

Caregiver Burden in Chronic Mental Illness: A Systematic Review

Kronik Ruhsal Hastalıklarda Bakımveren Yükü: Sistemantik Derleme

Serap YILDIRIM, Nihan YALÇINER, Cansu GÜLER

SUMMARY

Objectives: This systematic review analyzes caregiver burden in chronic mental illness and the factors associated with it.

Methods: The study was conducted by checking the Turkish Psychiatry Index, the Turkish Medical Index, the Turkish Medline, the National Council of Higher Education Thesis Center and the PubMed databases. The database research was performed in English and Turkish using keywords and synonyms for them. Twenty-three studies were included in this study.

Results: The majority of the studies included in the review were descriptive and studied schizophrenic patients' caregivers. They used a variety of measurement instruments. It was found that the burden perception of caregivers was moderate to severe and was influenced by different variables.

Conclusion: Experimental studies are insufficient to determine the burden of caregivers in Turkey, so experimental and qualitative studies should be conducted with different specific samples.

Keywords: Caregiver burden; psychiatric diagnosis; systematic review.

ÖZET

Amaç: Bu sistemantik derleme, ülkemizde kronik ruhsal hastalıklarda bakım veren yükünü ve yükü ilişkili olan faktörleri belirlemek amacıyla yapılmıştır.

Gereç ve Yöntem: Araştırma, Türk Psikiyatri Dizini, Türk Tıp Veri Tabanı, Türk Medline, YÖK Ulusal Tez Merkezi ve Pubmed veri tabanları kullanılarak yapılmıştır. Tarama, Türkçe ve İngilizce dilinde belirlenen anahtar sözcükler ve bu sözcüklerin eş anlamlıları kullanılarak gerçekleştirilmiştir. Araştırma kapsamına 23 çalışma dahil edilmiştir.

Bulgular: İncelemeye alınan çalışmaların büyük bir çoğunluğu tanımlayıcıdır ve şizofreni hastasının bakımverenleriyle yapılmıştır. Araştırmalarda farklı ölçüm araçları kullanılmıştır. Bakımverenlerin orta ve şiddetli düzeyde yük algılarının olduğu ve yükün farklı değişkenlerden etkilendiği saptanmıştır.

Sonuç: Ülkemizde bakım verenlerin yükünü belirlemeye yönelik deneysel çalışmalar yetersiz olup, bu alana özgü farklı örneklem gruplarıyla deneysel ve niteliksel çalışmaların yapılmasına gereksinim vardır.

Anahtar sözcükler: Bakımveren yükü; psikiyatrik tanı; sistemantik derleme.

Introduction

Chronic mental illnesses impair the emotional, thought and cognitive competences of people, change personal and individual habits and cause social and economic losses.^[1,2] Contemporary models for mental health services emphasize community-based treatments and the prevention of long-term hospitalization.^[3,4] Of people with chronic mental illnesses, 10% need care in the long term, and most live with their families.^[4,5] The approach of treating patients in society and their own environment has been adopted, and thanks to this, patient relatives have become primary caregivers, and their responsibilities have increased. This has also caused many problems.^[6-8] Most patients living with their families spend all day at home, and at least one family member, because of patient care, is distanced from social life and from production, and families experience physical, mental, emotional, social and economic problems.^[4,9-11]

The first studies of caregivers were conducted in the 1950s with people experiencing mental illnesses and with their relatives.^[7,12] The concept of burden perceived by caregivers was defined for the first time by Grad and Sainburg at the beginning of the 1960s to describe problems experienced by people who provide home care to people with mental illness.^[13]

Care burden is a concept that has been researched in the literature especially for many chronic diseases, is defined as a whole of physical, emotional, social or economic problems that family members experience due to patient disabilities.^[8,14,15] Caregivers who have many unfulfilled needs or who bear burdens have difficulty meeting functions, including providing care to their patients. Determining and burden will ensure that the needs of both patients and caregivers are met, and thus, the quality of life of both groups will improve.^[16] To reduce caregiver burden, the first thing that should be done is to determine the perceived burden.^[12] For determining caregivers' needs and planning proper interventions, it is important to know the studies that have been conducted to determine the burden of caregivers for patients with chronic disease. This systematic review was conducted to specify studies conducted with caregivers for chronic mental disease patients in Turkey, to determine their perceived burden and the factors that affect it, and to determine the kind of studies that are needed in this field.

Department of Mental Health and Psychiatric Nursing,
Ege University Faculty of Nursing, İzmir, Turkey

Correspondence (İletişim): Dr. Serap YILDIRIM.
e-mail (e-posta): camserap@yahoo.com

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Method

This systematic review was conducted to determine caregiver burden in chronic mental illnesses. Before initiating the literature review, the databases to be searched, keywords and their synonyms were specified. No date limitations were imposed for the search. The Turkish Psychiatry Index, the Turkish Medical Database, the Turkish Medline, the Turkish Council of Higher Education National Thesis Center and the Pubmed databases were searched. The keywords, chronic psychiatric disorder, burden of care, care burden, caregiver burden and family burden, were used as search terms. The study inclusion criteria were: studies conducted with families of adults with a chronic mental disease, Turkish and English studies conducted in Turkey and online full-text accessibility. Its exclusion criteria were: study reviews, scale studies conducted with families of individuals without a chronic mental disease, or with families of children with a chronic mental disease, studies not conducted in Turkey and studies lacking online full-text accessibility.

Study Selection

The researchers' search identified a total of 796 studies from the Turkish Psychiatry Index (8), the Turkish Medical Index (13), Turkish Medline (11), the National Council of Higher Education Thesis Center (57) and PubMed (707). Some studies were excluded from this study because 14 were same, and 740 were irrelevant. The remaining 42 studies were reassessed in terms of the study's inclusion and exclusion criteria. Finally, 17 studies were included and were examined.

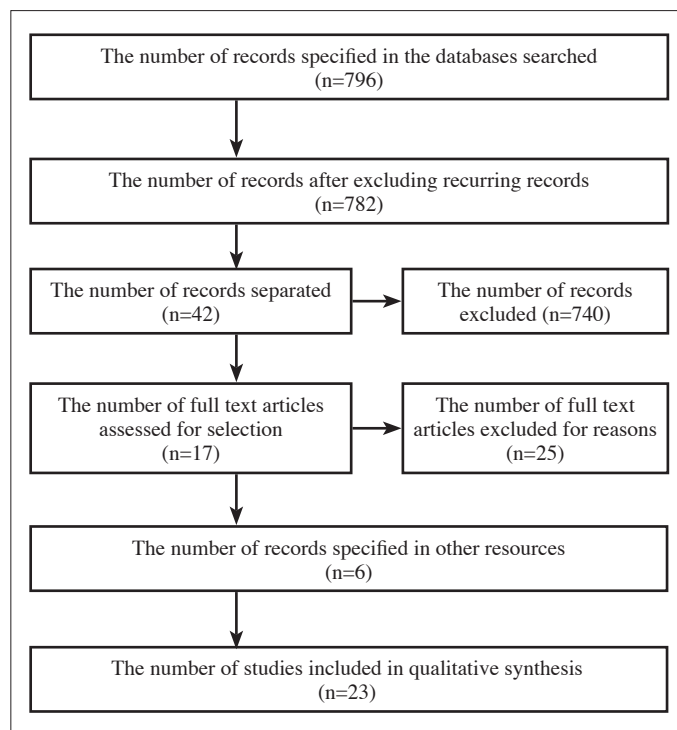


Figure 1. Selection of studies flow diagram.

After a manual search, six additional studies also included. As a result, the researchers reached a total of 23 studies (Figure 1).

Findings

The General Characteristics of the Studies

The studies were conducted between 2007 and 2016, and 7 of them were theses. Of the studies included, 20 had descriptive and 3 had quasi-experimental designs. Of the quasi-experimental studies, two used pre-test post-test design, and one used randomized controlled pre-test post-test design. Of the studies, 15 involved caregivers for patients with schizophrenia; 4 involved caregivers for patients with mixed mental illnesses; 2 involved caregivers for patients with dementia; 1 involved caregivers for patients with obsessive compulsive disorder, and 1 involved caregivers for patients with bipolar disorder. This study found that, among descriptive studies included, the study by Çetin et al. (2013) had the smallest study sample with 32 caregivers, and the study by Çetinkaya and Karadakovan (2012) had the largest study sample with 305 caregivers.^[17,18] Of the experimental studies, the study by Tanrıverdi and Ekinçi (2012) had the smallest study sample with 31 caregivers, and the study by Özkan et al. (2013) had the largest study sample with 62 caregivers (Table 1).^[19,20]

The Measurement Tools Used and Their Results

A variety of measurement tools were used to determine caregiver burden by the studies included in this study: the Zarit Burden Interview (ZBI), the Perceived Family Burden Scale (PFBS), the Caregiver Burden Inventory (CBI), the Disease Burden Assessment Scale (DBAS).^[12,21-24]

Zarit Burden Interview (ZBI)

This scale had two different Turkish reliability and validity studies performed. A total of 16 studies were conducted using the ZFBS developed by Zarit et al. (1980). The first of these was the reliability and validity study by İnci and Erdem (2008), and the second was the reliability and validity study conducted by Özlü et al. (2009).^[21,22,25]

Of the studies taken under analysis using the ZBI, nine used the form established by İnci and Erdem (2008). Of them, five, three and one were conducted with caregivers for patients with schizophrenia, mixed group patients and patients diagnosed with obsessive-compulsive disorder, respectively.^[21] The study conducted by Yıldırım (2014) with caregivers for 244 mental disease patients who visited a psychiatry clinic had the lowest total burden scale mean score at 23.6.^[11] A study by Durmaz and Okanlı (2014) with caregivers for 62 patients diagnosed with schizophrenia and monitored at home and in the hospital had the highest total burden scale mean score at 68.6 (scores on the scale range

Table 1. The general characteristics of the studies

Research	Method	Impairment	Sample (P/CG/HI/HIR)*
1 Özlü A, 2007	Descriptive study	Schizophrenia	CG (n=100)
2 Aydın A, Eker SS, Cangür Ş, Sarandöl A, Kırılı S, 2009	Descriptive study	Schizophrenia	P (n=50) CG (n=50)
3 Depçe AA, 2010	Descriptive study	Schizophrenia	P (n=50 alcohol and substance history+) P (n=50)
4 Gülseren L, Çam B, Karakoç B, Yiğit T, Danacı AE, Çubukçuoğlu Z, Taş C, Gülseren Ş, Mete L, 2010	Descriptive study	Schizophrenia	P (n=239) CG (n=239)
5 Akpınar B, Küçükgülü Ö, 1 Yener G, 201	Comparative	Alzheimer	CG (n=192)
6 Çınar İ, 2011	Descriptive study	Schizophrenia	CG (n=152)
7 Ak M, Yavuz F, Lapsekili N, Türkçapar MH, 2012	Descriptive study	Bipolar disorder	P (n=80) CG (n=80)
8 Arslantaş H, Adana F, 2012	Descriptive study	Schizophrenia	P (n=72) CG (n=72)
9 Çetinkaya F, Karadakovan A, 2012	Descriptive study	Dementia	P (n=305) CG (n=305)
10 Tanrıverdi D, Ekinci M, 2012	Pre-test - Post-test quasi-experimental study	Schizophrenia	CG (n=31)
11 Çetin N, Demiralp M, Oşaz F, Özşahin A, 2013	Descriptive study	Schizophrenia	CG (n=32)
12 Çiçek E, Çiçek İE, Kayhan F, Uğuz F, Kaya N, 2013	Comparative	OCD	P (n=40) CG (n=47)
13 Kaya Y, 2013	Descriptive study	Healthy individual	HI (n=40) HIR (n=45)
14 Özkan B, Erdem E, Demirel Özsoy S, Zararsız G, 2013	Randomized controlled experimental study	Schizophrenia	CG (n=130)
15 Yavaş Ayhan AG, 2013	Descriptive study	Schizophrenia	P (n=32 exp., n=30 control)
16 Yeşildağ Bayrak B, 2013	Descriptive study	Schizophrenia	CG (n=32 exp., n=30 control)
17 Yıldırım A, Buzlu S, Hacıhasanoğlu AR, Camcıoğlu TH, Erdiman S, Ekinci M, 2013	Pre-test - Post-test quasi-experimental study	Schizophrenia	CG (n=85)
18 Durmaz H, Okanlı A, 2014	Descriptive study	Schizophrenia	CG (n=140)
19 Erten E, Alpman N, Özdemir A, Fıstıkçı N, 2014	Descriptive study	Bipolar disorder	CG (n=34)
20 Pazvantoğlu O, Sarısoy G, Böke Ö, Alptekin Aker A, Özturan DD, Ünverdi E, 2014	Descriptive study	Schizophrenia	P (n=92) CG (n=92)
21 Yıldırım FG, 2014	Descriptive study	Psychiatric disorder	CG (n=244)
22 Türkmen SN, Dirgen Ö, Biçici Y, Uzun M, 2015	Descriptive study	Psychiatric disorder	CG (n=199)
23 Kızılırmak B, Küçük L, 2016	Descriptive study	Schizophrenia, bipolar disorder, depression, anxiety disorder, other mental illness	CG (n=243)

*P: Patient; CG: Caregiver; HI: Healthy individual; HIR: Healthy individual relative; Exp.: Experimental; OCD: Obsessive compulsive disorder.

from 0 to 88, and scores between 0-21, 21-40, 41-60 and 61-88 are considered none-low, slight-moderate, moderate-severe and severe, respectively).^[21,26] The total burden scale mean score was not reported by two of the studies included in this study.^[17,27]

The ZBI established by Özlü et al. (2009) was used by seven of the studies. One of them was conducted with caregivers for patients with bipolar disorder, while six were conducted with schizophrenia patients' caregivers.^[22] A study by Erten et al. (2014) with caregivers for patients who were monitored for a diagnosis of Bipolar I and were in the recovery period had the lowest total burden scale mean score at 45.6, while the control group of an experimental study conducted by Özkan et al. (2013) with schizophrenia pa-

tients' caregivers had the highest mean score at 96.5 (scores on the scale range from 22 to 110, and scores between 22-46, 47-55 and 56-110, are considered low burden, moderate level burden and severe level burden, respectively).^[20,22,28] The total burden scale mean score was not reported by one of the studies.^[29]

The Perceived Family Burden Scale (PFBS)

The PFBS' Turkish validity and reliability analyses were performed by Arslantas et al. (2011). It was used by 4 of the studies, all of which were conducted with caregivers for schizophrenia patients.^[23] A quasi-experimental study by Yıldırım et al. (2013) with caregivers for schizophrenia patients provided a family to family support program, and was

found to be the highest burden scale total mean score with a pre-test score of 49.6.^[30] A study by Gülseren et al. (2010) had the lowest burden scale total mean score at 20.9 (scores on the scale range from 0 to 96, and as total scores on the scale increase, burden perception increases).^[23,31]

The Caregiver Burden Inventory (CBI)

Küçükgüçlü et al. (2009) performed the CBI's Turkish validity and reliability analyses. It was used by two studies. Both were conducted with caregivers for Alzheimer's

patients.^[12] The total burden mean score of the study by Çetinkaya and Karadakovan (2012) was found to be 30.5, while this score was not reported in the study conducted by Akpınar et al. (2011). (Scores on the scale range from 0 to 100, and as total scores on the scale increase, burden perception increases).^[12,18,32]

The Disease Burden Assessment Scale (DBAS)

The DBAS' Turkish validity and reliability was performed by Aydemir et al. It was used by Kızıllırmak and Küçük (2016)

Table 2. The measurement tools used in this study and their results

Research*	Scales used	Results
1	Zarit Family Burden Scale	✓ Total burden scale mean score of caregivers was 60.5 ✓ Coping mechanisms including burn-out, despair and fatalistic perspective were associated with burden
2	Zarit Caregiver Burden Scale	✓ There was no total burden scale mean score of caregivers
3	Zarit Family Burden Scale	✓ Total burden scale mean score of people providing care to patients who used alcohol-substances was 80.6, of caregivers of patients who did not use alcohol-substances was 63.9
4	Perceived Family Burden Scale	✓ Caregiver burden and quality of life, anxiety level were associated ✓ Total burden scale mean score of caregivers was 20.9 ✓ Caregiver burden and social functionality level, depression and anxiety level were associated
5	Caregiver Burden Inventory	✓ Total burden mean score of females (54.6) was significantly higher compared to male caregivers (44.6)
6	Zarit Caregiver Burden Scale	✓ Total burden scale mean score of caregivers was 42.5
7	Zarit Care Scale	✓ The burden of caregiving was high in caregivers of both schizophrenia patients and patients with bipolar disorder; however, there was no significant difference between two groups
8	Perceived Family Burden Scale	✓ Subjective burden mean score of caregivers was 28.9, their objective burden mean score was 8.7
9	Caregivers Burden Inventory	✓ Total burden scale mean score of caregivers was 30.5
10	Zarit Caregiver Burden Scale	✓ While total burden scale mean score before psycho-education was 57.2, this score after the psycho-education was 34.3, and this difference was significant
11	Zarit Caregiving Burden Scale	✓ There was no total burden scale mean score of caregivers ✓ Burden and the dependency status in activities of daily living were associated
12	Zarit Caregiver Burden Scale	✓ Total burden scale mean score of caregivers of patients was 36.3, while the mean score of healthy individuals was 11.0 ✓ There was a relationship between poor insight and burden
13	Zarit Caregiver Burden Scale	✓ Total burden scale mean score of caregivers was 55.8 ✓ There was a relationship between the social functionality levels of the patients and burden
14	Zarit Family Burden Scale	✓ Pre-education burden scale mean score of patient relatives in the experimental group was 75.7, of patient relatives in the control group was 96.5 ✓ Family burden mean score of experimental group caregivers was significantly lower after the education and telephone follow-up
15	Zarit Caregiving Burden Scale	✓ Total burden scale mean score of caregivers was 51.8
16	Perceived Family Burden Scale	✓ Total burden scale mean score of caregivers was 39.4 ✓ Burden and quality of life were associated
17	Perceived Family Burden Scale	✓ After the education, objective (from 11.8 to 9.8), subjective (from 37.9 to 32.7) and total burden (from 49.6 to 42.6) scores of families were significantly lower
18	Zarit Burden of Care Scale	✓ Total burden scale mean score of caregivers was 68.6 ✓ There was a relationship between the burden of caregivers and their self-sufficiency
19	Zarit Caregiving Burden Scale	✓ Total burden scale mean score of caregivers was 45.6 ✓ Of caregivers, 44.9% had moderate or severe level of burden perception
20	Zarit Caregiver Burden Scale	✓ Total burden scale mean score of caregivers was 46.2 ✓ There was a relationship between functionality levels of patients and burden
21	Zarit Burden of Care Scale	✓ Total burden scale mean score of caregivers was 23.6
22	Zarit Caregiving Burden Scale	✓ Total burden scale mean score of caregivers was 29.0 ✓ As social support of families increased, the burden of care reduced
23	Disease Burden Assessment Scale	✓ Total burden scale mean score of caregivers was 45.4 ✓ Caregivers burden and risk of mental illness were associated

*See Table 1.

with 243 caregivers, and their burden scale mean score was found to be 45.4 (as total scores on the scale increase, burden perception increases).^[24,33]

Descriptive Characteristics That Affect Caregiver Burden

In most of the studies, the researchers examined the descriptive characteristics that affect caregiver burden. The descriptive characteristics that affect caregivers burden are examined in two groups: factors regarding patients and factors regarding caregivers. Although many different variables were examined in studies, the factors regarding patients that affect the caregiver burden are generally: age, gender, social security, marital status, diagnosis, symptoms, stage and duration of illness, dependency level, having received treatment and the presence of a comorbid diagnosis.^[6,14,17,18,28,31,33-38] On the other hand, the factors regarding caregivers are: gender, marital status, educational background, socioeconomic status, social support perception, having received education about the disease, mental status and medical condition.^[6,11,17,18,27,29,31-33,37,39-41]

Other Factors That Affect Caregiver Burden

This study found that, other than descriptive characteristics, some other variables that affect the caregiver burden were also examined. The studies conducted found positive significant relationships between caregiver burden and coping mechanisms,^[39] depression and anxiety levels,^[14,29,31] and risk of mental illness,^[33] and negative significant relationships between caregiver burden and quality of life,^[14,37] self-sufficiency levels,^[26] patients' functionality levels^[36,38] and social support levels.^[41]

The Results of the Experimental Studies

Of the studies examined, two used a pretest-posttest, quasi-experimental design, and one used a randomized controlled experimental design. All three were conducted with caregivers for schizophrenia patients. The study by Tanrıverdi and Ekinçi (2012) provided psychoeducation to patient relatives, and the study by Yıldırım et al. (2013) provided a family to family support program. Both studies found that caregiver burden was significantly reduced after their educational programs.^[19,30] Similarly, Özkan et al. (2013) provided psychoeducation to control group patient relatives and offered them telepsychiatric follow-ups after discharge. They also found that family burden mean score of the experimental group caregivers were significantly reduced after the education and telephone follow-up (Table 2).^[20]

Discussion

The existence of a patient with a chronic mental illness who needs a continuous care in a family can cause disorders in family functions and problems and burdens for family members.^[8] Therefore, determining the burden experienced by their caregivers, variables associated with burden and at-

tempts to reduce burden are highly important for both patients and caregivers. The first studies in Turkey of caregivers for patients with chronic mental illness were conducted in 2007, and ever-increasing numbers of studies of this issue have been carried out in recent years. Since this topic has only recently been studied, most of the studies conducted are descriptive. However, it is believed that more experimental and even qualitative studies should be conducted to understand in detail how caregivers experience perceived burden and to plan and introduce productive initiatives to reduce it. Of the 23 studies included in this study, 15 were conducted with caregivers for patients with schizophrenia. Schizophrenia is a chronic mental illness that has direct effects on both patients and family members who live with them, because it begins at early ages, affects emotions, thoughts and behaviors and considerably impair adaptation to the environment.^[7,27,39] Therefore, schizophrenia is the most important illness which causes the most burden for caregivers. The other eight studies included in this study were conducted with other mental illness groups (Table 1). There is a need for studies examining the burden of caregivers for patients with other chronic mental illnesses, which affect both patients and family members as much as schizophrenia.

This study found that, in the studies examined, four different measurement scales were used to determine caregiver burden, most often the Zarit Caregiver Burden Scale. The Zarit Caregiver Burden Scale is used more than other scales because it is inclusive, not specific to conditions requiring care, and its subdimensions are valid.^[22] Different measurement scales were used in studies, making it impossible to be clear on scale mean scores. However, an assessment may be done taking scale score intervals into consideration. Although providing care to relatives is considered an accepted, and even an expected, behavior in Turkish culture, the total burden mean scores of the caregivers indicate that they generally had moderate and severe levels of burden perception. This may be due to changes in lifestyles and traditional family structure. The support of family members has decreased as nuclear family structure has taken the place of the extended family structure in our gradually modernizing society, and as a result of which, caregiver burden has increased.^[8] Similar studies conducted in many countries have found similar results. A study by Alexander et al. (2016) with caregivers for schizophrenia patients found that caregivers perceived a moderate level of burden.^[42] A study by Bergvall et al. (2011) with caregivers for patients with Alzheimer's disease found that caregivers perceived a slight-moderate level of burden, and a study by Loi et al. (2015) with caregivers for patients with mental illness found that caregivers perceived a moderate-severe level burden.^[43,44] Luchsinger et al. (2015) found that caregivers for patients with mental illness perceived a

high level of burden, and Navidian and Bahari (2008) found that caregivers for patients with mental illness found that caregivers perceived a moderate-severe level of burden.^[42-46]

This study found that both descriptive characteristics that affect caregiver burden and other variables were examined by most of the studies. Although many results were obtained, this study determined that descriptive characteristics generally were: age, gender, diagnosis, stage and duration of illness, having received treatment, dependency level and the presence of a comorbid diagnosis for the patients, and, for the caregivers, gender, educational background, socioeconomic status, social support perception, having received education about the disease and mental condition. In addition, caregivers' coping mechanisms, depression and anxiety levels, risk of mental illness, quality of life, self-sufficiency levels, patients' functionality levels and social support levels were the other variables analyzed. A study conducted by Srivastava et al. (2016) with patients with dementia determined an inverse relationship between quality of life and burden perception.^[47] A study by Ampalam et al. (2012) showed that caregiver burden increased with the duration of illness and the age of caregivers, a study by Han et al. (2012) found that the factors that affect caregiver burdens were the profession of the patient, the educational background of the caregiver and coping mechanisms, and a study by Olawale et al. (2014) determined a relationship between caregiver burden and age of onset, number of hospitalizations and the presence of active symptoms.^[48-50]

The literature reports that the burden perceived by caregivers is associated with variables such as depression, anxiety, burn-out, impairment in physical health and social support.^[3,7,51] However, it is not possible to be clear on that care provision leads to the development of physiological and psychological problems or causes these problems, or that these problems make it difficult to provide care.

A few of the studies included in this research were experimental: two provided psycho-education, and one provided a family to family support program. The reason why the number of experimental studies is low and why these studies are not within the scope of family intervention studies is because this topic has recently started to be researched in Turkey. All three of the experimental studies examined found that education significantly reduced caregiver burden. Psycho-education, one of the family interventions, provides patients and their families information about the nature, treatment and care of mental illness and supports the development of their coping skills, which significantly reduces caregiver burden.^[52] Another family intervention is family to family support programs. Family to family support programs have been included in the mental illness system in the last decade because these programs fill the need for education that the mental

health system cannot meet.^[53] Published studies have found that participating in family support groups offered for families of people with a chronic mental illness makes care provision easier and contributes to reducing the burden and stress families experience.^[30,53]

Conclusion

This systematic analysis of the studies conducted in Turkey to determine the burden of caregivers for patients with chronic mental illness found that: the majority were descriptive, most were carried out with caregivers for schizophrenia patients, different measurement tools were used to determine burden, and the caregivers had moderate to severe levels of burden perception.

The experimental studies that have been conducted in Turkey to determine caregiver burdens are not sufficient. More experimental and qualitative studies with different specific sample groups should be conducted. Family intervention practices provided to caregivers are also important for analyzing this burden. Psycho-education and family to family support programs for caregivers should be popularized and included in the mental health system. The popularization of community-based mental health services and the improvement of home care services and day hospitals also reduce the burden of caregivers and make a contribution to improving their quality of life.

References

1. Gültekin BK. Ruhsal bozuklukların önlenmesi: kavramsal çerçeve ve sınıflandırma. *Psikiyatride Güncel Yaklaşımlar* 2010;2:583–94.
2. Buldukoğlu K, Bademli K, Karakaya D, Göral G, ve ark. Ruhsal hastalığı olan ebeveynle yaşamak. *Psikiyatride Güncel Yaklaşımlar* 2011;3:683–703.
3. Tel H, Ertekin Pınar Ş. Investigation of the Relationship between Burnout and Depression in Primary Caregivers of Patients with Chronic Mental Problems. *Journal of Psychiatric Nursing* 2013;4:145–52.
4. Alataş G, Kahiloğulları AK, Yanık M. Ulusal Ruh Sağlığı Eylem Planı 2011-2023. Ankara: 2011.
5. Çetinkaya Duman Z, Bademli K. Kronik psikiyatri hastalarının aileleri: Sistematik bir inceleme. *Psikiyatride Güncel Yaklaşımlar* 2013;5:78–94.
6. Yavaş Ayhan A. Şizofreni Hastalarına Bakım Verenlerin Sağlık Eğitimi Gereksinimleri ile Bakım Yükleri Arasındaki İlişkinin İncelenmesi. [Yayınlanmamış yüksek lisans tezi] Ankara: Gazi Üniversitesi, Sağlık Bilimleri Enstitüsü; 2013.
7. Schulze B, Rössler W. Caregiver burden in mental illness: review of measurement, findings and interventions in 2004-2005. *Curr Opin Psychiatry* 2005;18:684–91.
8. Gülseren L. Şizofreni ve aile: güçlükler, yükler, duygular, gereksinimler. *Türk Psikiyatri Dergisi* 2002;13:143–51.
9. Magliano L, Fiorillo A, Malangone C, De Rosa C, et al. Patient functioning and family burden in a controlled, real-world trial of family psychoeducation for schizophrenia. *Psychiatr Serv* 2006;57:1784–91.
10. Tel H, Saraç B, Günaydın Y, Medik K, ve ark. Psikiyatrik hastalık tanılı primer bakım vericilerinin sosyal destek durumunun belirlenmesi. *Psikiyatri Hemşireliği Dergisi* 2010;1:103–7.
11. Yıldırım FG. Psikiyatri Hastalarına Bakım Verenlerin Ruhsal Durumları ve Bakım Yükünün Değerlendirilmesi. [Yayınlanmamış yüksek lisans tezi] İstanbul: Haliç Üniversitesi, Sağlık Bilimleri Enstitüsü; 2014.

12. Küçükgüçlü Ö, Esen A, Yener G. The Reliability and Validity of The Caregiver Burden Inventory in Turkey. *J Neurol Sci* 2009;26:60–73.
13. Işık K. Yaşlı Hastaya Evde Bakım Verenlerin Yaşam Doyumları ile Bakım Yükleri Arasındaki İlişki ve Etkileyen Faktörler. [Yayınlanmamış yüksek lisans tezi] Malatya: İnönü Üniversitesi, Sağlık Bilimleri Enstitüsü; 2013.
14. Depçe AA. Erkek Şizofreni Hastalarında Bakım Veren Yükü Açısından Alkol ve Madde Kullanımı Varlığının Etkisi. [Yayınlanmamış Uzmanlık Tezi] İstanbul: Bakırköy Prof. Dr. Mazhar Osman Ruh Sağlığı ve Sinir Hastalıkları Eğitim ve Araştırma Hastanesi; 2010.
15. Liberman RP. Yetiyetiminden İyileşmeye: Psikiyatrik İyileştirim El Kitabı. Yıldız M, çev ed. İstanbul: Türkiye Sosyal Psikiyatri Derneği; 2011.
16. Yıldırım S, Engin E, Başkaya V. The Burden of Caregivers of Stroke Patients and the Factors Affecting the Burden. *Archives of Neuropsychiatry* 2013;50:169–74.
17. Çetin N, Demiralp M, Oflaz F, Özşahin A. The relationship between daily life activity levels of schizophrenia patients and care burden and expressed emotion statuses of their family members. *Anadolu Psikiyatri Derg* 2013;14:19–26.
18. Çetinkaya F, Karadakovan A. Demanslı hastaya bakım verenlerin bakım yükünün incelenmesi. *Turkish Journal of Geriatrics* 2012;15:171–8.
19. Tanrıverdi D, Ekinci M. The effect psychoeducation intervention has on the caregiving burden of caregivers for schizophrenic patients in Turkey. *Int J Nurs Pract* 2012;18:281–8.
20. Özkan B, Erdem E, Ozsoy SD, Zararsız G. Effect of psychoeducation and telepsychiatric follow up given to the caregiver of the schizophrenic patient on family burden, depression and expression of emotion. *Pak J Med* 2013;29:1122–7.
21. İnci FH, Erdem M. Validity and reliability of the burden interview and its adaptation to Turkish. *Journal of Anatolia Nursing and Health Sciences* 2008;11:85–95.
22. Özlü A, Yıldız M, Aker T. Zarit Bakıcı Yük Ölçeği'nin şizofreni hasta yakınlarında geçerlilik ve güvenilirlik çalışması. *Nöropsikiyatri Arşivi* 2009;46:38–42.
23. Arslantas H, Adana F, Dereboy F, Altınyazar V, et al. Algılanan Aile Yükü Ölçeği'nin Türkçe sürümünün geçerlilik ve güvenilirlik çalışması. *Nöropsikiyatri Arşivi* 2011;48:53–8.
24. Aydemir O, Dikici DS, Akdeniz F, Kalaycı F. Reliability and validity of the Turkish version of the burden assessment scale. *Nöropsikiyatri Arşivi* 2012;49: 276–81.
25. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980;20:649–55.
26. Durmaz H, Okanlı A. Investigation of the effect of self-efficacy levels of caregiver family members of the individuals with schizophrenia on burden of care. *Arch Psychiatr Nurs* 2014;28:290–4.
27. Ak M, Yavuz KF, Lapsekili N, Türkçapar MH. Evaluation of burden in a group of patients with chronic psychiatric disorders and their caregivers. *Düşünen Adam The Journal of Psychiatry and Neurological Sciences* 2012;25:330–7.
28. Erten E, Alpman N, Özdemir A, Fıstıkçı N. Bipolar I bozukluğu olan hastalarda dönem ve seyir özelliklerinin bakıcı yüküne etkisi. *Türk Psikiyatri Derg* 2014;25: 114–23.
29. Aydın A, Eker SS, Cangür Ş, Sarandöl A, et al. Şizofreni hastalarında bakım veren külfet düzeyinin, sosyodemografik değişkenler ve hastalığın özellikleri ile ilişkisi. *Nöropsikiyatri Arşivi* 2009;46:10–4.
30. Yıldırım A, Buzlu S, Aşlar RH, Camcıoğlu TH, et al. Şizofreni hastalarının ailelerine uygulanan aileden aileye destek programının hastalık hakkında bilgi, aile yükü ve öz yeterlilik üzerine etkisi. *Türk Psikiyatri Derg* 2013;25:1–7.
31. Gülseren L, Çam B, Karakoç B, Yiğit T, et al. The perceived burden of care and its correlates in schizophrenia. *Türk Psikiyatri Derg* 2010;21:1–8.
32. Akpınar B, Küçükgüçlü Ö, Yener G. Effects of gender on burden among caregivers of Alzheimer's patients. *Journal of Nursing Scholarship* 2011;43:248–54.
33. Kızılırmak B, Küçük L. Care Burden Level and Mental Health Condition of the Families of Individuals With Mental Disorders. *Arch Psychiatr Nurs* 2016;30:47–54.
34. Arslantaş H, Adana F. Şizofreni hastalarının bakım vericilerinin yük algısını ve duygu dışavurumunu etkileyen etkenler. *Anadolu Psikiyatri Dergisi* 2012;13:8–15.
35. Cicek E, Cicek IE, Kayhan F, Uguz F, et al. Quality of life, family burden and associated factors in relatives with obsessive-compulsive disorder. *Gen Hosp Psychiatry* 2013;35:253–8.
36. Kaya Y. Şizofreni Hastalarının Sosyal İşlevsellikleri ve Hastalara Bakım Veren Yakınlarının Bakım Yükü. [Yayınlanmamış yüksek lisans tezi] Ankara: Hacettepe Üniversitesi, Sağlık Bilimleri Enstitüsü; 2013.
37. Yeşildağ Bayrak B. Şizofren Hastaların Aile Üyelerinin Algılanan Aile Yükünün Yaşam Kalitesinin Belirlenmesi. [Yayınlanmamış yüksek lisans tezi] Sivas: Cumhuriyet Üniversitesi, Sağlık Bilimleri Enstitüsü; 2013.
38. Pazvantoğlu O, Sarısoy G, Böke Ö, Alptekin Aker A, et al. Şizofrenide bakım veren yükünün boyutları: Hastaların işlevselliğinin rolü. *Düşünen Adam The Journal of Psychiatry and Neurological Sciences* 2014;27:53–60.
39. Özlü A. Şizofreni Hastalarına Bakım Verenlerde Yük ve Travma Sonrası Gelişim ile İlgili Özellikler. [Yayınlanmamış yüksek lisans tezi] Kocaeli: Kocaeli Üniversitesi, Sağlık Bilimleri Enstitüsü; 2007.
40. Çınar İ. Şizofreni Hasta Ailelerinin Bakım Yükleri ve Sosyal Destek Düzeyleri Arasındaki İlişkinin İncelenmesi. [Yayınlanmamış yüksek lisans tezi] İzmir: Ege Üniversitesi, Sağlık Bilimleri Enstitüsü; 2011.
41. Nehir Türkmen S, Dirgen Ö, Biçici Y, Uzun M. Ruhsal bozukluğu olan bireylerin ailelerinde bakım yükü ve algılanan sosyal destek. *Uluslararası Hakemli Psikiyatri ve Psikoloji Araştırmaları Dergisi* 2015;5:55–75.
42. Alexander G, Bebee CE, Chen KM, Vignes RM, et al. Burden of caregivers of adult patients with schizophrenia in a predominantly African ancestry population. *Qual Life Res* 2016;25:393–400.
43. Bergvall N, Brinck P, Eek D, Gustavsson A, et al. Relative importance of patient disease indicators on informal care and caregiver burden in Alzheimer's disease. *Int Psychogeriatr* 2011;23:73–85.
44. Loi SM, Dow B, Moore K, Hill K, et al. The adverse mental health of carers: Does the patient diagnosis play a role? *Maturitas* 2015;82:134–8.
45. Luchsinger JA, Tipiani D, Torres-Patiño G, Silver S, et al. Characteristics and mental health of Hispanic dementia caregivers in New York City. *Am J Alzheimer's Dis Other Dement* 2015;30:584–90.
46. Navidian A, Bahari F. Burden experienced by family caregivers of patients with mental disorders. *Pakistan Journal of Psychological Research* 2008;23:19–28.
47. Srivastava G, Tripathi RK, Tiwari SC, Singh B, et al. Caregiver Burden and Quality of Life of Key Caregivers of Patients with Dementia. *Indian J Psychol Med* 2016;38:133–6.
48. Ampalam P, Gunturu S, Padma V. A comparative study of caregiver burden in psychiatric illness and chronic medical illness. *Indian J Psychiatry* 2012;54:239–43.
49. Han KC, Tsai YF, Chen MC, Chen YY. Violent schizophrenia patients: caregiver burden and related factors. *Hu Li Za Zhi* 2012;59:29–39.
50. Olawale KO, Mosaku KS, Fatoye O, Mapayi BM, et al. Caregiver burden in families of patients with depression attending Obafemi Awolowo University teaching hospitals complex Ile-Ife Nigeria. *Gen Hosp Psychiatry* 2014;36:743–7.
51. Atagün Mİ, Balaban ÖD, Atagün Z, Elagöz M, et al. Kronik hastalıklarda bakım veren yükü. *Psikiyatride Güncel Yaklaşımlar* 2011;3:513–52.
52. Pitschel GW. Family psychoeducation. *J Schizophrenia Res Soc* 2010;3:5.
53. Dixon L, Stewart B, Burland J, Delahanty J, et al. Pilot study of the effectiveness of the family-to-family education program. *Psychiatr Serv* 2001;52:965–7.