

Investigating Relationship Between Burden of Caregivers of Patients With Schizophrenia and Mental Health Conditions

Şizofreni Hastalarına Bakım Verenlerin Yükleri ve Ruhsal Sağlık Durumları Arasındaki İlişkinin İncelenmesi

Pınar HARMANCI,¹ Zekiye ÇETİNKAYA DUMAN²

SUMMARY

Objectives: This study aimed to analyze the relationship between the emotional, social, physical, and economic burden and mental health of caregivers of patients diagnosed with schizophrenia.

Methods: The study was performed between February 2009 and July 2010 at Ege University the Faculty of Medicine, Department of Psychiatry, Unit of Psychosis and Schizophrenia Solidarity Association of Izmir. The sample comprised 104 caregivers who met the inclusion criteria of the study. The data were collected using the data form regarding descriptive characteristics, general health questionnaire, and family burden form. The number and percentage distributions were used for the patients with schizophrenia and their caregivers. Correlation analysis was used to determine the relationship between the burden sub-dimensions and mental health of the caregivers.

Results: The results revealed that 86.5% of the caregivers had a high risk of mental health problems. A relationship was found between the mental health of the caregivers and their emotional, social, physical, and economic burdens. Mental health problems increased with the emotional, physical, and economic burdens of the caregivers.

Conclusion: The study highlighted the importance of developing social and professional support programs to improve the mental health of caregivers and help them cope with their burdens; developing action plans for implementation; and assessing the effect of these programs on the burden of caregivers. The results are also important in that a psychiatry nurse can foresee and recognize possible burdens and mental health disorders among caregivers, and ensure the inclusion of caregivers in the scope of developed or to be developed psychiatric support protocols.

Keywords: Caregiver; caregiver burden; mental health; schizophrenia disease.

ÖZET

Amaç: Çalışma; şizofreni tanılı bireylerin bakım verenlerinin duygusal, sosyal, fiziksel ve ekonomik yüklerinin ruhsal sağlık durumları ile ilişkisini incelemek amacı ile yapılmıştır.

Gereç ve Yöntem: Araştırma Şubat 2009 – Temmuz 2010 tarihleri arasında şizofreni hastalarının tedavi gördüğü ve izlendiği bir Üniversite Hastanesi'nin Psikiyatri Anabilim Dalı Psikoz Biriminde, İzmir Şizofreni Dayanışma Derneği'nde yapılmıştır. Çalışmanın örneklemini araştırmaya dâhil etme kriterlerine uygun 104 bakım veren oluşturmuştur. Verilerin toplanmasında; şizofreni hastası ve bakım veren tanıtıcı özellikler soru formları; 'Genel Sağlık Anketi' (G.S.A= General Health Question) ve 'Aile Yüğü Formu' kullanılmıştır. Şizofreni hastasının ve bakım vereninin sosyo-demografik verileri için sayı ve yüzde dağılımı kullanılmıştır. Bakım veren yük alt boyutları ile ruhsal sağlık durumları arasındaki ilişkiyi incelemek için korelasyon analizi kullanılmıştır.

Bulgular: Araştırma sonuçlarına göre; bakım verenlerin %86.5'inin ruhsal sağlık sorunları açısından yüksek risk taşıdığı bulunmuştur. Bakım verenlerin duygusal yükleri ($r=.538$; $p<0.01$), sosyal yükleri ($r=.586$; $p<0.01$), fiziksel yükleri ($r=.524$; $p<0.01$), ekonomik yükleri ($r=.529$; $p<0.01$) ile ruhsal sağlıkları arasında orta düzeyde anlamlı ilişki olduğu bulunmuştur. Bakım verenin duygusal, fiziksel ve ekonomik yükleri arttıkça ruhsal sağlık sorunlarının da arttığı belirlenmiştir.

Sonuç: Araştırmada şizofreni hastasına bakım verenlerin; ruhsal sağlık sorunları yaşamaları açısından yüksek risk taşıdığı, yüklerinin ruhsal sağlık durumlarını etkilediği, bakım veren yükünün artması durumunda ruhsal sağlık sorunlarının da arttığı bulunmuştur. Bu sonuçlar doğrultusunda; şizofreni hastasına bakım verenlerin ruhsal sağlık sorunları yaşama açısından riskli grup olduğu ve izlenmeleri önemlidir. Bakım verenlerin yükleri ve ruhsal sağlık durumlarının farklı zaman noktalarında (hastane yatışı, relaps ve iyileşme dönemleri) uzunlamasına incelendiği çalışmaların yapılması ve geliştirilen programların bakım verenlerin yüklerine ve ruhsal sağlık durumlarına olan etkisinin değerlendirilmesi önerilir.

Anahtar sözcükler: Bakım veren; bakım veren yükü; ruhsal sağlık; şizofreni hastalığı.

¹Department of Medical Services and Techniques, Çankırı Karatekin University Eldivan Medical Services Vocational School, Çankırı

²Department Psychiatric Nursing, Dokuz Eylül University Faculty of Nursing, İzmir

Correspondence (İletişim): Dr. Pınar HARMANCI.
e-mail (e-posta): forzapinar@hotmail.com

Psikiyatri Hemşireliği Dergisi 2016;7(2):82-86
Journal of Psychiatric Nursing 2016;7(2):82-86

Doi: 10.5505/phd.2016.15870

Submitted (Geliş tarihi): 01.06.2015 **Accepted (Kabul tarihi):** 31.03.2016

Introduction

Nowadays, reducing the length of hospital stay and preventing repetitive hospitalization are primary objectives in treating chronic mental disorders. This approach caused a deflection in meeting the care requirements of patients with schizophrenia who are provided health care services by health care institutions.^[1,2] Since individuals diagnosed with schizophrenia mostly live in the house with their families rather than in a health care institution, the disease is a source of

stress for not only patients but also their families.^[3-5] Families of patients diagnosed with schizophrenia are expected to assume the responsibility to care for patients and give them maximum support after discharge. However, schizophrenia has negative consequences, reducing the patient's quality of life and giving the family a hard time because of frequent exacerbations. Due to insufficiency, stigma, and discrimination caused by schizophrenia, patients and their families experience the lack of confidence and decline in self-esteem. They also feel inadequate while participating in spare time activities and at work.^[6,7] As a result of all these difficulties and not using efficient coping styles, caregivers bear social, emotional, economic, and physical burdens. The increase in burden leads to a deterioration in the mental health of caregivers.^[2] According to the World Health Organization (WHO) Mental Health Gap Action Programme (mhGAP) published in 2010, more than 21 million people suffer from schizophrenia worldwide, and their caregivers experience significant burden and stress because of mental disorder.^[8]

Family members of patients with a chronic mental disorder perform a caregiver role in addition to their domestic roles. Because of these multiple roles, they experience psychological problems such as anxiety, despair, anger,^[9] and sleeplessness.^[4-6] It has been reported that depression is a frequently encountered mental health disorder in caregivers, and the depression level increases with the care duration. The depression frequency in families providing care for a patient diagnosed with schizophrenia is two times more than the frequency in other families.^[5,10] Kadri et al. (2004) conducted a study with the families of a group of patients with schizophrenia and found that 86.7% of them had difficult days due to schizophrenia and 72% of them had psychological health problems such as sleep disorders.^[11]

All mental health disorders of family members of patients with schizophrenia, financial problems regarding treatment, social disabilities in patients and their families, and the fact whether the patient can fulfill his/her role within the family are defined as family burden.^[3,5,9] Burden is classified into an objective burden and a subjective burden. The objective burden comprises situations such as income loss, social activity limitations, and tension in the house. However, the subjective burden is expressed as an emotional distress resulting from patient's disruptive behaviors or a subjective distress level regarding the patient.^[12,13] Families experience sadness, fear, feeling of loneliness, anxiety of the future, shame, and increasing levels of cigarette and alcohol consumption. They have conflicting feelings against the patient and reject the seriousness of the disease. All these situations cause emotional, physical, and social burdens.^[3,14]

It is presumed that the burden shouldered by caregivers affect their mental health, which deteriorates as the intensity

of burden experienced increases.^[2] Marriage, job, financial matters, and legal problems were remarked as stressors in the family of a patient with mental disorder. Also, depending on the mental disorder, deterioration in social roles and conflict among family members were experienced; the stated stressors were an important determinant of family burden.^[4,5] It was pointed out that the increasing age and decreasing power of caregivers to meet the requirements as the duration of disease extends caused an increase in sadness among them.^[4]

Especially when a patient declines the treatment and displays violent behaviors, family burden becomes intolerable. Thus, family members form a risk group in terms of experiencing mental health problems.^[7] Due to the lack of social resources and programs to support patients and their families in Turkey, care provision has become difficult and the responsibility, stress, and burden of the family have increased.^[13]

Considering the consequences based on burden and stress, the family members of individuals experiencing chronic mental health disorders bear a high risk in terms of impairment of psychological health. However, the number of studies conducted at different times with families of individuals having various chronic mental health disorders is inadequate in terms of developing sufficient and reliable programs in units providing mental health service.

Determining the relationship between the emotional, social, physical, and economic burdens of caregivers of patients diagnosed with schizophrenia and their mental health problems can contribute to planning nursing interventions and developing family intervention programs to enable caregivers to cope with their burdens and protect and improve their mental health.

This study was performed to examine the relationship between the emotional, social, physical, and economic burdens of caregivers of patients diagnosed with schizophrenia and their mental health conditions.

In line with the determined objective, the study sought an answer for the following question.

-Is there any correlation between caregivers' emotional, social, physical, economic burden and their mental health conditions?

Materials and Method

Type and Sample of the Study

This descriptive and correlational (relational) study was conducted with 104 caregivers of patients diagnosed with schizophrenia between March 2009 and July 2010.

The inclusion criteria were as follows:

- 1) Bearing the primary responsibility of patients diagnosed with schizophrenia according to Diagnostic

and Statistical Manual of Mental Disorders, Fourth Edition (DSM-4) diagnostic criteria and spending most of the time with the patient.

- 2) Being at an adequate cognitive level to understand instruments to be used.
- 3) Agreeing to participate in the study after being informed about it.

The Place Where the Study Was Conducted and its Characteristics

This study was conducted at the Faculty of Medicine, Department of Psychiatry, Unit of Psychosis and Schizophrenia Solidarity Association of Izmir, where polyclinic service is provided to patients and their families on Mondays, Thursdays, and Fridays. Every month, approximately 60 patients benefit from the Unit of Psychosis.

The Schizophrenia Solidarity Association was founded in Izmir in 1997 to give support to patients with schizophrenia and their relatives. Approximately 290 family members are registered at the association. Patients participate in association activities with their families.

Data Collection Tools and Implementation

The data were collected using the data form regarding descriptive characteristics, the general health questionnaire, and the family burden form. The data form regarding descriptive characteristics was prepared reviewing the relevant literature.^[2,3,5,10]

The General Health Questionnaire (GHQ): The GHQ is a scale used as a first-stage screening in social works examining the risk of mental disorder. The 12-item GHQ is commonly preferred because it is short, has high sensitivity and specificity in distinguishing cases, and can be used in various socio-cultural environments. Kilic performed the validity and reliability analyses of this questionnaire by translating it into Turkish. The internal consistency coefficient (Cronbach's alpha) is 0.78, and the test-retest correlation coefficient is 0.84.^[15] Although it is stated that this scale can be confidently used in determining nonpsychotic depression and anxiety symptoms, it is recommended not to be used for patients with psychosis and mania and in determining chronic mental disorders. Each question of the GHQ has four possible response options. Options are ranked as follows: (1) not at all; (2) no more than usual; (3) rather more than usual; and (4) very often. The first two columns are scored as 0, and the last two columns are scored as 1. The minimum possible score of the scale is 0, and the maximum is 12. An increase in the score indicates a risk of mental disorder. It is remarked that individuals who obtain two or more points from the 12-item GHQ face a mental disorder risk.^[10,15] The study found the Cronbach's alpha level of the scale to be 0.86.

The Family Burden Form: The Family Burden Form developed by Avci in 2011 with 43 caregivers of patients with schizophrenia measures physical (9 questions), emotional (19 questions), social (7 questions), and economic (8 questions) burdens, and comprises 43 questions about these burden fields.^[3] Each question of the form has three options: "No," "Sometimes," and "Always." These options are scored as follows: "No" answer has zero point; "Sometimes" answer has one point; and "Always" answer has two points. The points vary by every burden field of the form. The minimum and maximum points by sub-dimensions are as follows: the physical burden, 0–18 points; the emotional burden, 0–38 points; the social burden, 0–38 points; and the economic burden, 0–16 points.

Between March 2009 and July 2010, the aforementioned forms were administered to caregivers of patients with schizophrenia on weekdays between 1100 and 1600 hours at the Faculty of Medicine, Department of Psychiatry, Unit of Psychosis and between 0800 and 1600 hours at the Schizophrenia Solidarity Association. The face-to-face interview method was used while administering the forms.

Data Analysis

Data entry was performed using Statistical Package for Science for Windows (SPSS) 15.00 software.

The socio-demographic variables of patients with schizophrenia and their caregivers were used in the data analysis, and the numbers and percentages were used for the assessment of caregivers' general health. The Pearson correlation analysis was performed to examine the relationship between the burden and mental health of caregivers.

Ethical Aspects of the Study

To conduct the study, permissions were obtained from the Department of Psychiatry and Schizophrenia Solidarity Association of Izmir. The ethics committee consent was obtained using a document with the register number 118 in the meeting numbered 44/2/09 and dated 19 February, 2009, of Dokuz Eylül University Nursing Faculty to perform this study.

Results

Introductory Characteristics of Patients With Schizophrenia and Their Caregivers

Of patients with schizophrenia receiving care, 51.9% were females and 48.1% were males; 42.3% were in the age range between 20 and 30 years, 52.9% were single, 44.2% were housewives or unemployed, 36.5% were high school graduates, 47.1% benefited from the Social Insurance Institute in the form of public insurance, and 47.1% stayed in hospital once or twice.

Table 1. Distribution of general health points of the caregivers (n=104)

The GHQ point	n	%
0-1 point (no risk)	14	13.5
2 and more points (risk)	90	86.5
Total	104	100.0

Table 2. Relationship between the burden of caregivers and their general health points

Sub-dimensions of the family burden form	GHQ	
	r	p
Emotional burden	0.538	<0.01
Social burden	0.586	<0.01
Physical burden	0.524	<0.01
Economic burden	0.529	<0.01

GHQ: The General Health Questionnaire.

Of the patient relatives providing care, 64.4% were females and 35.6% were males. The age of the caregivers ranged between 20 and 76 years (mean age 42.49 ± 14.02 years); 31.7% were in the 51 and older age group, and 27.9% were in the 20- and 30-year-old age group. A majority of caregivers were married (64.4%), officers (35.6%), and housewives or unemployed (34.6%). Also, 28.8% were mothers of patients, 23.1% were spouses of patients, and 24% were brothers or sisters of patients. Most of the caregivers (61.5%) defined their monthly income levels as "medium."

Mental Health Condition and Burden of Caregivers

The study determined 13.5% and 86.5% of the caregivers as having a high level of mental health problems with 0-1 and 2 and more points, respectively (Tables 1 and 2).

Discussion

Family members have to look after patients, and hence cannot take a vacation or spare time for themselves. The role assumed by caregivers of patients with schizophrenia causes stress and affects the mental health of the family.^[3,16-18] The present study demonstrated a relationship between the burden (emotional, social, physical, and economic) and mental health of caregivers. Their mental health problems were found to increase with their emotional, social, physical, and economic burdens. Gutiérrez-Maldonado et al. (2005) conducted a study to examine psychological distress and economic difficulties of caregivers of patients with schizophrenia and reported that 45% of the caregivers bore a high level of burden, and their psychological well-being accordingly deteriorated. The same study showed that an increase in the level of burden adversely affected the psychological well-being of caregivers.^[2]

WHO reported that some factors such as the productivity loss of caregivers in the family, failure of patients with schizophrenia to meet the needs of the family, disrupted roles of patients and their caregivers, or disruption of household routine resulted in economic burden. The same study emphasized that caregivers largely (51%) experience stress and burden because of these reasons, and their risk of mental disorder has increased accordingly. It was reported that caregivers suffer from neurotic depression at the rate of 50%.^[19] Ukpong (2012) conducted a study to examine the burden and stress in caregivers and demonstrated a relationship between unemployed patients and psychological distress of caregivers. He also stated that the employment of patients resulted in caregivers experiencing less burden and distress.^[20]

Esmek (2007) performed a study to determine the levels of coping with stress and social support among relatives of patients with schizophrenia and found that almost all patient relatives (81.6%) were influenced by the disease of patients, and nearly half of them (31.9%) had a mental disorder.^[7] This situation may be a result of the physical, emotional, social, and economic burdens experienced by the family. Aydın et al. (2009) conducted a study with 50 patients diagnosed with schizophrenia and their relatives in Turkey and found that the exacerbation of the disease and the increasing number of admissions to hospital increased the burden of the family.^[21]

The findings of the present study were important in terms of presenting the relationship between the burden and mental health of caregivers. However, the study had certain limitations. First, the results could not be generalized. Also, on the date when the study was suggested (February, 2009), no instrument could be found whose validity and reliability analyses had already been performed and which could be used to determine the burden of caregivers of patients with schizophrenia in Turkey.

Team approach is necessary to encourage family participation and cooperation in treating and rehabilitating patients with schizophrenia and to maintain the participation and cooperation. Nurses always interact with patients and families while providing care to patients diagnosed with schizophrenia. Hence, nurses can develop interventions and strategies to decrease the burden experienced by caregivers and help them cope with difficulties experienced by performing the roles of a counselor and an educator while providing care to the patient. To develop such interventions, it is important to understand the relationship between the mental health and burden of caregivers.^[4,22-24]

Conclusions

The study showed that caregivers of patients with schizophrenia form the risk group in terms of having mental health problems and hence need to be monitored. The longitudinal

studies that examine the burden and mental health conditions of caregivers at different time points (hospitalization and recovery period) can provide valuable data. It is also important to develop social and professional support programs intended to protect and improve the mental health of caregivers and help them cope with their burdens; to develop patterns and action plans for implementation; and to assess the effect of the developed programs on the burden of caregivers. The study results are also important in that a psychiatry nurse can foresee and recognize possible burdens and mental health disorders among caregivers, and also ensure the inclusion of caregivers in the scope of developed or to be developed psychiatric support protocols.

References

- Lowyck B, De Hert M, Peeters E, Wampers M, et al. A study of the family burden of 150 family members of schizophrenic patients. *Eur Psychiatry* 2004;19:395-401.
- Gutiérrez-Maldonado J, Caqueo-Urizar A, Kavanagh DJ. Burden of care and general health in families of patients with schizophrenia. *Soc Psychiatry Psychiatr Epidemiol* 2005;40:899-904.
- Avcı A, Bayraktar N. Şizofren hasta ailelerinin aile yükünün belirlenmesi. 40. Ulusal Psikiyatri Kongresi Bildiri Kitabı 2004. s. 771-2.
- Doornbos M. Predicting family health in families of young adults with severe mental illness. *J Fam Nurs* 2002;8:241-63
- Saunders JC. Families living with severe mental illness: a literature review. *Issues Ment Health Nurs* 2003;24:175-98.
- Oflaz F. Psikiyatrik hastaların eşlerinin psikososyal güçlükleri ve stresle baş etme yollarının incelenmesi. [Yayınlanmamış Yüksek Lisans Tezi] Ankara: GATA Sağlık Bilimleri Enstitüsü; 1995.
- Esmek M. Psikiyatri servisinde yatan şizofren hastaların sosyal destek ve stresle baş etme düzeylerinin belirlenmesi. [Yayınlanmamış Yüksek Lisans Tezi] Konya: Selçuk Üniversitesini Sağlık Bilimleri Enstitüsü; 2006.
- (WHO 2010) http://whqlibdoc.who.int/publications/2008/9789241596206_eng.pdf?ua=1 (Available at: 18.04.2015).
- Caqueo-Urizar A, Gutiérrez-Maldonado J. Burden of care in families of patients with schizophrenia. *Qual Life Res* 2006;15:719-24.
- Şengün İnan F. Factors Which Effect Mental Health of Caregivers of Schizophrenia Patients: Socio-Demographic Characteristics and Stress Coping Styles. *Anadolu Hemşirelik ve Sağlık Bilimleri Dergisi* 2013;16:205-11.
- Kadri N, Manoudi F, Berrada S, Moussaoui D. Stigma impact on Moroccan families of patients with schizophrenia. *Can J Psychiatry* 2004;49:625-9.
- Schene AH. Objective and subjective dimensions of family burden. Towards an integrative framework for research. *Soc Psychiatry Psychiatr Epidemiol* 1990;25:289-97.
- Gülseren L. Schizophrenia and the family: difficulties, burdens, emotions, needs. [Article in Turkish] *Türk Psikiyatri Derg* 2002;13:143-51.
- Doğan O. Şizofreni hastalarının evde bakımı. *Anadolu Psikiyatri Dergisi* 2001;1:41-6.
- Kılıç C. Common Methodological Errors in Psychiatric Research. *Türk Psikiyatri Dergisi* 1996;7:3-9.
- Howard PB. The experience of fathers of adult children with schizophrenia. *Issues Ment Health Nurs* 1998;19:399-413.
- Rungreangkulkij S, Chafetz L, Chesla C, Gilliss C. Psychological morbidity of Thai families of a person with schizophrenia. *Int J Nurs Stud* 2002;39:35-50.
- Laidlaw TM, Coverdale JH, Falloon IR, Kydd RR. Caregivers' stresses when living together or apart from patients with chronic schizophrenia. *Community Ment Health J* 2002;38:303-10.
- (WHO 2008). Integrating Mental Health into Primary Care: A Global Perspective. http://www.who.int/gho/publications/world_health_statistics/EN_WHS08_Full.pdf (Available at: 17.02.2015).
- Ukpong D. Burden and psychological distress among Nigerian family caregivers of schizophrenic patients: the role of positive and negative symptoms. [Article in Turkish] *Türk Psikiyatri Derg* 2012;23:40-5.
- Aydın A, Eker SS, Cangür Ş, Sarandöl A ve ark. The Association of the Level of Caregiver Burden with the Sociodemographic Variables and the Characteristics of the Disorder in Schizophrenic Patients. *Archives of Neuropsychiatry* 2009; 46 Supplement: 10-4.
- Stuart G. Principles and practice of psychiatric nursing. 8. ed. China: Mosby; 2005.
- Magliano L, Fadden G, Economou M, Xavier M, et al. Social and clinical factors influencing the choice of coping strategies in relatives of patients with schizophrenia: results of the BIOMED I study. *Soc Psychiatry Psychiatr Epidemiol* 1998;33:413-9.
- Doornbos MM. Professional support for family caregivers of people with serious and persistent mental illnesses. *J Psychosoc Nurs Ment Health Serv* 2001;39:38-45.