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Brief Report / Kısa Araştırma

The Dimensions of Caregiver Burden in Schizophrenia: The Role of Patient Functionality

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ABSTRACT

The dimensions of caregiver burden in schizophrenia: the role of patient functionality

Objective: The purpose of this study was to investigate the relationship between schizophrenia patients' functionalities and symptoms and caregiver burden subdimensions.

Method: Ninety-two schizophrenia patients and their caregivers were included. Patient functionality was evaluated using the Functional Remission of General Schizophrenia Scale; symptom severity and type were evaluated using the Positive and Negative Syndrome Scale and caregiver burden was evaluated using the Zarit Caregiver Burden Scale.

Results: According to our findings, while patients' positive symptoms were uncorrelated with caregiver burden, negative symptoms exhibited a direct linear correlation with the dependency and economic burden dimensions in particular. Patients' functionalities exhibited a significant reverse correlation with almost all caregiver burden dimensions (except for impairment in social relationships). The highest correlation was with the psychological tension and impairment of private life burden dimension.

Conclusion: In conclusion, a small number of negative symptoms and a good level of functionality are associated with less caregiver burden, and this correlation is more pronounced in certain burden dimensions, such as dependency, economic burden, psychological tension and impairment of private life.

Key words: Dimensions of caregiver burden, functionality, negative symptoms, schizophrenia

ÖZET

Şizofrenide bakım veren yükünün boyutları: Hastaların işlevselliğinin rolü

Amaç: Bu çalışmada şizofreni hastalarının işlevsellikleri ve hastalığın belirtileri ile bakım veren yükünün alt boyutları arasındaki ilişkilerin araştırılması amaçlanmıştır.

Yöntem: Çalışmaya 92 şizofreni hastası ve onların bakım verenleri dahil edilmiştir. Hastaların işlevselliği Şizofreni Hastalarında İşlevsel İyileşme Ölçeği ile, belirti şiddeti ve tipi Pozitif-Negatif Sendrom Ölçeği ile, bakım verenin yükü ise Zarit Bakıcı Yük Ölçeği ile değerlendirilmiştir.

Bulgular: Bulgularımıza göre, hastaların pozitif belirtileri bakım verenin yüküyle ilişkisizdir. Öte yandan, negatif belirtiler, özellikle bakım verenlerin bağımlılık ve ekonomik yük boyutlarıyla doğrusal yönde korelasyon göstermiştir. Hastaların işlevsellikleri bakım verenin hemen hemen tüm yük boyutlarıyla (toplumsal ilişkilerde bozulma boyutu hariç) anlamlı derecede ters korelasyon göstermiştir. En yüksek korelasyonun ruhsal gerginlik ve özel yaşamın bozulması yük boyutu arasında olduğu bulunmuştur.

Sonuç: Sonuç olarak, hastaların negatif belirtilerinin az ve işlevsellik düzeylerinin iyi olması ile bakım veren yükü arasında daha az bağıntı olduğu, bu bağıntının bağımlılık, ekonomik yük, ruhsal gerginlik ve özel yaşamın bozulması gibi bazı yük boyutlarında daha belirgin olduğu görülmüştür.

Anahtar kelimeler: Bakım veren yükü boyutları, işlevsellik, negatif belirtiler, şizofreni

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INTRODUCTION

The difficulties experienced by family members, who look after individuals with severe psychological diseases are generally known as the "caregiver burden" (1). Schizophrenia heads the list of the psychological diseases that impose the greatest burden on family members (2). Studies have investigated and revealed various factors leading to burdens in caregivers of schizophrenia patients. Some of these are associated with the patient and disease (age, gender, severity and type of symptoms, number of episodes etc.), some are

associated with the caregiver (gender, proximity to patient, personality characteristics, socioeconomic and cultural characteristics etc.), while others involve external factors (social support, degree of social labeling, and quality, accessibility of psychological health services, etc.) (3-6). The effects of some of these on caregiver burden have been consistently shown in studies, while results regarding the effects of others are still controversial (7).

Previous studies generally agree that a severe level of symptoms affects the caregiver burden (2,8,9). In contrast, one recent study from Turkey reported no correlation between symptom severity and caregiver burden (4). On the other hand, results concerning which symptom group is more correlated with burden are inconsistent (3). There are studies reporting that both positive and negative symptoms are independently correlated with caregiver burden (10,11), as well as studies reporting that positive (2,12,13) or negative (6,14-16) symptoms led to caregiver burden.

Raising levels of functionality is one of the main aims in schizophrenia treatment. Schizophrenia patients' loss of functionality or increasing levels of functionality with remission being associated with caregiver burden was first emphasized by Lefley (17). In one of the earliest studies on the subject, Magliano et al. (18) reported that the family burden decreased in proportion to improvement in the patient's social functionality. Another study concluded that patients' daily hours of work was a predictor of caregiver burden (19). It has been suggested that measures aimed at increasing patients' functionality will have a positive impact on caregivers, and studies testing these measures have shown that increasing levels of patient functionality reduces the caregiver burden (18,20-22). One of these studies found that patients' general functionality was the strongest predictor of family burden among the various factors assessed (severity and type of disease symptoms, executive function, quality of life and degree of stress) (23). One of the two studies investigating the association between caregiver burden and functionality in Turkey determined that patients' social functionality level was correlated with family functionality but provided no analysis of the direction of that correlation (24). The other study showed a correlation between compromise in social functionality (particularly the dimensions of independence-competence and interpersonal functionality) and family burden. This result was interpreted by the authors as impairment of social functionality leading to family members assuming greater responsibility and spending more time with patients, thus increasing their burden (2).

Schene et al. (25) proposed that the caregiver burden is multidimensional. Caring for a patient may lead to burden directly or indirectly. However, previous studies have not investigated, which caregiver burden subdimensions are correlated with disease symptom groups or areas of functionality in which, impairment is observed. The purpose of this study was to investigate that subject.

METHOD

Participants

The study population consisted of patients monitored and treated with a diagnosis of schizophrenia by the psychosis unit of the psychiatry department of a university hospital, and the relatives caring for them. Our psychosis unit is a special unit clinic open for one full day a week at which patients are assessed by a member of the teaching staff together with an assistant doctor, in which each patient is interviewed by a psychologist with experience in the area and in which 15 patients on average are assessed per day. A semi-structured interview form and various scales routinely administered by the same interviewers [Clinical Global Impression Scale (CGI) and the Positive and Negative Syndrome Scale (PANSS)] were used (26,27). Throughout the study period, patients attending with relatives for follow-up interviews in our psychosis unit, and their relatives, were invited to take part in the study according to their order of arrival. Patients aged 18-65, diagnosed with schizophrenia for at least one year according to DSM-IV-TR, clinically stable and accepting to participate were included in the study. The CGI, routinely applied to monitored patients by

our psychosis unit, was used for the assessment of clinical stability (26). Patients who had a score of 5 or less (CGI<6) in the disease severity subscale in CGI were regarded as clinically stable. Patients with a condition that might prevent application of the study scales, with mental retardation or with severe physical disease or disability were excluded. Inclusion criteria for caregivers were to be living with the patient permanently, to be primarily responsible for patients' attendance in the course and departure from hospital follow-ups and drug provision and drug compliance, and to be willing to participate in the study. Caregivers with severe physical disease or disability and with conditions that might prevent the interview or the application of the scales were excluded. Ninety-two schizophrenia patients and their caregivers were eventually included.

Measures

The participants were administered an assessment form prepared by the researchers, and sociodemographic and clinical data were obtained. Patients were also administered the CGI, PANSS and the Functional Remission of General Schizophrenia Scale (FROGS), and caregivers were administered the Zarit Caregiver Burden Scale (ZCBS).

Clinical Global Impression Scale (CGI): CGI is a semi-structured interviewer-administered scale which was developed by Guy (26) in 1976. The scale consists of three dimensions, illness severity, improvement and side-effects. Only the first dimension was used in this study. Patients were classified, on the basis of the scale protocol, between "1" (not ill) and "7" (seriously ill). Patients scoring 5 or less were included in the study.

Positive and Negative Syndrome Scale (PANSS): This semi-structured interview scale was developed by Kay et al. (27) and consists of 30 items on a 7-point severity classification. Seven of the psychiatric parameters assessed by PANSS belong to the positive syndrome subscale, seven to the negative syndrome subscale and the remaining 16 to the general psychopathology scale. The reliability and validity of the Turkish-language version of the scale were established by Kostakoglu et al. (28).

Functional Remission of General Schizophrenia Scale (FROGS): The original version of the scale (The Functional Remission of General Schizophrenia Scale - FROGS) was developed by Llorca et al. (29). The validity of the Turkish-language version was investigated by Emiroglu et al. (30) The FROGS is a 5-point Likert scale (1-no remission, 2-partial remission, 3-satisfactory remission, 4-almost complete remission, 5-perfect remission) consisting of 19 items examining improvement in functionality independent of patients' symptoms. It is administered at a semi-structured interview in approximately 30 min. Assessment is based on information received from the patient in person and the family, and involves the previous one month. It consists of four subscales, social functionality, health and treatment, daily living skills and occupational functionality. Subscale scores and total score are calculated. Maximum possible score from the scale is 95 and minimum possible score is 19. Internal consistency of the original version is 0.90, and that of the Turkish-language version 0.89.

Zarit Caregiver Burden Scale (ZCBS): Developed by Zarit et al. (1) to assess the caregiver burden in relatives of patients with dementia, the scale has also been used in later studies to assess the caregiver burden in families of schizophrenia patients (31). The original version consists of 22 items. At investigation of the validity and reliability of the Turkish-language version three items were removed, and the Turkish-language version consists of 19 items (32). The scale is a 5-point Likert-type assessment – never, rarely, sometimes, often or almost always. A high score shows a high caregiver burden. The internal consistency of the Turkish-language version (Cronbach alpha=0.83) has been validated, and five subdimensions are described in structural validity (1-psychological tension and impaired private life, 2-irritability and restrictedness, 3-impaired social relations, 4-economic burden and 5-dependence).

Statistical Analysis

Pearson correlation analysis was used to determine direction and strength of correlation between patients' symptom degrees (PANSS) and caregiver burden (ZCBS), and correlation between patients' level of functionality (FROGS) and caregiver burden (ZCBS). Analyses were performed for patients' total scale scores and subscale scores. Correlation coefficients above r=0.250 were regarded as presence of correlation. Significance threshold was set at 0.95 ($p<0.05$). Higher significance values ($p<0.01$, $p<0.001$) are shown separately in the tables. Statistical analysis of study data was performed on SPSS 16.0.

RESULTS

Sociodemographic Characteristics and Scale Score Data of Patients and Caregivers

Patients' sociodemographic characteristics, various disease characteristics and scores from the study scales are given in Table 1.

Caregivers of all the patients included in the study were related to them by either blood or marriage. The majority of caregivers (68.5%) were women, 39 (42.4%) being the patient's mother, 22 (23.9%) the wife, 17 (18.5%) the father, 11 (12%) a sibling, 2 (2.2%) a child of the patient and 1 (1.1%) an aunt. Caregivers' ZCBS subscale and total scores were as follows: psychological tension and impaired private life subscale: 15.83±6.85, irritability and restrictedness subscale 6.63±2.71, impairment in social relations subscale 5.29±2.49, economic burden subscale 12.16±4.18 and dependence subscale 6.53±2.69. Total score was 46.23±14.99.

Table 1: Patients' sociodemographic and disorder characteristics and PANSS and FROGS scores

	Mean±SD / % (n= 92)
Age	33.82±10.61
Gender	Female 51.1%
Years of education	10.47±3.64
Marital status	Single 72.8%
Age at onset of disease	22.11±7.00
Duration of disease	11.70±8.58
Number of episodes	4.46±4.32
PANSS	
Positive subscale	13.31±4.67
Negative subscale	16.11±5.11
General psychopathology	24.52±5.05
Total	53.85±12.44
FROGS	
Social functioning	21.82±4.85
Health and treatment	14.58±2.82
Daily life skills	21.64±4.66
Occupational functioning	5.84±2.01
Total	63.84±12.96

PANSS: Positive-Negative Syndrome Scale, FROGS: Functional Remission of General Schizophrenia Scale

Correlations Between Schizophrenia Patients' Symptom Severity and Symptom Subtype and Caregiver Burden

Examination of correlation between total PANSS score and symptom subtype scores with total caregiver burden revealed that positive symptom and general psychopathology scores exhibited no correlation, while total PANSS score exhibited threshold correlation (r=0.25), while negative symptom scores exhibited relative correlation (r=0.28). Examination of correlation between PANSS total and subscale scores and caregiver burden subdimension scores similarly revealed correlation only between negative symptoms and certain burden dimensions. The only exception was that total PANSS score exhibited correlation with the dependence burden dimension (r=0.30). The burden dimensions exhibiting correlation with negative symptoms were dependence and economic burden (r=0.37, r=0.29, respectively).

Correlations Between Schizophrenic Patients' Functionality and Caregiver Burden

Generally, a significant reverse correlation was observed between both total functionality score (r=0.44; $p<0.001$) and functionality subscores (r=0.39-0.42; $p<0.001$) and caregiver burden. The caregiver subdimensions exhibiting the greatest correlation with all functionality scores (total and subscore) were psychological tension and impaired private life (r=0.42-0.38). The burden dimension with

Table 2: Pearson correlation coefficients between patient symptom scores and caregiver burden scores

	PANSS positive	PANSS negative	PANSS general psychopathology	PANSS total
ZCBS- Psychological tension and compromise of private life	0.20	0.22*	0.14	0.22*
ZCBS- Irritability and restrictedness	0.20	0.09	0.08	0.15
ZCBS- Impairment in social relations	0.07	0.06	0.02	0.05
ZCBS-Economic burden	0.20	0.29**	0.08	0.23*
ZCBS-Dependence	0.22*	0.37***	0.16	0.30**
ZCBS-Total	0.24*	0.28**	0.11	0.25*

PANSS: Positive-Negative Syndrome Scale, ZCBS: Zarit Caregiver Burden Scale, *p<0.05, **p<0.01, ***p<0.001

Table 3: Pearson correlation coefficients between patients' functionality scores and caregiver burden scores

	FROGS-Social functioning	FROGS-Health and treatment	FROGS-Daily life skills	FROGS-Occupational functioning	FROGS-Total
ZCBS- Psychological tension and compromise of private	-0.38***	-0.37***	-0.38***	-0.39***	-0.42***
ZCBS- Irritability and restrictedness	-0.21*	-0.25*	-0.29**	-0.26*	-0.28**
ZCBS- Impairment in social	-0.24*	-0.23*	-0.18	-0.19	-0.23*
ZCBS-Economic burden	-0.31**	-0.31**	-0.34**	-0.30**	-0.34**
ZCBS-Dependence	-0.33**	-0.33**	-0.34**	-0.25**	-0.35**
ZCBS-Total	-0.40***	-0.39***	-0.42***	-0.39***	-0.44***

FROGS: Functional Remission of General Schizophrenia Scale, ZCBS: Zarit caregiver Burden Scale, *p<0.05, **p<0.01, ***p<0.001

the second highest correlation with functionality other than occupational functionality was dependence (r=0.34-0.33). Occupational functionality had a higher correlation with the economic burden dimension (r=0.30). In contrast, the impairment of social relations dimension exhibited no correlation with patients' functionality scores. Similarly, the irritability and restrictedness burden dimension correlation was relatively low compared to those of other subdimensions (r=0.25-0.29).

DISCUSSION

According to our findings, positive symptoms of schizophrenia were not correlated with caregiver burden, while generally, disease severity and particularly negative symptoms were positively correlated with the burden of schizophrenia patient caregivers. This result is consistent with the findings of some previous studies (10,25). Additionally, our findings concerning relations between symptom subtypes and caregiver burden are supported by those of previous studies (6,14-16). Although Provencher and Mueser (14) reported a correlation between subjective caregiver burden and both symptom groups, they concluded that there was only a correlation between objective caregiver burden and negative symptoms. Ukpong (6) also reported that negative symptoms such as anhedonia and affective bluntness were powerful predictors of caregiver burden. On the other hand, previous studies on the subject have not investigated which subdimensions of caregiver burden are associated with disease severity and types of symptoms. We determined no correlation between total positive symptom score and caregiver burden subdimensions. However, a positive correlation was observed between total PANSS score and dependence dimension and between negative symptoms and economic burden and dependence subdimensions. These findings suggest that there was an association between patients' negative symptoms and caregivers' perceptions of that their patients are dependent on them and cause an excessive economic burden. As patients' negative symptoms increase, their need for support in terms of basic functions such as feeding and personal care rises. Patients are then unable to work because of these symptoms and cannot contribute to the family budget. They may even require a paid caregiver. For all these

reasons, there may be a positive correlation between caregivers' perceptions that their patients are dependent on them and cause an economic burden.

In terms of our findings concerning relations between schizophrenia patients' functionality and caregiver burden, high functionality was generally associated with a low level of burden. Previous studies on this subject, both in Turkey and elsewhere, have reported a negative correlation between patient functionality, and particularly social functioning, and caregiver burden (2,18,23,24). Similarly, various studies that have tested the effect of measures such as psychoeducation and family therapies have also shown that an increase in patients' level of functionality is associated with a decrease in caregiver burden (18,21,22). From this perspective, our findings concerning the relationship between functionality and caregiver burden are compatible with those of previous studies. However, the variety of tools used in measuring functionality in most of these studies restricts the comparability of the results.

On the other hand, previous studies have not investigated, which subdimensions of caregiver burden are associated with impaired areas of functionality. Our study focused on this. According to our results, the dimension consistently most powerfully correlated with all areas of functionality was psychological tension and compromise of private life. This finding suggests that there is a more widespread association between impairments in all areas of functionality and burdens arising in caregivers' psychological health and private lives compared to other burden dimensions. This finding may lead to problems involving all other burden dimensions directly or indirectly affecting the psychological health and private lives of caregivers. Patients' social functioning was negatively correlated with caregivers' economic burden and dependence burden. Some previous studies have reported an association between schizophrenia patients' social functioning and caregiver burden (2,18,22,24). Patients' having less difficulty in entering into social life, such as joining an association, being able to establish communication with other people and being able to meet their own needs, such as going shopping, may well be associated with a decrease in the perception of a dependence burden arising in caregivers. Patients' functioning in terms of their own health and self-medication and daily life skills exhibits a powerful reverse correlation with dependence burden and economic burden in caregivers. One would expect there to be a reverse correlation between elevated functionality in terms of attending hospital unaccompanied, albeit on occasion, being able to obtain drugs and using these appropriately on a regular basis, and dependence and economic burdens in caregivers. In addition, the same positivity applies to caregivers of patients, who can meet basic needs such as personal care and feeding and who have little need of care givers for these activities. Our findings support the idea of an association between schizophrenia patients possessing high skills in these areas of functionality and a lower perception of economic and dependence burdens in caregivers. Occupational functioning in our patients exhibited a more powerful reverse correlation with caregivers' economic burden compared to the other burden subdimensions (with the exception of psychological tension and impairment of private life). Being able to work on a regular basis, even if only part-time, is an important marker of functionality for patients. Inability to work, especially for male schizophrenia patients, is associated with a family economic burden. Patients being unable to discharge this role expected of them is a stress factor for themselves and increases the caregiver's economic burden dimension (12,16,33). Patients who are housewives having functional difficulties with housework and being in need of receiving help from outside also exhibits a similar association with caregiver economic burden. Our study results support the idea of a reverse correlation between patients' occupational functionality and economic burden in caregivers. However, on the basis of our findings, impairment in social relations, irritability and restrictedness exhibited either a weak or no correlation with patient functionality. This may be interpreted as patients' levels of functionality being less associated with dimensions of caregiver burden.

The most important limitation of this study is that it

is cross-sectional. Therefore, it does not reveal whether or not changes in patients' functionalities and symptom levels lead to changes in caregiver burden, nor what type of changes these might be. Characteristics of caregivers with the potential to affect caregiver burden (age, level of education, economic status, level of knowledge of the disease, psychiatric disease, physical disease etc.) were not included in the calculation. Similarly, characteristics concerning the patient and disease that have a potential to affect caregiver burden were given in the results section but not included in the analysis. Finally, while the analysis technique we used (Pearson correlation analysis) showed whether or not there was a correlation between variables, and the power and direction of such correlation, it prevented us from making any comment on the cause and effect relationship between variables.

Degree of dependence burden and economic burden developing in association with care provision in caregivers exhibit correlation with patients' negative symptoms and functionalities. This is not surprising given the association between negative symptoms and functionality. On the other hand, the burden most created by care provision in caregivers is psychological tension and compromise of private life. In contrast, caregivers' social relations were not affected by their caregiver roles. To the best of our knowledge, apart from investigation of the Turkish-language version of the ZCGS (32), this study is the first to assess the subdimensions of the burden of caregivers looking after schizophrenia patients. In addition, again to the best of our knowledge, it is the first study that investigates the relations between schizophrenia patients' functionality subfields and caregiver burden.

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