Quality of Life and Associated Risk Factors in Caregivers of Patients with Obsessive Compulsive Disorder

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INTRODUCTION: Obsessive compulsive disorder (OCD) is a chronic disease that affects social relationships, and occupational and academic performance of patients and their relatives due to cognitive, emotional, and behavioural aspects of the disease. Quality of life (QoL) in relatives of patients with OCD has previously been reported and compared with caregivers of patients with other psychiatric conditions. However, there are few studies available in the literature regarding the causality of QoL in caregivers of patients with OCD.

OBJECTIVE: The aim of this study was to evaluate QoL of caregivers of patients with OCD and predictors of QoL of the family caregivers.

METHODS: The study population comprised of 68 patients with OCD and their caregivers. The dependent variable of this study is “QoL of caregivers” as assessed by the short version of the World Health Organization Quality of Life questionnaire (WHOQOL-BREF-TR). The Structured Clinical Interview for DSM-IV/Clinical Version (SCID-I/CV), Yale-Brown obsessive-compulsive scale (Y-BOCS), Y-BOCS symptom checklist, Hamilton Depression Rating Scale (HAM-D), and WHOQOL-BREF-TR were completed by the patients, whereas the SCID-I/CV, WHOQOL-BREF-TR, and Burden Assessment Scale (BAS) were completed by the caregivers. Student’s t-test, MWU, ANOVA, Kruskal-Wallis ANOVA, and Spearman’s correlations were used in univariate analyses, and multiple linear regression tests were run in multivariate analyses. Critical VIF values were taken as 5.0 for detecting collinearity among independent variables in the regression analyses. Type 1 error was taken as 0.05 in the analyses.

RESULTS: Linear regression analysis showed that caregivers’ sex, education level, occupational status, disease burden, and patients’ sex, physical QoL, and disease severity were predictors of caregivers’ QoL. Moreover, disease burden was the only common predictor that affected all four dimensions (physical, psychological, social relations, environmental) of the caregiver’s QoL, and as the perceived disease burden increased, the caregiver’s QoL deteriorated.

Introduction

Obsessive compulsive disorder (OCD) is a chronic disease characterized by obsessions and/or compulsions, which can be exacerbated occasionally, negatively affecting the individual’s daily functions, social relationships, and occupational functioning [1–3]. OCD is one of the leading causes of disability and reduced quality of life (QoL), with impairment in a number of domains. Moreover, QoL remains an important issue to address in the management of OCD, irrespective of illness severity [4].

OCD affects patients and their social environment, i.e. family members, friends, and society [1,2,5]. Family cohesion is defined as the involvement of family members in the rituals of the patient to meet the needs of the patient with the disease. Relatives may have to adjust their daily activities to adapt to the symptoms of the disease because of the clinical features of OCD disease. The patient’s obsessions, ambivalence, trust-seeking behaviour, avoidance behaviours, needs for approval, and rituals may result in over-dependence on family members [6]. As a result of family cohesion, tasks and responsibilities of the patient become a burden for the caregiver, causing worsening of the prognosis of OCD, and deteriorating interfamily functionality [6–8]. The most common problems that caregivers of patients with OCD experiences are intrafamilial conflict, depression, burnout, anger, problems in social, and interpersonal relationships [8–10], feeling of insecurity, embarrassment, isolation, and stigmatization [9–12]. It has been shown in many studies that caregivers of patients with OCD are more affected by the disease than most psychiatric disorders [13,14] and OCD patients’ caregiver carries the burden of the disease [12,15]. Some studies have evaluated the emotional burden on family members of patients with OCD [13,16,17], which has been considered to be similar or even greater than that of affective [16,18] or schizophrenic disorders [19].
The spread of the concept of disease burden in OCD caregivers, the increase of related research, and the results have made it necessary to investigate QoL in caregivers. There are only a few studies in the literature on QoL in caregivers of patients with OCD. A number of comparative studies showed that the QoL of caregivers of patients with OCD was worse than in the general population [20,21]. QoL in caregivers of patients with OCD has been reported to be inversely related with the QoL of the caregivers. Higher perceived burden negatively affected caregivers’ QoL, by causing disruption of inter-family relations.

From all these studies, it became important to investigate the causality of disease burden and other variables in the quality of care of caregivers of patients with OCD for preventive mental health and better management of OCD. The aim of the present study was to evaluate QoL and predictors of QoL in family caregivers of patients with OCD.

Materials and methods

The study protocol was approved by the Institutional Ethics Committee (approval date and number: March 14th, 2013; 2047848661) and the study was conducted between December 2013 and September 2014 at Celal Bayar University Hafsa Sultan Hospital, Department of Psychiatry. The participants approved and signed written informed consent forms.

A structured clinical interview (SCID) [25] with the patients was conducted in the outpatient clinic. Following the SCID, the patients completed a sociodemographic data questionnaire, the Yale-Brown Obsessive Compulsive Scale (YBOCS) [26], Yale-Brown Symptom Checklist, Hamilton Depression Rating Scale (HAM-D) [27], and the World Health Organization Quality of Life Scale Brief Version (WHOQOL-BREF) [28] (versions in Turkish) [29].

The caregivers of patients who had lived with the patients for at least for 1 year also completed the sociodemographic questionnaire, Burden Assessment Scale (BAS), and WHOQOL-BREF after a structured clinical interview.

Patients with a comorbid psychiatric disorder according to DSM-IV, except depressive disorder, depressive symptomatology, nicotine dependence, and the presence of neurologic/or physical disease and mental retardation were excluded. The exclusion criteria for the caregivers were the presence of a comorbid psychiatric disorder according to DSM-IV, except nicotine dependence, and the presence of neurologic/or physical disease and mental retardation.

A total of 81 patients with OCD and caregivers were included in the study. Seven patients with comorbidities that could affect their QoL (1 with multiple sclerosis, 1 with chronic kidney failure, 1 with ulcerative colitis, 3 with alcohol abuse, and 1 with an amputated arm) and 6 caregivers who could not complete the self-reported scales were excluded. The remaining 68 patients with OCD and 68 caregivers who met the research criteria were enrolled in the study.

Sociodemographic Questionnaire: A questionnaire to investigate the participant’s demographic characteristics such as age, sex, marital status, socioeconomic status, parents’ education level, caregivers’ characteristics, and clinical characteristics including disease duration and a detailed treatment history.

Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I): A semi-structured interview for making major DSM-IV Axis I diagnoses, which was described by First et al. [25], and translated into Turkish by Özkırkçügil et al. [30].

Yale-Brown Obsessive Compulsive Scale (YBOCS): A semi-structured scale, which was developed to rate the severity and type of symptoms in patients with OCD by Goodman [26]. YBOCS is composed of 19 items, the first 5 items assess obsessions, and items 6–10 assess compulsions. Item 11 assesses the individual’s insight. The Yale-Brown Symptom Checklist is used along with YBOCS to create a report of the symptoms.

Hamilton Depression Rating Scale (HAM-D): A scale developed by Hamilton to determine the severity of depression. A total score of 0–51 is obtained from this 17-item scale. The cut-off point for the Turkish version has been defined as 7.

World Health Organization Quality of Life Scale Brief Version (WHOQOL-BREF): A shorter version of WHOQOL. It was developed in a multicenter study in 1998 (WHOQOL Group) [28] and measures four domains: physical health, psychological health, social relationships, and environment. WHOQOL-BREF was translated into Turkish by Eser et al. [31]. Each domain is scored and higher scores represent a better QoL.

Burden Assessment Scale (BAS): A 19-item self-report scale developed to assess the burden of families with a seriously mentally ill member by Reinhard et al. [32]. The validity and reliability of the Turkish version of BAS have been shown by Aydemir et al. [29].

Statistical analysis

Uni- and multivariate analyses were performed, in addition to descriptive analyses. The caregivers’ QoL
(assessed in four dimensions of WHOQOL-BREF) was considered as a dependent variable for this study; normality was tested using the Shapiro–Wilk test. Student’s t-test was used for parametric comparisons, the Mann–Whitney U test was used for non-parametric comparisons, and the Kruskal–Wallis ANOVA was used for ε3 group non-parametric variable comparisons. Tukey’s B and Mann–Whitney U tests were used for parametric and non-parametric post-hoc comparisons, respectively, in variance analyses. Spearman’s correlations were used to compare two continuous variables. Multiple linear regression analyses were performed to determine the association between the caregivers’ QoL and the variables that had been found to be significant in univariate analyses. Critical variance inflation factors (VIF) were taken as 5.0 for detecting collinearity among independent variables in the multiple regression analyses.

Statistical analyses were performed using SPSS ver. 15.0. Type 1 error was taken as δ0.05 in the statistical analyses.

Results

Demographic findings

The mean age of the patients was 36.00 ± 12.36 years and 44.19 ± 13.49 years for the caregivers. The majority (79.4%) of the patients were female, whereas only 45.6% were female in the caregivers group. More than half of the caregivers (54.4%) were patients’ spouses; parents represented almost one quarter (23.5%) and the remaining were siblings, children or friends. The demographic characteristics are summarized in Table 1.

The mean duration of illness was 8.05 ± 7.17 years and the mean duration of treatment was 3.98 ± 4.76 years. The YBOCS, HAM-D, and WHOQOL-BREF results of the patients and BAS and WHOQOL-BREF results of the caregivers are given in Table 2.

| Patient QoL score | Caregiver QoL score |
|-------------------|---------------------|
| Physical          | 12.97 ± 3.20        |
| Psychological     | 12.37 ± 2.43        |
| Social relations  | 12.22 ± 3.65        |
| Environmental     | 13.64 ± 2.48        |

Notes: YBOCS: Yale-Brown Obsession Compulsion Scale; HAM-D: Hamilton Depression Rating Scale; BAS: Burden Assessment Scale.

Table 2. Clinical characteristics of the patients and scale scores of the patients and caregivers.

| Variable | Mean | SD | n | % |
|----------|------|----|---|---|
| Duration of the disease (years) | 8.05 | 7.17 | 37 | 54.4 |
| Duration of the treatment (years) | 3.98 | 4.76 | 31 | 45.6 |
| Depressive disorder as a comorbidity | 22 | 32.4 | 10.72 | 4.41 |
| Use of psychotropics | 57 | 83.8 | 9.63 | 5.25 |
| History of psychotherapy | 4 | 5.9 | 20.35 | 7.88 |
| History of admission to the hospital | 17 | 25.0 | 8.25 | 5.71 |
| YBOCS obsession score | 38.51 | 13.34 |
| Physical | 12.97 | 3.20 |
| Psychological | 12.37 | 2.75 |
| Social relations | 12.22 | 3.65 |
| Environmental | 13.64 | 2.48 |
| Caregiver’s QoL score | 14.73 | 2.43 |
| Physical | 14.23 | 2.12 |
| Psychological | 13.86 | 3.07 |
| Social relations | 14.73 | 2.43 |
| Environmental | 14.23 | 2.12 |

Notes: YBOCS: Yale-Brown Obsession Compulsion Scale; HAM-D: Hamilton Depression Rating Scale; BAS: Burden Assessment Scale.

Univariate analyses

The four WHOQOL dimensions (physical, psychological, social, and environmental) scores of the caregivers are the dependent variables of this study.

QoL vs. caregiver characteristics

Caregivers’ QoL scores were found to be positively correlated with their education level and adversely correlated with perceived disease burden (BAS score) in all four dimensions (p < .05). Psychological dimension scores were significantly higher in male caregivers, and social and environmental dimension scores were significantly higher in caregivers whose mothers had more than elementary school education (p < .05). Caregivers who were employed in a paid job had significantly higher scores in physical and environmental...
dimensions than those who were unemployed; environmental QoL scores were significantly decreased in low-income caregivers (p < .05) (Tables 3 and 4).

QoL vs. patient characteristics
Caregivers of male patients had lower psychological dimension scores, and the duration of OCD was adversely correlated with physical and social dimension scores (p < .05). Similarly, the patients’ YBOCS (obsession and compulsion and overall) scores and HAM-D score were adversely correlated with the caregivers’ QoL. The YBOCS obsession score was associated only with physical and environmental dimensions; other scale scores (YBOCS compulsion score, YBOCS total score, HAM-D score) were found to be associated with all dimensions of QoL (p < .05). QoL scores were assessed for both caregivers and patients in this study. The patients’ QoL scores were correlated with the caregivers’ QoL scores; physical, social, and environmental QoL dimensions were significantly correlated between the caregivers and patients (p < .05) (Tables 3–5).

Table 3. The association between the dimensions of quality of life in the caregivers with patients’ and caregivers’ characteristics.

| Variable | Caregivers’ quality of lifea | Physical (r)b | Psychological (r)b | Social relations (r)b | Environmental (r)b |
|----------|-----------------------------|--------------|-------------------|-----------------------|--------------------|
| Age      | −0.11                       | −0.03        | −0.18             | −0.07                 |
| Education level | 0.34**  | 0.25      | 0.37**             | 0.29**                |
| BAS score | −0.35***                    | −0.48***     | −0.42***           | −0.52***              |
| Age      | −0.06                       | −0.03        | −0.03             | 0.00                  |
| Education level | −0.01  | −0.12      | 0.12              | 0.11                  |
| Duration of the disease | −0.24*  | −0.19      | −0.30*             | −0.21                 |
| Duration of the treatment | −0.20  | −0.06      | −0.22             | −0.21                 |
| YBOCS obsession score | −0.24*  | −0.20      | −0.22             | −0.27*                |
| YBOCS compulsion score | −0.35** | −0.38**    | −0.39*             | −0.29**               |
| YBOCS total score | −0.37** | −0.36**    | −0.38**            | −0.35**               |
| HAM-D score | −0.25*  | −0.26*     | −0.28*             | −0.24*                |
| Physical QoL score | 0.19   | 0.29*      | 0.37**             | 0.32**                |
| Psychological QoL score | 0.17   | 0.12      | 0.19              | 0.19                  |
| Social relations QoL score | 0.33**  | 0.24*     | 0.27*             | 0.40**                |
| Environmental QoL score | 0.29*   | 0.33**    | 0.31*             | 0.42**                |

Notes: YBOCS: Yale-Brown Obsession Compulsion Scale; HAM-D: Hamilton Depression Rating Scale; BAS: Burden Assessment Scale.

*aWHOQOL-BRE TR: World Health Organization Quality of Life questionnaire brief form.

*bSpearman’s Rho.

*p < .05; **p < .01; ***p < .001.

Table 4. The association between the dimensions of quality of life and sociodemographic characteristics in the caregivers.

| Variable (n) | Physical dimension (Mean ± SD) | Psychological dimension (Mean ± SD) | Social relations dimension (Mean ± SD) | Environmental dimension (Mean ± SD) |
|--------------|--------------------------------|-----------------------------------|--------------------------------------|-------------------------------------|
| Sex Male (37) | 15.84 ± 2.79                  | 15.47 ± 2.45                      | 14.12 ± 3.24                         | 14.63 ± 2.17                        |
| Female (31)   | 15.50 ± 2.76                  | 13.84 ± 2.14                      | 13.54 ± 2.88                         | 13.76 ± 1.99                        |
| Marital Status Married (53) | 15.15 ± 3.08 | 14.77 ± 2.59 | 13.61 ± 3.22 | 14.21 ± 2.27 |
| Other (15)    | 15.50 ± 1.75                  | 13.81 ± 3.22                      | 14.04 ± 2.56                         | 13.92 ± 1.49                        |
| Perceived income level Low (10) | 13.49 ± 3.64 | 13.20 ± 3.08 | 12.40 ± 3.21 | 12.27 ± 1.89 |
| Middle (45)   | 15.28 ± 2.62                  | 14.84 ± 2.18                      | 13.93 ± 3.12                         | 14.40 ± 1.86                        |
| High (13)     | 16.44 ± 2.40                  | 15.54 ± 2.46                      | 14.77 ± 2.58                         | 15.18 ± 2.36                        |
| Occupational status Working (31) | 16.09 ± 2.39 | 15.20 ± 2.16 | 13.93 ± 3.01 | 14.83 ± 1.97 |
| Not working (37) | 14.51 ± 3.00 | 14.34 ± 2.60 | 13.80 ± 3.16 | 13.72 ± 2.13 |
| Mother’s education level Illiterate–Literate (36) | 14.63 ± 3.05 | 14.27 ± 2.83 | 12.70 ± 3.30 | 13.70 ± 2.27 |
| Elementary school and higher (32) | 15.91 ± 2.44 | 15.25 ± 1.81 | 15.16 ± 2.18 | 14.83 ± 1.79 |
| Father’s education level Elementary school and lower (52) | 14.91 ± 2.96 | 14.56 ± 2.60 | 13.43 ± 3.26 | 13.97 ± 2.09 |
| Middle school and higher (16) | 16.28 ± 2.11 | 15.29 ± 1.76 | 15.25 ± 1.81 | 15.08 ± 2.05 |
| Relation to the patient Parent (16) | 14.71 ± 2.34 | 13.70 ± 2.38 | 13.16 ± 2.57 | 13.66 ± 1.97 |
| Spouse (37)   | 15.21 ± 3.31                  | 15.00 ± 2.48                      | 13.90 ± 3.30                         | 14.40 ± 2.38                        |
| Sibling, Friend, Child (15) | 15.23 ± 2.83 | 14.73 ± 2.43 | 13.86 ± 3.07 | 14.23 ± 2.12 |

*p < .05; **p < .01; ***p < .001.

*aStudent’s t-test; bMann–Whitney U; cKruskal–Wallis ANOVA.
Table 5. The distribution of the quality of life dimension scores according to the patients’ sociodemographic characteristics.

| Variable (n) | Physical dimension (Mean ± SD) | Psychological dimension (Mean ± SD) | Social relations dimension (Mean ± SD) | Environmental dimension (Mean ± SD) |
|--------------|---------------------------------|------------------------------------|----------------------------------------|------------------------------------|
| sex          |                                 |                                    |                                        |                                    |
| Male (37)    | 14.08 ± 3.23                    | 13.14 ± 2.31                       | 13.61 ± 1.96                           | 13.68 ± 2.01                       |
| Female (31)  | 13.53 ± 2.67                    | 13.14 ± 2.31                       | 13.92 ± 3.31                           | 14.37 ± 2.14                       |
| marital status |                                 |                                    |                                        |                                    |
| Married (44) | 15.28 ± 3.10                    | 14.98 ± 2.40                       | 14.00 ± 3.10                           | 14.42 ± 2.30                       |
| Other (24)   | 15.14 ± 2.32                    | 14.27 ± 2.48                       | 13.61 ± 3.07                           | 13.88 ± 1.74                       |
| perceived income level |                                 |                                    |                                        |                                    |
| Low (10)     | 15.25 ± 3.71                    | 14.93 ± 2.43                       | 13.31 ± 3.49                           | 13.64 ± 2.30                       |
| Middle (46)  | 14.98 ± 2.77                    | 14.53 ± 2.43                       | 13.65 ± 3.04                           | 14.18 ± 2.06                       |
| High (12)    | 16.19 ± 2.26                    | 15.33 ± 2.55                       | 15.11 ± 2.74                           | 14.92 ± 2.20                       |
| occupational status |                                 |                                    |                                        |                                    |
| Working (14) | 14.81 ± 2.36                    | 13.85 ± 2.75                       | 14.66 ± 2.21                           | 14.34 ± 2.09                       |
| Not working (54) | 15.34 ± 2.95                  | 14.96 ± 2.32                       | 13.65 ± 3.24                           | 14.20 ± 2.15                       |
| mother’s education level |                                 |                                    |                                        |                                    |
| Illiterate–Literate (19) | 15.21 ± 2.11                  | 15.61 ± 1.97                       | 14.40 ± 3.25                           | 14.17 ± 2.01                       |
| Elementary–Middle school (39) | 14.98 ± .34                    | 14.23 ± 2.60                       | 3.70 ± 3.14                            | 14.03 ± 2.29                       |
| ≥High school (10) | 16.22 ± 1.52                  | 15.00 ± 2.22                       | 15.33 ± 2.10                           | 15.11 ± 1.48                       |
| father’s education level |                                 |                                    |                                        |                                    |
| Illiterate–Literate (13) | 15.34 ± 2.21                  | 15.48 ± 1.76                       | 12.61 ± 2.91                           | 14.11 ± 1.82                       |
| Elementary–Middle school (40) | 14.72 ± 3.21                  | 14.45 ± 2.59                       | 13.96 ± 2.98                           | 13.80 ± 2.16                       |
| ≥High school (10) | 16.49 ± 1.76                  | 14.84 ± 2.51                       | 14.66 ± 3.30                           | 15.49 ± 1.86                       |

*Student’s t-test; t Mann Whitney U; *Kruskall Wallis ANOVA.

**Multivariate analyses**

Linear regression analysis was performed to determine predictors of the caregivers’ QoL dimensions in variables that had been found to be significant in univariate analyses. The regression analysis results are shown in Table 6.

Table 6. Summary of multiple linear regression reduced final models for variables predicting caregivers’ quality of life dimension scores (n = 68).

| Variable | B       | Std Beta | p        | VIF |
|----------|---------|----------|----------|-----|
| physical QoL (R² = 0.447) |         |          |          |     |
| Constant | 19.89   | -        | <.001    |     |
| sex      | -1.32   | -0.23    | .02      | 1.003|
| education level | 0.15     | 0.24     | .02      | 1.054|
| BAS score | -0.10   | -0.49    | <.001    | 1.001|
| psychological QoL (R² = 0.484) |         |          |          |     |
| Constant | 14.23   | -        | <.001    |     |
| sex      | -1.41   | -0.20    | .01      | 1.217|
| BAS score | -0.04   | -0.20    | .05      | 1.572|
| patient’s sex | 1.59    | 0.27     | .02      | 1.316|
| YBOCS compulsion score | -0.16  | -0.34    | <.001    | 1.358|
| social relations QoL (R² = 0.367) |         |          |          |     |
| Constant | 12.59   | -        | <.001    |     |
| education level | 0.16     | 0.24     | .03      | 1.082|
| BAS score | -0.06   | -0.25    | .03      | 1.182|
| patient’s physical QoL score | 0.21   | 0.22     | .05      | 1.135|
| environmental QoL (R² = 0.400) |         |          |          |     |
| Constant | 16.11   | -        | <.001    |     |
| education level | 0.12     | 0.26     | .02      | 1.052|
| BAS score | -0.07   | -0.47    | <.001    | 1.053|

Notes: The variables significant in the univariate analyses—entered to the Regression Models: Physical dimension: Caregiver’s sex, education, employment, and BAS score and patient’s duration of illness, YBOCS obsession and compulsion scores, HAM-D score and patient’s social and environmental QoL scores; Psychological dimension: Caregiver’s sex, education level, BAS score and patient’s sex, YBOCS compulsion, HAM-D score; Social relations dimension: Caregiver’s own education, mother’s education, BAS score and patient’s duration of illness, YBOCS compulsion and HAM-D score, patient’s physical, social, and environmental QoL scores; Environmental dimension: Caregiver’s education, employment, income, mother’s education, BAS score and YBOCS obsession, compulsion scores, HAM-D score, patient’s physical, social, and environmental QoL scores.

All of the four Regression Models showed considerable R² values and VIF analyses showed no collinearity between independent variables.

**Physical dimension**

The caregivers’ sex, education level, and BAS score were found as predictors for the caregivers’ physical QoL (p < .05).

**Psychological dimension**

The caregivers’ sex, BAS score, patients’ sex, and YBOCS compulsion were found as predictors for the caregivers’ psychological QoL (p < .05).

**Social relations dimension**

The caregivers’ education level, BAS score, and patients’ WHOQOL-BREF physical dimension score were found as predictors for the caregivers’ social relations QoL (p < .05).

**Environmental dimension**

The caregivers’ education level and BAS score were found as predictors for the caregivers’ environmental QoL (p < .05).

**Discussion**

In this study, we aimed to assess factors that affected the QoL of the caregivers of patients with OCD. Although there are several studies in the literature focusing on QoL in caregivers’ patients with OCD, they do not demonstrate the dimensions and causality regarding QoL.

We found a significant association between the caregivers’ QoL and their sex, education level, and their
mothers’ education level. Caregivers’ QoL scores were significantly higher in males, those who were employed, had a high education level, and a highly educated mother. These findings are consistent with the literature as the dimension scores of QoL are expected to be lower in women, and individuals with lower education [21,33,34]. In addition, the lower QoL scores in the caregivers who did not work may be attributable to spending more time with the patients, and therefore, having greater exposure to the patients’ symptoms. To our knowledge, our study is the first to evaluate the effect of mother’s education level on QoL. The caregivers whose mothers had higher levels of education had significantly higher social relations and environmental dimension scores, suggesting that their mother’s higher education level provided better economic conditions, more knowledge about the disease, showing a more positive attitude and coping better with the negative feelings caused by the disease. Mother’s higher education level has been associated with a positive effect on social relations in previous studies [35,36].

We observed significantly lower psychological dimension scores in the male patients’ caregivers, inconsistent with previous studies, suggesting that the patients’ sociodemographic characteristics did not affect the caregivers’ QoL [21,23]. This may arise from the given importance of male sex and individuals’ expectations in our society.

Increasing duration of illness and higher YBOCS total and HAM-D scores worsened caregivers’ QoL. OCD has a negative effect on the patient’s functionality, and as the duration of the disease increases, patients may stop working and become dependent on their caregivers for care, and costs of treatment, resulting in greater disease burden deterioration in the caregivers’ QoL. Previous studies also demonstrated that the duration and the severity of disease had an adverse effect on the caregiver’s quality of life, consistent with our findings [21–23,37]. In another study conducted in young patients with OCD, disease severity was associated with caregiver burden but not with caregiver QoL [24].

We found a positive correlation between the patients’ and the caregivers’ QoL dimension scores and a significant association between their QoL dimension scores, except the patients’ psychological dimension score. Although no studies have focused on this aspect in the literature, several authors investigated the level of disability or functional level of the patient as a part of studies on caregivers’ QoL [21,23]. The fact that the description of QoL covers both functionality level itself and its attributed importance by the individuals also supports the importance of our findings. Alternatively, the negative effect of the patients with lower physical, social relations, and environmental scores on the caregivers’ QoL in all dimensions may be related to the need for more care by the patient due to the worsened body health and social relationship with restrictive social and occupational life of caregivers.

Numerous studies reported on caregivers’ QoL and disease burden separately [16,18,23,24,38]; however, there is only one report in the literature on the causality relationship of these two variables [22]. Our findings suggesting a negative correlation between disease burden and caregivers’ QoL is also consistent with their study; as the perceived disease burden increases, the caregiver’s QoL deteriorates.

According to regression analysis, disease burden (as measured using the BAS score) is the only common predictor that affects all four dimensions (physical, psychological, social relations, environmental) of the caregiver’s QoL. The disease burden may manifest as experiencing intense sadness, anxiety, responsibility, and guilt for the patient, interruptions in social life such as postponing social activities, arguments with other individuals to fulfil the patient’s needs, decrease in functionality, and additional costs for the patient’s treatment, which inevitably have an adverse influence on the caregiver’s QoL. To our knowledge, this is the first study to evaluate disease burden as a predictor of caregivers’ life quality.

The regression analysis also revealed that the caregivers’ sex and education level were predictors of their own physical QoL. Maintaining a daily routine, mobility, liveliness, and ability to work are indicators of an individual’s physical QoL. Physical QoL is majorly affected by age and morbidity. Our study group consisted of relatively young and middle-aged adults with no physical and/or psychological morbidity, which minimized the influence of age and morbidity and therefore brought sex and educational status to the forefront. Physical and psychological QoL scores are expected to be lower in female and under-educated individuals; this has been shown in many studies in the literature [21,33,34]. On the other hand, in our society, the caregivers were generally female, which may explain these findings.

In addition to caregiver’s sex and disease burden, the patient’s sex and YBOCS compulsion scores were found to be predictors for the caregiver’s psychological QoL. Contrary to our findings, there are studies showing that the QoL of the caregiver is not affected by the sex of the patient [21,23]. In our study, the significantly lower psychological QoL scores in the male patients’ caregivers may be related to the disappointment, sadness, and shame that occurs in our society as a result of the importance attributed to male identity and the failure of expectations. On the other hand, compulsion severity was found as a predictor of the caregiver’s psychological QoL, which suggests that compulsions are more likely to affect caregivers more than obsessions because of the outwardly observable behaviour.
Disease burden, education level, and the patient’s QoL physical score were predictors for the caregiver’s social relation QoL. In studies investigating the QoL of patients and caregivers, it has been shown that a worsening social dimension is associated with stigmatization [20,39]. The stigmatization of patients may also affect caregivers negatively; caregiver’s social relations may be deteriorated, social life may be restricted, and QoL may be adversely affected. Education level is a crucial factor in coping with stigmatization because a higher education level can improve the patient’s and the caregiver’s social relation QoL by reducing the perceived stigmatization and/or preventing stigmatization by others. Nevertheless, the patients’ physical QoL scores were found to be a predictor of the caregivers’ social relation QoL score; as the patient’s need for physical help increases, the social life of the caregivers is also restricted.

In our study, the caregiver’s education level was one of two predictors along with disease burden that affected the environmental dimension of QoL. Considering that the WHOQOL environmental dimension is an indicator of an individual’s financial status, influenced by social, physical, health, wealth and educational circumstances, as demonstrated in the global reliability and validity study [40,41], one can conclude that education level affects environmental QoL by its influence on financial status and accessibility to resources.

In conclusion, disease burden is the most crucial factor that affects all four dimensions of a caregiver’s QoL; as the perceived disease burden increases, the caregiver’s QoL deteriorates.

Disease burden should be minimized via support, caregiver education, family interviews to improve the patient’s caregiver’s QoL. Physicians should focus on patients’ social and occupational expectations from themselves, their relationships with people with whom they live, and the caregivers’ attitudes towards OCD, the patient, as well as the treatment of the symptoms. Caregivers should be informed about the disease with appropriate rehabilitation therapies, and their needs should also be taken into consideration in the management of patients with OCD.

Limitations

The study sample is not a population representative sample and includes only patients with OCD in a limited age range who presented to a university hospital’s outpatient wards, resulting in a limitation for the generalization of our findings to the community. In our study, the condition of the caregiver in the form of mental and physical well-being is an important advantage to better assess the effect of OCD on the caregiver’s QoL, as well as a limitation in reflecting the external reality due to excluded comorbidities. Another potential limitation of this study is the nonrandom pairing of patients and caregivers, which may lead to confound the results of the study. The fact that we did not evaluate Axis II diagnoses is another limitation for the assessment of factors affecting QoL in the study group. The lack of a control group is the final limitation of our study.

Disclosure statement

No potential conflict of interest was reported by the authors.

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References

[1] Hollander E. Treatment of obsessive-compulsive spectrum disorders with SSRIs. Brit J Psychiat Suppl. 1998;35:7–12.
[2] Stein DJ, Roberts M, Hollander E, et al. Quality of life and pharmaco-economic aspects of obsessive-compulsive disorder. A South African survey. S Afr Med J=Suid-Afrikaanse tydskrif vir geneeskunde. 1996;86 (12 Suppl):1579, 82–85.
[3] Bozukluk OK. Ruhsal Bozuklukların Tamsal ve Sayımsal El Kitabı, Yeniden Gözden Geçirilmiş Tam Metin (DSM-IV TR). Korgül E., editor. Ankara: Hekimler Yayı̇n Birliği̇; 2007. p. 660–671.
[4] Pozza A, Lochner C, Ferretti F, et al. Does higher severity really correlate with a worse quality of life in obsessive–compulsive disorder? A meta-regression. Neuropsychiat Dis Treat. 2018;14:1013–1023.
[5] Hollander E, Kwon J, Stein D. Obsessive-compulsive and spectrum disorders: overview and quality of life issues. Year Book Psychiat Appl Ment Health. 1998;1998(10):437–438.
[6] Laidlaw TM, Falloon IR, Barmfather D, et al. The stress of caring for people with obsessive compulsive disorders. Community Ment Health J. 1999;35 (5):443–450.
[7] Ferrão YA, Shavitt RG, Bedin NR, et al. Clinical features associated to refractory obsessive–compulsive disorder. J Affect Disord. 2006;94(1):199–209.
[8] Pedley R, Bee P, Berry K, et al. Separating obsessive-compulsive disorder from the self. A qualitative study of family member perceptions. BMC Psychiat. 2017;17(1):326.
[9] Hollander E, Kwon JH, Stein DJ, et al. Obsessive-compulsive and spectrum disorders: overview and quality of life issues. J Clin Psychiatry. 1996;57(Suppl):3–6.
[10] Gupta M, Giridhar C, Kulhara P. Burden of care for neurotic patients: correlates and coping strategies in relatives. Indian J Soc Psychiat. 1991;7:8–21.
[11] Black DW, Gaffney G, Schlosser S, et al. The impact of obsessive-compulsive disorder on the family: preliminary findings. J Nerv Ment Dis. 1998;186(7):440–402.
[12] Torres AR, Hof NT, Padovani CR, et al. Dimensional analysis of burden in family caregivers of patients with obsessive–compulsive disorder. Psychiat Clin. Neurosci. 2012;66(5):432–441.
Cooper M. Obsessive-compulsive disorder: effects on family members. Am J Orthopsychiat. 1996;66(2):296–304.

Thomas JK, Kumar PS, Verma AN, et al. Psychosocial dysfunction and family burden in schizophrenia and obsessive compulsive disorder. Indian J Psychiat. 2004;46(3):238.

Oza H, Parikh MN, Vankar GK. Comparison of caregiver burden in schizophrenia and obsessive-compulsive disorder. Arch Psychiat Psychoth. 2017;19(2):32–41.

Vikas A, Avasthi A, Sharan P. Psychosocial impact of obsessive-compulsive disorder on patients and their caregivers: a comparative study with depressive disorder. Int J Soc Psychiat. 2011;57(1):45–56.

Neto EBS, Teles JBM, dos Santos Rosa LC. Sobrecarga em familiares de individuos com transtorno obsessivo-compulsivo. Arch Clin Psychiat. 2011;38(2):47–52.

Magliano L, Tosini P, Guarnieri M, et al. Burden on the families of patients with obsessive-compulsive disorder: a pilot study. Eur Psychiatry. 1996;11(4):192–197.

Kalra H, Nischal A, Trivedi JK, et al. Extent and determinants of burden of care in Indian families: a comparison between obsessive-compulsive disorder and schizophrenia. Int J Soc Psychiatry. 2009;55:28–38.

Stengler-Wenzke K, Kroll M, Matschinger H, et al. Quality of life of relatives of patients with obsessive-compulsive disorder. Compr Psychiat. 2006;47(6):523–527.

Albert U, Salvi V, Saracco P, et al. Health-related quality of life among first-degree relatives of patients with obsessive-compulsive disorder in Italy. Psychiatr Serv. 2007;58(7):970–976.

Grover S, Dutt A. Perceived burden and quality of life of caregivers in obsessive-compulsive disorder. Psychiat Clin Neurosci. 2011;65(5):416–422.

Cicek E, Cicek IE, Kayhan F, et al. Quality of life, family burden and associated factors in relatives with obsessive-compulsive disorder. Gen Hosp Psychiat. 2013;35(3):253–258.

Wu MS, Hamblin R, Nadeau J, et al. Quality of life and burden in caregivers of youth with obsessive-compulsive disorder presenting for intensive treatment. Compr Psychiat. 2018;80:46–56.

First M, Spitzer R, Gibbon M, et al. Structured clinical interview for DSM-IV Axis I disorders-clinical version (SCID-CV). Washington, DC: American Psychiatric Press; 1997.

Goodman W, Price L, Rasmussen S, et al. Yale-Brown Obsessive Compulsive Scale (Y-BOCS). Arch Gen Psychiat. 1989;46:1006–1011.

Hamilton M. Development of a rating scale for primary depressive illness. Br J Clin Psychiat. 1976;6(4):278–296.

Group W. Development of the World Health Organization WHOQOL-BREF quality of life assessment. Psychol Med. 1998;28(3):551–558.

Aydemir O, Dikici DS, Akdeniz F, et al. Reliability and validity of the Turkish version of the burden assessment scale. Arch Neuropsych. 2012;49(4):276–281.

Özkürkçügil A AO, Yıldız M, et al. DSM-IV Eksen I Bozukluklar İçin Yapilandırılmış Klinik Görüşmenin Türkçe’ye uyarlanması ve güvenilirlik çalışması. İlaç ve Tedavi Dergisi. 1999;12:233–236.

Eser E, Fidaner H, Fidaner C, et al. WHOQOL-100 ve WHOQOL-BREF’in psikometrik özellikleri. Psikiyatri Psikofarmakoloji (3P) Dergisi. 1999;7(Suppl 2):23–40.

Reinhard SC, Gubman GD, Horwitz AV, et al. Burden assessment scale for families of the seriously mentally ill. Eval Program Plann. 1994;17(3):261–269.

Holter ÖG, Svaare H, Egeland C. Gender equality and quality of life. A Norwegian perspective. Oslo: Reprocentralen, University of Oslo; 2009.

Bonsaksen T. Exploring gender differences in quality of life. Ment Health Rev J. 2012;17(1):39–49.

Baumrind D. Harmonious parents and their preschool children. Dev Psychol. 1971;4(1):99–102.

Baumrind D. New directions in socialization research. Am Psychol. 1980;35(7):639–652.

Gururaj G, Math SB, Reddy J, et al. Family burden, quality of life and disability in obsessive compulsive disorder: an Indian perspective. J Postgrad Med. 2008;54(2):91.

Ramos-Cerqueira A, Torres AR, Torresan RC, et al. Emotional burden in caregivers of patients with obsessive-compulsive disorder. Depress Anxiety. 2008;25(12):1020–1027.

Schulze B, Angermeyer MC. Subjective experiences of stigma. A focus group study of schizophrenic patients, their relatives and mental health professionals. Soc Sci Med. 2003;56(2):299–312.

Leung K, Wong W, Tay M, et al. Development and validation of the interview version of the Hong Kong Chinese WHOQOL-BREF. Qual Life Res. 2005;14(5):1413–1419.

Izutsu T, Tsutsumi A, Islam MA, et al. Validity and reliability of the Bangla version of WHOQOL-BREF on an adolescent population in Bangladesh. Qual Life Res. 2005;14(7):1783–1789.