Factors Associated with Disease-Specific Health Related Quality of Life in Women with Anorexia Nervosa

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Abstract

Background: Health-related quality of life is severely affected in patients with anorexia nervosa due to both physical and psychological consequences of the disease, but it is still uncertain whether the same factors affect both clinical outcome and quality of life. It is also unknown whether there are differences between patients and controls in terms of self-reported physical, psychological and social well-being.

Methods: Women with anorexia nervosa were recruited from specialized eating disorder centers in the five regions of Denmark. Healthy, normal-weight controls were invited via online social media to participate in the study. Six questionnaires including study characteristics, quality of life, eating disorder symptomatology, depression, work and social adjustment and psychological well-being were completed online by all participants.

Results: 211 women with anorexia nervosa and 199 controls participated in the study. Women with anorexia nervosa reported significantly lower quality of life, both in terms of disease-specific HRQoL using the Eating Disorders Quality of Life Scale and on measures of general health, psychological well-being, and work functioning. Psychological and cognitive factors were highly associated with poor quality of life (p-value<0.05).

Conclusions: Our findings suggest that attention to and management of disordered self-assessment and thought processes may be of special importance to women with anorexia nervosa and their families. It is possible that greater emphasis on such aspects alongside weight gain could enhance patient-clinician alliance and contribute to better treatment outcomes.

Background

The physical and psychological consequences of anorexia nervosa (AN) are severe and affect many aspects of the patient's life. Treatment typically requires a multifaceted approach including psychiatric, nutritional, and psychological elements [1], and this has encouraged a change of focus from assessment of purely clinical parameters to inclusion of patient-reported assessments of quality of life [2]. The term health-related quality of life (HRQoL) is used in the clinical field to refer to quality of life aspects related to ill-health, disability, and treatment and is a multidimensional concept that describes physical, social, and psychological well-being and functioning.

The use of patient-reported outcome is particularly relevant in AN due to the ego-syntonic nature of the disease and omitting this may lead to large discrepancies between what the patient experiences (i.e. the patient-reported outcome) and what the clinician rates (i.e. the clinician-reported outcome) [3]. In obsessive-compulsive disorder, being another ego-syntonic condition, the use of patient-reported outcome measures was possibly better than clinical measures in predicting prognosis after treatment [4]. Generic measures of HRQoL questionnaires (i.e. for use in any patient group and the general population) have been used when assessing HRQoL in AN and have found significantly impaired HRQoL compared to

healthy controls or other illnesses (somatic as well as psychiatric) [5]. Generic questionnaires may be less sensitive to aspects of AN, however, and disease-specific HRQoL questionnaires are also needed [5, 6].

Several disease-specific questionnaires have been developed for use in AN, e.g. the Eating Disorders Quality of Life Scale (EDQLS) [7], the Eating Disorders Quality of Life questionnaire (EDQOL) [8], and the Quality of Life for Eating Disorders (QOL ED) [9]. These measures have been developed in different countries and with different goals and characteristics, and so far, none of them have become a gold standard for use in AN. However, the EDQLS was developed and validated in both clinical [7] and non-clinical settings [10] and has recently been translated to Danish [11] and validated in a Danish sample (Winkler et al - submitted). Two unique aims for developing the EDQLS were to minimize ego-syntonic responding and attain suitability for adolescents.

Exploring non-clinical outcome measures such as HRQoL is still a relatively new concept in AN research compared to measuring pure clinical characteristics. While parameters such as body mass index (BMI) and age were determined as significant predictors of clinical outcome [5], the new focus on HRQoL raises the question whether the same factors influence both HRQoL and clinical outcome. Furthermore, it is unknown whether factors associated with HRQoL are identical for women with AN and healthy controls.

In a study of 63 outpatients with AN who completed the EDQoL [12], improvement of HRQoL following treatment for AN depended on symptom change and weight gain, while Martin et al. [13] found that somatic or psychiatric comorbidities were more powerful predictors of QoL outcome in AN. Similarly, in a cross-sectional study using a generic measure, Weigel et al. [14] found that HRQoL in AN was more strongly associated with comorbidity (and BMI) than with age, duration of disease, and current psychopathology.

The overall aim of the current study was to explore factors associated with disease-specific HRQoL in what we believe is the largest study in AN to date and which also includes healthy controls. First, we investigated differences between women with AN and healthy female controls in terms of eating disorder pathology, depressive symptomatology, psychological well-being, work functioning, and health-related quality of life assessed using both generic Short-Form 36 (SF-36) and disease-specific (EDQLS) instruments. Secondly, we investigated which factors were associated with poorer disease-specific quality of life in terms of the overall EDQLS score and the subscale scores.

Material And Methods

Study participants

Participants were women with AN and female controls who were recruited within a larger cross-sectional study (in review).

Women with AN were recruited from the specialized eating disorder centers in the five regions of Denmark. Inpatients and outpatients who were diagnosed with AN were invited to participate using an

online survey. Participants were recruited between June 14th 2017 and March 10th 2019 and were compensated 20 euros for their participation. Inclusion criteria were BMI < 18.5 kg/m2 and age between 13 and 40 years. Exclusion criteria were male gender, age < 13 years or > = 40 years, and BMI within the normal range. If participants were below 18 years of age, their BMI was converted into BMI-for-age percentiles according to WHO's growth reference [15]. Among adolescents, a BMI-for-age percentile below 10 indicates underweight, while a normal weight range is represented by a BMI-for-age percentile between 10 and 85 [16].

Healthy, normal-weight controls were recruited through online invitations on the social media platform Facebook. An invitation to participate in the study was uploaded on the first author's media platform and encouraged to be shared among her followers. Inclusion criteria for controls were female gender, age between 13 and 40 years, and a normal BMI (18.5–24.9). Controls were excluded if they used regular medication other than oral contraceptives or vitamins.

When participants accessed the QR code or internet link provided in the invitation, they were automatically directed to a platform for either women with AN or controls as relevant. The first questions determined the participant's eligibility (inclusion and exclusion criteria) before redirecting them to the first of seven questionnaires. The total time for completion was approximately two hours, and it was possible to save answers and return for completion later if needed. In questionnaires where the phrasing "eating disorder" was used, controls were asked to rephrase this to "eating".

The data were automatically uploaded to a secure online web application via Open Patient data Explorative Network (OPEN) at Odense University Hospital.

Ethics

The project was approved by the Danish Data Protection Agency (File no. 17/3218) and the Regional Committees on Health Research Ethics for Southern Denmark. The study is registered with ClinicalTrials.gov with the registration number NCT03230435. Participants were thoroughly informed regarding the aim of the study, with legal guardians giving consent for participants under 18 years old.

Questionnaires

Inhouse questionnaire: Women with AN were asked to complete questions on duration of AN, nadir BMI, and maximum BMI. All participants were asked to provide information about medication, alcohol consumption, drug use, and level of education.

The EDQLS was used as a disease-specific HRQoL questionnaire for eating disorders. It was developed in Canada in 2005 [7] to minimize the effect of ego-syntonic answers of respondents with AN, bulimia nervosa (BN), or eating disorder not otherwise specified (EDNOS). The EDQLS includes 40 items in 12 subscales. Each item is rated on a five-point Likert scale, where higher scores indicate better HRQoL. The total maximum score is 200. The EDQLS has been translated to Danish, with the back translation being checked for congruence to the original connotations in English by the developers [11]. A current validation

study found excellent internal consistency of the total score of the EDQLS (in review) (Cronbach alpha: 0.94), and the scale was received positively in an initial pretest with six patients.

The Short-Form 36 (SF-36) comprises 36 questions on physical and emotional health that are summarized into eight subscales, with higher scores indicating better health [17]. The eight subscales are Physical functioning, Role physical, Bodily pain, General health, Vitality, Social functioning, Role emotional, and Mental health. The SF-36 has been translated into Danish and validated in a Danish sample [18].

The Eating Disorder Inventory-3 (EDI-3) [19] has 91 items measuring the severity of eating disorder behavior [19]. It has been validated in a Danish sample [19, 20]. The 91 items are divided into 12 subscales of Drive for thinness, Bulimia, Body dissatisfaction, Low self-esteem, Personal alienation, Interpersonal insecurities, Interpersonal alienation, Interoceptive deficits, Emotional dysregulation, Perfectionism, Ascetism, and Maturity fears. Items are rated on a four-point scoring system where higher scores indicate a higher level of ED psychopathology.

The Beck Depression Inventory (BDI) [21] has been used in both clinical and research settings since its development in 1961. The total score is based on 21 questions (each rated between 0 and 3), with higher scores indicating more symptoms of depression. A total score of 0–13 indicates minimal depression, 14–19 indicates mild depression, 20–28 indicates moderate depression, and 29–63 indicates severe depression. It has been validated in a Danish sample [22].

Psychological well-being was assessed using the WHO-5 well-being index (WHO-5) [23, 24]. This comprises five items, each rated on a six-point Likert scale, where higher scores indicate greater well-being. Total scores are stratified into three groups where a score < 35 indicates a risk of psychopathology, a score of 35–50 indicates a lower score than the general population, and a score above 50 is similar to the general population. The WHO-5 was developed in Denmark and has shown adequate validity in a range of clinical areas [25].

The Work and Social Adjustment Scale (WSAS) is a short questionnaire on functional impairment [26]. It comprises five items inquiring about the extent to which a disorder influences the individual's daily activities. Each item is scored on a nine-point Likert scale. Scores under 10 indicate non-pathological impairment, scores of 10–20 indicate significant impairment, and scores over 20 indicate severe impairment. The WSAS has not been validated in a Danish sample but has been translated into Danish and validated in a Norwegian sample [27].

Statistical analysis

EDQLS domain scores and total scores were summarized and compared by participant group using t-tests. Median EDQLS total scores and predictor variables were compared by participant group (women with AN vs. controls) using t-tests [28]. The association between variables and EDQLS outcome score was investigated using multiple regression analyses with bootstrapped standard errors (500 replications) in two models (Model I: women with AN, and Model II: controls). For the regression analyses, R^2 was

reported to determine the amount of explained variance in the EDQLS ratings. We subsequently performed regression analysis including the EDI-3 subscales to investigate the potential predictive value of each subscale on EDQLS. P-values < 0.05 were considered statistically significant.

Statistical analyses were conducted in the statistical program STATA (StataCorp. 2019. *Stata Statistical Software: Release 16*. College Station, TX: StataCorp LLC).

Results

The data set had no missing values as the branching logic in the online research electronic data capture (REDCap) demanded complete registration for inclusion into the study.

A total of 607 persons accessed the survey link. Two-thirds of these (n = 417) completed all questionnaires (9 men, 211 women with AN, and 190 female controls). The male respondents were excluded from the current study, leaving 401 participants.

Participant characteristics and comparisons are reported in Table 1. Controls were slightly older than the women with AN and, as expected, had significantly higher BMI. Among the women with AN aged 13–17 years, 57% had a self-reported BMI-for-age percentile under 10%, indicating underweight. In contrast, none of the controls were under the 10th percentile for BMI-for-age.

Table 1
Characteristics of women with AN and healthy, normal-weight controls. Data are medians (+ interquartile range).

	Women with AN (n = 211)	**Controls (n = 190)**	**p-value**
Age (years)	21.7 (7.7)	23.9 (8.6)	**< 0.05**
BMI (kg/m^2)	16.5 (2.1)	21.7 (1.9)	**< 0.05**
Nadir BMI (kg/m^2)	14.5 (2.1)	n/a	n/a
Maximum BMI (kg/m^2)	22.1 (6.7)	n/a	n/a
On medication (%)	31	0	**< 0.05**
Currently using drugs (%)	1.9	0.5	0.20
Current alcohol user yes/no (%)	0.5	0	0.33
Duration of AN (years)	5.5 (6.7)	n/a	n/a
EDQLS total score	99 (25.7)	160.7 (21.1)	**< 0.05**
SF-36 Physical functioning	78.5 (20.8)	95.9 (9.2)	**< 0.05**
SF-36 Role physical	52.5 (32.8)	89.8 (16.5)	**< 0.05**
SF-36 Bodily pain	63.3 (24.8)	83.2 (19.7)	**< 0.05**
SF-36 General health	50.1 (22.2)	79.4 (18.2)	**< 0.05**
SF-36 Vitality	28.9 (21.8)	61.6 (19.4)	**< 0.05**
SF-36 Social functioning	42.2 (27.1)	87.6 (18.0)	**< 0.05**
SF-36 Role emotional	46.2 (30.4)	81.6 (21.1)	**< 0.05**
SF-36 Mental health	37.1 (19.4)	73.7 (16.1)	**< 0.05**
EDI-3 total score	174.2 (57.5)	70.6 (51.6)	**< 0.05**
BDI total score	31.4 (12.9)	7.2 (8.1)	**< 0.05**
WHO-5 total score	38.4 (18.8)	69.4 (16.1)	**< 0.05**
WSAS score	23.2 (9.6)	4 (6.8)	**< 0.05**

Abbreviations: AN, anorexia nervosa; BMI, body mass index; EDQLS, Eating Disorders Quality of Life Scale; SF-36, Short-Form 36; EDI-3, Eating Disorder Inventory-3; BDI, Beck Depression Inventory; WHO-5, World Health Organization well-being index; WSAS, Work and Social Adjustment Scale.

n/a: not applicable

	Women with AN (n = 211)	Controls (n = 190)	p-value
13–17-year-olds with BMI-for-age under 10th percentile, N (%)	43 (57%)	0	**< 0.05**

Abbreviations: AN, anorexia nervosa; BMI, body mass index; EDQLS, Eating Disorders Quality of Life Scale; SF-36, Short-Form 36; EDI-3, Eating Disorder Inventory-3; BDI, Beck Depression Inventory; WHO-5, World Health Organization well-being index; WSAS, Work and Social Adjustment Scale.

n/a: not applicable

The women with AN had significantly impaired HRQoL (measured by EDQLS), worse health status (SF-36), higher eating disorder psychopathology (EDI-3), more symptoms of depression (BDI), poorer well-being (WHO-5), and higher burden of functional impairment (WSAS).

The women with AN had a significantly lower score on all subscales of the EDQLS (Table 2) compared to the controls, reflecting impaired HRQoL.

Table 2
EDQLS median scores for women with AN and healthy controls.

	Women with AN (n = 211)*	Controls (n = 190)
EDQLS dimensions		
Cognitive	7.7 (2.6)	12.6 (1.8)
Education	6.9 (2.8)	13.3 (1.8)
Family and close relationships	8.6 (2.6)	13.2 (1.9)
Relationships with others	7.8 (2.6)	12.3 (2.3)
Future/outlook	9.7 (3.1)	13.6 (1.7)
Appearance	6.4 (2.3)	9.9 (2.4)
Leisure	9.3 (2.3)	13.0 (1.6)
Psychological	7.8 (2.8)	12.0 (2.1)
Emotional	6.3 (2.3)	10.8 (2.4)
Values and beliefs	6.4 (2.5)	10.4 (2.5)
Physical	6.8 (2.8)	11.3 (2.3)
Eating Disorders	15.2 (5.8)	28.3 (4.9)
Total EDQLS score	99 (25.7)	160.7 (21.1)
Data are medians with (interquartile ranges)		
* All AN values were significantly lower than control values ($p < 0.001$).		
Abbreviations: AN, anorexia nervosa; EDQLS, Eating Disorders Quality of Life Scale.		

Multiple regression analyses were conducted separately for women with AN and controls to identify factors associated with the EDQLS score. Both regression models explained 77% of the variance (adjusted $R^2 = 0.77$). The models included the total scores for the EDI-3, BDI, WSAS, and WHO-5 as well as the scores for the eight subscales of the SF-36 and the clinical variables of age and BMI (the AN model also included nadir BMI, maximum BMI, and duration of disease).

Model I for the women with AN showed that EDI-3 total score, BDI total score, the SF-36 subscale scores for Role Emotional and Vitality, and patient age significantly predicted the total EDQLS score (Table 3). Model II for controls showed that only EDI-3 total score and the SF-36 subscale score for General Health predicted the total EDQLS score.

Table 3
Multiple regression showing effect of independent variables on EDQLS total score for women with AN and controls.

	Model I (n = 211)		**Model II (n = 190)**	
	Women with AN		**Healthy controls**	
	Coefficient	p-value	Coefficient	p-value
EDI-3 total score	-0.21	**< 0.001**	-0.21	**< 0.001**
BDI total score	-0.42	**0.004**	-0.22	0.37
WHO-5 total score	0.07	0.5	-0.02	0.37
WSAS score	-0.28	0.11	0.14	0.52
SF-36 Physical functioning	0.08	0.11	-0.04	0.74
SF-36 Role physical	-0.01	0.86	0.13	0.14
SF-36 Bodily pain	-0.06	0.3	-0.05	0.39
SF-36 General health	0.08	0.16	0.15	**0.03**
SF-36 Vitality	0.21	**0.01**	0.08	0.23
SF-36 Social functioning	0.03	0.56	0.15	0.10
SF-36 Role emotional	-0.14	**< 0.001**	0.01	0.86
SF-36 Mental health	0.01	0.9	0.17	0.06
Age	0.42	**0.03**	-0.14	0.1
BMI	-0.1	0.8	0.52	0.22
Nadir BMI	-0.33	0.61	-	-
Maximum BMI	0.11	0.57	-	-
Duration of AN	-0.34	0.06	-	-
R-squared	*0.79*		*0.79*	

Multiple regression analyses with bootstrapped standard errors (500 replications).The coefficients can be interpreted as showing that e.g. for every 1 unit increase in EDI-3 score, we can expect to see a negative 0.21 drop in EDQLS score.

Abbreviations: EDQLS, Eating Disorders Quality of Life Scale; AN, anorexia nervosa; EDI-3, Eating Disorder Inventory-3; BDI, Beck Depression Inventory; WHO-5, World Health Organization well-being index; WSAS, Work and Social Adjustment Scale; SF-36, Short-Form 36; BMI, body mass index.

We next examined which factors of each EDI-3 subscale were associated with the EDQLS total score. We found that for women with AN, six of the EDI-3 subscales significantly predicted EDQLS score (Drive for

thinness, Low self-esteem, Personal alienation, Interpersonal insecurity, Emotional dysregulation, and Maturity fears; Table 4). For controls, only four of the EDI-3 subscales significantly predicted EDQLS score (Drive for thinness, Personal alienation, Interpersonal insecurity, and Emotional dysregulation). These regression models explained 71% of the variance of the EDQLS.

Table 4
Multiple regression showing effect of EDI-3 scores on EDQLS total score for women with AN and controls.

	Women with AN (n = 211)		**Healthy controls (n = 190)**	
		p-value		p-value
EDI-3 subscales				
Drive for thinness		**0.000**		**0.001**
Bulimia		0.22		0.79
Body dissatisfaction		0.14		0.48
Low self-esteem		**0.000**		0.23
Personal alienation		**0.03**		**0.002**
Interpersonal insecurities		**0.003**		**0.03**
Interpersonal alienation		0.55		0.63
Interoceptive deficits		0.11		0.67
Emotional dysregulation		**0.02**		**0.02**
Perfectionism		0.93		0.3
Ascetism		0.57		0.59
Maturity fears		**0.008**		0.54
R-squared	*0.71*		*0.71*	

Abbreviations: AN, anorexia nervosa; EDI-3, Eating Disorder Inventory-3; EDQLS, Eating Disorders Quality of Life Scale.

Discussion

Our study results show that women with AN reported significantly impaired function compared to healthy, normal-weight controls on all aspects measured, i.e. disease-specific HRQoL (EDQLS), generic health status (SF-36), eating disorder psychopathology (EDI-3), psychological well-being (WHO-5), work functioning (WSAS), and depressive symptomatology (BDI). In addition, poorer HRQoL (lower EDQLS score) in AN were predicted by more severe eating disorder symptoms (higher EDI-3 score), more

symptoms of depression (higher BDI score), poorer psychological health (lower scores for SF-36 emotional role and vitality), and older age.

Comorbid mental disorders are common in AN and can require more intensive management of AN [29] as well as contribute to poorer outcome in terms of weight gain [30]. Our study participants were not asked about diagnosed comorbidities, and the high use of medication in the AN group indicated high psychiatric comorbidity. Among women with AN, 31% (n = 65) reported daily use of medication, with antidepressants representing almost half of this (n = 30). Ten of these were taking daily antipsychotic medication, while the remaining 25 women took daily medication for a somatic disorder (e.g. diabetes, thyroid disorder). Study participants with AN reported a significantly higher level of depressive symptoms compared to controls, with median scores indicating severe depression. A recently published scoping review found that comorbid depression was a negative predictor of prognosis in AN [29].

The current study confirms the significantly impaired HRQoL measured by SF-36 and EDQLS in women with AN, as reported previously [2, 6]. Our finding that severe psychopathology in terms of eating disorders symptoms and depression predicted poorer disease-specific HRQoL is in line with AN studies assessing generic HRQoL with SF-36 [31] and EQ-VAS [14]. Several identical subscales of the EDI-3 were associated with poorer HRQoL in *both* women with AN and controls, but it appeared that impaired HRQoL in AN was also associated with low self-esteem and fear of reaching adulthood. We also found that poorer specific HRQoL was associated with low levels of vitality (SF-36 VT score) and limitations in everyday life due to emotional problems (SF-36 RE score). These may be important aspects of AN to consider during treatment as they are likely to contribute to low motivation for completion of treatment. Jones et al. [32] suggested that motivation may be important for treatment completion, with completers being more motivated to improve their symptoms and their general quality of life.

Finally, we found that higher age predicted more impaired HRQoL in women with AN. In the general population, SF-36 scores for physical health decreased with age while SF-36 scores for mental health showed no clear age pattern [33]. Age has not previously been identified as a predictor for disease-specific HRQoL in AN [13], although higher age has been associated with poorer clinical outcome in AN [34, 35]. In population-based studies, aging itself has been perceived to decrease QoL, but this effect tends to diminish when controlled for other factors [36].

It is interesting that eating disorder pathology measured by EDI-3 was associated with HRQoL in both women with AN and controls. The EDI-3 measures psychological constructs that are clinically relevant in individuals with eating disorders, and the controls were not expected to exhibit eating disorder behavior. Eating disorders are likely to be present as a continuum, however, and include milder forms of disordered eating that would be present in a general population—and particularly in a young, female control group as in the current study. In future studies it would be interesting to investigate differences in HRQoL between patients with an ED, people with elevated ED symptoms but not a diagnosis, and people with non-disordered eating. The validity and reliability of applying the EDI-3 to healthy people has been questioned [37, 38] as it has been designed specifically for individuals with eating disorders. When we used

regression analysis to further investigate the predictive value of the EDI-3 subscales, we found similar results for women with AN and controls in terms of Drive for thinness, Personal alienation, Interpersonal insecurities, and Emotional dysregulation. However, Low self-esteem and Maturity fears were additionally associated with poorer HRQoL only in women with AN. Self-esteem issues and fear of adulthood/maturing are both inherent features of people with AN and appear to play a significant role in determining self-reported HRQoL. While low individual body weight, i.e. as characterized in drive for thinness, may be a means of coping with the psychological conflict and imbalance of an eating disorder, the psychopathology in terms of emotional dysregulation and personal alienation may be consequences of the disorder. However, these factors may also very well be present in young females not diagnosed with an eating disorder but simply going through the tumultuous time of adolescence/early adulthood. When these different factors occur together, they appear to be related to a particularly low quality of life.

As expected, women with AN had a significantly lower median BMI compared to healthy controls, as well as a lower BMI-for-age percentile. However, about 40% of the 13–17-year-olds with AN had a BMI-for-age percentile in the normal range despite being diagnosed with AN and in treatment at specialized centres for the AN. The participants in our study thus comprised patients at very different stages of AN. We found that BMI (including BMI-for-age) did not predict HRQoL in any of the regression models. This is in line with Abbate-Daga et al. [31], who found that eating disorder symptomatology but not BMI had an impact on HRQoL. It is in contrast, however, to the findings of Bamford et al. [12], who reported that changes in BMI predicted improvement in HRQoL. The latter study comprised a different and smaller selection of AN individuals than our study as it included 63 adults with severe and enduring AN. This might explain the difference in results as patients with severe and enduring AN would be expected to have a higher burden of eating disorder symptomatology and to be more physically affected by their emaciated state, thus lowering their HRQoL. The abovementioned findings contribute to the argument that BMI cannot stand alone in determining outcome, but it is important to include PRO measures. It could be used in monitoring treatment response. In previous studies nadir BMI has been determined to be a strong predictor of mortality/poor outcome in AN [39], but in this study BMI was not associated with HRQoL, which needs to be considered when assessing outcome.

The strengths of our study are that it represents the largest AN cohort study to date, includes a wide range of assessment measures, and collects data from treatment-seeking individuals in all regions of Denmark. The analyses are further strengthened by the absence of missing values on the assessment measures. A limitation of the current study is that the controls were significantly older than the women with AN (median 24 years vs. 22 years). Recruitment of controls was achieved by advertising online through social media, and the results reflect self-selection. Thus, the control group is perhaps best described as normal-weight women who did not take regular medication.

The results of this study would be useful as reference material for intervention studies where EDQLS is included as an effect parameter. We further hope that the study results will help to stimulate interest in patient-reported outcome measures in AN, which presents very special challenges in the form of patient egosyntonicity and ambivalence. Biomedical effect measures cannot stand alone in AN as ‘successful’

treatment in terms of anthropometric and biomedical effect parameters can also be associated with reduced patient-reported quality of life.

Conclusion

The current study confirms that women in treatment for AN have a profoundly impaired quality of life, both in terms of disease-specific HRQoL and on measures of general health, psychological well-being, and work functioning. We found that poorer HRQoL in women with AN was predicted by more severe eating disorder symptoms, more symptoms of depression, poorer psychological health (emotional role and vitality), and older age. Low self-esteem and maturity fears appeared to in particular predict poorer HRQoL in women with AN. Apart from age, these factors are psychological and cognitive in nature, suggesting that attention to and management of disordered self-assessment and thought processes may be of special importance to women with AN and their families. It is possible that a greater emphasis on such aspects alongside weight gain could enhance patient-clinician alliance and contribute to better treatment outcome.

Abbreviations

AN Anorexia nervosa

BDI Beck Depression Inventory

BMI Body mass index

EDI-3 Eating Disorder Inventory-3

EDQLS Eating Disorders Quality of Life Scale

HRQoL Health-related quality of life

SF-36 Short-Form 36

WHO-5 World Health Organization well-being index

WSAS Work and Social Adjustment Scale

Declarations

Ethics approval and consent to participate:

The project was approved by the Danish Data Protection Agency (File no. 17/3218) and the Regional Committees on Health Research Ethics for Southern Denmark. The study is registered with ClinicalTrials.gov with the registration number NCT03230435. Participants were thoroughly informed regarding the aim of the study, with legal guardians giving consent for participants under 18 years old.

Consent for publication:

Not applicable.

Availability of data and materials:

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests:

The authors declare that they have no competing interests.

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Authors' contributions:

All authors contributed to study design, interpretation of data, and writing the manuscript. LAW was responsible for recruitment of participants, data collection and analysis. All authors read and approved the final manuscript.

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