

The Relationship Between the Burden of Caregiving and Loneliness in Primary Caregivers of Patients with Schizophrenia

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Abstract

Objective: This study aims to determine the relationship between the burden of caregiving, and loneliness in primary caregivers of patients with schizophrenia.

Method: The study was conducted at the Community Mental Health Center of a university hospital. The sample of the study was found to be 58 primary caregivers. The data were collected using an introductory information form that was prepared by the researchers to inquire about socio-demographic characteristics. The Zarit Caregiver Burden Scale and UCLA Loneliness Scale.

Results and Discussion: Participants' burden of care and loneliness scores are higher than average. Due to the burden of care, women, marriages, literate and mothers have formed a risk group? There is a weak correlation between the burden of care and loneliness in the direction of the results obtained from study, and the burden of the caregivers has reached the result that they feel more alone.

Conclusion: There is a weak correlation between the burden of care and loneliness in the direction of the results obtained without the work, and the burden of the caregivers has reached the result that they feel more alone.

Keywords: Primary caregivers; Patients; Schizophrenia

Introduction

In the report published by the World Health Organization in 2001, 25% of the world population has a mental health problem and it is explained that the parents who care for these people have significant stress and burden due to mental illness. The report also considers schizophrenia to be one of the top five diseases that cause stress and stress in the family of mental illnesses [1]. Because schizophrenia patients often live with their parents at home, family members play an important role in the care of the patients with schizophrenia. One of the family members has to take care of the patient as the primary caregiver. As the primary caregiver is at the centre of the patient's daily life, as the responsibility to care for the patient increases, it becomes a one-way, addictive, intense and long-lasting obligation that puts the caregiver's life into trouble [2].

Giving care to the patient with schizophrenia can have a negative impact on the primary caregiver. Psychosocial and economic difficulties may be seen in primary caregiver who has to give long-term care in schizophrenia. These difficulties can lead to emotional problems such as burden, depression, anxiety, burnout, physical health impairment, social isolation and economic difficulties, stress, guilt, loneliness, anxiety, fear, stress, anger, loss and hopelessness [2-4].

Caregivers of patients with schizophrenia experience high levels of burden and psychological morbidity, as well as social isolation, impaired physical health and financial difficulties [5]. Once caregivers cannot cope effectively with the difficulties they experience, they feel a burden in social, emotional, economic and physical aspects [6]. The burden of the caregiver is categorized into two groups: objective and subjective. The objective burden is described as the observable, concrete changes resulting from the disease. The subjective burden, on the other hand, includes emotional difficulties that come out of individual assessments regarding the caregiver and the disturbing behavior of the patients [7]. Several studies also suggest that Caregivers of patients with schizophrenia are at a high risk for

experiencing burden [8-10]. Caring for patient with schizophrenia has been associated with subjective burden, depression, distress, reduced quality of life, lower social [11].

Primary caregivers of patients with schizophrenia often face daily stressors of having to manage the unpredictable and bizarre behaviour of their relative with schizophrenia, external stressors of stigma and isolation, emotional frustration such as guilt and loneliness, family conflict, and burnout in the caring process [12,13]. For many carers, frustration, anger, loneliness and despair are common [14]. In a study conducted in Iran revealed that six major themes included fears and anxiety for the future, psychosomatic impact, feeling isolated and loneliness, financial impact, change in lifestyle and family functioning, and lack of support and knowledge in experiences of primary caregivers [15].

Despite the fact that there are many studies evaluating the burden level of caregivers in the literature, there was no study evaluating the loneliness they experienced. Examining the relationship between the burdens of primary caregivers, and loneliness will allow for the development of interventions and program content that will help caregivers effectively cope with their burdens, and loneliness. Thus, this study aims to determine the relationship between the burden of caregiving, and loneliness in primary caregivers of individuals with patients with schizophrenia.

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Research Questions

1. Does the primary caregiver's burden differ from the socio-demographic characteristics?
2. Does the level of loneliness differ according to socio-demographic characteristics?
3. Is there a relationship between the primary caregiver's burden of care and loneliness?

Materials and Methods

This study was designed to identify the relationship between caregiving burden and loneliness in primary caregivers for patient with schizophrenia.

The study was conducted at the Community Mental Health Center of a university hospital. The Community Mental Health Center has been in service since April 2015. The center has a physician, an assistant, a part-time psychologist, a nurse, a teacher for five occupational therapies, a secretary and a security worker. In the center there are a training hall, an occupation room, an interview room, a patient observation room, a group therapy room, a recreation room, a team room, a library and a kitchen. The center serves between 08.00-17.00 hours on weekdays. Average 68 patients with schizophrenia registered in the Community Mental Health Center. The diagnoses of these patients are from the nursing home with 15 patients with schizophrenia, bipolar and psychosis. An average of 25 patients per day comes to the center. Physician nurses work together with centralized attention exercises, group therapy, social mental skills training, cinema therapy and sports applications. At the same time, paintings, handicrafts, music and culinary activities are held in the presence of teachers.

Sample of the study

The study's sample consisted of individuals over the age of 18 who gave primary care to patients with schizophrenia from a Community Mental Health Center. The sample of the study was found to be 58 primary caregivers.

Inclusion criteria

- Being literate (able to understand and complete survey forms)
- Living with the patient for at least six months and being the primary caregiver

Exclusion criteria

- Not having any mental disorder

Data collection tools

The data were collected using an introductory information form that was prepared by the researchers to inquire about sociodemographic characteristics. The Zarit Caregiver Burden Scale and Ucla Loneliness Scale.

Zarit Caregiver Burden Scale

This scale was developed by Zarit, Reever, and Bach-Peterson in 1980, and it is utilized to examine the stress of those who provide care to individuals with special needs, or to older adults. The scale can be completed by the caregivers or the researchers through asking questions. It consists of 22 statements that determine the effect of caregiving on the individual's life. This was a Likert-type scale including items scored from "0" to "4", which refer to never, rarely, often or almost every time

[16]. A minimum of 0 (zero) points and a maximum of 88 points can be obtained from the scale. The scale has no cut-off point. Scale items reference social and emotional concerns. Higher scale points mean the respondents have a higher level of difficulty [16,17]. The validity of the Caregiver Burden Scale was examined by Fadime Hatice İnci in 2006 using the language equivalence, content equivalence and structural equivalence methods of the scale; the reliability of the scale was examined using internal consistency, item analysis and test-retest reliability methods. The internal consistency coefficient of the scale was found to range from 0.87 to 0.94, its test-retest reliability was found to be 0.71 [17]. The alpha score obtained in this study was 0.79.

UCLA Loneliness Scale

The UCLA loneliness scale is a likert type self-assessment scale used to determine the general level of loneliness of the individual. The original form of the scale has a rating of between 20 items (1) and 1 "Totally Disagree" (Russell, Peplau (4)), which is positive, meaning that there is no semantically loneliness and the other 10 items are negative, meaning semantically only individuals and Cutrona. The highest score that can be taken from the scale is 80 and the lowest score is 20. High scores indicate that individuals are experiencing more loneliness. Validity and reliability studies in our country were carried out by Demir and he conducted a total of 72 analyzes on the internal consistency of the scale and the cronbach alpha internal consistency coefficient was calculated as 0.96. The test retest reliability coefficient of the scale was found to be 0.94. The UCLA Loneliness Scale appears to have been used in many studies on loneliness in the world and in our country.

Data collection

The data were collected by the researchers through the face-to-face interview method. Before starting the research, all the forms in the study of the two primer caregivers applied and the clarity of the questions assessed. Pre-application forms are not included in the sampling.

Independent variables

- Socio-demographic characteristics (gender, age, marital status, educational status, working status)

Dependent variables

- Burden level
- Loneliness Level

Data analysis

In the analysis of the data, IBM 21 package program was used. In the comparison of sociodemographic data and scales, t test was used in independent groups and Pearson correlation analysis was used in evaluating the relationship between scales.

Research ethics

It was initiated before institutional and ethical approval was obtained before the research began. The informed consent form was read to the individuals before the questionnaire forms were filled and verbal approvals and signatures of the individuals were obtained.

Results

When the descriptive characteristics of caregivers participating in the survey are examined, it is seen that the average age is 46.35 ± 7.66 , 68.1% is female, 53.2% is primary school graduate, 85.2% of the

patients were married, 47.6% had a chronic disease and 61.7% of them had a mother's care for 9.32 ± 3.22 years. When the characteristics of the area of care were examined, it was found that 38.30 ± 10.16 , 71.3% of the average age was male and 9.23 ± 5.24 years.

When the average of caregiver burden and loneliness scale scores of caregivers were examined, it was seen that average of care load score was 53.87 ± 21.61 and that of loneliness score was 56.97 ± 6.44 (Table 1).

When the caregiver characteristics of the caregivers are compared with the average of the burden scale points; There was statistically significant difference between gender and care load averages ($p < 0.05$) and the burden of women was found to be higher than that of men. The marital status was found to be statistically significant, literate and mother ($p < 0.05$) There was no statistically significant difference between the groups in terms of period and burden scale point average ($p > 0.05$) (Table 2).

When the mean scores of the loneliness scale were compared with the descriptive characteristics of the caregivers, were significantly higher and the difference was statistically significant ($p < 0.05$). It was found that the mean scores of the loneliness scale were higher and the difference was statistically significant when married, primary and high school graduates and mothers ($p < 0.05$). There was no statistically significant difference between the groups in terms of the mean duration of care and loneliness scale scores, and the difference was not significant ($p > 0.05$) (Table 2).

Scale	Mean \pm SD	Range of point
Burden	53.87 ± 21.61	17-88
Loneliness	56.97 ± 6.44	16-80

Table 1: Distribution of average scores of caregivers from scales.

Variables	Burden scale	Loneliness Scale
Gender		
Female	56.46 ± 21.04	58.06 ± 6.11
Male	52.65 ± 21.95	56.46 ± 6.63
Test value, p	t: 0.51	t: 0.084
	p: 0.03'	p: 0.02'
Marital status		
Married	56.09 ± 19.76	57.80 ± 6.97
Single	49.56 ± 24.94	55.37 ± 5.09
Test value, p	t: 4.234	t: 3.659
	p: 0.04'	p: 0.04'
Education		
Literate	57.87 ± 19.61	54.06 ± 4.07
Primary school and upper	51.80 ± 22.61	58.48 ± 6.97
Test value, p	t: 0.793	t: 9.476
	p: 0.02'	p: 0.01'
Caregiving duration		
2-10 year	53.82 ± 20.90	56.05 ± 5.00
11-20 year	53.90 ± 22.36	57.50 ± 7.16
Test value, p	t: 0.131	t: 2.302
	p: 0.02'	p: 0.136
Relationship		
Mother	54.68 ± 20.02	55.65 ± 5.91
Another'	52.55 ± 24.52	59.11 ± 6.86
Test value, p	t: 2.093	t: 1.442
	p: 0.01'	p: 0.02'
p<0.05 "Another (Children and wife)		

Table 2: Comparison of caregiver characteristics of caregivers with burden and loneliness point averages.

Variables	Burden	Loneliness
Burden	1.00	1.00
Loneliness	r: 0.457 p: 0.02'	
r: Pearson co-relation test, p<0.05		

Table 3: The relationship between caregivers' burden and loneliness points average (r, p).

When the relationship between caregivers' care burden and loneliness level point average is examined; there was a weak relationship between burden and loneliness in the positive direction (r: 0.457 p: 0.02) (Table 3).

Discussion

This study sought to understand the consequences of family caregiving to patients with schizophrenia. Caring for patients with schizophrenia has been associated with burden and loneliness. When the descriptive characteristics of the study were examined, the majorities of the caregivers participating in the study was female, was married, and were primary school graduates. According to the results obtained from study there was a weak correlation between the burden and loneliness in the positive direction.

This study showed that women, particularly mothers, literate and married consider themselves to have higher levels of the burden of caregiving. A review study reported that, in the epidemiological data women, and most frequently the mother, are the principal caregivers in schizophrenia this can be attributed to gender role expectations that females should assume a primary caregiving role [18]. In traditional Turkish culture the role of mother tends to require the female to be the primary caregiver for patient with schizophrenia. These gender differences may be related to traditional Turkish culture.

In this study caregiver patient with schizophrenia burden scores are higher than average. In a study conducted by Hsiao and Tsai reported that caregivers of patients with schizophrenia experienced a moderate level of burden. Prior studies about caregiver burden found that caregivers of patients with schizophrenia experienced burden too [8-10]. In a study conducted by Zhou reported that higher levels of caregiver burden provide the strongest correlation of living with a schizophrenic patient. In another study of burden among caregivers found that the most distress in relation to patients' problem behaviors and the least distress in relation to patients' role dysfunction [19]. This finding illustrates the importance of examining caregiver burden in relation to different domains.

In this study there was a weak relationship between the burden of care and loneliness in the positive direction. Similarly Srivastava reported that the perceived burden has a serious impact on the caregiver's such as frustration, despair, loneliness and anger, which have an influence on the course of the schizophrenic illness of the patient under care. From this point of view, it is plausible that care burden leads the caregivers to emotional status negatively and caregivers feel lonelier as their care burden increases. Therefore nurses should gather information regarding the coping strategies used by the family caregivers to assess their impact on caregiver burden and loneliness.

Conclusion and Recommendations

Participants' burden of care and loneliness scores are higher than average. Due to the burden of care, women, marriages, literate and mothers have formed a risk group? In terms of loneliness, women, marriages, those with primary education and higher education, and

mothers have formed a risk group. There is a weak correlation between the burden of care and loneliness in the direction of the results obtained without the work, and the burden of the caregivers has reached the result that they feel more alone. Psychiatric-mental health nurses can readily teach adaptive coping skills to regulate the caregivers' burden of caregiving, loneliness as a part of their health promotion and education practices in clinical areas or community settings.

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