

# Development and Validation of a Questionnaire to Measure Quality of Life in Caregivers of Patients with Schizophrenia and Affective Disorders (SAC-QoL)

Ali Soltaninejad,<sup>1\*</sup> Ernst von Kardorff,<sup>1</sup> Mohammad Kamali,<sup>2</sup> and Mahin Eslami Shahrabaki<sup>3</sup>

<sup>1</sup>Department of Rehabilitation Sciences, Faculty of Humanities and Social Sciences, Humboldt University of Berlin, Berlin, Germany

<sup>2</sup>Department of Rehabilitation Administration, Faculty of Rehabilitation Sciences, Iran University of Medical Sciences, Tehran, IR Iran

<sup>3</sup>Faculty of Medicine, Kerman University of Medical Sciences, Kerman, IR Iran

\*Corresponding author: Ali Soltaninejad, Aristotelessteig 2, 10318 Berlin, No: 88.12.02.04, Germany. Tel: +49-017672246183, E-mail: soltaninejad.ali@gmail.com

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## Abstract

**Background:** Severe mental illnesses, such as schizophrenia and affective disorders, have considerable effects on the life of not only patients, but also their caregivers.

**Objective:** The aim of this study was to develop a self-administered quality of life (QoL) questionnaire for the assessment of QoL in caregivers of patients with schizophrenia and affective disorders.

**Methods:** Based on a mixed method approach and purposive sampling method, a sample consisting of 196 caregivers was recruited from 2 psychiatric hospitals in Tehran and Kerman, Iran, as well as a charity center in Kerman during 2015 - 16. A 67-item questionnaire was developed in the qualitative phase of the study, consisting of semi-structured interviews with 45 caregivers, comments of an expert panel, and some items from other relevant questionnaires. The item reduction in the quantitative phase was based on item distribution, missing data per item, inter-item correlation, and factor analysis. The reliability coefficient (Cronbach's alpha) was calculated for all the dimensions. Convergent validity was assessed by Pearson's correlation coefficient test, and discriminant validity was analyzed, using student's t test and analysis of variance (ANOVA).

**Results:** The final version of the questionnaire included 21 items and 7 dimensions: emotional burden (5 items); dealing with patient symptoms (3 items); relationship with the therapeutic team (3 items); relationship with family (2 items); financial burden (3 items); relationship with the extended family and friends (2 items); and latent worry (3 items). The 7 dimensions could explain 78.45% of the total variance. Item internal consistency was satisfactory for all the dimensions, ranging from 0.77 to 0.96 for each item. Cronbach's alpha coefficient ranged from 0.74 to 0.89 in the whole sample. The SAC-QoL index was significantly correlated with all the dimensions of the world health organization QoL-BREF (WHOQoL-BREF) scale ( $r$ , 0.32 - 0.65). Also, the predefined hypotheses confirmed the discriminant validity ( $P < 0.01$ ).

**Conclusions:** The SAC-QoL questionnaire revealed acceptable psychometric properties. Therefore, it can be considered as a valid and reliable measure of QoL in caregivers of patients with schizophrenia and affective disorders. Moreover, it would be useful for clinicians and authorities to focus on caregivers who are primary providers of healthcare services.

**Keywords:** Affective Disorders, Caregiver, Quality of life, Questionnaire, Schizophrenia

## 1. Background

The world health organization (WHO) defines quality of life (QoL) as an individual's perception of life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns (1). Mental illnesses, especially schizophrenia and affective disorders, can have detrimental effects on both patients and caregivers (2). In fact, caregivers of patients with mental disorders experience a significant burden, including emotional, physical, financial, and psychosocial problems, resulting in reduced QoL.

Reduced QoL of caregivers may affect their ability to care for the patients, restrict their roles and activities, and

increase their psychosomatic symptoms, anxiety, or depressive symptoms. Moreover, it can affect continuity of care and optimal patient treatment (3-7). Since families and friends live with about 50-90% of patients with chronic psychiatric diseases, they are the key providers of health care, influencing the patients' adherence to treatment and development and evaluation of health programs and policies (7-9).

Although in the past few years, several studies have focused on the burdens, coping strategies, QoL, and other issues of caregivers of patients with mental disorders (2-6), some studies have focused on stigmatization of families of mentally ill patients (10), and only 1 study has proposed a specific questionnaire for QoL evaluation in care-

givers of schizophrenic patients (6). However, the mentioned study had not included a large group of caregivers of patients with mental disorders (eg, affective disorders) or patients' relatives including the spouse, siblings, and children. Therefore, the current study was performed in a different cultural context, and the strengths and weaknesses of previous questionnaires, which were used by the authors to develop the draft of the questionnaire, were taken into account (7).

To the best of our knowledge, no QoL scale has been specifically developed for caregivers of patients with schizophrenia and affective disorders. There are some generic questionnaires, including WHOQoL-BREF and 36-item short-form health survey (SF-36), to measure QoL in the general population, comprised of healthy and unhealthy individuals (11). However, these measures are not designed to assess the impact of disease on family caregivers; therefore, they cannot measure specific dimensions of caregivers' QoL, which are affected by a specific disease.

Assessment of the impact of a specific disease on family caregivers can allow comparisons between different diseases in terms of the influence on family members. Also, the affected areas of family caregivers' lives can be identified to have a better understanding of dimensions where more support is required (12). The tool developed in the present study may be an improvement over the existing measures, as it evaluates QoL in a large group of family caregivers of patients with schizophrenia and affective disorders. Moreover, this scale can be compared with other available measures, as it was developed in a different cultural and social context.

Development of an instrument for evaluating QoL in caregivers of patients with mental disorders could be useful in the assessment of caregivers' QoL and help improve the health of patients and their caregivers. In other words, it helps caregivers better manage their ill relatives. In addition, managers can plan for the improvement of caregivers' QoL.

## 2. Objective

The present study aimed to develop and validate a new specific instrument to measure QoL in caregivers of patients with schizophrenia and affective disorders.

## 3. Materials and Methods

Development and validation of this self-administered, multidimensional QoL instrument were done, based on the triangulation technique (13). We conducted face-to-face, semi-structured interviews with 45 caregivers, used

the comments of an expert panel, utilized relevant questionnaires for both general and specific populations (eg, WHOQoL-BREF, Schizophrenia Caregiver QoL, Caregiver Oncology QoL Questionnaire, and QoL index), and applied a quantitative method in this study (7, 11, 14-16).

Data were collected from 3 psychiatric centers in Tehran and Kerman, Iran, including Shahid Beheshti hospital (in Kerman with 200 psychiatric inpatient beds), Razi hospital (Tehran), and Golestan-e Salamat charity center (Kerman). Razi hospital is the largest psychiatric center in the Middle East with nearly 1375 psychiatric inpatient beds, and Golestan-e Salamat is a charity center with about 300 inpatient beds.

The inclusion criteria were as follows: (1) age range of 15 - 65 years; (2) diagnosis of schizophrenia or affective disorders according to the Diagnostic and statistical manual of mental disorders (DSM-IV); and (3) availability of caregivers for the assessments. Disease duration of at least 1 year was required for enrollment in the study. Caregivers (minimum age, 18 years) needed to be identified as family caregivers of patients with either schizophrenia or an affective disorder. To participate in the study, the caregivers were required not to have any mental disorders, as confirmed by a psychiatrist. On the other hand, the exclusion criterion for the caregivers was living with another family member who suffered from a chronic non-psychiatric disease.

The ethics committee of the psychiatric hospital, affiliated to Kerman University of Medical Sciences, approved the present study. All the participants were given oral and written information regarding the purpose and relevance of the study. Oral and written informed consents were provided by the family caregivers, and they were free to leave the study whenever they pleased. The interviews were conducted anonymously, using a number-based identification system.

During 1 month, the researchers identified the caregivers of patients with schizophrenia and affective disorders, who played the main caring role for these patients (identified by asking the patient or medical staff). Then, the research group asked the patients if they could contact the caregivers. After the patient's consent was obtained and the inclusion criteria were evaluated and confirmed among caregivers who intended to participate in the study, information was collected via interviews and self-report questionnaires (completed by the caregivers). The collected data included: (1) sociodemographic characteristics of the caregivers and sociodemographic and clinical characteristics of the patients (Table 1); and (2) QoL questionnaires including the self-administered SAC-QoL and WHOQoL-BREF scales, which were completed by the caregivers.

WHOQoL-BREF is a validated generic QoL questionnaire, consisting of 26 items and 4 dimensions: physical health, psychological health, social relationships, and environmental health. Each dimension is scored from 4 to 20 or 0 to 100 (17). According to a study by Yousefy et al. (2010) on the reliability and validity of WHOQoL-BREF in an Iranian population, consisting of 2936 clinical and 2956 nonclinical subjects, Cronbach's alpha coefficients for the entire study sample, clinical sample, and non-clinical subjects were 0.82, 0.82, and 0.84, respectively (11).

Overall, development and validation of SAC-QoL consisted of 2 phases: (1) item generation, and (2) item reduction and validation.

### 3.1. Phase 1: Item Generation

The content of the questionnaire was derived from semi-structured interviews by a trained interviewer according to a guide, previous questionnaires, and comments of the expert panel. All interviews were audiotaped and transcribed. The interviews continued until data saturation; ultimately, 45 interviews, each lasting 18 to 50 minutes (arithmetic mean, 30.2 minutes), were conducted.

Data analysis was performed according to inductive content analysis (18-20). In the first step of coding, categories were derived from the statements; comparison of statements resulted in primary categories. In the second step of coding, the primary categories were reviewed, and categories with the same content were further classified to obtain a set of relevant topics. Finally, 74 items were identified based on the interviews and previous questionnaires. The items were rated, using a 6-point Likert scale: "not at all", "a little", "somewhat", "a lot", "very much", and "not applicable".

Based on the experts' and caregivers' comments about different aspects of the questionnaire, items, which were ambiguous, misunderstood, or rarely answered, were reworded or omitted. Ultimately, this procedure led to a primary questionnaire, comprised of 67 items. Item generation by means of interview ensured the content validity of the scale, as it reflects the concrete experience of caregivers. Moreover, comments of experts and caregivers about the raw content of the questionnaire, along with the integration of some items from previously validated questionnaires, ensured the face validity of the scale.

### 3.2. Phase 2: Item Reduction and Validation

Item reduction and validation were accomplished through both statistical analysis and assessment of expert comments. To reduce the number of items ( $n = 67$ ), each item was reviewed for adverse characteristics related to item distribution (21, 22). The first step of item reduction

was as follows: expert comments, ceiling or floor effects  $> 70\%$ , absolute skewness value  $> 4$ , and correlation coefficients  $> 0.80$  with other items. At the end of this step, 15 items were removed. In the second step of item reduction, 2 sequential factor analyses with the following features were performed: R-type correlation matrix, principal component analysis, orthogonal method, varimax rotation, eigenvalue  $> 1$  (23), percentage of explained variance  $> 60$ , and loading factor  $> 0.40$ .

Item internal consistency (IIC) was assessed by measuring the correlation of each item with its scale; a correlation corrected for an overlap of at least 0.40 was recommended (24). Moreover, item discriminant validity (IDV) was assessed by the greater correlation of each item with its scale than other scales (25). Also, internal consistency reliability was assessed by measuring Cronbach's alpha coefficient; a coefficient of at least 0.7 was expected for each dimension. In general, Cronbach's alpha measures the significance of the correlation between the items of each domain and all items in the questionnaire (26).

### 3.3. Discriminant Validity

This method was applied to determine the extent to which the questionnaire could detect different groups and subgroups. This method evaluated the association of SAC-QoL scores with sociodemographic variables and clinical features to explore discrimination of respondents according to 3 predefined hypotheses:

1) Caregiving duration is correlated with the caregiver's QoL. An increase in caregiving duration may decrease the caregiver's QoL.

2) Caregivers of patients with major depressive disorder (MDD) experience higher levels of QoL than caregivers of patients with bipolar mood disorder (BMD) or schizophrenia.

3) There is no significant difference in QoL between caregivers of patients with schizophrenia and BMD.

The comparison of mean values was performed, using student's t test and analysis of variance (ANOVA). Data analysis was performed, using SPSS version 22 (27-30).

### 3.4. Convergent Validity

Convergent validity was examined by assessing the correlation of questionnaire dimension scores with WHOQoL-BREF scores. The fundamental assumption was that scores of questionnaire dimensions would have a more significant correlation with WHOQoL dimension scores than dissimilar scales.

## 4. Results

In order to avoid confusion, only the results of the final factor analysis are reported.

Among 226 eligible caregivers, 18 refused to participate in the study, and 12 did not complete the questionnaire properly; therefore, the study sample consisted of 196 caregivers. Among 196 caregivers, 159 (81.1%) and 36 (18.4%) were female and male, respectively. The mean age of the subjects was  $44.42 \pm 8.54$  years, and 65.8% of the participants were married. The majority of the caregivers (86.2%) resided in urban areas, and 47% were the patients' partners or children. The characteristics of the caregivers and their patients are shown in Table 1. The 7-factor structure could explain 78.45% of the total variance.

### 4.1. Scoring System

The mean item scores in each dimension were computed for each individual to obtain a score for each dimension. The scores of negatively worded items were reversed so that lower scores indicated higher QoL. Missing value analysis was used to substitute the missing items with the mean of non-missing items. A global QoL index was used to determine the mean of individual dimensions. In order to convert the raw scores into transformed scores in all dimensions, a 4 - 20 scale was used; higher scores indicated lower QoL (17).

### 4.2. Construct Validity

#### 4.2.1. Factor Analysis

Following face and content validity, as mentioned above, principal component factor analysis was employed to design the structure of the questionnaire. Kaiser's criterion for the measurement of sample adequacy was good (adequacy, 0.659; df, 210;  $P = 0.000$ ). Factor extraction was performed, based on Eigen values above 1. Finally, 7 factors, explaining 78.45% of the total variance, were extracted.

Based on the item reduction and factor analysis, the final version of SAC-QoL with 7 dimensions was developed (cf. Appendix 1 in the supplementary file). The 7 dimensions, which were named according to their constituent items, consisted of 21 items: emotional burden (EB, 5 items); dealing with patient symptoms (DPS, 3 items); relationship with the therapeutic team (RTT, 3 items); relationship with family (RF, 2 items); financial burden (FB, 3 items); relationship with the extended family and friends (REF F, 2 items); and latent worry (LW, 3 items).

All factor loadings were within the acceptable range (0.718 - 0.917) (Table 2). IIC was also satisfactory for all the dimensions, ranging from 0.77 to 0.96 for each item; therefore, each item should have a significant correlation with

its scale. Furthermore, the items should have a greater correlation with their own scale than other scales (IDV). The scale characteristics are presented in Table 3.

#### 4.2.2. Reliability

Cronbach's alpha coefficient was measured to explore the reliability of each dimension in the scale and global index. Internal consistency reliability ranged from 0.74 to 0.89, indicating high internal consistency in the study sample. Cronbach's alpha coefficient of at least 0.7 was expected for each scale.

#### 4.2.3. Convergent Validity

In order to explore the external validity of the scale, the dimensions and global score (index) of SAC-QoL were compared with WHOQoL-BREF dimensions. The SAC-QoL index was significantly correlated with the scores of all WHOQoL-BREF dimensions ( $r, 0.32 - 0.65$ ). Also, the physical health dimension indicated medium to high correlation with EB and FB and low correlation with RTT, RF, and LW. Moreover, psychological dimension showed medium to high correlation with EB and low correlation with RTT, FB, REff, and LW. The dimension of social relationships was only poorly correlated with all dimensions of SAC-QoL, except DPS and FB. In addition, environmental health showed high to medium correlation with EB, FB, and LW and low correlation with DPS. The results are demonstrated in Table 4.

#### 4.2.4. Discriminant Validity

All dimensions of SAC-QoL and the global index had positive relationships with caregiving duration, except in dimensions of RTT, FB, and REff (Table 5). Since higher scores in SAC-QoL indicated lower QoL, increased caregiving duration was associated with reduced caregiver's QoL; therefore, the first hypothesis was confirmed. Comparison of patients' disease (schizophrenia, BMD, and MDD) showed significant differences in the global index and all dimensions, except EB, RTT, and RF.

Analysis of variance (ANOVA) and Scheffe's post hoc test indicated a significant difference in QoL among caregivers of MDD patients and those caring for schizophrenia and BMD patients. Also no significant difference was observed in the QoL of caregivers of patients with schizophrenia and BMD. Therefore, a higher QoL was reported in caregivers of MDD patients, compared to those caring for patients with schizophrenia or BMD; accordingly, the second and third hypotheses were confirmed.

The results of student's t test and ANOVA showed no significant difference between males and females in terms of SAC-QoL dimensions. Educated caregivers had higher QoL in dimensions of DPS and FB. Conversely, they experienced

**Table 2.** Factor Loadings for 7 Extracted Subscales after Varimax Rotation

Items	Dimensions						
	EB	DPS	RTT	RF	FB	REff	LW
1) Have you felt sad or depressed?	0.832						
2) Have you felt exhausted?	0.828						
3) Have you run out of energy?	0.803						
4) Have you felt helpless?	0.718						
5) Have you felt hopeless?	0.804						
6) Have you been able to understand your patient's behaviors?		0.823					
7) Have you been able to manage bizarre and disruptive behaviors of your patient?		0.896					
8) Do you have enough information about the disease and process of treatment?		0.823					
9) Have you been understood by doctors and nurses?			0.886				
10) Have you been helped and supported by doctors and nurses?			0.888				
11) Have you been satisfied with the information given by doctors and nurses?			0.775				
12) Have you been understood by your family?				0.899			
13) Have you been helped and supported by your family?				0.917			
14) Have you had financial difficulties in facing your family member's illness?					0.804		
15) Have you had housing difficulties?					0.847		
16) Have you had transportation difficulties?					0.819		
17) Have you been understood by your extended family and friends?						0.881	
18) Have you been supported by your extended family and friends?						0.839	
19) Are you worried about your patient living independently without daily family support?							0.823
20) Are you worried about regular financial support for your patient?							0.796
21) Are you worried about who should be in charge of your patient if you are not available?							0.856

Abbreviations: DPS, dealing with patient symptoms (3 items); EB, emotional burden (5 items); FB, financial burden (3 items); LW, latent worry (3 items); REff, relationship with the extended family and friends (2 items); RF, relationship with family (2 items); RTT, relationship with the therapeutic team (3 items).

**Table 3.** Characteristics of the Dimensions of the Final Version of 21-Item SAC-QoL

SAC-QoL	IIC, Min-Max	IDV, Min-Max	MV, %	Floor, %	Ceiling, %	Cronbach's Alpha	Mean (SD)
EB	0.77 - 0.87	0.03 - 0.31	2	1	1	0.88	12.32 (2.32)
DPS	0.82 - 0.92	0.10 - 0.39	0	1	9.2	0.87	15.14 (2.94)
RTT	0.83 - 0.89	0.001 - 0.27	0	2	2.5	0.83	11.72 (2.72)
RF	0.95 - 0.96	0.03 - 0.25	0	13.3	3	0.89	8.75 (3.16)
FB	0.83 - 0.92	0.05 - 0.50	0	2	42.9	0.85	17.22 (3.37)
REff	0.88 - 0.90	0.02 - 0.27	0.5	1.5	3.6	0.74	13.12 (2.55)
LW	0.87 - 0.92	0.003 - 0.49	0	0.5	24.5	0.87	16.07 (3.17)
Index	Not applicable	Not applicable	2	0	1	0.76	13.53 (1.28)

Abbreviations: IDV, item discriminant validity; IIC, item internal consistency; MV, missing value.

lower QoL in dimensions of RF and REFF. Caregivers who lived in rural areas showed higher QoL in DPS and FB and lower QoL in RF dimension. However, no significant difference was observed between employed and unemployed caregivers in terms of QoL, except EB dimension in which employed caregivers perceived lower emotional burden. The scores of SAC-QoL dimensions (ie, EB, DPS, FB, and LW) had a significant positive correlation with the age of the caregiver; therefore, advancing age was associated with re-

duced QoL.

#### 4.2.5. Acceptability

The average time required for completing the questionnaire was about 4 minutes. The proportion of missing data was very low and never exceeded 2% per dimension and global index.

**Table 4.** Correlations Between SAC-QoL and WHOQoL-BREF Scores

	EB	DPS	RTT	RF	FB	REF F	LW	Index
Physical health	0.46 <sup>a</sup>	0.12	0.16 <sup>b</sup>	0.16 <sup>b</sup>	0.42 <sup>a</sup>	0.10	0.27 <sup>a</sup>	0.49 <sup>a</sup>
Psychological health	0.56 <sup>a</sup>	0.14	0.21 <sup>a</sup>	0.14	0.38 <sup>a</sup>	0.16 <sup>b</sup>	0.36 <sup>a</sup>	0.54 <sup>a</sup>
Social relationships	0.28 <sup>a</sup>	0.04	0.17 <sup>b</sup>	0.21 <sup>a</sup>	0.10	0.34 <sup>a</sup>	0.16 <sup>b</sup>	0.32 <sup>a</sup>
Environmental health	0.54 <sup>a</sup>	0.38 <sup>a</sup>	0.11	0.01	0.63 <sup>a</sup>	0.006	0.45 <sup>a</sup>	0.65 <sup>a</sup>

<sup>a</sup>Correlation is significant at 0.01 (2-tailed).<sup>b</sup>Correlation is significant at 0.05 (2-tailed).**Table 5.** Comparison (mean  $\pm$  SD) and Correlation (r) of SAC-QoL Scores According to Caregivers' Characteristics and Patients' Disease

	EB	DPS	RTT	RF	FB	REF F	LW	Index
<b>Gender of the caregiver</b>								
Female	12.38 (2.14)	15.19 (2.90)	11.64 (2.61)	8.68 (3.03)	17.37 (3.16)	13.02 (2.45)	16.17 (3.08)	13.53 (1.20)
Male	12.07 (3.00)	14.85 (3.16)	12.07 (3.22)	9.11 (3.75)	16.48 (4.16)	13.50 (2.96)	15.67 (3.58)	13.51 (1.60)
P value	0.565	0.530	0.389	0.522	0.232	0.315	0.441	0.935
T	0.57	0.63	0.86	0.73	1.21	1.00	0.85	0.68
<b>Education</b>								
Elementary	12.57 (1.70)	16.08 (2.55)	12.06 (2.50)	8.20 (2.40)	17.89 (2.57)	12.72 (1.90)	16.63 (2.35)	13.74 (0.99)
Secondary	12.22 (2.51)	15.32 (2.71)	11.47 (2.69)	8.57 (2.82)	17.30 (3.32)	13.06 (2.17)	15.88 (3.26)	13.47 (1.07)
University	12.05 (2.83)	12.64 (3.00)	11.72 (3.23)	10.42 (4.68)	15.60 (4.39)	14.18 (4.14)	15.45 (4.18)	13.25 (2.10)
P value	0.487	0.000	0.404	0.003	0.005	0.025	0.150	0.170
F	0.72	18.29	0.91	6.09	5.48	3.75	1.91	1.78
<b>Place of residence</b>								
Urban regions	12.38 (2.31)	15.39 (2.80)	11.78 (2.72)	8.45 (2.78)	17.67 (2.82)	13.20 (2.50)	16.18 (2.91)	13.60 (1.21)
Rural regions	11.93 (2.45)	13.49 (3.47)	11.36 (2.83)	10.64 (4.71)	14.19 (4.99)	12.56 (2.86)	15.17 (4.55)	12.99 (1.67)
P value	0.388	0.014	0.476	0.032	0.002	0.242	0.290	0.104
t	0.86	2.61	0.71	2.26	3.41	1.17	1.08	2.14
<b>Type of disease</b>								
BMD	12.08 (2.18)	14.64 (3.39)	12.23 (2.96)	9.06 (3.41)	17.62 (3.44)	13.49 (2.59)	16.72 (2.89)	13.70 (1.43)
Schizophrenia	12.50 (2.37)	15.74 (2.33)	11.42 (2.54)	8.53 (2.66)	17.72 (2.76)	12.78 (2.17)	16.70 (2.74)	13.63 (1.12)
MDD	11.84 (2.28)	13.42 (3.63)	12.14 (2.97)	9.17 (4.45)	14.53 (4.30)	14.00 (3.61)	12.44 (2.88)	12.79 (1.48)
P value	0.313	0.000	0.153	0.465	0.000	0.040	0.000	0.006
F	1.16	8.79	1.89	0.76	12.16	3.27	28.78	5.30
<b>Occupational status</b>								
Unemployed	12.72 (2.10)	15.21 (3.07)	11.99 (2.68)	8.98 (3.49)	17.04 (3.37)	13.19 (2.42)	16.28 (3.14)	13.70 (1.24)
Employed	11.85 (2.45)	15.06 (2.87)	11.49 (2.80)	8.44 (2.82)	17.35 (3.93)	13.13 (2.74)	15.85 (3.25)	13.35 (1.31)
P value	0.010	0.730	0.217	0.244	0.535	0.873	0.351	0.058
t	2.59	0.34	1.24	1.16	0.62	0.15	0.93	1.90
Caregiving duration (r)	0.17 <sup>a</sup>	0.159 <sup>a</sup>	0.022	0.148 <sup>a</sup>	0.067	-0.049	0.174 <sup>a</sup>	0.162 <sup>a</sup>
Caregiver's age (r)	0.227 <sup>b</sup>	0.227 <sup>b</sup>	0.032	-0.07	0.197 <sup>b</sup>	-0.036	0.221 <sup>b</sup>	0.205 <sup>b</sup>

<sup>a</sup>Correlation is significant at 0.05 (2-tailed).<sup>b</sup>Correlation is significant at 0.01 (2-tailed).

## 5. Discussion

The self-administered instrument developed in the present study is an innovative tool for QoL assessment in caregivers of patients with schizophrenia and affective disorders. This questionnaire, which was developed based on qualitative interviews with caregivers, comments of the expert panel, and previous relevant questionnaires, showed

acceptable face and content validity. Considering the discrepancies in the opinions of involved caregivers and the expert panel, content of QoL measures should be derived from their points of view (31).

Correlations between WHOQoL-BREF and SAC-QoL showed that the scores of some dimensions, such as EB, LW, FB, and Ref F, have medium or high correlations,

whereas dimensions, including DPS and RTT, indicated specific burdens of caregivers of patients with schizophrenia and affective disorders. In concordance with previous studies on the QoL of caregivers of chronic diseases, “relationship with the healthcare system” and “coping with patients” were the main specific dimensions of such instruments (14, 32).

As the results showed, the psychometric properties of the questionnaire, including reliability and validity, were acceptable. The instrument could explain 78.45% of total variance, thus showing good internal consistency. The internal consistency reliabilities for the 7 dimensions were high (Cronbach’s alpha > 0.70). In addition, the hypotheses, which aimed to explore IDV, were confirmed. The results indicated that caregivers who cared for their patients for longer periods had lower QoL, except in dimensions of RTT, FB, and REff (no significant correlation). This finding is consistent with some previous studies (33, 34), which showed that longer duration of caregiving is equivalent to lower QoL. One explanation is that managing patient symptoms for a long period results in frustration, helplessness, and other emotional burdens and leads to less professional or social support.

The present results showed a negative relationship between QoL and caregivers’ age, except in RTT, RF, and REff dimensions (no significant correlation). This result is in contrast to previous studies, which showed that older caregivers perceive fewer burdens (7, 35). One reason is that in the present study there was a positive relationship between age and caregiving duration. Therefore, older caregivers tolerated more difficulties because of having patients with severe symptoms, less improvement, long-term care, and insufficient support by family or government (as the main coping strategy).

In the current study, there was no significant difference between females and males in terms of QoL dimensions, which is consistent with some previous studies (36, 37) and in contrast with some others (9, 38). Since our study sample consisted of fewer mothers in comparison with other kinship bonds, it is not surprising to find no major difference between males and females in terms of QoL. Mothers are generally the primary caregivers and experience the greatest burden, as they feel more responsible and committed to most aspects of the patient’s daily care.

As expected, caregivers with higher education had higher QoL than those with lower educational levels in DPS and FB dimensions. Most previous studies have indicated that educated caregivers have adequate information about the disease, which helps them adopt better strategies to cope with the patient’s symptoms; also, it is not surprising that higher education is equal to lower financial burden (39-41). In addition, an interesting finding was that ed-

ucated caregivers had lower QoL in dimensions of RF and REff.

According to Scheffe post hoc test, patient’s progress is mostly associated with the help and support of family and friends rather than being only understood by them. One explanation is that families and friends do not pay enough attention to educated caregivers, since they normally have better financial conditions; however, it should not be forgotten that these individuals need assistance, besides financial support. This problem is also true for caregivers who live in rural areas despite having better financial conditions, given the support provided by the government, lower costs of living in rural areas, and fewer expectations in comparison with city dwellers; in fact, these caregivers do not receive enough support by their families. Another explanation may be that educated caregivers and those living in rural areas less frequently ask their family or friends for help.

Based on the findings, type of disease was significantly associated with QoL. The results showed that caregivers of MDD patients had higher QoL than caregivers of schizophrenia and BMD patients, which is concordant with previous studies (42, 43). One explanation is that caregivers, who have patients with schizophrenia or BMD, have more trouble handling bizarre and disturbing behaviors of the patients and managing their fluctuating emotions.

### 5.1. Limitations

Lack of information on the clinical severity of mental disorders was one of the limitations of the present study; in fact, such information could be useful in the analysis of construct validity. In addition, the present instrument was developed with respect to the main burdens and problems of Iranians, affecting their QoL. Therefore, further studies are needed to investigate the validity and reliability of this instrument in different cultural contexts with larger sample sizes. Also, reproducibility and sensitivity to change should be explored in ongoing research studies.

### 5.2. Conclusions

The SAC-QoL revealed acceptable psychometric properties. Therefore, it can facilitate a valid and reliable assessment of QoL in caregivers of patients with schizophrenia and affective disorders. Moreover, this scale can be useful for clinicians and authorities to determine the need for assistance (including personal counseling, financial support, or community-based assistance) in this specific group of caregivers. Furthermore, measurement of caregivers’ QoL is important for preventive strategies, as caregivers are the primary care providers for their ill relatives over long periods (even lifelong sometimes).

## Supplementary Material

Supplementary material(s) is available [here](#).

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## Footnotes

**Authors' Contribution:** Ali Soltaninejad, Ernst von Kardorff, and Mohammad Kamali conceived and designed the study. Ali Soltaninejad collected the clinical data. Mahin Eslami Shahrababaki interpreted the clinical data. Ali Soltaninejad performed statistical analysis and drafted the manuscript. Ernst von Kardorff revised the manuscript critically for important intellectual content. All the authors read and approved the final manuscript.

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**Table 1.** Characteristics of the Caregivers and Their Patients

Statistics	No. (%)
<b>Caregivers</b>	
<b>Sex</b>	
Female	159 (81.1)
Male	36 (18.4)
Missing	1 (0.5)
<b>Marital status</b>	
Married	129 (65.8)
Single	32 (16.3)
Divorced	28 (14.3)
Widowed	5 (2.6)
Missing	2 (1)
<b>Relationship with the patient</b>	
Spouse	46 (23.5)
Father	10 (5.1)
Mother	7 (3.6)
Sister	35 (17.9)
Brother	39 (19.9)
Child	46 (23.5)
Others	13 (6.6)
<b>Occupational status</b>	
Unemployed	86 (43.9)
Part-time	71 (36.2)
Full-time	24 (12.2)
Retired	10 (5.1)
Missing	5 (2.6)
<b>Place of residence</b>	
Urban	169 (86.2)
Rural	25 (12.8)
Missing	2 (1)
<b>Educational level</b>	
Elementary	69 (35.2)
Secondary	94 (48)
University	33 (16.8)
Mean age	44.42 ± 8.54
<b>Patients</b>	
<b>Sex</b>	
Female	56 (28.6)
Male	138 (70.4)
Missing	2 (1)

<b>Marital status</b>	
Married	63 (32.1)
Single	117 (59.7)
Divorced	8 (4.1)
Widowed	6 (3.1)
Missing	2 (1)
<b>Occupational status</b>	
Unemployed	173 (88.3)
Part-time	9 (4.6)
Retired	3 (1.5)
Early retired	10 (5.1)
Missing	1 (0.5)
<b>Place of residence</b>	
Urban	169 (86.2)
Rural	25 (12.8)
Missing	2 (1)
<b>Educational level</b>	
Elementary	94 (48)
Secondary	94 (48)
University	7 (3.5)
Missing	1 (0.5)
Urban	169 (86.2)
Rural	25 (12.8)
Missing	2 (1)
<b>Type of disease</b>	
Schizophrenia	120 (61.2)
BMD	47 (24)
MDD	29 (14.8)
Mean age	39.49 ± 11.47

Abbreviations: BMD, bipolar mood disorder; MDD, major depressive disorder.