The new questionnaire Health-Related Quality of Life for Eating Disorders showed good validity and reliability

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Abstract

Background and Objectives: To describe the development and investigate the psychometric properties of a new instrument to measure health-related quality of life (HRQoL) for individuals with an eating disorder (ED).

Methods: Seven focus groups were convened and an extensive literature review was carried out to generate the items. The first draft of the questionnaire was pilot tested. Three hundred twenty-four ED patients took part in the final field study. The 12-Item Short Form Health Survey, the Eating Attitudes Test-26, and two items from the Eating Disorders Inventory-2 also were applied to examine the concurrent validity. Factor analysis, item scale correlation correcting for overlap, test–retest, Cronbach's α coefficient, known-groups validation, and the sensitivity of the questionnaire in different populations also were examined.

Results: The final Health-Related Quality of Life in Eating Disorders (HeRQoLED) questionnaire consisted of 50 items. Principal axis factor analysis identified eight subscales. Concurrent validity showed correlations > .40 with the criteria measures. Excellent reliability and stability were obtained. The HeRQoLED was sensitive in discriminating both between known-different groups and from the general population.

Conclusion: The results provide evidence of the good psychometric properties of the new HeRQoLED questionnaire, except for one domain, which had to be eliminated. © 2006 Elsevier Inc. All rights reserved.

Keywords: Eating disorders; Health-related quality of life; Psychometrics; Questionnaire development; Validity; Reliability

1. Introduction

Emphasis recently has been placed on the importance of health-related quality of life (HRQoL) in assessing states of health and outcomes of medical care, especially in chronic diseases. The term HRQoL does not have a unique definition; however, there is broad agreement that it is a subjective, multidimensional construct comprising three major aspects of functioning: physical, psychological, and social [1].

After reviewing the literature, we found that few studies have focused explicitly on measuring the HRQoL in patients with anorexia nervosa (AN) and bulimia nervosa (BN) [2–6]. Interestingly, most studies were concerned with the relationship between binge eating disorder and HRQoL

[7–12]. Padierna et al. [4] reported that patients with AN and BN had a perception of improvement in HRQoL after 2 years of treatment. Nevertheless, these patients were still more dysfunctional compared with the general population. All the studies reviewed may be limited due to the use of a generic HRQoL instrument that "may fail to capture the extent of the disability caused by the illness" [5] for the groups of patients with an eating disorder (ED). The creation of a specific HRQoL instrument would allow greater discrimination of severity of disease and responsiveness to treatment [6,13,14].

To offset these deficiencies, we developed the Health-Related Quality of Life in Eating Disorders (HeRQoLED) self-report questionnaire, which is comprised of 50 questions that measure eight health-related domains, including one symptom index (10 items). It also contains three single items that are not used to score any of the domains but provide useful data for clinical practice. They provide

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information about the regularity of menstrual periods, the effect of certain behaviors on the perception of the patient's quality of life, and the motivation of the patient to change his or her ED.

2. Aims of the study

We sought to develop an instrument to measure the HRQoL in ED patients. Its psychometric properties were explored, and we also wanted to test whether the HeRQoLED questionnaire could discriminate between subjects with an ED and a group comprised of members of the general population.

3. Material and methods

3.1. Participants and procedures

Four psychiatrists experienced with EDs, from three health centers in Bizkaia, Spain, collaborated in the recruitment of participants. The criteria for inclusion in the study were that participants had to (1) be diagnosed with an ED, according to the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (*DSM-IV*) criteria [15]; (2) be treated on a regular basis in one of the three centers; (3) not have a clinically serious multiorganic disorder, cerebral organic deterioration, or acute psychosis that would prevent the questionnaire from being completed; and (4) agree to participate voluntarily after being informed personally by his or her psychiatrist and after providing informed consent. At the time of the investigation, 394 patients fulfilled these criteria. All the measurement instruments were mailed to the participants. Two reminders also were sent at 15-day intervals. The first reminder was a letter in which patients again were requested to complete the measurement instruments that were sent previously. In addition to a letter, the second reminder included all the measurement instruments. Three hundred twenty-four questionnaires were returned (response rate: 82.23%). There was also a clinical questionnaire, completed by the psychiatrists for all 394 patients. This contained information of a sociodemographic and clinical nature.

A test–retest was performed with 48 patients to assess the stability of the questionnaire. Patients had to be in relatively stable physical and psychological condition in accordance with their psychiatrist's criteria, and in the retest, patients had to answer negatively to the transitional question "Has a major event occurred in your life since the last time you completed the questionnaire, which might be having an influence on your current physical and/or mental state?" Approximately 15 days elapsed between both applications. Of the 48 patients selected, 39 (81.25%) completed the questionnaire on both occasions.

To create a comparison group, 305 university and nonuniversity students were recruited from the general population of the surrounding area. To normalize the sample with that of the patients with ED, mainly women were asked to collaborate. All participants were informed previously about the characteristics of the research and its voluntary nature.

3.2. Creation of the HeRQoLED

First, seven focus groups were formed: four with patients with an ED, two with family members of patients with an ED, and one with a multidisciplinary group of experts [16] to determine which aspects of the patients' lives were most affected by the disorder. Based on an analysis of the contents of the focal groups, the domains most commonly affected by ED were identified.

Second, an extensive bibliographic review was carried out to find articles and questionnaires dealing with the identified domains, questionnaires measuring HRQoL, and specific questionnaires for ED [17–37].

Third, members of the research group (four psychiatrists, two clinical epidemiologists, and one psychologist) selected the items that could be used to construct the questions in the HeRQoLED from the reviewed questionnaires. No items were found that measured physical symptoms in ED, and, therefore, they were created according to the criteria of the research group. A pilot study ($n = 124$ patients with ED) was conducted to evaluate the comprehensiveness and acceptability of the questionnaire. Descriptive and exploratory factor analyses were performed. Finally, based on these results, the research team changed the wording of some items and the response scale, included new items, or removed those that did not provide sufficient information. This final version was mailed to the patients with an ED in the field study.

3.3. Scoring the HeRQoLED

The HeRQoLED provides a profile of the subject according to eight domains. All questions are answered on an adjectival scale with five or six discrete responses, with 0 indicating never or nothing and 4 or 5 a lot or always. The higher the score on the domain, the lower the patient's perception of his or her quality of life. The total score for each domain is computed by adding the scores assigned to each item making up the domain and standardizing the results on a scale of 0 to 100. One item in the body image domain and three in the mental health domain are reverse scored before computing the domain score, because a high response in these items indicates a better perception of health. The simple mean imputation method [38] was used when individual items from a domain were missing, only if the respondent had completed at least half of the items in that domain. This method consists of estimating the missing values from the mean value for those items that are available and was applied after ending the scale development phase.