncooperative', 'non-compliant' and 'impervious to treatment' (Kaplan & Garfinkel, 1999; Vandereycken & Vansteenkiste, 2009). AN is one of the few psychopathologies that can be considered ego-syntonic, i.e. the individual values their symptoms (Schmidt & Treasure, 2006). Strober (2004) suggests that AN is an ego-syntonic disorder because it serves an adaptive organising function for the individual to fix underlying psychological problems. It is argued that the functional nature of AN contributes to why the disorder is so resistant to treatment, as patients are reluctant to give up something they feel compelled to do in order to achieve positive outcomes (Geller et al., 2001; Nordbo et al., 2006).

To date, there has only been one randomised controlled study that has specifically focused on patients with the severe and enduring form of AN. Touyz, Le Grange, Lacey, and Hay (2013) found that cognitive behavioural therapy (CBT) and specialist supportive clinical management (SSCM) were both acceptable for adults with SE-AN, had good retention rates and produced significant improvements, with CBT superior at 12-month follow-up in terms of ED symptoms and 'readiness to recover'. However, the evidence remains sparse for this specific group despite the high levels of disability and dependency resulting from SE-AN. As most patients with SE-AN are unlikely to fully recover, Touyz and Hay (2015) argue that instead of solely focusing on symptom reduction, a holistic recovery model is required in order to support patients in improving their quality of life and general functioning.

To inform such a model, qualitative research is potentially a useful way of gaining insight into the person as a whole and not just focus on physical symptoms and behavioural patterns. Of the limited number of qualitative studies which have begun to explore the lived experience of individuals with SE-AN, in agreement with the qualitative AN studies described above, the majority also identify the functional ego-syntonic role of AN for chronic sufferers. Participants describe SE-AN as providing a sense of identity, control, comfort and even pride in their ability to control their weight and a profound sense of ambivalence towards recovery. They often identify treatment as a means of maintaining and managing their disorder, rather than a means of overcoming it (Fox & Diab, 2015; Hannon et al., 2017; Robinson et al., 2015).

Moreover, some aspects of treatment were identified as unhelpful by informants with SE-AN. Fox and Diab's (2015) participants criticised the perceived inexperience of outpatient therapists in preventing inpatient admission as well as a perceived pessimism on the part of staff in their ability to recover. Participants described being passed around different services and criticised re-feeding treatments and the use of nasal gastric tubes, often describing the experience as profoundly traumatic due to loss of control. Dawson, Rhodes, and Touyz (2014) who carried out a qualitative study of eight women who 'had done the impossible' (i.e. had fully recovered from SE-AN) stress that according to these women's reports recovery had been a lengthy and complex journey for them consisting of four phases: unable/unready to change; a tipping point when motivation increased; taking action against AN; and finally reflection and rehabilitation. These authors also emphasise the importance of self-efficacy as well as the support from others in the recovery process. Hannon et al.'s (2017) SE-AN participants praised a novel community-driven care model as it allowed them to maintain a sense of safety and control compared to inpatient treatment. However, there remains a scarcity of research that has specifically focussed on patients with SE-AN and further exploration is required to determine how clients with SE-AN make sense of their treatment.

The current study aims to explore the general experiences of women with SE-AN as well as their experiences in regard to their treatment. The study used Interpretative Phenomenological Analysis (IPA: Smith, Flowers, & Larkin, 2009), as this allows consideration of participants' experiences of living with and being treated for SE-AN, and thus to enrich our understanding of SE-AN and how best to approach treatment.

Method

Participants

Six women with a diagnosis of AN and experiencing AN symptoms, aged between 33 and 48 years (mean = 36 years), participated in the study. $N = 6$ is within the recommended sample size for studies that utilise IPA (Smith et al., 2009). As inclusion criteria, all participants had received a diagnosis of AN from their psychiatrist according to ICD-10, had maintained a BMI of below 17.5 kg/m^2 and received a variety of clinical interventions over a number of years but had not made sustained progress, with duration of illness ranging between 14 and 28 years (mean = 21 years). Three participants reported purging symptoms in addition to restriction. An overview of participant