

Psychosocial burden on informal caregivers of patients with bipolar mood disorders

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Objectives

The aim of this study was to detect and measure the extent of psychosocial burden and psychiatric morbidity among the caregivers of bipolar mood disorder patients and to correlate psychosocial burden of bipolar disorder on caregivers with the severity of the clinical condition of the patients.

Methods

This study was conducted on a randomly selected group of 130 bipolar mood disorder patients and their 130 main caregivers. Patients were diagnosed according to the *Diagnostic and Statistical Manual of Mental Disorders*, 4th ed., text revision, and were subjected to psychiatric and physical examination, as well as global assessment of function for patients. Caregivers were subjected to a semistructured clinical interview and medical examination, as well as to the following tools: (a) Caregiver Strain Index, (b) Caregiver Self-Assessment Questionnaire to measure the degree of burden, (c) Hamilton Anxiety Rating Scale, and (d) Hamilton Depression Rating Scale.

Results

The study found a significant burden on caregivers of bipolar mood disorder patients of the severe type, with and without psychotic features. In addition, caregivers of bipolar mood disorder patients of the severe type, with and without psychotic features, were found to have significant anxiety and depression. A strong negative correlation was found between burden on caregivers and the severity of the clinical condition of the patients on using the global assessment of function scale. Further, a strong positive correlation was found between burden on caregivers and frequency of hospitalization, age of caregivers, severity of depression and anxiety of caregivers, and frequency of electroconvulsive therapy.

Conclusion

There are many factors affecting the degree of burden and psychiatric morbidity among caregivers of bipolar mood disorder patients. Hence, it is recommended that more services be introduced for caregivers to save cost expenditure.

Keywords:

depression, mania, parent, stress

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Introduction

The prevalence of psychiatric illness is scarce in Egypt; however, a survey study by Ghanem *et al.* [1] found that the overall prevalence of mental disorders in their surveyed sample was 16.93%, and mood disorders were one of the most common mental disorders (6.43%). There are no national social welfare and community rehabilitation programs for the mentally ill, and the families have to bear the major burden of care. Although there has been an increased clinical interest [2], only a few studies reference caregivers of patients with bipolar affective disorders. The available data are primarily derived from expert-conducted, self-generated questionnaires [3–5], and the small sample size of the studies is a limitation [6]. Currently, only one qualitative study exists that evaluates the impact of bipolar affective disorders on family and partners [7].

Informal caregivers are usually unpaid nonprofessionals, such as family and friends, who have a significant role in the care and support of individuals affected by severe psychiatric illnesses [8]. Caregivers are not a uniform group; they come from every background and all walks of life. They may be daughters or sons, spouses or partners, friends or neighbors [9]. Caregiving includes a lot of different activities such as shopping, telephoning, visiting, lifting, bathing, dressing, feeding, managing incontinence, managing financial and legal affairs, providing social activity, supervising medication, managing healthcare, listening, talking, and providing emotional support [10].

Families of people with mental illnesses inevitably experience some form of burden as they are heavily relied upon. This burden is unique to carers of people with mental illnesses [11]. Families of patients with psychotic disorders experience high levels of burden.

Moreover, there is evidence that a large number of caregivers have rates of depressive symptoms that are as high as 38–60% [12]. Among the numerous psychiatric disorders seen in caregivers, depression is reported to be one of the first symptoms experienced and also the most enduring psychological outcome in this group [13,14]. Anxiety disorders are also commonly seen among caregivers, especially panic attacks, phobias, and generalized anxiety disorders [15]. Other psychiatric disorders that may be seen in this group of individuals include substance and alcohol use disorders and chronic sleep disturbances [16,17]. Studies have shown that approximately one-third of relatives caring for individuals with psychosis have elevated levels of anxiety or depression related to the caring role, and these caregivers were mainly elderly mothers [18].

The aim of this study was to detect and measure the extent of psychosocial burden and psychiatric morbidity among the caregivers of patients with bipolar mood disorders and to correlate psychosocial burden and psychiatric morbidity among caregivers with the severity of the clinical conditions of patients with bipolar mood disorders.

Methods

Location and date of the study

This work was carried out at the Department of Psychiatry, Mansoura University Hospital, Mansoura city, Egypt. Patients and their caregivers were consulted in outpatient and inpatient clinics of the department from March 2008 to October 2009.

Patients

The study was a cross-sectional study including a randomly selected group of 130 patients with bipolar mood disorder and their 130 caregivers, who were recruited in the order in which they contacted the Psychiatric Department for admission or follow-up. The sample size was calculated using Epi-Info program, version 6 (Centers for Disease Control and Prevention, Atlanta, Georgia, USA). The total number of bipolar patients registered at the outpatient clinic in the year before the study was 2316 patients. The expected percentage of patients with depression in the study by Goldstein *et al.* [12] was 38% and the worst expected result was 50% at 99% confidence level. Hence, the sample size was 104 patients and after adding 10% for correction of errors, it became 115 patients; an additional 15 patients were added to account for those who dropped out, making the sample size 130 patients. Patients of both sexes, with age ranging from 15 to 50 years, were included. Patients were excluded from the study if they had no caregivers and if their mood disorders were due to a general medical condition or were substance induced. Bipolar mood disorders were diagnosed according to the *Diagnostic and Statistical Manual of Mental Disorders*, 4th ed., text revision [19]. Mood disorders were classified as moderate when symptoms or functional impairment was between mild and severe. Mood disorders were classified as severe without psychotic features when several

symptoms were in excess of those required to make the diagnosis and when the symptoms markedly interfered with occupational functioning or with the usual social activities or relationships with others, whereas they were classified as severe with psychotic features when the patients were delusional or had hallucinations. Full remission from bipolar mood disorder was considered when there were no significant signs or symptoms of the condition over the past 2 months [20]. The diagnosis was made only if the patient was interviewed by at least two of the authors.

Caregivers were included if they were family members; spent most of their time with the patient, providing them daily care; administered medication to the patient; were severely distressed because of the patient's illness; and were having strong emotional relations with the patient. They were excluded from the study if they had severe medical illnesses, neurological disorders, or a history of drug abuse; were suicidal or mentally retarded; or refused to participate in the study.

Assessment

In this study, all patients were subjected to the following assessments: (a) psychiatric clinical examination, (b) physical examination to exclude patients with serious medical illnesses, and (c) global assessment of function [21] for evaluation of the clinical condition of the patient.

All the caregivers were subjected to a semistructured clinical interview and medical examination in addition to the following assessment tools: (a) Caregiver Strain Index [22] to measure the burden related to caregiving, (b) Caregiver Self-Assessment Questionnaire [23] (adapted from the American Medical Association Caregiver Self-Assessment tool) to measure the degree of burden, (c) Hamilton Depression Rating Scale (HDRS) [24] for the assessment of the degree and severity of depression, and (d) Hamilton Anxiety Rating Scale (HARS) [25] for the assessment of the degree and severity of anxiety.

The Caregiver Strain Index (CSI) was translated into Arabic by the authors and the translation was further presented to three professors of psychiatry at Mansoura University, Faculty of Medicine. The professors were asked to evaluate the clarity of the items and their suitability for measuring caregiver strain within the Egyptian population. Thereafter, the index was presented to a small sample of patients ($n = 25$). Total correlation of the items in the scale ranged from 0.192 to 0.695 (Chronbach's $\alpha = 0.932$); all were very highly significant. In addition, the scale was translated, validated, checked for cultural compatibility, and doctor rated by researchers in Alazhar University [26].

The Caregiver Self-Assessment Questionnaire (CSAQ) was also translated into Arabic by the authors and the translation was further presented to three professors of psychiatry at Mansoura University, Faculty of Medicine. They were asked to evaluate the clarity of the items and the suitability of the scale within the Egyptian population. Thereafter, it was presented to a small sample of patients ($n = 25$). Total correlation of the items in the scale ranged from 0.110 to 0.763 (Chronbach's $\alpha = 0.926$); all were very highly significant.

HDRS and HARS were used to assess the severity of depressive and anxiety disorders and the symptomatic overlap between them. These are objective tools with established validity and reliability. The Arabic version has been used in many Egyptian studies. HDRS is the most widely used observer rating scale for the assessment of severity of depression [27]. In addition, the concurrent validity of HDRS is higher than that of other observer rating scales [28]. Its inter-rater reliability is also consistently high [29]. HARS was specially developed to rate clinical anxiety in patients already diagnosed with anxiety [25].

Ethical consideration

The Ethics and Research Committee of the hospital approved the study protocol. All the participants had to provide signed informed consent forms after the purpose of the study and the protocol had been explained to them and before any intervention was performed. The process of data collection was noninvasive and was carried out without undue risks to the patient.

Statistical analysis

Data entry and analysis were carried out using SPSS program, version 19.0 (SPSS Inc., Chicago, Illinois, USA), on an IBM computer. The data of the patients and caregivers were statistically analyzed by normal distribution of variables. The data of the caregivers were analyzed using one-way analysis of variance and Pearson's correlation coefficient. All *P*-values are two tailed and the level of significance was chosen at *P* less than 0.05.

Results

On the basis of the *Diagnostic and Statistical Manual of Mental Disorders*, 4th ed., text revision, criteria, bipolar mood disorders were classified into the following subtypes: moderate mood disorders, 30 (23.1%); severe without psychotic features, 36 (27.7%); severe with psychotic features, 31 (23.8%); partial remission, 15 (11.5%); and complete remission, 18 (13.8%). The mean age of the patients was 33.3 ± 4.01 years. Of the patients, 75 (57.7%) were male and 55 (42.3%) were female. Most of them, as well as their caregivers, came from rural areas [78 (60%)], whereas the rest came from urban area [52 (40%)]. A majority of the patients were divorced or single [57 (43.8%) and 32 (24.6%), respectively],

whereas the rest were married or widowed [24 (18.5%) and 17 (13.1%), respectively]. Most of patients were illiterate or primary scholars [40 (30.8%) and 33 (25.4%), respectively], whereas the rest were preparatory scholars, secondary scholars, or university graduates [24 (18.5%), 26 (20%), and seven (5.4%), respectively]. In addition, the majority of patients were housewives, farmers, or workers [41 (31.5%), 38 (29.2%), 35 (26.9%), respectively], whereas the rest were professionals [16 (12.3%)].

In the present study, the mean age of the caregivers was 65 ± 2.3 years. Of them, 61 (46.9%) were male and 69 (53.1%) were female. The majority of caregivers were married [64 (49.2%); 33 (25.4%) of them were divorced. Caregivers came from rural and urban areas [78(60%) and 52 (40%), respectively]. Most of them were either spouse or parents of the patient [64 (49.2%) and 31 (23.9%), respectively], whereas the rest were either offspring, siblings, or friends of the patient [15 (11.5%), 14 (10.8%), and six (4.6%), respectively]. Most of the caregivers were illiterate or primary scholars [41 (31.5%) and 35 (26.9%), respectively], whereas the rest were preparatory scholars, secondary scholars, or university graduates [25 (19.2%), 26 (20%), and 3 (2.3%), respectively]. In addition, the majority of caregivers were housewives, farmers, or retired professionals [42 (32.3%), 33 (25.4%), and 33 (25.4%), respectively], whereas the rest were professionals or workers [13 (10%) and 9 (6.9%), respectively]. Of the caregivers, eight (6.2%) had diabetes mellitus, four (3.1%) had hypertension, four (3.1%) had duodenal ulcer, and two (1.5%) had cholecystitis.

Burden on caregivers of patients with bipolar mood disorders of the severe type with psychotic features was more than that on caregivers of those with bipolar mood disorders of the severe type without psychotic features, moderate type, or in partial remission or complete remission, according to both CSI and CSAQ. The differences are statistically significant ($F = 127.2$ and 147.8 , respectively, $P < 0.001$; Table 1).

Severity of depression and anxiety among caregivers of patients with bipolar mood disorders of the severe type with psychotic features was more than that among caregivers of patients with bipolar mood disorders of the severe type without psychotic features, moderate type, or in partial or complete remission, according to HDRS and HARS. The differences are statistically significant ($F = 955.452$ and 593.961 , respectively, $P < 0.001$; Table 2).

Table 1 Burden on caregivers of patients with different types of bipolar mood disorders assessed using CSI and CSAQ and analyzed by the ANOVA test

	Burden on CSI		ANOVA	Burden on CSAQ		ANOVA
	Mean	SD	<i>F</i>	Mean	SD	<i>F</i>
Bipolar mood disorders						
Moderate	3.7	1.12		5.6	1.22	
Severe without psychotic features	6.8	1.40		9.6	1.34	
Severe with psychotic features	8.3	1.10	127.2***	10.3	1.27	147.8***
Partial remission	3.0	1.46		4.8	1.66	
Complete remission	1.7	0.84		3.0	0.91	
Total	5.3	2.69		7.4	3.03	

ANOVA, analysis of variance; CSAQ, Caregiver Self-Assessment Questionnaire; CSI, Caregiver Strain Index.

***Significant, $P < 0.001$.

Table 2 Severity of depression and anxiety in caregivers of patients with different types of bipolar mood disorders assessed using HDRS and HARS and analyzed by the ANOVA test

Bipolar mood disorders	Depression on HDRS		ANOVA	Anxiety on HARS		ANOVA
	Mean	SD	F	Mean	SD	F
Moderate	16.6	1.22	955.452***	16.8	0.76	593.961***
Severe without psychotic features	22.9	0.81		25.0	1.38	
Severe with psychotic features	29.8	2.15		28.2	2.53	
Partial remission	14.0	0.93		14.8	0.77	
Complete remission	7.2	1.00		8.2	1.52	
Total	19.91	7.56		20.4	7.08	

ANOVA, analysis of variance; HARS, Hamilton Anxiety Rating Scale; HDRS, Hamilton Depression Rating Scale.

***Significant, $P < 0.001$.

Table 3 Correlation between burden on caregivers, assessed using both CSI and CSAQ, and some clinical variables of both caregivers and bipolar patients

Caregiver burden	CSI	CSAQ
Clinical variables		
Age of caregivers	0.360 ^a	0.302 ^a
Severity of depression in caregivers, assessed using HDRS	0.900 ^a	0.889 ^a
Severity of anxiety in caregivers, assessed using HARS	0.906 ^a	0.926 ^a
Age of patients	0.056	0.064
Onset of bipolar disorder	-0.113	-0.120
Duration of bipolar disorder	0.120	0.113
Number of attacks of bipolar disorder	0.118	0.101
Global assessment of function scale in patients	-0.837 ^a	-0.854 ^a
Frequency of hospitalization	0.995 ^a	0.997 ^a
Frequency of electroconvulsive therapy	0.254 ^a	0.245 ^a

CSAQ, Caregiver Self-Assessment Questionnaire; CSI, Caregiver Strain Index; HARS, Hamilton Anxiety Rating Scale; HDRS, Hamilton Depression Rating Scale.

^aCorrelation is significant at the 0.01 level (two tailed).

Table 3 shows a strong negative correlation between the burden on caregivers of patients with bipolar mood disorders, assessed using CSI and CSAQ, and the severity of the clinical condition of the patients, assessed using the global assessment of function scale. Further, a strong positive correlation was observed between burden on caregivers of patients with bipolar mood disorders, assessed using both CSI and CSAQ, and the frequency of hospitalization; age of the caregivers; severity of depression and anxiety of the caregivers, assessed using HDRS and HARS; and the frequency of electroconvulsive therapy.

Discussion

This study was conducted to highlight and assess the extent of psychosocial burden and psychiatric morbidity among caregivers of patients with bipolar mood disorders. This study showed significant burden on caregivers of patients with bipolar mood disorders (CSI: $F = 127.2$, $P < 0.001$ and CSAQ: $F = 147.8$, $P < 0.001$).

Caregivers (relationship with patients, age, and physical competence)

In this study, most of the caregivers were either spouses or parents of the patient, whereas the rest were offspring, siblings, or friends of the patient. The mean age of the caregivers in this study was 65 ± 2.3 years, and some of them showed physical morbidity – that is, 6.2% of caregivers had

diabetes mellitus, 3.1% had hypertension, 3.1% had duodenal ulcer, and 1.5% had cholecystitis. This may make caregiving more difficult for older caregivers because of age-associated impairments in physical competence [30]. In this work, there were positive associations between age and burden on caregivers ($r = 0.360$ and 0.302 , respectively, $P < 0.01$). This finding is in concordance with that of the study by Lawton *et al.* [31], who showed that there was a positive association between age and caregiver burden among Whites but a negative association among African-Americans, suggesting that older African-Americans were less likely to find caregiving physically burdensome.

Caregiver sex

Female caregivers were found to have more problems as regards the quality of the relationship with the patient, whereas male caregivers experienced more constraints on their own autonomy, uncertainty in their judgment of a patient's capacity, and uncertainty because of the changing symptoms of illness. In a study by Reinares *et al.* [32], being female was associated with higher subjective burden; however, this finding was not statistically significant. In addition, 39% of female caregivers, compared with 16% of male caregivers, qualified as being at risk for clinical depression as per the Center for Epidemiologic Studies-Depression Scale [33]. In this study, females (53.1%) were more prevalent than males (46.9%). These results reflected the tendency of women to desire more harmony in relationships or be more affected by the lack of harmony. However, these results showed that male caregivers also suffer, albeit in different aspects of the relationship.

Caregiver occupational status

Rita and his colleagues' [34] study concluded that unemployed caregivers experienced more interference with their own social contacts. In this study, the majority of caregivers were housewives, farmers, or retired professionals (32.3, 25.4, and 25.4%, respectively), whereas 10 and 6.9%, respectively, were professionals and workers. Employed caregivers probably have higher self-esteem and prestige because of their occupations and experience fewer negative reactions in their social settings as a consequence of a member of their family being ill compared with unemployed caregivers.

Degree of patient illness

The interrelation between the burden experienced by the caregivers and the severity of illness is well known. Caregivers of patients with a severe degree of illness reported feelings of uncertainty because of their lack of understanding consequences of the changing in illness symptoms which is very common.

Bipolar disorder imposes a significant burden on a personal, medical, and socioeconomic level [35]. In this study, it was observed that the caregivers of patients with severe types of mood disorders experienced the highest level of burden compared with caregivers of patients with other types of mood disorders. The explanation for the relationship between caregiver burden, evaluated using CSI and CSAQ, and the different types of mood disorders may be that mild and moderate types of mood disorders are associated with minor impairment in occupational functioning, social activities, and relationships with others, thus leading to lesser burden on the caregivers in comparison with that associated with the severe types of mood disorders.

Psychiatric morbidity among caregivers

In this study, the mean age of patients with bipolar mood disorders was 33.3 ± 4.01 years. Among them, 57.5% were males. The majority of them (60%) came from rural areas and were divorced (43.8%) or single (24.6%). Most of them were illiterate (30.8%) or primary scholars (25.4%). The caregivers mainly were housewives (31.5%), farmers (29.2%), or workers (26.9%). All these characteristics of patients with bipolar mood disorders may be considered as factors associated with psychiatric morbidity among caregivers. These results are consistent with those of the study by Okewole *et al.* [36], who estimated the factors associated with psychiatric morbidity in caregiver, for example, the low level of functioning as assessed by the clinician, the high degree of impairment as assessed by the caregiver, the high level of caregiver burden, and the low educational level of the patient. In accordance with the results of the present study, previous studies have shown that a higher percentage of patients were men [37,38]. However, the sex and age of the patient were not significantly associated with psychiatric morbidity in the caregiver.

In addition, in this study, the severity of depressive and anxiety symptoms in caregivers of patients with the severe type of bipolar mood disorders with psychotic features, assessed using HARS and HDRS, was higher than that in caregivers of patients with other types of bipolar mood disorders – for example, severe type without psychotic features, moderate type, and showing partial or complete remission. However, all results showed statistically significant differences ($F = 955.452$ and 593.961 , respectively, $P < 0.001$). These results are in concordance with those of a previous study by Levin [39], who found that many caregivers reported high levels of anxiety, sleeplessness, depression, and exhaustion. Cuijpers [40] stated that about one-third of caregivers suffered from clinical depression. Beavers and Hampson [41], in their study, found that a large number of caregivers of patients with mood disorder had rates of depressive symptoms as

high as 38–60%; these family members often went untreated. Cayton *et al.* [42] found that caregivers most frequently reported stress or depression as characteristic of their life: tiredness, 66%; depression, 40%; stress, 70%; and loneliness, 36%. The frequency with which behavioral disturbances manifest in the patient has been identified as the strongest predictor of caregiver distress and plays a significant role in the caregiver's decision to institutionalize the patient [43]. The literature has consistently demonstrated that the frequency of behavioral problems is a more reliable predictor of caregiver burden and depression compared with functional and cognitive impairments of the individual. Carers face unfamiliar and unpredictable situations, which increases stress and anxiety. Anxiety may be increased if the behavioral problem of the patient cannot be consistently managed. Anxiety is associated with depression, stress, and physical ill health [44].

A larger number of psychiatric hospitalizations, a high score on the Brief Psychiatric Rating Scale, and being hospitalized at baseline are associated with increased levels of caregiver burden [45,46]. These caregivers more often reported anger in situations of conflict and uncertainty concerning judgment of the patient's capacity (mad or bad) [47]. The results of all these studies are in line with our results (Table 3); that is, there was a strong negative correlation between burden on caregivers, assessed using both CSI and CSAQ, and the severity of the clinical condition of the patients, assessed using the global assessment of function scale. Further, a strong positive correlation was observed between burden on caregivers and frequency of hospitalization, age of caregivers, severity of depression and anxiety of caregivers, and frequency of electroconvulsive therapy.

Limitations

This study depends to some extent on the subjective response of the patients and caregivers, which may be liable to errors. Although we aimed to include all relevant sociodemographic and clinical characteristics of patients and their caregivers, some variables that influence the type and/or severity of burden may have been missed (e.g. socioeconomic status, religion, personality of caregivers).

Patients and caregivers may misinterpret terms and symptoms because of their lower education level, which should be explained in a popular language. The result is limited by the unavailability of some standardized questionnaires to describe the coping mechanisms of the caregivers. Sometimes, one session was not enough to complete the interview; hence, the interview was completed in more than one session, which made the patients and caregivers uncooperative. The burden of the caregiver may be the change in the patient's behavior according to the phase he/she is in: acute episode or remission. Further longitudinal studies are required to assess this variable.

As the results of this study are based on an Egyptian sample of caregivers of patients with bipolar mood

disorders, the social network and support system, which depend on the cultural conditions, have to be taken into account before generalizing these findings. Therefore, further studies and between-country comparisons of the situation of caregivers of patients with bipolar mood disorders and their individual needs are necessary.

Conclusion and recommendations

Bipolar mood disorders carry enormous medical, financial, educational, and social burden for the affected individuals and their caregivers. There are many factors affecting the degree of burden experienced by the caregivers, as well as the occurrence of psychiatric morbidity among caregivers.

These factors interact and are related to each other in a complex manner; hence, it is difficult to predict whether there is a single factor that is responsible for the burden experienced by the caregivers and for the occurrence of various psychiatric disorders among the caregivers. Therefore, these factors could be classified as caregiver factors and patient factors. Caregiver factors include age and sex of the caregiver; relationship between the caregiver and the patient; and educational, economic, and financial status of the caregiver. All of the above factors play an important role in the determination of burden experienced by the caregivers, as well as the extent of psychosocial burden and psychiatric morbidity among the caregivers of patients with bipolar mood disorders. The patient factors include age, sex, marital status, education, and occupation of the patient; severity of the clinical condition; score on the global assessment of function scale; frequency of hospitalization, and frequency of electroconvulsive therapy. All the above factors play an important role in the determination of burden experienced by the caregivers.

Therefore, it is recommended that more services for the caregivers of patients with bipolar mood disorders be introduced. It is better to introduce psychoeducational programs, as well as effective and early interventions, to assess and manage the burden experienced by the caregivers of patients with bipolar mood disorders in order to save time and expenditure of money.

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Conflicts of interest

There are no conflicts of interest.

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