

# Health-Related Quality of Life and Eating Disorders: A Review and Update

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## ABSTRACT

**Objective:** The aim of this article is to provide a narrative review of empirical studies related to health-related quality of life (HRQOL) and eating disorders and to report recent changes in the measurement of HRQOL in eating disorders.

**Method:** Twenty-five articles of central importance to the topic were identified in a systematic search of six databases. All articles were selected based on a consensus relevancy rating process. Key themes were extracted from the articles and validated by all authors.

**Results:** We identify six themes in the extant empirical literature.

**Discussion:** We discuss these six themes and review them in light of the fact that they are identified in studies using only generic measures of HRQOL. Four recently developed disease-specific HRQOL measures specific to patients with eating disorder are discussed. © 2008 by Wiley Periodicals, Inc.

**Keywords:** eating disorder; health-related quality of life

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## Introduction

The assessment of outcome in the treatment of eating disorders (EDs) is complex.<sup>1</sup> Despite this complexity, treatment decisions, as well as empirical research, rely heavily on the accurate assessment of ED outcomes, and these assessments remain the “cornerstone of empirical investigation.”<sup>2</sup> There has been considerable empirical work in the assessment of EDs in recent years, and the field has seen many changes and advances.<sup>2</sup> However, one area that has seen very little change, until recently, is the application of quality of life (QOL) or health-related QOL (HRQOL) measures in the ED field. This is in spite of the fact that over a decade ago Miller<sup>3</sup> pointed out that these measures are important and largely neglected in ED research and prac-

tice. Since then, many other researchers and clinicians have echoed his sentiments.<sup>4–11</sup>

## How Is Outcome Currently Measured in Patients with ED?

Outcome of patients with ED is most commonly assessed in three very broad formats: self-report questionnaires, semistructured interviews, and clinical interviews. Many self-report questionnaires are currently available<sup>12</sup>; however, according to Pike et al.,<sup>13</sup> seven self-report questionnaires are used most often to assess patients with ED: the Eating Disorder Inventory-2 (EDI-3<sup>14</sup>), Body Shape Questionnaire (BSQ<sup>15</sup>), Three-Factor Eating Questionnaire (TFEQ<sup>16</sup>), Mizes Anorectic Cognitions Questionnaire (MAC<sup>17</sup>), Bulimia Test-Revised (BULIT-R<sup>18</sup>), Questionnaire on Eating and Weight Patterns-Revised (QEWPR<sup>19</sup>), and the Eating Disorder Examination Questionnaire (EDE-Q<sup>20</sup>). Other self-report questionnaires (e.g., Eating Attitudes Test<sup>21</sup>) have also been used. While a number of semistructured interviews are commonly administered to patients with EDs,<sup>22</sup> the Structured Clinical Interview for DSM-IV (SCID-I<sup>23</sup>) and the Eating Disorder Examination<sup>24</sup> are most commonly used in the ED field. Finally, clinical interviews have also been used to assess patients with ED. Both unstructured interviews, as well as observer-based rating scales (e.g., Morgan–Russell scale<sup>25</sup>), have been used under the general rubric of clinical interviewing to assess the central features of EDs.

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These assessment tools yield several types of information. The SCID and the EDE, for example, are frequently used to provide the determination of "diagnosis/no diagnosis." This dichotomous variable is commonly used to determine the degree to which a particular treatment can produce the remission of a disorder (for example, see Ref. 26). Also, symptom frequency, as measured by a host of the aforementioned instruments, is frequently used as a marker of improvement or deterioration over time (for example, see Ref. 27). Finally, continuous or semicontinuous total or subscale scores from self-report questionnaires are often used as an index of change in response to treatment (for example, see Ref. 28) or to compare illness status across groups or subgroups of patients (e.g., for example, see Ref. 29).

### **Health-Related Quality of Life**

While these outcome measures have proven useful, there recently has been increasing interest in measuring other aspects of lives of patients with ED that are affected by their disorder,<sup>30</sup> such as functioning in various life domains or the patients' self-perceived QOL. A tradition of QOL measurement has arisen in other areas of healthcare based on patient preference for these types of measures from patients and their importance in reorienting the definition of treatment recovery to broader life domains.<sup>31</sup> One means of assessing the impact of an ED on various important aspects of a person's life is to assess HRQOL.

HRQOL measures are generally included in a much broader category of measures, called Patient Report Outcomes (PROs). Some believe HRQOL measures, and more generally PROs, are important measures, because they are reported directly from the patient and are not filtered through and (mis)interpreted by a health care professional such as a physician or assessor.<sup>32,33</sup> Unfiltered information directly from patients and research participants is important. Imagine the following scenario: an assessor determines that a patient has lower shape and eating concerns at the end of treatment than at the beginning of treatment. However, the participant reports that her condition is still impacting her life as negatively and in as many areas (psychologically, physically, socially) as at the beginning of treatment. In spite of the reduction in shape and eating concerns, is this individual best described as "improved"?

HRQOL is a multidimensional construct that typically assesses physical, psychological, and social dimensions and considers the patient's perceptions

of the impact of an illness and its treatment on these domains.<sup>34,35</sup> According to Fayers & Machin,<sup>36</sup> HRQOL is primarily composed of information falling under the general rubric of the following areas: general health, physical functioning, physical symptoms and toxicity, emotional functioning, cognitive functioning, role functioning, social well-being and functioning, sexual functioning, and existential issues. Testa and Simonson<sup>37</sup> define HRQOL as the "physical, psychological, social domains of health, seen as distinct areas that are influenced by a person's experiences, beliefs, expectations and perceptions" (p. 835). Some of the first measures that purported to assess HRQOL tended to measure health status or functioning in a limited number of domains. For example, the Nottingham Health Profile assesses three domains, emotional, social, or physical distress, while the Medical Outcomes Study 36-Item Short Form (SF-36<sup>38</sup>) contains 36 items that generally fall into one of two domains, physical or mental health. Newer HRQOL instruments tend to assess a more comprehensive set of domains, which are measured by means that place great importance on the patients' views and preferences.

For the purposes of this review, we broadly define HRQOL as the impact that an individual's health has on various areas of his/her life, such as physical, emotional, or social domains. When referring to ED-specific HRQOL, we similarly define this construct as the impact that an ED, ED symptomatology, or the sequelae of an ED (e.g., treatment for the ED or comorbid conditions) have on various areas of an individual's life.

Empirical study of HRQOL in EDs has only recently been conducted. In 2005, Hay and Mond<sup>8</sup> summarized the findings of studies that used HRQOL measures in ED research. The earliest study they reported was published in 1994, and only 15 papers were found up to 2005 that measured HRQOL (or QOL) in patients with ED. Until 2005, the most commonly used measures that intended to address HRQOL were health status measures, such as the SF-36<sup>38</sup> (or its shorter versions) and the Nottingham Health Profile.<sup>39</sup> Although sometimes considered HRQOL measures, these two measures are generally considered to assess health status, not HRQOL.<sup>40</sup> Hay and Mond<sup>8</sup> report that the only measure of HRQOL used in the ED literature before 2005 were the WhoQol and the WhoQol-bref. Further, none of the studies they report make use of an HRQOL measure specifically designed to measure the unique impact that an ED has on HRQOL, and none of them use an instrument that has been designed for and developed

with patients with ED. This circumstance provides significant limitations of our understanding of HRQOL in EDs and led Hay and Mond to conclude that "... the impact upon peoples 'quality of life' secondary to ED is a relatively neglected area of research."<sup>8</sup>

### ***Generic versus Disease-Specific HRQOL Measures***

HRQOL measures can be characterized as either "generic" or "disease-specific."<sup>36</sup> Generic HRQOL instruments are designed to assess HRQOL as it applies to all (or most) people without reference to a specific group or disease state. However, those interested in HRQOL realized long ago that patients with particular disease states may have different sets of issues that specifically apply to them. For example, some patients with cancer may have symptoms or side effects of treatment that may impact their HRQOL that would not be particularly relevant to sufferers of heart disease. Impairment and treatment effects also seemed to apply differentially to those with different mental health concerns; individuals with schizophrenia, for example, are likely to be impacted by their disease differently from those with mood disorders. To deal with the different courses, treatments, and concerns of a variety of different illnesses, researchers began to develop instruments that tapped domains of life that applied to patients who suffered from specific illnesses or diseases (i.e., disease-specific HRQOL instruments). While this disease-specific approach was founded largely in the cancer literature, it has expanded to include many diseases and illnesses. Because disease-specific instruments are designed for and with the clinical sample of interest, these instruments tend to more precisely measure HRQOL in the samples they were designed for use with.<sup>36</sup> At the time of the Hay and Mond publication,<sup>8</sup> no disease-specific HRQOL instruments for ED were available.

The field has witnessed rapid development in HRQOL research in EDs in the few years since Hay and Mond published their review. In this paper, we summarize the current HRQOL (and QOL) literature in a set of broad themes, and then describe new developments in disease-specific measurement of HRQOL. We further describe new findings generated from the use of these disease-specific instruments. This review is also intended to provide researchers and clinicians with comparative information that will assist in options for measuring HRQOL in patients with ED.

## **Method**

Articles reporting on HRQOL or QOL in EDs were identified in a systematic literature search of the following databases: PubMed, PsycInfo, Academic Search Premier, SCOPUS, Google Scholar, and CINAHL. The search strategy used in the PubMed database can be found in the Appendix, and comparable search strategies were implemented in the other databases. As can be seen in the Appendix, we were looking for articles that used HRQOL or QOL measures with research participants who met DSM criteria for anorexia nervosa (AN), bulimia nervosa (BN), binge ED (BED), or ED not otherwise specified (EDNOS), or had significant ED symptomatology. These initial searches resulted in the identification of 366 unique articles. A review of the title and abstract of these articles (conducted by SE) identified 56 articles that were at least somewhat relevant to our review objectives. Next, three authors (SGE, CEA, CLH) independently read and classified the 56 abstracts into one of three categories: "Yes, relevant," "Possibly relevant," and "No, not relevant." Manuscripts that received one vote of "Yes, relevant" and at least one additional vote of "Yes, relevant" or "Possibly relevant" were retained for the review ( $N = 36$ ). Of these 36 articles, 25 were determined to be of central importance and were included in the review. Two additional articles that were cited in the initial article set, which had not been identified in the initial search, were added to the material for the review. The first author read all articles and extracted key themes. The other authors also read the articles and validated and added to the themes and conclusions in an iterative process.

## **Results**

Three-fourth of the 27 articles in this review were published in 2004 or more recently, confirming our impression of just how recent most of the HRQOL and ED research is. The research reviewed in the current study is quite diverse. For example, the included studies were conducted in North America, South America, Europe, and Australia and published in a very diverse set of journals. The primary authors also have very diverse training, with most having backgrounds in psychology (primarily clinical, health, and social), psychiatry, and epidemiology. Finally, studies found include patients with ED with AN, BN, subclinical variants of AN and BN, and BED.

The relative paucity of literature on the topic of HRQOL and ED necessarily limits the number of conclusions that can be made about the area

of research. In spite of this, we identify six general themes in the HRQOL and ED literature. These six themes are as follows: (1) patients with ED report lower HRQOL than normal controls, (2) HRQOL impairment occurs in patients with full DSM diagnoses as well as those who have subthreshold ED symptomatology, (3) family caregivers of patients with ED experience HRQOL impairment, (4) HRQOL impairment in patients with ED is considerable, (5) patients with ED receiving treatment report improvements in HRQOL, and (6) there are gender differences in HRQOL in patients with ED.

First, research examining combined samples of different ED diagnoses (anorexia nervosa, bulimia nervosa, BED, and EDNOS) shows that patients with ED have lower HRQOL than normal controls.<sup>9,41–48</sup> The HRQOL differences between patients with ED and normal control participants appear to be considerable. For example, Doll et al.<sup>44</sup> found sizable differences (~10 points) between individuals with a probable history of an ED and normal control participants on the scale scores of the SF-36 for Role-Physical, Role-Emotional, Social Functioning, Mental Health, Vitality, Bodily Pain, and General Health (Cohen's  $d$  range = 0.15–0.43). Similarly, Mond et al.<sup>9</sup> found large group differences in the mental HRQOL domain and more modest differences in the physical HRQOL domain. Compared to normal controls, ED participants reported a 17.3 point lower Mental Component Summary score (Cohen's  $d$  = 1.68) on the SF-12. Further, patients with ED reported a 3.77 point lower Physical Component Score than control participants (Cohen's  $d$  = 0.42). Research suggests that a pooled sample of AN and BN participants also report lower HRQOL than controls.<sup>49</sup> Finally, AN participants<sup>50</sup> and patients with BED report lower HRQOL<sup>51–53</sup> than comparison groups of normal controls.

Second, a formal diagnosis that meets all DSM criteria does not appear to be necessary for HRQOL impairment to occur. Hay<sup>54</sup> found that participants who reported considerable, but subthreshold, ED symptomatology also demonstrate significant HRQOL impairment. Findings are somewhat contradictory as to which ED symptoms appear to be most related to decrements in HRQOL. While Hay showed that binge eating predicted 23% of the HRQOL variance and extreme weight control measures predicted only 5%, Mond et al.<sup>55</sup> and Gonzalez-Pinto et al.<sup>56</sup> found that purging behavior appears to be particularly associated with lower HRQOL. Finally, motivations for exercising, as well as reactions to not exercising, appear to predict HRQOL.<sup>57</sup>

Third, studies also show that EDs not only negatively impact the patient with ED, but they also result in HRQOL impairment in family caregivers of these patients. de la Rie et al.<sup>6</sup> found that caregivers of patients with ED reported significantly lower scores in both the physical and mental domains of the SF-36 than a group of normal controls. Specifically, scores on Vitality, Social Functioning, Emotional Role Functioning, and Mental Health subscales of the SF-36 were lower in the caregivers than in the normal controls. This finding is consistent with other research suggesting that family caregivers of individuals with EDs experience significant burden of care.<sup>58</sup>

Fourth, research further suggests that the impact of EDs on patients' HRQOL is substantial and comparable to other serious illnesses and disorders. In addition to reporting that patients with AN and BN reported lower HRQOL than healthy control patients, Keilen et al.<sup>49</sup> also found that patients with ED were impaired at a level comparable to or greater than patients awaiting coronary surgery for angina, candidates for heart/lung transplantation, and patients selected for heart transplantation. Similarly, Spitzer et al.<sup>48</sup> found that EDs were associated with HRQOL impairment relatively similar or greater than other psychiatric disorders (e.g., somatoform disorder and alcohol abuse) as well as a number of serious medical concerns (e.g., diabetes, cancer, pulmonary disorders). Further, Spitzer et al. found that patients with ED experienced greater levels of bodily pain and impairment in social functioning than those who did not have an ED.

Fifth, and very encouragingly, research shows that HRQOL of patients with ED appears to improve with treatment.<sup>59</sup> Halvorsen and Heyerdahl<sup>60</sup> found that patients with AN reported improved life satisfaction scores following inpatient treatment for their ED. Similarly, Padierna et al.<sup>11</sup> found that patients with AN and BN who received psychotherapy consisting of cognitive-behavioral treatment, psychoeducation, motivational therapy, social skills training, nutritional counseling, and therapy focused on body image reported improvements in both physical and mental health domains of the SF-36. In spite of these improvements, participants' scores were still significantly lower than a comparison group of normal controls after 2 years of treatment.

The sixth and final theme reported in this review is that there appear to be some gender differences in HRQOL among those with an ED. Life satisfaction appears to be more closely tied to the diagnosis of bulimia nervosa for women than men.

TABLE 1. Descriptive information on the four eating disorder-specific HRQOL instruments

|                                       | EDQOL                                                                                | EDQLS                                                                                                                                                                                                                                    | HeRQoLEDv2                                                                                                                                    | QOL ED                                                                                                                                                                   |
|---------------------------------------|--------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Reference                             | Engel et al. <sup>7</sup>                                                            | Adair et al. <sup>5</sup>                                                                                                                                                                                                                | Las Hayas et al. <sup>64</sup>                                                                                                                | Abraham et al. <sup>4</sup>                                                                                                                                              |
| Number of Items                       | 25                                                                                   | 40                                                                                                                                                                                                                                       | 55                                                                                                                                            | 20                                                                                                                                                                       |
| Age range of validation sample        | 18–66                                                                                | 14–60                                                                                                                                                                                                                                    | 16–60                                                                                                                                         | 14–28                                                                                                                                                                    |
| Average number of minutes to complete | 5                                                                                    | 5                                                                                                                                                                                                                                        | 5–10                                                                                                                                          | 5                                                                                                                                                                        |
| Recall period                         | 30 days                                                                              | 1 week                                                                                                                                                                                                                                   | 4 weeks                                                                                                                                       | 28 days/3 months                                                                                                                                                         |
| Total score                           | Yes                                                                                  | Yes                                                                                                                                                                                                                                      | No                                                                                                                                            | Yes                                                                                                                                                                      |
| Subscale scores                       | Yes                                                                                  | Yes                                                                                                                                                                                                                                      | Yes                                                                                                                                           | Yes                                                                                                                                                                      |
| Domains or subscales                  | Psychological, physical/cognitive, financial, and work/school                        | Cognitive functioning, education/vocation, family and close relationships, relationships with others, future/outlook, appearance, leisure, psychological health, emotional health, values and beliefs, physical health and eating issues | Symptoms, restrictive behaviors, bingeing, body image, mental health, emotional role, physical role, personality traits, and social relations | Behavior, ED feelings, psychological feelings, perceived affect on daily living (relationships, work/study, social), acute medical status, body weight, and global score |
| Languages available                   | English, French, Spanish, German, Swedish, Portuguese, Chinese, Japanese, and Hebrew | English, French, and Spanish                                                                                                                                                                                                             | English and Spanish                                                                                                                           | English, German, and Hindi                                                                                                                                               |

Gamma and Angst<sup>61</sup> found that while the diagnosis was significantly correlated with lower life satisfaction in women, no such comparable correlation was found for men. Also, while lack of eating control appears to predict life satisfaction in both men and women, BMI appears to predict lower life satisfaction only for women.<sup>62</sup>

Discussion

Studies to date have confirmed that HRQOL concerns are significant in patients with ED and highlight the importance of assessing HRQOL in clinical samples. Findings in this literature review are based on research using generic HRQOL measures. We believe that these findings are reliable and support this notion by pointing out that the themes we identify in this article are supported by multiple HRQOL/ED studies or have similar support from studies implementing assessment tools conceptually overlapping with HRQOL (e.g., burden of care). Findings show that lives of patients with ED are impacted in ways that are much farther reaching than their eating symptomatology: they suggest that patients with ED are impaired in other important domains of their lives, such as social, psychological, and physical. While these studies have been an excellent first step in gaining understanding

about the varied ways in which lives of patients with ED are impaired by their disorder, they are limited in that they make use of HRQOL assessment instruments that are not specifically designed for the population of interest: patients with ED.

Disease-Specific HRQOL Instruments for EDs

Researchers in the field have recently acknowledged some of the limitations of generic HRQOL measures in assessing patients with ED and offered some suggestions as to how to better measure HRQOL in this group.<sup>63</sup> One potentially fruitful way to measure HRQOL in patients with ED would be to employ the use of a disease-specific HRQOL instrument. Until recently, no disease-specific instrument has been available for use with patients with ED. However, in 2006 and 2007, four ED-specific HRQOL instruments were reported.<sup>4,5,7,64</sup> As the authors of these instruments, we briefly describe them and summarize key features about them in the section below (also see Table 1). These instruments are the first of their kind in this area and provide researchers and clinicians several new options for assessing HRQOL in patients with ED. Because the means of demonstrating validity and reliability are so varied across the four instruments, readers are referred to the original articles for details regarding the psychometric properties of the instruments.

### ***ED-Specific Health-Related Quality of Life Instruments***

**The Eating Disorders Quality of Life Instrument.** The Eating Disorders Quality of Life (EDQOL)<sup>7</sup> instrument is a 25-item, four domain, self-report questionnaire designed to assess HRQOL in adults with ED symptomatology. It was designed to apply to people who have symptoms commonly seen in patients with AN, BN, and EDNOS (BED or subclinical variants of these disorders). The EDQOL was validated with a large sample ( $N = 538$ ) using a combination of techniques from both classical test theory<sup>65</sup> and item response theory.<sup>66,67</sup>

**The Eating Disorders Quality of Life Scale.** The Eating Disorders Quality of Life Scale (EDQLS)<sup>5,68</sup> is a 40-item, 12 domain, self-administered HRQOL scale that was designed and tested to be developmentally appropriate for young adolescents and adults with EDs (AN, BN, and EDNOS). Several stages of input from ED health professionals, families, and patients with EDs were used to develop and reduce the item set. Content was selected to minimize duplication with existing symptom assessment instruments and to minimize ego-syntonic responding. The EDQLS has a Flesh–Kincaid reading level of grades 5–7 and also allows for patient-nominated areas of QOL (individual assessment). It was validated in a multisite, longitudinal study.<sup>5</sup>

**The Health-Related Quality of Life in Eating Disorders Questionnaire.** The Health-Related Quality of Life in Eating Disorders questionnaire (HeRQoLEDv2)<sup>64</sup> is the second version of the Spanish HeRQoLED. The HeRQoLEDv2 was developed to measure the impact that an ED has on the primary areas of QOL for patients with an ED (including AN, BN, EDNOS, and BED). Besides the nine subscales found in Table 1, the HeRQoLEDv2 also contains three single items that assess the regularity of menstrual periods, a global scale of the impact of ED behaviors in their HRQOL perception, and a question based on Prochaska and DiClemente stages of change model.<sup>69</sup>

**The Quality of Life for Eating Disorders.** The Quality of Life for Eating Disorders (QOL ED)<sup>4</sup> consists of 20 self-report questions in six domains developed and validated to assess HRQOL in patients with ED. The QOL ED is part of a larger computer-generated and computer-reported examination of eating and exercise behavior, attitudes and feelings, the Eating and Exercise Examination.<sup>70,71</sup> The QOL ED was initially designed as a measure of change to be used by health insurance assessors for assessment of outcome in an EDs treatment unit. It also is appro-

priate for use in both clinical and research settings for studying eating and exercise. The instrument was designed to be applicable to all EDs; AN, BN, and EDNOS (including BED).

The ED field has very quickly gone from having very little empirical literature on the use of HRQOL measures in EDs to many relevant studies and new data on the topic. Similarly, the field has very rapidly gained four standardized and validated disease-specific instruments that are available for use with patients with ED. While these instruments have some similarities, they vary in length, subscales, or domains assessed, methods of development, characteristics of the validation sample, etc. The decision as to which specific instrument best fits the needs of any one particular researcher or clinician depends on many factors, including the specific domains of interest, their relationship with other relevant measures, the characteristics of the respondents, etc.

### ***Future Directions for HRQOL Assessment***

There are two very general categories of uses for the HRQOL measures outlined in this paper: clinical and research. There are a few clinical uses of ED-specific HRQOL that are worthy of mention. For example, the therapist of an patient with ED who scores particularly low on the “relationships with others” scale of the EDQLS at intake may acquire useful information by probing further into this topic in session, as well as focusing therapeutic approaches on the improvement of relationship functioning for that patient. Another possible use is program evaluation, for treatment centers to be able to demonstrate effectiveness of their treatment interventions. HRQOL information may be informative about the extent to which changes in care processes are effective. Finally, similar information may be required by third-party payers as a means of demonstrating that the treatments the organization provides are effective. For example, the EDQOL has recently been used by a hospital inpatient unit to demonstrate to an insurance company that their inpatient treatment is indeed benefiting patients substantially and in important areas of their lives (Tantillo M, Personal communication, December 14, 2007).

There are several ways of categorizing the possible research uses of HRQOL measures.<sup>36,72</sup> One way to consider research uses of ED-specific measures would be to review the types of variables that HRQOL data may be used for. For example, the most obvious and typical use of HROQL data in health services research is as an outcome variable to demonstrate both efficacy and effectiveness of

treatments for EDs. Also, HRQOL may be conceptualized as a mediating variable in studies aiming to understand associated mechanisms of action in EDs and their recovery. Finally, ED-specific HRQOL may also serve as a moderating variable, where the strength and/or direction of relationship between two variables changes for different levels of HRQOL. This type of moderating relationship has been found in the obesity HRQOL literature,<sup>29</sup> and it seems plausible that baseline levels of ED-specific HRQOL may serve to moderate treatment efficacy.

HRQOL measures are not without limitations. Although the benefits of collecting data that is neither filtered nor biased by a third-party (e.g., physician or psychologist) are self-evident, there may be times when this is less than ideal. For example, patients who demonstrate an extreme of lack insight may not provide accurate information when assessed. According to Mond et al.,<sup>9</sup> the egosyntonic nature of restricting patients with anorexia nervosa leads them to be of particular concern in this regard. However, patients with ED of any diagnosis may lack insight, and this is problematic regardless of the specific form of assessment.<sup>73</sup>

Finally, we highlight some potentially fruitful avenues of study regarding HRQOL in patients with ED. Diagnostic differences in HRQOL have generally not been demonstrated in previous research.<sup>47</sup> However, this finding has been based on research using generic HRQOL measures rather than ED-specific measures of HRQOL. As previously mentioned, these generic measures tend to have less sensitivity (than ED-specific HRQOL measures) to differences that may exist between different diagnoses of EDs. For the first time, diagnostic differences in HRQOL may be able to be elucidated. Another important area of study would be that of clinically meaningful change and ED-specific HRQOL. Comparable work has been done in other disease-specific areas of HRQOL,<sup>74</sup> and furthering our understanding of this topic would improve the utility of ED-specific HRQOL instruments. Determining how much change must occur for patients to find important and clinically meaningful information is an important issue in HRQOL and ED, and some information is now available relevant to the topic.<sup>75</sup> Related to this, demonstrating that disease-specific instruments can accurately detect HRQOL changes over time is important and worthy of study. Some work in this area has already been done, and the responsiveness of the disease-specific instruments looks very promising.<sup>75</sup> Finally, including ED-specific HRQOL measures in

the assessment of existing and new forms of treatment for EDs could be a valuable addition to this line of research.

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## Appendix

Search (“Eating Disorders”[MeSH:noexp] OR (eating disorder[Text Word] OR eating disorders[Text Word] OR eating disordered[Text Word]) OR (bulimia[Text Word] OR anorexia nervosa[Text Word]) OR (binge eating[Text Word] OR (binge eater[All Fields] OR binge eaters[All Fields]) OR binging[Text Word] OR bulimic[Text Word]) OR (“Bulimia”[MeSH] OR “Bulimia Nervosa”[MeSH] OR “Anorexia Nervosa”[MeSH])) AND (((“sf 36”[All Fields] OR sf-36[All Fields] OR “sf 12”[All Fields] OR sf-12[All Fields] OR euroqol[All Fields] OR “nottingham health profile”[All Fields] OR “sickness impact profile” OR (“Sickness Impact Profile”[MeSH])) OR (((“Happiness”[MeSH] OR happiness OR happy) OR (“Personal Satisfaction”[MeSH] OR satisfaction) OR (“Quality of Life”[MeSH] OR “quality of life”))) Limits: English, Publication Date from 1980, Humans.