Exploring health-related quality of life in eating disorders by a cross-sectional study and a systematic review

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Abstract:

**Objective:** We aimed to analyze health-related quality of life (HRQoL) in subgroups of eating disorder (ED) patients by using the brief version of WHOQoL questionnaire (WHOQoL-BREF) before treatment administration. In addition, we carried out a systematic review of the literature on HRQoL in ED patients.

**Methods:** Eighty female ED patients (26 with bulimia nervosa, 33 with anorexia nervosa, 7 with binge eating disorder and 14 with ED not otherwise specified) completed the WHOQoL-BREF. HRQoL scores were compared among ED subgroups and clinical information (presence of previous contacts, length of illness, psychiatric comorbidity) were considered in the analysis. The systematic review was carried out by means of an accurate data mining of PsychInfo and Medline databases and other available sources.

**Results:** ED subgroups differed only for Psychological Health HRQoL scores ($F=4.072$, $df=3$; $p=0.01$). No differences were found between inpatients and outpatients, treatment naïve and previously treated patients and patients with or without psychiatric comorbidity. HRQoL scores were not significantly correlated to length of illness within each ED subgroup. The systematic review shows that with few exceptions ED patients have a poorer HRQoL than the healthy population of control and sometimes the mental component of HRQoL is the most involved dimension. Moreover, there are no differences in the HRQoL among ED groups, even if AN patients in some studies have a lower HRQoL scores. Furthermore, BED patients have a poorer HRQoL than obese patients who do not have binge episodes. Finally, all treatments were positively correlated with an improvement on general and specific QoL dimensions.

**Conclusions:** In our study ED patients reported reduced HRQoL principally in the Psychological Health dimension, with no difference between patients with and without psychiatric comorbidity. The analysis of the literature add some relevant information on HRQoL in ED and may address the future research toward the exploration of specific questions.
**Introduction**

According to the World Health Organization (WHO), HRQoL refers to the patient’s ability to enjoy normal life activities and the level of personal satisfaction with the cultural or intellectual conditions under which patient lives [1]. Such definition emphasizes the subjective perception of well-being, which is influenced by physical, psychological and social functioning [2]. As reviewed by Engel and colleagues [3], most of studies investigating the quality of life (HRQoL) in eating disorder (ED) patients measured the effects of abnormal eating behavior on health status but not on health related quality of life (HRQoL).

Specifically, the HRQoL is associated with the degree of illness-related disability and effects of medical interventions on perceived HRQoL [4-5]. Indeed, people with ED often report poor HRQoL [6], which is explicitly correlated to illness’ severity and its effects on cognitive performance [7-8]. Cognitive impairments may significantly reduce adherence to individualized rehabilitation programs, thus favoring chronicity and psychosocial deterioration [9]. Moreover, ED are frequently associated with comorbid psychiatric disorders, especially anxiety, somatoform and depressive disorders, which further prevent recovery and increase the probability of resistance to treatment efforts [10-11].

Hence, the assessment of HRQoL in ED is crucial to predict the clinical outcome in patients undergoing specific treatments, as well as the risk of relapse and recurrence [12]. Although some ED-specific instruments have been used to assess HRQoL [13], none of them offers a global viewpoint of patient’s perception of HRQoL. Conversely, the World Health Organization Quality of Life (WHOQoL) questionnaire [1] measures patient’s subjective awareness of illness related to physical and psychosocial dysfunctioning.

In the current study, we used the brief version of WHOQoL questionnaire (WHOQoL-BREF) to explore whether HRQoL differed among ED subgroups at the beginning of the psycho-nutritional rehabilitation program; furthermore, we investigated the effects of comorbid DSM-IV diagnosis, setting of care and an history of previous treatment on self-perceived HRQoL in ED patients. Moreover, since we were interested to compare our results with the existing literature, we carried out a systematic review of HRQoL in ED with the aim to analyze the published studies taking into account their design, methods and principal results.

**Methods**

In our cross-sectional study we recruited eighty female ED patients (mean age: 28.24±11.28 SD; range: 13-61 years) attending the Centre for Eating and Weight Disorders of the local Socio-Health Unit (ASSL “Veneto Orientale”, Portogruaro, Italy). Patients’ diagnoses were established
using the DSM-IV-TR criteria for Anorexia Nervosa, Bulimia Nervosa, and Binge Eating Disorder. Subjects who did not meet full diagnostic criteria were classified as Eating Disorder Not Otherwise Specified. Exclusion criteria included the presence of clinically relevant multiorganic disorder or cerebral organic impairment and patients not completing the assessment for language barriers. All patients were informed about the main objectives of our search and all signed written informed consent.

Our study was carried out in compliance with the Helsinki Declaration, using the database of Centre for Weight and Eating Disorders of Portogruaro, a credited agency of the Regional Health System. Patients gave their written consent to the use of their data for both clinical and research purposes at the time of their first contact with the Centre. Since no new instrument or investigation were used, a specific request to the local ethics committee was not advanced, being valid the principle of the availability for research of the data gathered in the clinical practice.

All participants were assessed for self-perception of HRQoL using the WHOQoL-BREF [1] at the beginning of treatment. This questionnaire is a 26-item short version of the WHOQoL scale measuring the subjective perception of quality of life associated with physical and psychological health, social performance and environment’s characteristics. The Physical Health scale specifically investigates activity of daily living, dependence on drugs and medical supports, level of energy, mobility, pain and discomfort, sleep and rest, work capacity. The Psychological Health scale explores body image and appearance, positive and negative feelings, self-esteem, spirituality and personal believes, cognitive functioning. The Social Relationship scale measures quality of social relationships, social support and sexual activity. Finally, the Environment scale evaluates individual’s socio-economic conditions (as financial resources, freedom, physical safety and security) and the availability of facilities in living and working context (accessibility to health and social care, home environment, chances for acquiring new information and skills, recreation and leisure activities, physical environment and transport).

Items are scored on a Likert five-point scale, were “1” means severe discontent and “5” great approval; patients had to evaluate their quality of life considering the two weeks preceding the administration of the questionnaire. The mean score of items within each scale was multiplied by 4 in order to be comparable to those of the 100-items WHOQOL scale.

Finally, height and weight were measured to calculate the body mass index (BMI: kg/m²).

**Statistical analysis**
Data were analyzed using SPSS Version 16.0 for Windows [14] and STATA 10.0 [15]. The statistical significance (alpha) was set at p<0.05. Firstly, data were inspected for normality using the Shapiro-Wilk test.

Socio-demographic and clinical variables were compared among ED subgroups using the Kruskal-Wallis or Fisher’s exact test, as appropriate. Finally, an analysis of covariance (multivariate ANCOVA) was used to examine whether 1) there were significant differences between ED subgroups, after controlling for age and length of illness; 2) there were differences for HRQoL scores between ED inpatients and outpatients, ED patients with and without history of previous treatment, patients with and without comorbid DSM-IV diagnosis, controlling for ED diagnosis. Bonferroni’s correction for multiple comparisons was also applied.

Finally, Pearson’s correlation analysis was performed to explore the relationship between HRQoL scores and length of illness.

Systematic review

In order to place our study within the frame of the current knowledge on HRQoL in ED, we conducted a systematic review of the literature in this field. The aims of the review were to select published papers written in English which analyzed quantitatively the health-related quality of life (HRQoL) in subjects with ED, in order to:

- test the hypothesis that HRQoL is poorer in ED subjects than in healthy individuals
- explore the existence of different levels of HRQoL among different ED
- explore whether ED subjects have different impairments on mental vs. physical dimension of HRQoL
- explore the existence of differences in HRQoL between obese subjects and subjects with BED
- analyze the efficiency of ED-specific HRQoL instruments as compared with more general instruments
- analyze the efficacy on HRQoL of the treatment proposed for ED, including bariatric surgery

An accurate data mining was conducted by consulting PsychInfo and Medline databases and other available sources, such as the references included in the papers reviewed. The databases were examined thoroughly using the keywords “quality of life, QoL, HRQoL, functional impairment, eating disorders, anorexia nervosa, bulimia nervosa, binge eating disorder”.

We consulted also other reviews on this topic, with the aim to examine the data already gathered. In particular, three reviews are worth consulting. The review by Engel et al. [3] is a narrative review
focused on the instruments used to measure the HRQoL in ED patients. The Authors identified four ED-specific HRQoL instruments (the 25-item EDQOL, the 40-item EDQLS, the 55-item HeRQUoLED and the 20-item QOL-ED) and discussed their relevance in the field of the treatment of ED. A second review was carried out by Passarelli-Tirico et al. [16], who classified the papers according to the quality of the design, as defined by the Australian governative Agency NHMRC. The shortcomings of this review are that it is not in English and does not include the results of HRQoL analyses. The third review was carried out by Jenkins et al. using a narrative approach [17]. This is a comprehensive review, which allows to enter into the details of the papers and to analyze specific issues such as the HRQoL associated with subclinical ED pathology, BMI, or purging and other compensatory behaviors. However, it does not include a general table to compare the studies and does not attempt to systematically describe the research design, the setting or the type of assessment used.

In our review we included papers that used validated HRQoL instrument and classified patients according to definite diagnoses, although we considered also papers that assessed the patients according to eating dimensions or to subclinical levels of disordered eating. Consequently, the accuracy of the assessment is quite variable, ranging from simple ED questionnaires to clinical or semi-structured interviews. Most frequently, the assessment was conducted with instruments of the EDE series, either questionnaire or interview. Other structured instruments were the SCID or the PRIME-MD. Finally we excluded from our review those papers who analyze the HRQoL in obese patients without attempting to assess the presence of a whatsoever ED within the sample.

Results

All relevant socio-demographic and clinical data of our cross-sectional study are reported on Table 1a and 1b. Fifty-nine out of 80 subjects were outpatients (73.8%) whereas the remaining 21 (26.3%) were inpatients. Among all patients, 33 (41.3%) were affected by AN (mean age: 26.1 years ±10.6 SD), 26 (32.5%) were affected by BN (mean age: 27.5 years ±8.0 SD), 7 were diagnosed as BED subjects (8.8%) (mean age: 41.6 years±14.0 SD) and 14 patients suffered from EDNOS (17.5%) (mean age: 28.1 years±13.3 SD). In addition, 14 patients (11 inpatients and 3 outpatients) fulfilled DSM-IV criteria for other ED: two for Borderline Personality Disorder (2.5%), nine for Major Depressive Disorder (11.3%) and one each for Bipolar Disorder, Alcohol Abuse and Social Phobia. Forty-six patients had an history of previous therapies for ED (25 inpatients and 21 outpatients) whereas the remaining 34 subjects were all treatment-naïve ED inpatients.

ED subgroups significantly differed for age ($\chi^2=8.293$, $p=0.040$), BMI ($\chi^2=54.916$; $p<0.001$), age at onset ($\chi^2=; p=0.02$), age at first evaluation ($\chi^2=8.198$; $p=0.04$) and length of illness
(χ² = 9.585; p=0.022). Also, differences among ED subgroups were found for marital status (p<0.001), setting (p=0.005), history of previous treatments (p<0.001) but not for educational level or living conditions, occupational status, proportion of patients completing their studies and DSM-IV psychiatric disorder comorbidity (p>0.05). Significant differences emerged when considering the presence of a history of previous treatments for ED, both between ED inpatients (100% untreated) and outpatients (54.3% untreated) (p<0.001) and between patients with psychiatric comorbidity (14.2% untreated) and without psychiatric comorbidity (48.5% untreated) (p=0.03). In opposition, no difference was detected for psychiatric comorbidity between inpatients (81% no comorbidity) and outpatients (85.7% no comorbidity) (p>0.05).

HRQoL scores

All ED patients’ HRQoL scores were below normative population values (Table 2). Results of ANCOVA showed that ED subgroups differed only for Psychological Health QoL scores (F=4.072, d.f.=3; p=0.01; ANCOVA, age and length of illness as covariates). As to respect to illness’ awareness, differences among ED subgroups did not reach statistical significance (p>0.05, Fisher’s exact test) (Table 2).

No differences for HRQoL scores were found between inpatients and outpatients, as well as treatment naïve or previously treated patients (p>0.05). Also, ED patients with a DSM-IV comorbid diagnosis did not differ from those without psychiatric comorbidity for HRQoL scores (p>0.05; ANCOVA, ED diagnosis as covariate). Ultimately, HRQoL scores were not significantly correlated to length of illness within each ED subgroup (p>0.05, Pearson’s correlation analysis).

Evidence from the literature

As it shown in Table 3, three main typology of study could be identified in the literature. The first one is the population survey, carried out with different methods and with dissimilar response rates. Some were postal surveys, others were conducted via telephone, and further more used a face to face interview. A second type of design is the cross-sectional analysis of samples of subjects attending outpatients ED centers or of patients waiting for a gastric by-pass surgery. The third type of design is the cohort prospective study. Within this category, there is one single multi-wave survey and a number of papers focused on treatments: within the latter studies, we can enumerate RCT studies with drugs, one study with a specific psychotherapy (CBT) treatment, studies on patients who attended a nutrition program or other unspecified programs in ED centers and one study which evaluated a gastric by-pass surgery intervention.
An important issue is the preference accorded from most studies to the SF-36 scale or its derivatives for the assessment of HRQoL. The SF-36 is a well-known but unspecific instrument for the study of ED and allows a distinction between mental component symptoms (MCS) and physical component symptoms (PCS). Other generic instruments include for example the WHO scale WHO-BREF, which was used in a few studies. More specific instruments are EDQoL, the HeRQUoLED, the EDQLS, the IWQOL, but only few studies adopted them.

The main evidence that comes out from our systematic review is that with few exceptions ED patients have a poorer HRQoL than the healthy population of control. Frequently MCS is the most involved dimension, which means that ED patients are particularly vulnerable to impairment in the QoL because of their psychic difficulties, being the physical component less harming. But this is not always the rule.

Another piece of evidence is that frequently there are no differences in the HRQoL among ED groups. AN patients in some studies have a lower HRQoL and this is particularly evident when a specific instrument is used, like the EDQoL.

Among potential surgical patients waiting for a GBP, most - but not all - studies conclude that BED patients have a poorer HRQoL than obese patients who do not have binge episodes.

Finally, when we consider the efficacy of the treatment on HRQoL measures, all treatments were positively correlated with an improvement on the general and, when examined, specific QoL dimensions. However, when compared with healthy individuals, their HRQoL remained still below the norm.

**Discussion**

In our cross-sectional study we took in consideration an heterogeneous group of ED patients. As we can see from Table 3, this is quite the rule for cross-over HRQoL studies on ED patients, which for the most part include patients of different ED diagnoses. Although our sample size is on average with the other studies, the main difference of our research is that we included both outpatients and inpatients.

Our study confirmed results obtained by previous investigations, demonstrating that ED patients experienced reduced HRQoL. Surprisingly, ED inpatients and outpatients did not differ as for HRQoL scores. Most ED inpatients in our sample were AN, thus confirming that anorexic behaviors implicate an high risk of organic complications and require a large amount of intensive medical care [48]. It is possible that AN inpatients did not report greater limitations in comparison to the other subgroups, because of a poor perception of psychosomatic distress [49-50].
When we consider the HRQoL in the ED groups, the only difference was present in the Psychological domain, were patients with EDNOS reported the highest HRQoL scores. It has to be considered that EDNOS patients represents an heterogeneous category of subjects with a variety of disturbed eating behaviors, affecting general functioning in different ways and generating different levels of distress [51-52]. Probably, our EDNOS patients were not severely distressed; therefore, they identified just a modest decline of HRQoL. Conversely, patients with BED obtained the lowest mean HRQoL scores for Psychological Health. These data are in agreement with previous studies, which documented greater health dissatisfaction, increased risk of main medical disorders [53], difficulties in regulating emotions [54] and concurrence of personality traits as well as mood and anxiety disorders [55-56] in binge eaters. Differently from other papers [57], our study showed that none of BED sufferers had a definite comorbid DSM-IV diagnosis, even though they perceived poor psychological well-being. This may depend on the presence of sub-threshold psychiatric symptoms not fulfilling full criteria for a DSM-IV diagnosis.

In our study, we found no differences in HRQoL between ED patients with and without a comorbid DSM-IV diagnosis, as well as between patients with and without an history of previous treatments. Moreover, HRQoL scores were not significantly correlated to length of illness within each ED subgroup.

It is worth noting that a considerable proportion of outpatients had received previous specific interventions whereas none of the inpatients had an history of previous treatments. We may speculate that patients with severe ED symptoms did not seek help because of their low illness’ awareness. Also, this finding may suggest that primary care physicians did not identify ED as a feasible diagnosis in subjects presenting a variety of somatic symptoms, such as important weight alterations, repetitive vomiting or bingeing [58]. Therefore, medical and psychological interventions were dramatically delayed, favoring chronic course.

Over 85% of patients with comorbid psychiatric diagnosis reported an history of previous treatment for ED, in comparison to the 50% of patients without coexisting psychiatric diagnosis. These results are in contrast to previous surveys demonstrating that ED are frequently linked to Major Depressive Disorder, Anxiety Disorders and Substance or Alcohol Abuse [59]. It is possible that ED relapses and successive hospitalizations reduce the response to treatment of comorbidity [60-61]. Consequently, the combination of severe ED psychopathology with another psychiatric disorder contribute to chronicity of illness and should be considered as relevant prognostic factor influencing long-term outcomes of rehabilitation programs and increasing financial dependence on society [62-64].
Finally, other issues on HRQoL evaluation can be drawn from the studies carried out with a research design different from that of our study. In particular, the main evidences coming out from the present review are the followings:

- the surveys confirmed that ED patients have a poorer HRQoL than the general population and this is evident in particular when considering the mental component of the quality of life;
- among the obese patients, quite invariably the BED had a poorer HRQoL than non-BED subjects. This is an important piece of information, since it supports the idea that there is a need of specific treatments for BED, which are not simply an adaptation of general nutrition intervention;
- in the cohort studies, we can distinguish general programs aimed to treat the ED from specific psychotherapies and RCT with psychotropic drugs. Even if the published data seem to reassure that many treatments are able to improve the HRQoL, we remain with the doubt whether the amelioration was due to some specific characteristics of the treatment or was a generic result of the caring of these patients. Much has to be done in order to respond to the question “what aspect of treatment improve HRQoL of ED patients?”.

As the last comment, we must highlight the fact that most studies used general scales for measuring the HRQoL, and in particular the SF-36. Since much fewer information comes from studies that used specific scales (such as EDQOL), it is not possible to draw conclusion on the advantages of the latter scales. On the other hand, the analysis of the table that summarizes the existing literature may suggest that the use of ED specific scales is able to increase the probability to discover subtle differences in HRQoL among different ED groups or between pre- and post-treatment scores.

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Competing interests

In the past five years none of the Authors received reimbursements, fees, funding, or salary from an organization that may in any way gain or lose financially from the publication of this manuscript, either now or in the future. None of the Authors hold any stocks or shares in an organization that may in any way gain or lose financially from the publication of this manuscript, either now or in the future. There are not non-financial competing interests (political, personal, religious, ideological, academic, intellectual, commercial or any other) to declare in relation to this manuscript.
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Additional files provided with this submission:

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