

Burden and Burden-related Features in Caregivers of Schizophrenia Patients

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ABSTRACT

Burden and burden-related features in caregivers of schizophrenia patients

Objective: Burden, social support and coping methods in caregivers of patients and the relationship between these variables were cross-sectionally evaluated in this study.

Method: Demographic form, Zarit Caregiver Burden Scale, Multidimensional Scale of Perceived Social Support and Ways of Coping Inventory were administered to the caregivers. The correlation of specified load levels with respect to the disease and characteristics of the caregivers were investigated.

Results: The mean burden score of caregivers participated in the study was 60.45 points. By gender, burden in female caregivers was higher than men. The burden of employed caregivers was higher than unemployed. Statistically significant negative correlation between monthly income and burden was found. Helplessness and fatalistic attitudes were statistically correlated with burden.

Conclusion: Caregivers who are not able to use effective coping styles have heavier burdens. Caregivers using nonfunctional coping styles, should be helped to change their attitudes.

Key words: Burden, caregivers, coping strategies, social support, schizophrenia patients



ÖZET

Şizofreni hastalarının bakımıyla ilgilenenlerde yük ve ilişkili özellikler

Amaç: Bu çalışmada, şizofreni hastalarının bakıcılarında hastalığa bağlı yük, sosyal destek, baş etme yolları ve bu değişkenler arası ilişki kesitsel olarak değerlendirildi.

Yöntem: Bakıcılara Demografik Form, Zarit Bakıcı Yük Ölçeği, Çok Boyutlu Algılanan Sosyal Destek Ölçeği ve Baş Etme Yolları Ölçeği uygulandı. Belirtilen yük düzeyinin hastalık ve bakım verenin özellikleri ile ilişkisi incelendi.

Bulgular: Çalışmaya katılan bakıcıların yük ölçeğinden aldıkları puan ortalamaları 60.45'dir. Cinsiyete göre bakıldığında kadın bakıcılarda yük, erkek bakıcılara göre; çalışan bakıcıların yükü, çalışmayanlara göre daha yüksek bulunmuştur. Kişi başına düşen aylık gelir ile yük arasında olumsuz yönde ve istatistiksel olarak anlamlı bir ilişki bulundu. Çaresizlik ve kaderci yaklaşımın yük ile ilişkili olduğu bulundu.

Sonuç: Hastalıkla etkin başa çıkma yollarını kullanamayan bakıcıların yükleri daha yüksek olmaktadır. Eğer bakıcılar hastalıkla baş etmede işlevsel olmayan yollar kullanıyorsa, değiştirilmesi yönünde yardımcı olunmalıdır.

Anahtar kelimeler: Yük, bakıcılar, başa çıkma stratejileri, sosyal destek, şizofreni hastaları

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INTRODUCTION

Behaviors of a mentally ill person generate a need for care. This phenomenon is named as "burden" as a matter of caregiver (1). Burden as a concept, is considered from two angles; objective and subjective. Objective burden is explained through the psychological effects of impaired familial relations, reduced social activity and economical constraints while the subjective burden is related with depression, anxiety, embarrassment for social situations and frustration for own disturbing behaviors (2-3).

Magliano et al. (4) then, stated that the "burden on caregiver" covers the physical, emotional and economical difficulties experienced in the course of care giving; a majority of people responsible for providing care to schizophrenic patients is exposed to physical, psychological and economical burden.

Studies about the burden on the family of the schizophrenic patient are clustered in two groups; studies? about patient-related factors such as symptomatic pattern and social functioning or studies investigating family-related factors such as social support and emotional assertion. Problems associated

with self-esteem and activity are stated to generate more burden than the offensive conduct does (5,6). In another study investigating the relationship between the clinical features of the illness and the burden on family, positive symptoms, manic/hostile attitudes and disabilities are reported to increase the burden (7,8).

There are a number of studies, observing the relationship between the burden and socio-demographics of those who provide care to schizophrenic patients. Caregivers of female patients in a study, reported more contentment and less experience of problems than reported by the caregivers of the male patients. Younger patients had more conflict with parents and a more negative perception by their parents when compared to older cases (9). In another study, burden was assessed to be higher among mothers of the patients, older caregivers, those with lower educational level, caregivers of younger patients and unemployed individuals (10). Zahid and Ohaeri (11) demonstrated a higher level of emotional adversity in less educated cases and caregivers of female patients. Right together with the demographic variants, duration of illness, duration of daily care, accommodation of the caregiver and the patient, stigmatization, problems related to the communication with healthcare providers and violence generated by the patient either to own self or others are the predictors of burden on the caregiver (12,13).

Karancı (14) investigated the causality attributes, burden and expectations from the healthcare professionals, of the relatives of the patients. Relatives of the patients were observed to face with economical burden associated with the care and treatment of the patient, in addition to their familial disputes and emotional problems. The results of this study revealed that only 41.5% of the patients were granted a social support whereas many patients who have applied for social support hardly receive welfare grants after years (15).

Families of schizophrenic patients experience a social isolation alongside the financial burden of patient care and medical services. This situation often leads to limitation of social and leisure time activities. Some

studies displayed that schizophrenia remarkably restricts the caregivers and make them concerned about future (6,16). It has been justified that the social isolation is an outweighing burden over the financial and occupational problems. This was suggested to be destructing the relationship between the patient and the caregiver and depleting the resources needed to cope with the disease (1).

The reviewed literature reveals that the local studies about the burden on the caregivers of schizophrenic patients are relatively few. A study investigating the relationship of the burden on the caregivers of the schizophrenic patients with the socio-demographic variables and the characteristics of the illness showed that the level burden on the caregiver, which is inversely proportional with the level of education was related with the age of the patient, number of aggravations and hospitalization (17). The same study demonstrated no significant correlation between the psychopathology scores and the burden on the caregiver. Existence of studies showing the reduced burden on the family by a good social support as well as the relevance of burden and coping ways with culture; together with the lack of local studies investigating the relationship between burden and social support, make it necessary to study the association between the burden and the related variables.

In this study, the burden, social support and coping skills of the caregiver of schizophrenic patients were assessed. It was intended that identification of the social support given to families as well as the methods used to cope with the anxiety and stress might be helpful to the specialists who collaborate with the families of schizophrenic patients, in designing the psychosocial and educational programs for families.

METHOD

This is a descriptive and cross-sectional study. The members of the case group, in this study, was recruited from the relatives of the schizophrenia patients who have been followed up as outpatient (in the polyclinics of Daytime Hospital and Rehabilitation Center at

Bakirkoy Training and Research Hospital for Psychiatry, Neurology and Neurosurgery) and had been hospitalized during acute aggravations. The study had been carried out with 100 relatives of patients between November 2006 and March 2007. Participating relatives were informed about the aim and the method of the study and written consent was obtained.

Inclusion Criteria

Relatives who have been living with the patient for more than a year time, taking a hefty part of responsibility when compared to other family members in the care of the patient, and being 18-65 years old, willingness to participate in the study and being literate were the inclusion criteria.

Existence of a mental or bodily disability hindering interviews as well as the problems associated with perception and the use of language were the exclusion criteria.

Only one relative or caregiver was recruited for each patient.

Measures

Caregiver's Socio-demographics Form: A form was developed to evaluate the demographic and clinical characteristics of the patients and caregivers. The form designed for the caregivers is consisting of the age, sex, marital status, duration of marriage, total number of children, educational status, profession, occupational details, and economical power of the caregiver as well as the proximity of the relationship with the patient. In the patient's demographic and clinical profiling form, age, sex, duration of illness, number of hospitalizations, existence of violent behaviors, suicidality, forensic problems, occupational details before the onset of the disease and at present, familial history of a mental illness took place.

Zarit Caregiver Burden Scale: Zarit Caregiver Burden Scale (ZCBS) was launched by Zarit et al. (18,19) in 1980. This scale is used to rate the difficulty experienced by the individuals providing

care to those who are in need of care. This 22-item scale that can be filled in by either the responder or an investigator, measures the impact of caregiving on the caregiver's life. This likert-type scale has five options for each item as never, rarely, sometimes, often or usually. The scale score is directly proportional with the intensity of difficulty. The Spanish version of this scale, which was developed by Martin (20) has been used for the relatives of Alzheimer's disease patients. The internal consistency (α), test-retest reliability and interrater reliability of this scale were calculated as 0.91, 0.86 and 0.63, respectively. The majority of the items generally deal with social and emotional issues and increase in total scale score is interpreted as increased difficulty (10). ZCBS was validated by Ozlu et al. (21) in 2009. A factorial analysis was carried out for structural validation of ZCBS and five factors were determined. The internal consistency coefficient was found to be 0.83.

The Ways of Coping Checklist: The ways of coping define the cognitive and behavioral strategies used by the individual when intrinsic or extrinsic stressful conditions are met. The Ways of Coping Checklist (WCC) that was launched by Folkman and Lazarus in 1985 (22), was used by Gunes (23) in a study conducted right after earthquake Marmara in 1999 and four factors were determined as problem oriented approach ($r=0.83$), fatalism ($r=0.77$), helplessness ($r=0.73$) and avoidance approach ($r=0.55$), by making a factorial analysis. In our research, The WCC that was harvested from this study was used. The total score of this scale is calculated by inverse scoring of the items related to avoidance and helplessness. In this case, increased scores mean better coping. In 2005, Cigerli (22) employed the 42-item The WCC developed for the study carried out by Gunes et al. (23) to find out the coping ways used as well as the frequency of usage by the parents of the disabled children.

Multidimensional Scale of Perceived Social Support: Multidimensional Scale of Perceived Social Support (MSPSS) is a 12-item, user-friendly scale that

subjectively rates the efficiency of social support procured from three different sources (24). The scale comprises three sources, each consisting of four items. These are family, friend and a special person. The internal consistency, test-retest correlations and validity correlations of the scale and its sub-scales are acceptable (25). A higher score means better social support.

Statistical Analysis

SPSS 13 was used for statistical analyses. Frequency values for categorized variables and descriptive statistics for continuous variables were calculated. Pearson Correlation Coefficient and t test for the continuous and discrete variables were used to calculate the relationship between burden and demographic variables, respectively. The power and direction of the relationship between variables were determined by correlation analysis. Independent group t test was used in the comparison of groups.

RESULTS

The study was carried out in 100 caregivers of schizophrenic patients. The ages of the caregivers ranged between 20-65 years with a mean age of 49.51

years. Participants were consisting of 71 females (71%) and 29 males (29%). Out of all participants, 75 were married (71.4%), 11 single (10.5%), 6 divorced (5.7%) and 8 were widow. Almost all participants were either a family member or a relative (47 mothers, 20 siblings, 15 fathers, 12 spouses, 4 secondary relatives and 2 children).

Mean scores of ZCBS, The WCC as well as its sub-scales and MSPSS made by the participating caregivers were displayed (Table 1).

Pearson Correlation Coefficient for the relationship between burden and demographic variables was calculated. A statistically significant and inversely proportional relationship between the total burden score and monthly earning per pole was found ($r=-0.410$, $p<0.01$). Independent group t test was used to assess the relationship between the burden and the independently coupled demographic variables. Burden in females (Mean=62.56) was found to be higher than the one in males (Mean=55.27). Burden in unemployed population (Mean =66.15) was found to be higher than the one in employed participants (Mean=55.96) (Table 2 and 3).

A statistically significant and directly proportional relationship between the caregivers' total burden score and total coping ($r=0.328$, $p<0.01$), helplessness ($r=0.535$, $p<0.01$) and fatalism ($r=0.535$, $p<0.01$) scores were found (Table 4).

Table 1: Distribution of total scores of ZCBS, WCC and MSPSS

	Mean±SD	Range
Zarit Caregiver Burden Scale	60.45±15.41	28-97
The Ways of Coping Checklist	100.43±7.56	85-116
Problem-Oriented Subscale	42.82±4.31	28-51
Fatalism Subscale	25.64±3.10	17-30
Helplessness Subscale	19.71±3.35	10-27
Avoidance Subscale	12.26±1.55	9-17
Multidimensional Scale of Perceived Social Support	52.58±18.30	12-84

ZCBS:Zarit Caregiver Burden Scale, WCC:The Ways of Coping Checklist, MSPSS: Multidimensional Scale of Perceived Social Support

Table 2: Correlation of burden with sociodemographic variables

	Carregiver age	Duration of marriage	Patient age	Duration of illness	Number of Hospitalizations	Number of suicidal attempts	Monthly income per pole
Burden total score	-0.309	-0.022	0.046	0.107	0.039	0.056	-0.410*

* $p<0.01$

Table 3: Relationship of burden with sociodemographic variables

	n	Mean±SD	p
Sex of caregiver			
Female	71	62.56±15.45	0.028*
Male	29	55.27±14.28	
Occupation of caregiver			
Unemployed	78	66.15±14.47	<0.001**
Employed	22	55.96±14.73	

*p<0.05, **p<0.01 statistically significant

Table 4: Correlation between perceived burden and other variables

	Pearson Correlation Coefficient (r)	p
Zarit Caregiver Burden Scale	0.525	<0.001
The Ways of Coping Checklist	0.148	0.529
Problem-Oriented Subscale	0.535	<0.001
Fatalism Subscale	0.255	0.05
Helplessness Subscale	-0.079	0.141
Avoidance Subscale	-0.008	0.303

DISCUSSION

In this study, assessment of the relationship between the burden on the caregivers of schizophrenic patients and their demographics, coping strategies as well as social support provided to caregivers was aimed. There was no significant difference between sexes of the caregivers. Burden on females was more than that of males. In a study carried out by Cassidy and Junbauer (26), mothers were reported to take the overall responsibility of providing care to schizophrenic patients. In conjunction with this finding, we could say that patient care has generally been undertaken by women (mothers) in our country.

Number of hospitalizations and aggravations are considered to have the potential to increase the burden by affecting the caregiver socially and economically. Aydin et al. (17) found that the burden on the caregiver was associated with the age of the patient, number of aggravations as well as hospitalizations and educational level. Another study that observed no significant association between these variables supports our findings (27). Our findings could be relevant to the disease features of the patients participated in our study.

The financial loss due to unemployment of the patient as well as the treatment costs are the other difficulties faced by the caregiver. Related literature states that the cost of care and treatment affects the financial conditions of the family and contributes to the burden remarkably (14,15). Our findings revealed also that there was an inversely proportional relationship between the monthly income per pole and the burden. It could be suggested that caregivers should be supported financially to prevent an increase in burden because of decreased income.

Duration of care that prevents the caregiver to fulfill the responsibilities to own self might be challenging. In our study, burden on the unemployed cases was found to be more than that of the employed ones. The fact that the employed caregivers can find other fields of satisfaction in the professional life whereas the unemployed caregivers has to spend more time with the patient and take more responsibilities about caring the patient could be an explanation of this situation. In a study by Scazufca et al. (28), being employed was found to decrease the burden on the caregiver. However, Aydin et al. (17) observed that there was a significant relationship between the duration of care and the level of depression and anxiety though there was no significant association of duration of daily care with burden. This finding was reported to be explicable with the caregiver's perception of care as a meritorious conduct rather than a matter of complaint, where the sensible burden is emerged with depressive beefs. In another study carried out by Gulseren et al. (29), a positive association of burden with the anxiety and depression levels of relatives was recorded. Based on this, better working conditions and economical support by the state appear to be important for the caregivers.

Daily care and healthcare provided to the patient affect the economical conditions of the family and becomes an important burden item. Difficulties of care force the caregiver to get a leave from the workplace frequently or seek for a part-time job. This situation often inhibits the caregiver's financial power and career. Moreover, state initiatives such as mandatory employment quota for schizophrenic individuals, establishment of rehabilitation centers, vocational

courses for schizophrenic patients would be important both for the rehabilitation of the patient and to reduce the burden on the caregiver.

In the study of Cigerli et al. (23), helplessness was recorded to be a more preferred method of coping by mothers, than fathers were. The ranking of vogue to coping ways for mothers was problem oriented and then fatalism, helplessness and then avoidance as the least frequent method; whereas for fathers the most frequently appealed ways were problem oriented and then fatalism, avoidance and helplessness in order. There was a significantly positive relationship of burden with helplessness and fatalism in our study as well. In the related literature, caregivers of the schizophrenic patients are reported to use often the emotional coping ways (30) and religiousness might be reducing the stress and self-accusation (31). Our findings in this respect are in conformance to the literature.

Some families of the schizophrenic patients are able to cope with the stress and crisis situations even with a higher strength at the end of an experience, whereas

some others fail to cope with the stress. One of the leading causes of the anxiety in the family for future is uncertainty. At this point, keeping the family informed by healthcare providers and establishing support groups to help the family cope with the anxiety regarding the future is considered important for reducing the helplessness approach of the family and replacing the emotional coping ways with problem-oriented strategies.

These findings reveal that sharing the responsibilities with the caregivers of the schizophrenia patients, doing the best not to pass the whole responsibility down to the family, supporting the family with respect to the cost of care and carrying out the activities to prevent or reduce the burden on the family would be beneficial.

Lack of assessment of anxiety and depression symptoms of caregivers as well as their association with burden is one of the limitations of our study. Evaluation of the burden on the caregivers together with the social support and coping ways in the same research is the prevailing feature of the study.

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