Patient- and clinician- reported outcome in eating disorders

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ABSTRACT

Patient-reported outcome is increasingly applied in health sciences. Patients with eating disorders (EDs) characteristically have a different opinion of their needs to that of the health professionals, which can lead to ambivalence towards treatment and immense compliance difficulties. This cross-sectional study compared data assessed by the clinician to patient-reported measures in patients with a history of EDs.

We included data from a cohort of patients with EDs (n=544) referred to a specialized ED unit in Denmark. Patient-reported measures included the Eating Disorder Inventory-2 (EDI-2) and the Short Form 36 (SF-36), and clinical data included remission status and body mass index (BMI). We found a positive association between BMI and EDI-2 scores for anorexia nervosa (AN) and eating disorder not otherwise specified (EDNOS), reflecting increasing ED symptomatology with increasing BMI. This association was not observed in bulimia nervosa (BN). We did not find a correlation between SF-36 scores and BMI in any of the diagnostic groups.

1. Introduction

Eating disorders (EDs) are serious diseases with an often chronic course and potentially fatal outcome. Patients with EDs have impaired health related quality of life (HRQoL) compared to the general population, even after remission (Pohjolainen et al., 2016). Clinicians often classify patients with EDs based on weight, menstrual status and eating behaviour. However, one of the major obstacles in comparing ED research studies is the lack of a clear consensus on what defines remission. Furthermore, patients and clinicians may not define remission in the same way.

Discrepancies between patient-reported outcome (PRO) and clinician-reported outcome have been described in other medical fields (Chassany et al., 2006; Xiao et al., 2013; Janssen et al., 2016), but have not been thoroughly researched in EDs. Studies performed on opioid dependent patients (Trujols et al., 2013) reported large discrepancies between patient-reported and clinician-reported improvement and emphasized the need to develop outcome measures that better reflect the patient's perspective. Similarly, in depressive disorders, patients viewed other aspects important to remission than those defined by the clinician, important (Zimmerman et al., 2006). The authors then developed an assessment tool incorporating the aspects patients perceived as important in determining remission.

The discrepancies reported between PRO and clinician-reported outcome are not necessarily unfavorable, but can be viewed as a source of information in future studies. In obsessive-compulsive disorders, it has been demonstrated that PRO measures are better at predicting outcome than clinician-reported measures (Subramaniam et al., 2014). Including both the patient's and clinician's perspective can ultimately strengthen the validity of the outcome prognosis.

The high drop-out rates and lack of compliance characteristic for patients with EDs can be viewed as a consequence of the discrepancy in goals between the clinician and the patient. A review from 2012 found vast differences between the patient's perspective of their needs and the opinion of the health professional (Westwood and Kendal, 2012). Patients viewed treatment as a threat to the sense of self (Rieger et al., 2001) and did not perceive themselves as unwell or in need of treatment. One way to strengthen the alliance between patient and clinician is to ensure that they are at the same expectancy and motivational level. A clinician is trained to perform a task, but the patient might still be contemplating or preparing themselves to receive treatment. This leads to a mismatch between the two and can ultimately lead to "treatment resistance". Aligning expectations would strengthen the alliance between the clinician and patient, and thus

increase the chance of treatment success.

PRO measures are increasingly applied in clinical practice, as PRO data can be used to assess symptom severity, function and treatment efficiency. PRO consists of statements from the patient without any assessment or interpretation by a clinician, and reflects the patient's perspective on treatment, symptoms, well-being etc. This information is especially valuable in mental illnesses, as symptoms may not be observable to others and may be missed by the clinician. In the field of EDs, PRO measures such as the Eating Disorder Inventory-2 (EDI-2) can be used to assess patient symptoms and behaviours with the objective of enhancing the clinician's understanding of the effect the disease or treatment has on the patient's life (Clausen et al., 2009).

A dominant feature of anorexia nervosa (AN) is its egosyntonic nature in which weight loss is perceived acceptable and desired. Egosyntonic disorders are difficult to treat as patients find their situation acceptable and consistent with their self-concept. Patients with egodystonic disorders, such as bulimia nervosa (BN), exhibit thoughts and behaviours incongruent with their self. However, patients with BN often seek help later than patients with AN and hence have a longer duration of disease when treatment starts, which complicates the treatment process. Treatment is further complicated by the fact that a large proportion of patients with egosyntonic AN switch to dystonic BN during the course of the disease (Eddy et al., 2008). This is an important issue when assessing treatment outcome in patients with EDs. A more patient-centred approach might enhance the therapeutic alliance and thereby increase the likelihood of successful treatment and decrease drop-out rates.

Previous studies have examined the ED patient's perspective on the burden of disease and its impact on everyday life (Winkler et al., 2014). Furthermore, a vast amount of knowledge has been obtained regarding prognosis and outcome from the clinician's point of view; however we need to know more about the association between PRO and clinical measures to determine how we can use PRO information supplied by patients with dominant ego-syntonic or ego-dystonic behaviour. Furthermore, knowledge regarding discrepancies between markers for outcome can assist in developing future outcome assessment tools and defining remission.

The aim of this cross-sectional study was therefore to examine the correlation between clinician assessed outcome (remission status and body mass index) and patient-reported health-related quality of life and eating disorder symptomatology in patients with eating disorders or a history of eating disorders.

2. Methods

2.1. Participants

Data were drawn from a larger dataset of patients referred to the Centre for Eating Disorders, Odense University Hospital, Denmark from January 1st, 1994 to December 31st, 2004. The cohort has previously been described in detail elsewhere (Stoving et al., 2011, 2012; Winkler et al., 2015). Upon referral, patients participated in a preadmission assessment conducted by trained health professionals to establish a diagnosis and determine the treatment course. Diagnoses were converted into the terminology of the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV) (Association, 1994) for uniformity and included AN, BN and eating disorder not otherwise specified (EDNOS). In 2008, all patients referred to the centre in the abovementioned time frame were identified through an electronic patient administrative system to retrieve potential candidates for the present study. All potential participants were invited to undergo a clinical assessment, and complete self-reported questionnaires regarding quality of life and ED symptomatology, which was carried out during 2008 and 2009. Included in the invitation was a consent form which patients were requested to complete at the clinical assessment before initiation. The study was approved by the local ethics committee

(file no. S-VF-20050144). The study is registered in ClinicalTrials.gov, number NCT00267228.

2.2. Clinical assessment

A trained medical doctor performed the clinical assessment. Height was measured using a wall-mounted stadiometer and weight was measured on a calibrated platform scale. In addition to BMI we calculated the percentage of median BMI (%MBMI), which is defined as the distance from median BMI for age and gender according to reference values (Nysom et al., 2001) to the actual BMI. Information regarding the patient's menstrual status, eating/purging behaviour, weight and use of psychopharmacological drugs in the preceding six months was gathered through interview. As no strict consensus has been agreed upon regarding remission status in patients with EDs (Bardone-Cone et al., 2010), this study defined remission stringently, with patients classified as being in full remission when the following three criteria were met: 1) % ideal body weight (IBW) consistently above 85%, 2) no bulimic or purging episodes within the last six months and 3) no treatment with psychotropic drugs or psychotherapy within the last six months.

2.3. ED symptomatology

Patients were invited to complete the EDI-2 questionnaire to assess their current ED symptomatology. The EDI has been used for more than 20 years to assess ED pathology and is a widely used self-report measure of psychological traits clinically relevant in individuals suffering from EDs (Garner et al., 2002). The EDI-2 consists of 91 questions that make up 11 subscales measuring ED pathology and psychopathology, and has been validated in Danish samples (Clausen et al., 2009). A higher total score represents a higher burden of disease level of symptomatology.

2.4. HRQoL

No disease-specific HRQoL questionnaire has been validated in a Danish sample. Therefore, we used the SF-36 to assess HRQoL in participants. The SF-36 is a generic, self-report questionnaire (Ware and Sherbourne, 1992) consisting of eight subscales that assess physical functioning (PF), role limitations due to physical health problems (RP), bodily pain (BP), general health perception (GH), vitality (VT), social functioning (SF), role limitations due to emotional problems (RE) and general mental health (MH). The sum for each subscale is transformed into a 0–100 scale with higher scores indicating better HRQoL. The scores can be summarized in a mental component scale (MCS) and physical component scale (PCS), where a score of 50 represents the general population mean.

2.5. Statistical analysis

Normality of data was evaluated mathematically by Shapiro-Wilk test and visually by normal probability plots. Data are presented as mean (± standard deviation (SD)) or median and interquartile range (IQR), as appropriate. Study characteristics were compared in the diagnostic groups, stratified by remission status by one-way ANOVA or Kruskal-Wallis tests, according to distribution of data. To examine the association between BMI and ED symptomatology and HRQoL, we performed linear regression analyses with EDI or SF-36 scores as dependent variables and BMI or %MBMI as independent variables. We compared SF-36 scores to a Swedish norm population (Sullivan et al., 1995), as Danish population norm has yet to be validated and published, by Mann-Whitney U test. The Swedish population is socio-economically comparable to the Danish (Westergaard-Nielsen, 2008). In all regression models we adjusted for remission status. Statistical analyses were conducted using Stata version 13.1.