Quality of life among caregivers of patients with bipolar disorder

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Background
Bipolar disorder (BD) is often associated with great caregiver burden. However, fewer studies exist on BD caregivers. Caregiver burden is associated with increased mental health service utilization, health problems, and costs. This study aimed to assess the quality of life (QoL) of BD caregivers and the factors affecting it.

Patients and methods
We conducted a cross-sectional study on 100 bipolar patients with their caregivers at the outpatient clinics of The Institute of Psychiatry, Ain Shams University Hospitals, and Abbassia Hospital for Mental Health.

Results
Regarding the caregivers, age is considered a determining factor of their QoL, while there was insignificant difference on the caregivers' QoL regarding their sex. The caregiver who was employed and those who was not sharing the same house with the patient scored higher on QoL score. Regarding BD patients, the patient's sex had a direct correlation on the QoL of the caregiver, while the patient's age, mood state, severity of depression, and illness duration showed insignificant correlation on the caregivers' QoL.

Conclusion
The age of the caregiver is a determining factor of the QoL. Also caregiver's QoL was not related to their sex or the patients' mood.

Introduction

Quality of life (QoL) has been defined by the WHO as an individual's perception of their position in life in the context of the culture and the value systems in which they live and in relation to their goals, expectations, standards, and concerns It is a broad ranging concept incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, beliefs of each person, and their relationship to salient features of the environment (). QoL is a crucial component that is involved in delivering an integral service to an ill person and their family and underlies the subjective perspective of the patient and the family (Caqueo-Urizar et al., 2009).

Bipolar disorder (BD) is characterized by manic or mixed episodes alternated by depressive episodes. Every episode of bipolar illness is considered a stressful life event for family members that affect their QoL and even when the illness is stabilized, the fear of new relapses is often present (Reinares et al., 2006). An exploration and evaluation of caregivers' QoL could be useful in promoting the patients' health and his QoL, maintaining caregivers'

health and caregiving ability, and developing new care strategies (Richieri et al., 2011). Caregiver's burden is affected by disruptive behaviors of the mentally ill person, changes in their daily life activities, strained social relationships, lack of social support, deteriorating finances, decreased opportunity for leisure activities, exhaustion, and the stigma related to mental illness of their family member, termed stigma by association (Sibitz et al., 2002).

In addition to experiencing caregiver's burden, family caregivers may show negative cognitions or thinking patterns that can precede clinical depression (Beevers et al., 2007). Indeed, caregiver's burden has been associated with depressed mood and depressive symptoms (Perlick et al., 2007). Furthermore, a large percentage of female spouses of mentally ill persons have been found to suffer from affective disorders: 38.8% suffer from depressive disorders, 23.9% from anxiety disorders, and 20.9% from somatoform

disorders (Wittmund *et al.*, 2002). Steele *et al.* (2010) found that the majority of studies examining psychiatric symptoms in bipolar caregivers reported the presence of caregiver symptoms, with ~46% of caregivers reporting depression and ~32.4% reporting mental health service use. This evidence supports examining and treating caregivers of patients with BD as potential with symptoms that would benefit from evaluation and treatment.

The negative experiences of the caregivers may influence their ability to take care of the patient, restrict their roles and activities, and increase their psychosomatic, anxious, or depressive symptoms (Steele *et al.*, 2010). This is an important concern because the participation of family caregivers is essential for the optimal treatment of patients by ensuring treatment submission, continuity of care, and social support (Perlick *et al.*, 2004). This study aims to value the QoL and the factors affecting it in the caregivers of the patients suffering from BD.

Patients and methods

The present study was a cross-sectional study carried out at the Outpatient Clinics of The Institute of Psychiatry, Ain Shams University Hospital and Abbassia Hospital for Mental Health in the period from January to April 2019. The study was approved by the ethics committee of Ain Shams University with reference number (FWA 00006444). Also detailed written consent was obtained from all participants and all of them had the right to withdraw anytime during the research without affecting their treatment or the given service.

Inclusion criteria

The study included those who fulfilled the following criteria: caregivers (spouse or first-degree relative) to patients who have the diagnosis of BD (identified by the patient). Those included were in the age range from 18 to 60 years. Caregivers of both sex were included.

Exclusion criteria

Caregivers who refuse to give consent. The caregivers who have any psychiatric disorders or comorbid medical illness.

Data collection

The data collected included the following:

(1) Sociodemographic characteristics of the caregivers: sex, age, employment status, relationship to the patient, and sharing home.

(2) Sociodemographic and clinical characteristics of individuals with BD: sex, age, diagnosis according to fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), illness duration, and symptom severity.

Tools used
Tools for the patients

(1) Structured Clinical Interview for DSM-IV Axis I Disorders: it is used to diagnose an axis I diagnosis. It is a semistructured diagnostic interview, which has been updated for DSM-IV. It begins with a section on demographic information and clinical background. Then there are seven diagnostic modules focused on different diagnostic groups: mood, eating, and adjustment disorders. Both required and optional probes are provided, and skip outs are subjected when no further questioning is warranted (Missiry*et al.*, 2004).
(2) Hamilton Depression Rating Scale (HDRS): the HDRS was designed to measure the severity for depressive symptoms in patients with depressive illness. The HDRS is a checklist of items that are ranked on a scale of 0–4 or 0–2. Four indicate the greatest severity (Hamilton, 1960).
(3) Young Mania Rating Scale: the Young Mania Rating Scale was to measure the severity of symptoms and gauge the effect of treatment on mania severity. The scale has items based on the patient's subjective report of his or her clinical condition (Young*et al.*, 1987).

Tools for the caregivers

(1) General health questionnaire: the general health questionnaire was initially developed as a first-stage screening instrument for psychiatric illness in order to identify potential cases and will be used here for screening of caregivers of BD patients with a cutoff score of 28 (Okasha, 1988).
(2) PCASEE QoL scale: the PCASEE QoL scale is a clinical instrument designed for interview administration; it provides information on symptoms and functioning over the last month. It is a 30-item self-rating scale rate from 0 to 5. High scores reflect less impaired or unimpaired functioning and six domains are covered: (P) physical component, (C) cognitive component, (A) affective component, (S) social component, (E) economic component, and (E) ego functioning (Goldberg and William, 1983).

Statistical analysis

Data were collected, tabulated, and statistically analyzed using SPSS 22.0 for Windows (SPSS Inc., Chicago, Illinois, USA) and MedCalc 13 for Windows (MedCalc Software bvba, Ostend, Belgium). Continuous data are expressed as the mean±SD and median (range), and the categorical data are expressed as a number (percentage). Continuous variables were checked for normality by using the Shapiro–Wilk test. A sample t test was used to compare two groups of normally distributed data, while Mann–Whitney U test was for nonnormally distributed data. Kruskal–Wallis H test was used to compare between more than two groups of nonnormally distributed data. Categorical data were compared using the χ^2 test or Fisher's exact test when appropriate. Spearman's rank correlation coefficient was calculated to assess relationship between PCASEE and various study variables; (+) sign indicates direct correlation and (–) sign indicates inverse correlation. Also, values close to 1 indicate strong correlation and values close to 0 indicate weak correlation. All tests were two sided. P value less than 0.05 was considered statistically significant; P value less than 0.001 was considered highly statistically significant; and P value was considered statistically insignificant.

Results

Data of the patients

In this observational study, we collected data from 100 patients with a mean age of 47.47 years (SD=13.5), 50% were men, 36% were diagnosed with depressive episodes, and 64% with manic episode with a mean disease duration of 9.09 years (SD=6.25) (Table 1).

Regarding the patients' sex and its effect on the PCASEE score of the caregivers, there was statistically significant difference on the score regarding the patients' sex where the mean (SD) score was for men was 68.82 (11.24) and for women was 78.04 (14.08) and the P value was 0.01. However, there were insignificant differences on PCASEE score regarding the patients' diagnosis with a mean (SD) of 74.5 (12.89) for the patients diagnosed with depressive disorder versus 78.70 (15.17) for the patients diagnosed with manic disorders and the P value is 0.55 (Table 2).

According to the Hamilton scale, it was found that 19% were with mild depression, 62% with moderate depression, and 19% were with severe depression, while Young mania scale showed 41% of patients had mild mania, 10% with moderate mania, and 49% with severe mania (Table 3).

Patient Hamilton mean score was 20.22 (4) and Young mania mean score was 38.08 (9.6).) (Table 4).

Table 1 Baseline demographic characteristics of the included patients

Variables	Patients (N=100) [n (%)]
Age	
Mean (SD)	47.47 (13.5)
Median (IQR)	49 (21)
Sex	
Female	50 (50)
Male	50 (50)
Current diagnosis	
Depressive episode	36 (36)
Manic episode	64 (64)
Illness duration (years)	
Mean (SD)	9.09 (6.25)
Median (IQR)	7 (10)

IQR, interquartile range.

Table 2 Difference on PCASEE score regarding patient demographic data

Variables	PCASEE score	P
Male	68.82 (11.24)	<0.01*
Female	78.04 (14.08)	
Depress	74.5 (12.89)	0.55
Manic	72.83(13.89)	

Data reported as mean (SD). PCASEE, Physical component, Cognitive component, Affective component, Social component, Economic component, and Ego functioning. *Statistically significant difference.

Table 3 Classification of severity according to Hamilton and Young mania score

Variables	Percent of patients (N=100) (%)
Hamilton	
No depression	0
Mild	19
Moderate	61
Severe	19
Young mania	
Mild	41
Moderate	10
Severe	49

Table 4 Hamilton and Young mania score of the included patients and PCASEE score of caregivers

Variables	Mean (SD)/median (IQR)
Hamilton	
Mean (SD)	20.22 (4)
Median (IQR)	20 (4)
Young mania	
Mean (SD)	38.08 (9.6)
Median (IQR)	42 (17)

IQR, interquartile range.

Table 5 Baseline demographic characteristics of the caregiver

Variables	Caregiver (N=100) [n (%)]
Age	
Mean (SD)	41.16(15.17)
Median (IQR)	40 (28)
Sex	
Female	58 (58)
Male	42 (42)
Employment status	
Yes	72 (72)
No	28 (28)
Relationship to the patient	
Brother	11 (11)
Daughter	19 (19)
Ex-wife	1 (1)
Father	3 (3)
Husband	8 (8)
Mother	23 (23)
Sister	8 (8)
Son	20 (20)
Wife	7 (7)
Living in the same house	
Yes	80 (80)
No	20 (20)
Duration spent as a caregiver	
Mean (SD)	6.27(4.2)
Median (IQR)	5(5)
PCASEE	
Mean (SD)	73.43(13.5)
Median (IQR)	71(23)

IQR, interquartile range; PCASEE, Physical component, Cognitive component, Affective component, Social component, Economic component, and Ego functioning.

Table 6 Difference on PCASEE score regarding the caregivers' demographic data

Variables	PCASEE score	P
Male	76.02 (14.6)	0.1
Female	71.55 (12.3)	
Living in the same house	72.11 (12.86)	0.05*
Not living in the same house	78.70 (15.17)	
Employed	75.76 (13.78)	0.005*
Not employed	67.43 (10.82)	

Data reported as mean (SD). PCASEE, Physical component, Cognitive component, Affective component, Social component, Economic component, and Ego functioning. *Statistically significant difference.

Table 7 Correlation between PCASEE score and variables

Variables	PCASEE
Caregiver age	
Correlation coefficient (r)	−0.302**
P value	0.0020
Patient age	
Correlation coefficient (r)	0.1690
P value	0.0930
Hamilton	
Correlation coefficient (r)	−0.025
P value	0.8850
Young mania	
Correlation coefficient (r)	−0.668**
P value	0.0000
Illness duration	
Correlation coefficient (r)	−0.083
P value	0.4140

PCASEE, Physical component, Cognitive component, Affective component, Social component, Economic component, and Ego functioning. **Statistically significant difference.

Data of the caregivers

The study included 100 caregiver individuals with a mean age of 41.16 (SD=15.17), 42% were men, 23% were mothers, 20% were sons, 80% were sharing the same house, 72% were employed with a mean duration of 6.27 years (SD=4.2) spent as a caregiver.

PCASEE mean score was 73.43 (13.5) (Table 5). There was no statistically significant difference on PCASEE score regarding sex of the caregiver where the mean (SD) score was for men 76.02 (14.6) and for women 71.55 (12.3) and the P value was 0.1.

However, there was a significant difference on PCASEE score regarding whether the caregiver lives in the patient house or not with a mean (SD) of 72.11 (12.86) versus 78.70 (15.17), respectively, and the P value was 0.05 denoting if the caregiver not living in the same house with patient has a better outcome.

Significant difference on PCASEE scores and employment status of the caregiver with a mean (SD) of 75.76 (13.78) and 67.43 (10.82) for being not employed and a P value of 0.005 denoting if the caregiver is employed has a better outcome (Table 6). Correlation analysis showed a significant negative correlation between caregiver age and PCASEE score (r=−0.302, P<0.001), a significant negative correlation between Hamilton and PCASEE score (r=−0.025, P=0.885), a significant negative correlation between Young mania and PCASEE score (r=−668, P<0.001), a nonsignificant weak indirect correlation between illness duration and PCASEE score (r=−0.083, P=0.414), and a nonsignificant correlation between patient age and PCASEE score (r=+0.169, P=0.093) (Table 7).

Discussion

As psychiatric services move from hospital to community, families play an important role in the management of serious mental disorders. BD is a major public health problem and despite pharmacological improvements, it is a lifelong, debilitating condition, which can have a major

impact on the families and carers of people with the disorder (Kaas *et al*., 2003).

The life of close relatives of persons diagnosed with BD is associated with emotional distress, depression, and high frequency of use of mental health services. Most caregivers of patients suffering from BD experience significant disruption in social activities and leisure time, especially when the patient is unwell, which in particular refers to the partners (Deye *et al*., 2016).

The caregiving role, apart from being very demanding, is harmful to health and decreases the QoL as well. Hence, we conducted this cross-sectional study at the Institute of Psychiatry at Ain Shams University Hospital on 100 patients and their caregivers to evaluate the QoL of the caregiver of bipolar patients and the factors affecting it.

Regarding the caregivers
In our study, the age of the caregiver was a determining factor of their QoL, in agreement with our findings. There was a study conducted on 300 BD patients and their caregivers, who also used the same PCASEE scale. They found that the QoL decreased with increasing the age of the participants (Ndikuno *et al*., 2016). Our study showed that there was no significant difference on the QoL of the caregivers in relation to their sex. On the contrary, another study was conducted on 77 individuals with 44 spouses of BD I patients and 33 spouses of BD II to assess the level of caregiving burden among spouses of BD. Its results showed that women were generally more burdened with the patient care and men accept wife's mental illness more frequent than women, women experience more negative changes in the relationship due to the presence of husband's illness, while women are able to reconcile 23. The caregiver role with other everyday tasks more frequent than men. The difference in the results was mostly due to the lower number of participants and different tools used in the study (Aleksandra *et al*., 2015).

Concerning the sociodemographic characteristics of the caregivers, our study showed that the caregiver who was employed and who was not living in the same house scored higher on the QoL score, while no significant difference was found regarding other data. In contrast to our findings, a study conducted in Pakistan on 120 caregivers showed that caregivers who were married, less educated, lived in rural area, had a lower monthly income provide longer hours of care giving, and used avoidant coping behavior reported significantly higher caregiver burden than caregivers who were single, more educated, lived in urban area, and had better income. Mostly this discrepancy resulted from assessment of caregivers of several mental disorders not only BD and using different assessment tools (Siddiqui and Khalid, 2019). Another study that examined 350 caregivers and assessed QoL together with some psychiatric disorders showed that the primary caregivers who had lower education, living with the patients, and single or divorced/separated and unemployed were associated with lower QoL domain scores (Jeyagurunathan *et al*., 2017).

Regarding the patients
Our result showed that the patient's age had insignificant correlation with the caregiver QoL. This came in disagreement with the results of a study by Dos Santos *et al*. (2017), who examined 36 elderly BD patients and their care givers. They found that the caregivers' Qol is affected due to the patients' impairment and the patients' symptoms and not due to age. This disagreement resulted from the different age group of the patients as the older patients need more care and had more impact on their caregivers' burden.

Meanwhile, the results of this study showed that illness duration had insignificant correlation with the QoL of the caregivers, On the other hand, the results of the study by Siddiqui and Khalid (2019) suggested that the longer the duration of illness, with increased impairments of care recipients (decline in functional status, diminished physical capacity), the more the burden experienced by the caregivers.

Regarding disease severity, our findings showed that the severity of depression showed insignificant correlation on the care givers' QoL, while Young mania score correlated with it.

This came in agreement with Zhou *et al*. (2016), which showed that the patient symptom severity was a better predictor of caregiver's burden in the acute phase in both diseases. This was also supported by Aleksandra *et al*. (2015) who found that the leading cause of burden in the spouses of BD I patients is the manic episode, while in BD II; caregiver's burden was associated with depression.

Limitations
Our study is limited by being a cross-sectional study that precluded us from making inferences about causality.

In addition, because only the primary caregiver was studied, we cannot draw inferences about the nature or

the level of burden experienced by other family members.

Conclusion

Our study found that the age of the caregiver is a determining factor of their QoL. On the other hand, QoL for the caregiver was not related to their sex or patients' mood. Caregiver who was employed and those who was not living in the same house had higher QoL.

Recommendations

Psychoeducation as an effective intervention for the caregiver may reduce caregiver burden. Improving QoL for the caregiver was associated with better outcome in BD course. Future studies should focus on studying the social life of the caregiver and whether it may support BD patients, along with how far psychoeducation for the caregivers might affect the course of the disease.

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Conflicts of interest

There are no conflicts of interest.

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