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Original Article

Perceived care burden and related factors in primary caregivers of patients with bipolar disorder

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Abstract

Objectives: This study was carried out using a descriptive design to determine the perceived care burden of primary caregivers of bipolar patients and the related factors.

Methods: The sample of the study included caregivers of patients with bipolar disorder in the outpatient clinics and inpatient clinics of a university hospital in Istanbul. Data were collected between March and September 2018 using a personal information form and the Caregiver Burden Inventory. Mann Whitney U test, independent sample t test, Kruskal Wallis H test, one-way ANOVA, LSD, and Dunn's tests, and Spearman and Pearson correlation analyses were used to analyze the data.

Results: Analysis of the data indicated that 60.4% of the caregivers were women and that the mean age of the caregivers was 38.36±11.69 years. The caregivers' mean score on the Caregivers' Burden Inventory was 41.99±19.9, with the highest mean score on the subscales being 12.35±5.25 on the Developmental Burden subscale. Caregivers who resided in the same home as the patient, were children of the patient, voluntarily provided care, experienced frequent difficulties in performing their role, evaluated their spiritual life as weak, had a patient often needed help from someone else in self-care and treatment, were subjected to violence by their patients, and had a patient with a high frequency of symptoms associated with bipolar disorder or comorbidities had statistically significantly higher total scores on the Caregivers' Burden Inventory and on the Inventory's sub-scales than those of others ($p<0.05$). A statistically significant correlation was found between the number of days per week the caregivers provided care and the Time Dependence Burden subscale ($p<0.001$).

Conclusion: Caregivers of the patients with bipolar disorder had a nearly moderate level of burden. It is recommended that additional comparative studies involving larger samples of caregivers from different socioeconomic backgrounds be conducted on the subject of care burden.

Keywords: Bipolar disorder; care burden; caregivers; psychiatric nursing.

Bipolar disorder is a mood disorder whose symptoms generally manifest in early ages and become chronic, leading to deterioration in professional and social functions, and it has high rates of mortality and morbidity.[1,2] Bipolar disorder affects 1–3.7% of the general population, and to date, it has been estimated to be the sixth leading psychiatric disorder in the world.[1,3] It has been reported that bipolar disorder and unipolar disorder together, when compared to ischemic heart disease and cerebrovascular diseases, result in a lower quality of life and greater loss of productivity.[4] Bipolar disorder can negatively affect an individual's life in a variety of ways, such as disrupting their work-life and thus creating economic problems, compromising their ability to get married, upsetting familial and social relationships, and leading to drug abuse and even suicide.[5–7]

Both bipolar patients and their families are faced with significant lifetime changes and consequences as a result of the dis-

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What is known on this subject?

- Caregivers of individuals with bipolar disorder tend to experience a variety of burdens.

What is the contribution of this paper?

- This study found that caregivers of individuals with bipolar disorder experience nearly moderate level of burden, and that care burden is affected by clinical characteristics and characteristics related to care and not by caregivers' sociodemographic characteristics.

What is its contribution to the practice?

- This study will generate greater awareness about the factors affecting care burden and thereby contribute to understanding the needs of caregivers and provide psychiatric nurses and other health professional the necessary information to develop family education programs and counseling services aimed at decreasing care burdens and to use in planning and providing care.

order.[8] Despite changes in societal response or the healthcare system, families still have the most significant role in providing care to patients with bipolar disorder.[9–12] The various roles that caregivers of patients with bipolar disorder must assume, including providing treatment support, undertaking tasks unable to be performed by the patient, managing the patient's emotional fluctuations associated with the symptoms of mania and depression, and coping with the risk of suicide, can cause great distress to caregivers.[11,13–15]

The causes of the caregiver burden in bipolar cases include the chronic nature of the disorder, the loss of functionalities in many aspects of the patient's life, and the changes and difficulties the disorder creates for the caregiver's family, work, economic and social life.[7,13,16–18] Platt defines caregiver burden as the challenges, adversity, and complications that occur in the lives of patient relatives due to the increased responsibilities and duties related to caregiving.[4,8]

Perlick et al. (2016)[13] conducted a study with a large sample and found that 89% of the caregivers of bipolar patients experience caregiver burden, while van der Voort et al. (2007),[7] in their systematic review, reported that caregivers frequently experience burdens. A study conducted by Erten et al. (2014)[19] in Turkey found that nearly half of the caregivers (44.9%) experience moderate to severe care burdens.

Previous studies on the burden experienced by caregivers of patients with bipolar disorder found that they experience burdens related to problematic behaviors exhibited by the patient, such as violence,[20–23] hyperactivity, unpredictable actions,[5,21,22] excessive spending,[20] depression and sadness, withdrawal, and addictions,[20] as well as various other burdens, like distress in performing their roles, disruption of order and process within the house,[9] discontinuation of leisure activities, disruption of career, tension in family relationships,[21,23,24] decrease in social support,[14,22,25] stigmatization and social isolation,[6,7,10] decrease in family income/ economic problems,[6,21,22] negative effects on psychological and physical health,[6,20,26,27] and subjective distress and burnout; in cases where the caregiver is the spouse, the burdens are related to family planning, sexual relationship problems and apprehensions about having children.[7,9,10,20–22] Berk et al. (2013)[11] found that 89–91.9% of caregivers experience burdens related to symptoms of the disorder, 61–82% experience burdens related to the disorder's negative impacts on work, social life and leisure activities, and 52–65% experience burdens related to the disruptions in the role functions of the patient. Moreover, the cyclical nature of the disorder, having a recurring course of episodic symptom presentation to recovery and vice versa, can add to the caregiver burden.[4]

Study results on this subject have also indicated that the burdens assumed by caregivers negatively affect their quality of life and state of health.[12,16,17] Caregivers experiencing a high level of burden can suffer psychological problems, physical health issues, sleep issues, depression and anxiety, disruptions to their social relationships, and economic difficulties, and they tend to request health services more than others.[4,9,15,20] Previous studies indicated a positive relationship between anxiety depression levels and caregiver burden[26,27] and between care burden and depression, which suggest that the psychological effects of the caregiver burden may negatively affect the recovery of the patient by rendering the environment of the patient stressful and by diminishing the amount and quality of support provided.[4,13]

Throughout the world, including Turkey, research on care burden has tended to focus more attention on the burdens assumed by caregivers of patients with various physical disorders (patients with cancer, stroke patients, elderly patients, etc.) and psychiatric disorders except for bipolar disorder (schizophrenia, dementia, mental disability, etc.) than on the care burden of caregivers of individuals with bipolar disorder.[18,19,26] With the early onset of bipolar disorder, its episodic course and chronic nature, bipolar disorder can create a different care burden compared to other disorders in terms of its level and duration.[4] Furthermore, given that evidence has shown the caregiver burden to be closely related to clinical and social outcomes, it is important to assess the needs and difficulties of caregivers before planning the necessary interventions.[4,15] One of the roles of psychiatric nurses is to identify the needs of the patient's family as well as the patient and to support them by providing training and counseling.[17,28] It is stated that nurses can support families with burden by providing care, health promotion training and guidance.[10]

Given the limited research conducted on this subject in Turkey, this study was conducted to determine the perceived care burden of caregivers of patients with bipolar disorder and the affecting factors. The following research questions were developed to guide the study.

1. What is the level of care burden of the primary caregivers of patients with bipolar disorder?
2. What are the sociodemographic and clinical characteristics affecting the care burden of the primary caregivers of patients with bipolar disorder?

Materials and Method

Study Type

This study was performed using a cross-sectional, descriptive design.

Study Population and Sample

The study population included caregivers of patients with bipolar disorder receiving care in the outpatient and inpatient clinics of the Department of Psychiatry at a university hospital in Istanbul. The population and sample were determined based on the total of 15,935 patients who presented to the psychiatric polyclinics over the course of a year. Given that the incidence of the disorder is 1%, it was calculated that 160 patients with bipolar disorder presented to the psychiatric polyclinics in a year. Accepting these 160 patients as the population, it was determined, based on 95% confidence interval and 0.05 margin of error, that the study needed to include at least 113 patients. Since the data collection process was six months, the goal was to reach a minimum of 57 patient relatives, which translates as roughly half the annual 113 bipolar patients who present to the psychiatric clinics.

The study sample included the caregivers of 75 patients with bipolar disorder who applied to the Mood Outpatient Clinic on Wednesdays and Thursdays between March and September 2018, were hospitalized in the inpatient services during these dates, and met the inclusion criteria. No sampling method was applied in the study given that the goal was to reach all patients within the time period allotted for data collection. Among the participants, three were not primary caregivers of the patient, seven failed to fully complete the scale, and twelve did not wish to participate in the study. Therefore, the study was performed with 53 caregivers (70.66%) who voluntarily agreed to participate in the study. The study inclusion criteria were that the participants must be 18 years old or above, Turkish speaking (both patients and caregivers) and the primary caregiver of the patient. Professional or formal caregivers, non-primary caregivers, and non-Turkish speakers were excluded from the study. Only one relative of each patient was included in the study.

Data Collection Tools

Study data were collected using a personal information form and the Caregiver Burden Inventory (CBI).

Personal Information Form: This form was prepared by the researchers based on a literature review to collect data on the caregivers' sociodemographic characteristics, characteristics related to caregiving, and patients' sociodemographic and clinical characteristics.[4,5,7,8,13,14]

Caregiver Burden Inventory: Novak and Guest (1989) developed this scale to determine the burdens of caregivers of patients with cognitive disorders. The Turkish validity and reliability study of this scale was conducted by Küçükgüçlü (2004).[29] The Likert scale inventory includes 24 items and five subscales (Time-Dependence Burden (TDB), Developmental Burden (DB), Physical Burden (PB), Social Burden (SB), and Emotional Burden (EB)). Küçükgüçlü et al. (2004) found the Cronbach's alpha value to be 0.94 for the whole scale and 0.82–0.94 for the subscales in their reliability study of the inventory. Response options of the scale range from "not at all descriptive" to "very descriptive". Each subscale is scored a minimum of 0 points and a maximum of 20 points.[29] The total burden score ranges from 0 to 100. A higher score indicates a higher level of care burden. This study found the total Cronbach's alpha value for the whole scale to be 0.92 and 0.87 for TDB, 0.85 for DB, 0.85 for PB, 0.70 for SB, and 0.84 for EB, values of which indicated the scale to be highly reliable.

Data Collection: Informed consent forms were obtained from the participants after providing them with information about the study. The study data were then collected through surveys administered in a hospital room suitable for conducting interviews. It took an average of 30 minutes for the participants to complete the questionnaires. In cases where the participants were not able to understand a part of the questionnaire, they were provided explanations, without being encouraged to answer in a certain way.

Ethical Considerations

The ethical approval of this study was obtained from the Istanbul University- Cerrahpaşa Clinic Studies Ethics Committee (Approval number 65852, dated 16.02.2017). Additionally, after informing the relevant authorities of the institution where the study was conducted about the study, permission to conduct it was obtained from them. Participants were given information regarding the study and their oral and written permissions were obtained in accordance with the principles of the "Helsinki Declaration". Permission to use the Caregiver Burden Inventory was obtained from Dr. Özlem Küçükgüçlü through email.

Data Analysis

Statistical analysis of the data was conducted with the SPSS 21 (Statistical Package for the Social Science) software program (Istanbul University Information Technology Department Software License Server http://bilgiislem.istanbul.edu.tr/?p=6787). The Kolmogorov-Smirnov test was used for examination of normal distribution of data; descriptive statistics were used to determine number and percentage distribution of the data; independent sample t-test and one- way ANOVA were applied for normally distributed variables, while Mann Whitney U test was applied for the variables not normally distributed in two-group comparisons; and the Kruskal Wallis H test was applied for the comparison of more than two groups. For post-hoc tests, LSD and Dunn's test were used, and Spearman and Pearson correlation analyses were performed to identify the relationship between variables. Cronbach's alpha reliability coefficient was calculated as part of the reliability analysis of the Caregiver Burden Inventory. Statistical significance was set at $p<0.05$.

Results

The Caregivers' Sociodemographic Characteristics and Caregiving Characteristics

The caregivers' mean age was found to be 38.36±11.69 years, and 60.4% were female and married, 30.2% were the patient's

Table 1. Caregiver Burden Inventory and Subscale Scores (n=53)

Caregiver Burden Inventory	Mean+SD	Min.-Max.
Time dependence burden	8.96±5.14	0.00–20.00
Developmental burden	12.35±5.25	1.00–20.00
Physical burden	9.48±6.01	0.00–20.00
Social burden	6.47±4.79	0.00–20.00
Emotional burden	4.71±4.39	0.00–20.00
CBI Total Scale	41.99±19.90	6.25–92.00

SD: Standard deviation; Min.: Minimum; Max: Maximum.

spouse, and 73.6% lived in the same house as the patient for whom they were providing care. Furthermore, 47.2% of the caregivers had university undergraduate or higher degrees, 52.8% worked full/part-time, 47.2% had income equal to their expenditures, and 83% had a physical disorder.

In terms of the characteristics related to caregiving, it was found that 83% of the caregivers voluntarily provided care, 47.2% were evaluated their spiritual status as moderate, 52.8% usually had difficulty performing their roles, 69.8% received support during the caregiving process, and 43.4% participated in family education programs on the disorder. The mean durations of the caregivers' provision of care in terms of days, weeks and years were found to be 6.45±5.42 hours a day, 5.75±2.05 days a week, and 5.77±6.89 years, respectively.

Demographic and Clinical Characteristics of the Patients with Bipolar Disorder

The mean age of the patients receiving care was found to be 41.53±14.20 years, and the amount of time since their bipolar diagnosis was found to be 7.68±9.10 years. Based on the information provided by the caregivers, 45.3% of the patients had a comorbid disorder that was psychological or physical, 47.2% frequently showed disorder symptoms, 67.9 % often needed the help of another person, 47.2 % did not regularly use their medications, and 83% rarely used violence (physical, emotional, economic, sexual).

Caregivers' Care Burden and Affecting Factors

Table 1 presents the participating caregivers' mean total Caregiver Burden Inventory score and their mean subscale scores. The mean total Caregiver Burden Inventory score was found to be 41.99±19.90.

Impact of Caregivers' Demographic Characteristics and Caregiving Characteristics On Their Care Burden

In evaluating care burden based on demographic characteristics, no statistically significant difference was found between the caregivers' sex, marital status, level of education, work status, income status, having a physical disorder, and care burden (p>0.05).

Table 2 presents the distribution of the mean total Caregiver Burden Inventory score and subscale scores based on the caregivers' characteristics related to caregiving. Accordingly, no significant difference was found between the caregivers' status of receiving support from another person when providing care, receiving family education on the disorder and its treatment and the burden of the caregivers (p>0.05). Caregivers who were children of the patient (p=0.006), who were living in the same house with the patient (p=0.000), or who were voluntarily providing care (p=0.034) had a higher mean TDB score, with the difference between them being statistically significant. The care burden was determined to be higher in the caregivers who usually experienced difficulties performing their roles (mean scores: TDB (p=0.031), DB (p=0.017), PB (p=0.000), SB (p=0.004), EB (p=0.021) and CBI total (p=0.001)), compared to that of those rarely having difficulty in performing their roles. Furthermore, the care burden was found to be higher in the caregivers who evaluated their spiritual-religious practices as being weak (mean scores: TDB (p=0.000), DB (p=0.013), PB (p=0.025) and CBI total (p=0.002)), compared to that of those who evaluated their spiritual-religious practices as being strong, with the difference between them being statistically significant.

Impact of Clinical Characteristics of The Patients With Bipolar Disorder On Care Burden

When the care burden scores were evaluated according to the clinical characteristics of the individuals receiving care (Table 3), the caregivers who had a patient often needed the help from someone else had higher mean TDB (p=0.000), DB (p=0.001), PB (p=0.013), and CBI total (p=0.009) scores compared to those of the caregivers who needed help rarely, with the difference between being found to be statistically significant. The caregivers of the patients with comorbid diseases had statistically significantly higher mean DB (p=0.009), PB (p=0.028), and CBI total (p=0,015) scores compared to those of the caregivers of patients with no comorbid diseases. The caregivers whose patients showed frequent symptoms of the disorder had statistically significantly higher mean TDB (p=0.001), DB (p=0.000), PB (p=0.006), and CBI total (p=0,000) scores compared to those of the caregivers of patients who rarely showed symptoms. The caregivers of patients who were usually violent towards them had statistically significantly higher mean TDB (p=0.024), PB (p=0.034), SB (p=0.003), and CBI total (p=0.012) scores compared to those of the caregivers of the patients who were rarely violent towards them. No significant difference was found between the patients' regular use of their medications and CBI (p>0.05).

No correlation was found between the caregiver's age, the duration in years that they provided care, the average daily hours devoted to the care of the patient, the age of the patient with bipolar disorder, the time of diagnosis and total CBI and subscale scores. However, there was a statistically significantly high and positive correlation between the number of days per week

Table 2. Comparison of characteristics related to caregiving and mean CBI Scores (n=53)

Characteristics	Burden	TDB	DB	PB	SB	EB	CBI Total
Relationship	Parents	9.14±4.45	11.57±5.99	9.28±7.02	6.00±7.23	4.85±6.38	40.85±25.43
	Spouse	9.68±4.11	12.00±4.69	9.14±5.85	6.75±4.89	4.37±2.72	41.95±16.88
	Sibling	6.40±4.99	11.20±5.24	7.50±5.65	5.00±4.42	3.60±3.74	33.70±18.24
	Son/Daughter	12.30±4.60	13.92±4.42	10.67±5.39	7.07±4.09	4.07±2.95	48.05±17.98
	Other	4.57±5.31	12.71±7.67	11.07±7.71	7.28±4.27	8.14±7.24	43.78±26.99
	Test	F=4.169	F=0.456	F=0.516	KW=2.650	KW=4.379	F=0.740
		p=0.006	p=0.767	p=0.725	p=0.618	p=0.357	p=0.569
Living in the same house	Yes	10.53±4.57	12.66±4.83	9.61±5.86	6.51±5.09	4.28±3.94	43.61±19.81
	No	4.57±4.05	11.50±6.40	9.10±6.64	6.35±3.99	5.92±5.44	37.46±20.18
	Test	t=-4.306	t=0.710	t=0.269	Z=-0.334	Z=-0.993	t=0.992
		p=0.000	p=0.481	p=0.789	p=0.738	p=0.321	p=0.326
Voluntarily providing care	Yes	9.63±5.01	12.43±5.09	9.68±6.14	6.27±4.96	4.47±3.96	42.50±20.51
	No	5.66±4.71	12.00±6.30	8.47±5.54	7.44±3.94	5.88±6.27	39.47±17.47
	Test	t=2.185	t=0.223	t=0.548	Z=-1.082	Z=-0.469	t=0.413
		p=0.034	p=0.825	p=0.586	p=0.286	p=0.650	p=0.681
Physical disorder	Yes	9.00±3.9	11.77±2.77	9.44±4.80	5.33±4.06	3.77±3.38	39.33±10.31
	No	8.95±5.40	12.47±5.64	9.48±6.28	6.70±4.93	4.90±4.58	42.53±21.39
	Test	t=-0.157	t=-0.557	t=-0.151	Z=-0.690	Z=-0.601	t=-0.679
		p=0.981	p=0.583	p=0.984	p=0.506	p=0.568	p=0.503
Having difficulty in roles	Usually	10.39±5.37	13.96±4.54	12.14±5.99	8.25±4.90	5.64±4.82	50.39±18.68
	Rarely	7.36±4.45	10.56±5.49	6.50±4.52	4.48±3.85	3.68±3.68	32.58±17.06
	Test	t=2.222	t=2.468	t=3.891	Z=-2.898	Z=-2.305	t=3.609
		p=0.031	p=0.017	p=0.000	p=0.004	p=0.021	p=0.001
Evaluation of spiritual status	Weak	14.60±4.06	16.30±3.49	13.50±6.89	9.40±7.02	5.10±4.77	58.90±2.68
	Moderate	8.96±4.45	12.24±5.35	9.55±4.78	6.72±3.90	4.92±4.13	42.39±16.12
	Strong	5.83±3.88	10.33±4.88	7.15±6.16	4.50±3.65	4.22±4.74	32.04±17.30
	Test	F=14.006	F=4.763	F=3.992	KW=4.803	KW=1.045	F=7.276
		p=0.000	p=0.013	p=0.025	p=0.091	p=0.593	p=0.002
Received family education	Yes	10.21±4.18	12.69±5.12	10.05±5.51	6.86±3.63	4.00±2.74	43.83±15.08
	No	8.00±5.65	12.10±5.41	9.04±6.43	6.16±5.55	5.26±5.31	40.57±23.08
	Test	t=1.577	t=0.406	t=0.604	Z=-1.117	Z=-0.027	t=0.588
		p=0.121	p=0.686	p=0.504	p=0.264	p=0.978	p=0.559
Received support in care	Yes	8.70±4.91	12.78±4.42	9.25±5.47	5.78±3.96	4.40±3.58	40.93±16.65
	No	9.56±5.76	11.37±6.85	10.00±7.28	8.06±6.15	5.43±5.94	44.43±26.43
	Test	t=-0.555	t=0.756	t=-0.410	Z=-1.079	Z=-0.344	t=-0.490
		p=0.581	p=0.458	p=0.684	p=0.280	p=0.731	p=0.629

t: Independent Sample t-test; MWU (Z): Mann-Whitney U Test; F: One-Way ANOVA; KW: Kruskal Wallis H Test. TDB: Time-Dependence Burden; DB: Developmental Burden; PB: Physical Burden; SB: Social Burden; EB: Emotional Burden; CBI: Caregiver Burden Inventory.

that care was provided to the patient with bipolar disorder and the time-dependence burden subscale (r:0.426; p<0.001).

Discussion

This study found that the primary caregivers of patients with bipolar disorder had nearly moderate level of care burden. Consistent with this study, Reinares et al. (2006)[5] reported that the burden of caregivers of patients with bipolar disorder was moderate. Perlick et al.,[9] and in Turkey, Erten et al.[19] (2014) found that nearly half of the caregivers had a moderate or severe level of burden. Other studies on this subject have reported the levels of care burden to be high.[5,7,20] Studies measuring subjective burden in caregivers of patients with bipolar disorder have reported burden rates of between 31% and 70%.[8,20] In the literature review, there was no study found evaluating the care burden of caregivers of patients with bipolar disorder using the Caregiver Burden Inventory. The use of different measurement tools and the inclusion of sample groups with different characteristics and sizes could explain the different levels of care

Table 3. Comparison of clinical characteristics related to patient and mean care Burden Inventory Scores (n=53)

Characteristics	Burden	TDB	DB	PB	SB	EB	CBI Total
Need help from another person	Frequently	10.61±4.61	13.94±4.10	10.86±5.38	6.88±4.39	4.52±3.62	46.84±16.26
	Rarely	5.47±4.51	9.00±5.92	6.54±6.38	5.58±5.56	5.11±5.80	31.72±23.32
	Test	t=-3.812	t=3.535	t=-2.570	Z=-1.282	Z=-0.561	t=2.738
		p=0.000	p=0.001	p=0.013	p=0.200	p=0.575	p=0.009
Comorbid disease	Yes	10.29±5.40	14.33±4.80	11.45±6.24	7.50±5.77	5.58±5.26	49.16±21.50
	No	7.86±4.72	10.72±5.11	7.84±5.39	5.62±3.68	4.00±3.45	36.05±16.59
	Test	t=1.745	t=2.628	t=2.261	Z=-0.996	Z=-0.961	t=2.506
		p=0.087	p=0.011	p=0.028	p=0.319	p=0.337	p=0.015
BFrequency of symptoms	Frequent	11.64±4.90	15.24±3.81	12.00±5.85	8.08±5.00	5.44±4.45	52.40±18.68
	Sometimes	7.11±3.47	10.64±4.19	8.30±5.53	4.88±3.95	4.58±4.79	35.54±13.65
	Rarely	5.72±5.02	8.45±6.15	5.56±4.68	5.27±4.67	3.27±3.52	28.29±19.38
	Test	F=8.602	F=10.529	F=5.717	KW=5.163	KW=3.028	F=9.055
		p=0.001	p=0.000	p=0.006	p=0.076	p=0.220	p=0.000
Using violence	Usually	12.44±5.83	14.55±4.18	13.33±5.37	10.77±4.49	5.77±3.49	56.88±17.63
	Rarely	8.25±4.75	11.90±5.37	8.69±5.88	5.59±4.39	4.50±4.56	38.94±19.11
	Test	t=2.321	t=1.390	t=2.138	Z=-2.925	Z=-1.610	t=2.597
		p=0.024	p=0.171	p=0.034	p=0.003	p=0.116	p=0.012
Taking medications regularly	Yes	9.33±5.73	11.66±5.05	9.16±5.55	6.83±5.17	3.55±2.81	40.55±19.61
	Not always	8.12±4.79	11.88±5.57	9.15±6.39	5.68±4.25	4.80±4.34	39.63±18.89
	No	10.40±4.97	14.80±4.46	10.87±6.26	7.80±5.45	6.60±6.29	50.47±22.60
	Test	F=0.766	F=1.359	F=0.322	KW=1.040	KW=0.969	F=1.137
		p=0.470	p=0.266	p=0.726	p=0.594	p=0.616	p=0.329

t: Independent Sample t-test; MWU (Z): Mann-Whitney U Test; F: One-Way ANOVA; KW: Kruskal Wallis H Test. TDB: Time-Dependence Burden; DB: Developmental Burden; PB: Physical Burden; SB: Social Burden; EB: Emotional Burden; CBI: Caregiver Burden Inventory.

burdens reported. Moreover, since care is a multidimensional concept, it can be directly affected by individual characteristics and the individual's culture. In the literature, it is stated that the lower the education level of the caregiver, the higher the care burden.[24] The high education of most of the caregivers participating in this study likely contributed to the perceived burden of care being at nearly moderate level. Having social support has also been reported to be a significant factor in reducing the burden of the caregiver.[25] More than half of the participating caregivers in the present study indicated that they received support during caregiving. This finding could be attributed to the supportive nature of the Turkish family structure. It was further indicated that developmental and physical burdens were experienced the most by the caregivers, while emotional burdens were experienced the least. The caregivers had the highest score on the subscale of developmental burden on account of their inability to make plans for their own lives or to realize their expectations in life due to their caregiving responsibilities, issues that made their living conditions distinctly different from their peers. They had the lowest score on the emotional burden subscale, which indicated that they continued to have positive feeling for their patients despite all difficulties.

Conflicting results have been reported in studies examining the relationship between sociodemographic characteristics and care burden. Gania et al. (2019)[24] found that the care burden increases when the caregiver is a woman, older, employed in a low-income job, and has a lower level of education. Similarly, Reinares et al. (2006)[5] and Arciszewska et al. (2015)[30] indicated that there is a correlation between female gender and more care burden. Contrary to the findings in the literature, this study found no significant relationship between the caregivers' sociodemographic characteristics and care burden. This could be due to the small sample size. Previous studies have indicated that spouses/partners of the patients with bipolar disorder have more burden.[14,20,27] In this study, it was found that caregivers who were the children of the patients had a greater time-dependence burden. This could be attributed to the despair, fear, and stress resulting from the new responsibilities attending the change in the parent and child roles because of the disorder, as well as to the inability of the children responsible for the caretaking of their parent to devote time for their other responsibilities or for their own well-being on account of the inordinate amount of time they must spend caring for their parents. Similarly, those who were living in the same house as the patient and those who were voluntarily providing care to the patient had a greater time-dependence burden. When the caregiver shares the same house with the patient, the patient becomes their focal point, and the time the caregiver has for jobs outside of their care duties is greatly diminished, causing the caregiver to feel restricted. This finding is in parallel with the study results reported in the literature.[9,31] The Time Dependence burden experienced by the caregivers who were voluntarily providing care to their patients can be attributed to the same reasons stated for the caregivers who were living in the same house as their patient.

The literature on care burden indicates that spirituality is a valuable resource in coping with disorder and disability, and that the spiritual practices associated with one's belief systems serve to increase the well-being and quality of life of both the caregivers and their patients.[32,33] This study found that those who evaluated their spiritual-religious beliefs and practices as being weak had more Time Dependence, development, physical and total burden. This finding was consistent with the literature in showing that spiritual practices strengthen the coping abilities of caregivers and decrease their burdens.[32,33] Considering these findings, it is important that in helping caregivers to cope, psychiatric nurses should manage them holistically, evaluate their spiritual status, and support them.[34]

This study found that the caregivers who had difficulties performing their roles usually experienced a burden as well as the burdens related to each subscale. Some of the studies in the literature were found to be in agreement with these findings.[5,20] Caregiving is a role that requires major responsibility and determination. Included among the roles caregivers perform are helping with the self-care of the patient, supporting them in terms of finance and treatment, and undertaking the responsibilities the patients cannot perform.[9,13,21] When these roles are combined with the other roles in life (such as motherhood, fatherhood, professional roles, marriage roles, etc.), it becomes harder for the caregiver to perform the roles expected from them. Bauer et al. (2011)[14] and Dore and Romans (2001)[20] found that caregivers with children had difficulty performing the parent role while providing care to the patient. Magliano et al. (2009)[25] stated that half of the patients had problems in performing their parenting roles. Considering that most of the caregivers in this study were spouses, it is likely that they had to fulfill multiple roles and therefore their perceived care burden was higher. The studies by Siddiqui and Khalid (2019)[35] and Nallapaneni et al. (2015)[36] indicated the same in showing that married caregivers perceived more burden.

The literature indicates that psychoeducation reduces the care burden.[3,37] However, in this study, no difference was found between caregivers' family education status and care burden, a finding that could be related to the fact that the participating caregivers received family education from different people, in different contexts and with different methods or that most of them had not received family education. Furthermore, there was no difference found between the perceived burden of caregivers in terms of the caregivers having a physical disorder and receiving support, likely because the participating caregivers were young, only a few had health issues, most of the participants received support and the study was conducted with a small sample. In one study, it was reported that the care burden decreased as social support increased.[24]

A positive significant relationship was found between the number of days in a week that the caregiver provided care to the patient and the Time Dependence burden. Studies in the literature on this subject,[24,37] including one by Blanthorn-Hazell et al. (2018),[38] stated that the amount of time (hours) devoted to the care affects the caregivers' burden.

This study found that care burden was affected by the patient's clinical characteristics, the patient's frequent occurrence of symptoms, the need for the help of others in providing care, the presence of comorbid diseases in the patient, and the frequent use of violence by the patient. The caregivers who frequently needed the help of others in areas such as self-care, disorder process, and maintaining treatment, had more Time Dependence, developmental, and physical burdens. This finding, which is consistent with the literature on this subject, suggests that caregivers who needed help in performing their roles had difficulty allocating time for themselves and achieving life goals and had physical problems.[9,16,21,39]

The caregivers of patients with a comorbid disease had more development and physical burdens. As with other psychiatric disorders, comorbid physical or mental disorders are common in bipolar disorder.[40] This may increase the patient's dependence on the caregiver and cause the caregiver to engage in more physical activity to meet the needs of the patient, and hence increase the physical burden they experience. Moreover, this may cause the caregiver to feel a development burden, insofar as it restricts the amount of time the caregiver has to achieve their life goals. There were no study findings in the literature on the impact of comorbidities on care burden in bipolar patients.

This study found that the caregivers of patients with frequent disorder symptoms had more time-dependence, developmental, and physical burdens. When symptoms are frequently seen, the time that a caregiver devotes to managing the patient's problematic behaviors increases. This situation can result in the caregivers' missing out on many developments in their own life and physical fatigue. Patients with bipolar disorder may experience residual symptoms during the acute stage and afterward. Studies from the literature indicate that even in patients with a good prognosis and in remission, there are residual symptoms between episodes.[7,16] Berk et al. (2013)[11] stated that 89–91.9% of the caregivers' experience of burdens were associated with the disorder symptoms, and Pompili et al.[16] and van der Voort et al. (2007)[7] found in their systematic reviews that the presence of manic or depressive symptoms or symptoms between episodes was related to care burden. Magliano et al. (2009)[25] reported that as the symptoms and disability intensified, the perceived burden of caregivers increased.

The caregivers who were exposed to violence by the patients to whom they provided care had more Time Dependence, physical, and social burdens. Exacerbations during the course of the disorder may cause patients to have certain behavioral problems, like violence. Dore and Romans (2001)[20] indicated in their study that nearly half of the caregivers of patients with bipolar disorder reported being exposed to violence or feared that they would be exposed to violence, while one-fourth reported actually experiencing violence. These behaviors exhibited by the patients can cause caregivers to feel hopeless, angry, embarrassed, and stigmatized, potentially leading to their isolation from society and social burden. Blanthorn-Hazell et al. (2018)[38] found that caregivers of bipolar and schizophrenia patients who had agitation symptoms experienced a greater sense of burden and that this burden had a more dramatic effect on their lives. Ayyıldız and Gümüş (2019)[39] reported that caregivers of patients who inflicted violence on others had more burden, and Zhou et al. (2016)[41] found that the experience of violence is one of the factors affecting the burden of the caregivers of patients with bipolar disorder.

In this study, there was no difference was found between the patient's regular use of their medications and the burden perceived by the caregivers. Some studies have indicated there to be a positive relationship between low level of treatment compliance in patients with bipolar disorder and care burden.[9,14,24,36] The symptoms seen in the patient may decrease with treatment compliance. Continuing symptom management may result in the patients' fulfilling the roles in their lives more actively and thereby decrease the care burden. The different results found in this study could be attributed to the relatively small sample size.

This study has some limitations. First, as this study was conducted only with the caregivers of patients with bipolar disorder who were hospitalized in an inpatient unit at a university hospital in Istanbul and outpatients with bipolar disorder who were receiving follow-up care at the same university hospital in Istanbul, the results cannot be generalized to primary caregivers of all patients with bipolar disorder. Second, the care burdens of the caregivers of inpatients and outpatients were not compared in this study. Going forward, studies demonstrating how the burden changes in outpatient and inpatient caregivers are needed. Lastly, the study sample was very limited in size due to the loss of caregivers who did not want to participate in the study. Therefore, studies involving more patient relatives are recommended.

Conclusion

This study, conducted to examine the care burden of primary caregivers of patients with bipolar disorders and the related factors, found that the caregivers experienced a nearly moderate level of care burden, with the developmental burden being experienced the most and the emotional burden, the least.

This study found that care burden was affected by a number of different factors, including caregivers who are the child of the patients, live in the same house as the patients, have difficulties performing their roles, voluntarily choose to provide care, and have weak spiritual-religious practices, and are usually exposed to violence by the patients, patients who show frequent symptoms, patients with comorbidities to bipolar disorder, and patients who require the help of others in self-care and treatment. Moreover, a positive relationship was found between the amount of time per week care is provided to the patient and the Time Dependence burden.

In line with the results obtained through this study, it is recommended that comparative studies with a larger sample of caregivers of different socio-economic levels and institutions be conducted. It is furthermore recommended that strengthening programs that are aimed at helping caregivers who have difficulties performing their roles learn how to cope with the issues caused by the disorder and to support them in providing care to the patients be developed and effectively implemented. The fact that caregivers experience the burden of Time Dependence indicates that they cannot spare time for their own needs, which leads to the final recommendation that the number of health institutions and the services they offer be expanded so that caregivers can have a place to leave their patients when needed.

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