

Quality of life of patients with anorexia and bulimia nervosa

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Abstract

Anorexia nervosa and bulimia nervosa are the main types of serious eating disorders, particularly in adolescents and young female adults. They are similar concerning the sharp distortion of body image, morbid fear of gaining weight, concern with food and constant unrealistic desire for weight loss. This study aimed to assess the implication of eating disorders on the quality of life of patients with anorexia and bulimia nervosa. Six participants under treatment of eating disorders in a multidisciplinary team were evaluated. The instruments Eating Attitudes Test (EAT- 26) and the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) were used for data collection. The data indicate that the mental components of quality of life of participants are more impaired than the physical components. The “General Health Perceptions” were the most favored domain, followed by “Bodily Pain” and “Physical Functioning”. “General Mental Health” is the most impaired domain. The results show that participants’ quality of life is preserved, except for “General Mental Health” (psychological distress and well-being) and “Role Limitation Due to Emotional Problems”. “Quality of life” is an indicator to be considered, especially by the multidisciplinary team.

Key words: Bulimia Nervosa. Anorexia Nervosa. Quality of life. Mental Health.

Introduction

Eating disorders (ED) are psychiatric conditions that affect mainly young female adults; they cause serious biopsychosocial losses and high morbidity and mortality rates. Anorexia nervosa (AN) and bulimia nervosa (BN) are the two major types of disorders, whereby weight and body shape have an important influence in determining patients' self-esteem.¹

AN is mainly characterized by severe weight loss (as a result of strict self-imposed diets in an unbridled quest for thinness), distorted body image and amenorrhea.² In turn, BN is characterized by eating large amounts of food very quickly and with a feeling of loss of control, the so-called "bulimic episodes", accompanied by inappropriate compensatory methods for weight control, such as self-induced vomiting, use of medication (diuretics, laxatives, appetite suppressants), diets and strenuous exercise, caffeine abuse or cocaine use.²

The prevalence of AN is 0.5 to 3.7% and of BN, 1.1% to 4.2%, depending on the criteria used to define the disorders.³ The higher prevalence of eating disorders in the world population occurs in young patients aged between 12 and 25, and women (90% of cases). In contrast, Brazil does not have statistics for eating disorders. The low prevalence in the population and underreporting of cases appear as difficulties in establishing an accurate prevalence of EDs.³

Feeding behavior, in addition to the act of eating, also involves the experience of internal and external stimuli, with organic, psychological and social factors being taken into account.⁴ Thus, the act of eating transcends the nutritional value and sensory characteristics of food, while considering the presence of hidden motivations associated with psychological needs and emotional and conflicting experiences, which are independent of hunger.⁵

Several factors contribute to the predisposition, installation and maintenance of ED symptoms. Thus, the influence of family dynamics, the sociocultural environment and the functioning of a person's personality are recognized as determining components of the course of these disorders.^{6,7} In this context, family dynamic is seen as an important risk factor for the development of AN and BN, contributing to the construction of *apathologizing* social discourse, given that the attribution of blame often reserved for the family, helps parents and mothers feel even more helpless against the unusual character of their children's symptoms.⁸ Thus, EDs often disrupt families and complicate the way they operate.

As far as the socio-cultural environment is concerned, the importance given to physical appearance and to beauty standards in Western society, especially in recent decades, has contributed to an authentic "dictatorship of slender bodies." Mass media tend to perpetuate this ideal of thinness, since it reinforces the stigma attached to bodies that differ from such standards. This may influence the development and maintenance of ED symptoms.⁹

Finally, as regards emotional aspects, the literature reports that emotions and affection are rather disturbed in the context of psychopathological conditions marked by disturbance in eating behavior. Feelings of fear, guilt, shame and anxiety towards food emerge as a consequence.⁹

In the past five decades, the importance of assessing the quality of life has been on the rise, and priority is given to tools that are shorter and easier to use and understand. The definition of quality of life adopted by the World Health Organization (WHO) has three characteristics: *subjectivity* (emphasis on subjective perception, i.e., the individual himself), *multidimensionality* (considering physical, psychological and social aspects) and *bipolarity* (positive and negative dimensions). Thus, the notion of subjective well-being is valued, without ignoring the influence of external factors such as work and social relationships, in this perception.¹⁰

One of the instruments most frequently used around the world to assess the quality of life is the *Medical Outcomes Study 36-Item Short-Form Health Survey* (SF-36), created from the need to have a standardized instrument to address general concepts of health, non-specific for any medical condition, so as to be comprehensible and easy to use, with suitable psychometrics. In comparison, the concept of quality of life covered in this instrument is given by life-related health quality, which highlights the impact that prevention and treatment of an illness have on the “value of being alive.”¹¹

The SF-36 is useful for comparing general and sample populations, as for the relative impact of diseases, in order to differentiate the benefits produced by different treatments.¹¹ It consists of 36 questions that provide scores in the following domains of quality of life: a) Physical Functioning, as assessed from the performance of daily activities, such as the ability to take care of oneself, getting dressed, bathing, climbing stairs; b) Role Physical, indicated by the impact of physical health on performance of daily and/or professional activities; c) Bodily Pain, according to the level of pain and the impact on performance of daily and/or professional activities; d) General Health, perceived by the subjective perception of general health; e) Vitality, marked by the willingness of patients to perform daily tasks; f) Social Functioning, assessed by the consequences of the health condition on social activities; g) Role Emotional, assessed by the consequences of the emotional conditions in the performance of daily and/or professional activities; h) Mental Health, assessed by the mood and well-being scale.¹²

A systematic literature review,¹³ focusing on the quality of life of patients with EDs, showed greater impairment when compared to the quality of life of individuals without eating psychopathologies or to that of the normative population. The findings in that study suggest that the quality of life of individuals with AN and BN appears to be associated with higher emotional and social impairments in physical functioning, although the increase in physical activity may possibly be a psychopathological manifestation (one more tactic used to achieve weight loss), which makes such data doubtful.¹³

The review study also found that the most affected aspect of quality of life in patients with ED was the social functioning, which suggests that clinical and psychiatric aspects, together with social support and family involvement, have to be considered in the course of treatment and clinical planning of patients with ED. The presence of comorbidities, depressive or anxiety symptoms and the severity of the feed table were correlated with higher levels of loss.¹³

Another finding of the review indicates that the subscale “Physical Functional” of the SF-36 instrument, which involves performing basic activities and physical movement, has little or no impairment to the quality of life of subjects with EDs. This indicates that, the higher hyperactivity, the higher the level of quality of life in this domain. However, the best quality of life reflected by high physical functioning may be related to higher levels of eating psychopathology, but not the opposite, as could have been measured.¹³ Thus,

[...] as the assessment of quality of life is necessarily subjective, maybe it is not the mode of assessment of quality of life that should be resolved, but rather the very complexity of eating disorders. The results so far allow to reflect on ways to overcome the difficulties inherent in the assessment of quality of life in this group of patients, but not eliminate it, nor conclude which is the best way to do it [our translation] (p. 446).

Thus, given the complexity of clinical pictures of EDs, health professionals need to be aware of the uniqueness and the functioning of psychopathological phenomena underlying these clinical pictures, as well as their implications for clinical practice, so that more effective intervention strategies can be designed.^{6,9}

In addition to the SF-36 and its possible application in the context of assessing the implications of EDs, another instrument used primarily in this universe is the EAT, which aims to assess risk behavior and ED symptoms in patients or in population studies. Because it is easy to implement, efficient, economical, and also because there is no training required for administration, EAT is probably the most used of all self-report instruments in the area of EDs. EAT-26, its shortest version with 26 questions, does not diagnose the disorder, but detects clinical cases in high-risk populations and identifies individuals with anomalous concerns about weight and eating.¹⁴

Given the importance of studies on quality of life in EDs, considering its high incidence in contemporary society as well as the morbidity and mortality related to its diagnosis, this study aimed to raise awareness of the complex universe of EDs, expanding knowledge about the uniqueness of psychodynamic functioning and the psychopathological phenomena underlying the disorders, through the instruments SF-36 and EAT-26.

Context of study

The study was performed in the Ambulatory Care Clinic of Nutrition of a public hospital in São Paulo, with a team of expert nutritional doctors, physicians, nutritionists, psychiatrists, psychologists and student interns of psychology, and nurses and occupational therapists in cases of hospitalization. Most of these professionals work as volunteers in a big public university hospital that provides health care to people from different social classes because it is associated with Brazil's Unified Health System (SUS).

Types of health care offered to outpatients on a weekly basis include: individual clinical care provided by nutritional experts and dietitians; psychiatric care; individual psychotherapy treatment for some patients and families; psychodiagnosis; group of medical and nutritional guidance; and psychological support group for family members. On average, six to eight patients are seen in return visits.

Method

This is an exploratory descriptive study with a quantitative approach, with a convenience sample composed of patients who started to receive care during the second half of 2012. Six participants, four women and two men, were evaluated for ED treatment by a multidisciplinary team.

A basic principle adopted was the respect for volunteers and the institution. The study was approved by the Research Ethics Committee of Hospital das Clínicas (Clinical Hospital) of the School of Medicine of Ribeirão Preto (doc. no. 3749/2009). The participants were informed of the research objectives and data collection was made after they read and signed a consent form.

The assessments were conducted individually in a private room with adequate facilities and comfort, of the Hospital das Clínicas, School of Medicine of Ribeirão Preto.

The instruments used for data collection were the Eating Attitudes Test, EAT-26¹⁵ and the Short Form Health Survey, SF-36,¹⁶ administered face-to-face in outpatient return visits.

The results were analyzed according to the specific recommendations in the literature. In EAT, a score above 21 is indicative of ED. In SF-36, the results are transformed into a value ranging from 0 to 100, and, the closer to 100, the better that particular aspect of quality of life.

Results

Figure 1 shows the distribution of mean scores obtained in the areas of quality of life assessed by the SF-36.

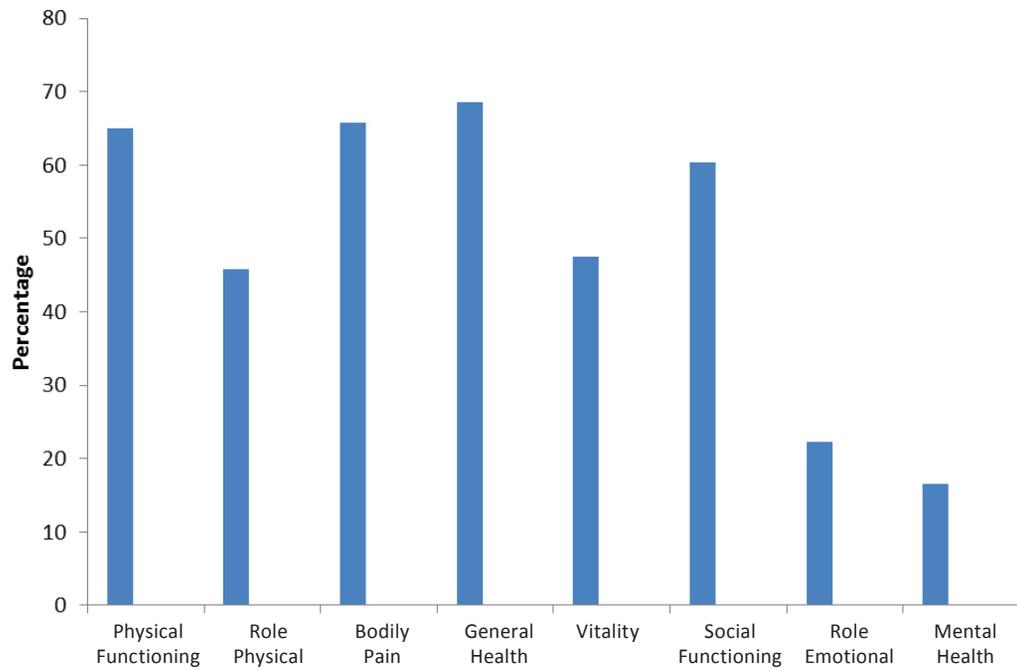


Figure 1. Average distribution of scores in eight domains assessed by the SF-36.

Figure 2 shows the scores for each participant in the Eating Attitudes Test (EAT-26).

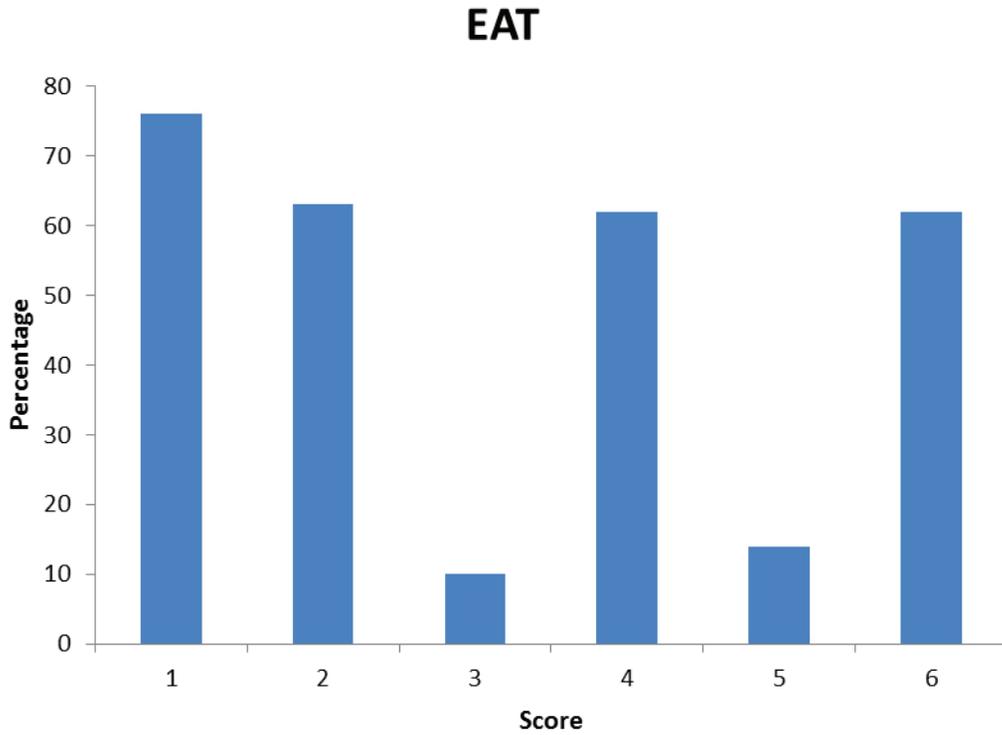


Figure 2. Distribution of scores on the EAT.

Discussion

The results for the data evaluated by the EAT-26 confirm the presence of ED symptoms in four participants. The mean score (47.8, SD = 28.3) was much higher than the cutoff point of the scale (21) for participants 1, 2, 4 and 6. The scores of participants 3 and 5 who were below the cutoff point (respectively, 10 and 14 points), which can be explained by the fact that they are under treatment.

In comparison, the data obtained by the SF-36 indicate that, on the general average, the participants' mental components of quality of life are more compromised than their physical components, especially when considering the low scores in the areas "Mental Health" (mean = 16.5, SD = 27.6) and "Role Emotional" (mean = 22.2, SD = 40.35). This corroborates the study by Tirico, Stefano and Blay (2010). The scores on "Mental Health" ranged between 16 and 44 and in "Role Emotional", between 0 and 100. It can be stated that due to their emotional condition, participants showed poor performance in their daily and/or professional activities. They also scored low in the domains of mood and psychological well-being.

The mean scores obtained in the domains "Role Physical" (mean = 45.8, SD = 51.0) and "Vitality" (mean = 47.5, SD = 42.8) are below 50, which suggests tendency to downgrade. This result is compatible with the clinical description of patients with EDs. The scores obtained in "Role Physical" and "Vitality" ranged between 0 and 100. These results are corroborated by clinical observation of EDs. Patients with severe degrees of malnutrition complain of physical complications, general weakness, susceptibility to fatigue and loss of vital energy.

The most favored domains are "General Health" (mean = 68.5, SD = 24.7), followed closely the "Bodily Pain" (mean = 65.8, SD = 38, 9) and "Physical Functioning" (mean = 65.0, SD = 34.3). These results indicate that participants self-assessed as having relatively good overall health (compared to the other domains assessed) as well as absence of pain and functioning. This latter area is expressed based on the performance of daily activities such as ability to take care of oneself, getting dressed, bathing, or physical motion.

The relatively high score of "Physical Functioning" also corroborates the literature,¹³ and may indicate a psychopathological manifestation of the disorder itself, because individuals diagnosed often undergo strenuous physical exercise or strictly restricting diets, in search of a thinner and thinner body, influenced by severe body image distortion and also by cultural/aesthetic standards disseminated by mass media.

As pointed out, the “Mental Health” was the most compromised domain of the participants in the present study. The characteristic psychopathological conditions of AN and BN are characterized by severe disturbances in eating behavior, caused by a morbid fear of gaining weight, by seeking to obtain relief from anxiety through food (bulimics or binge eating episodes) and by the feeling of guilt of eating, typically culminating in efforts to eliminate the foods ingested.⁹

The results for “Social Functioning” (Mean = 60.4, SD = 39.2) did not show scores as low as those reported in the literature.¹³ Thus, social support and family involvement seem to be somehow preserved in these patients, who are under treatment.

When comparing the results obtained in the instruments used, it is observed that the two participants who had lower scores on the EAT had better quality of life, with at least six of the eight components of the SF-36 preserved. This suggests that the symptoms impact on quality of life by worsening it. However, considering the limitations of this study and its design, the results do not provide empirical support for this hypothesis, which should be investigated in future studies.

Conclusions

It is observed that, in general, the quality of life of participants is relatively preserved, except for “Role Emotional” and “Mental Health”. This fact should be taken into consideration by the multidisciplinary team, since it can be indicative that the greater impairment in psychological aspects of vulnerability points to areas that need to be addressed when treatment is planned. Support psychotherapeutic approaches may be necessary, within a strategy aimed at strengthening the more mature psychological defenses, which may counteract the more archaic and maladaptive defenses.

Combined psychotherapy - individual or group therapy (or family psychotherapy) - can be an excellent resource to achieve a more integrated pattern of psychological functioning and maximize the therapeutic benefits arising from the other strategies employed, such as nutritional rehabilitation and drug monitoring.¹⁷

Moreover, the results also point to the importance of having a highly qualified multidisciplinary team that meets different needs and aspects of quality of life. The treatment of EDs requires the inclusion of qualified professionals in the care of mental components, which are often present in these compromised patients, even more often than the physical components.

One limitation of the study is the small sample size. Most scores showed a great range of variation, which distorts the meaning of the mean. This imposes the need to investigate larger samples. The instrument used to investigate the quality of life is generic, which suggests the need

for additional data through specific instruments. The study also would benefit from the inclusion of another instrument to identify the symptoms of EDs, such as standardized clinical interviews, in order to capture the dynamic nuances of clinical pictures.

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