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# Caregiving burden in family caregivers of patients with schizophrenia: A qualitative study

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## Abstract:

**INTRODUCTION:** After the psychiatric revolution and implementation of deinstitutionalization policies, caring for people with a mental health condition shifted from psychiatric hospitals to their families. In this way, family caregivers were forced to take full responsibility for taking care of the patients that lead to the occurrence of challenges for them. Only a few studies have investigated the caregiving challenges of family caregivers in patients with schizophrenia.

**AIM:** This study aimed to gain a better understanding of caregiving burden in family caregivers of patients with schizophrenia and its related factors.

**MATERIALS AND METHODS:** This qualitative study was performed based on 12 family caregivers of schizophrenia patients visiting a psychiatric hospital in Tehran in 2018. Sampling was carried out based on the purposive sampling method and was continued until data saturation. All interviews were recorded, transcript, and imported into the MAXQDA software. Then, qualitative content analysis was conducted based on Graneheim and Lundman's five-step method.

**RESULTS:** One theme, two main categories, and five subcategories were identified from the continuous analysis and data comparison. The "Perceived objective burden" as theme included two main categories: "Heavy involvement of caregivers" and "Challenges of the healthcare system".

**CONCLUSION:** The results of this study indicate that the family caregivers of the patients with schizophrenia encounter many problems related to multiple responsibilities in the caring process and challenges in the provision of mental health-care services. This finding could improve psychiatric and mental health nurses' knowledge and awareness about caregiving challenges in family caregiver of patients with schizophrenia and related factors.

## Keywords:

Caregiving burden, family caregivers, qualitative study, schizophrenia

## Introduction

Schizophrenia, as a chronic, severe, and debilitating disorder affects about 3–6.6 cases/1000 persons.<sup>[1]</sup> Concerning its remarkable prevalence of 1.1% in adult, it is estimated that 51 million people around the world suffer from the disorder.<sup>[2]</sup> Since the deinstitutionalization policies, the responsibility for taking care of 50%–90% of psychiatric patients was shifted to their families. In Iran, 65%–75% of patients

with schizophrenia return to their families after discharge from the hospital and their families took care of them.<sup>[3]</sup> Some results indicate that schizophrenia patients require 24-h home care.<sup>[4,5]</sup> Another research reported that 57.4% of these patients could not stay at home alone for more than 3 h.<sup>[6]</sup> Schizophrenia is one of the psychiatric disorders that often have specific caregiving needs.<sup>[7]</sup> Studies reveal that family caregivers have various tasks and help patients to perform their daily and self-care activities.<sup>[7,8]</sup> In general, family

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caregivers have many responsibilities for taking care of these patients. In addition to managing unexpected behaviors of the patients such as aggression and violence, they have to play multiple roles in caring for them which impose a heavy burden on them.<sup>[1]</sup> It was reported that 83%–95% of family caregivers of schizophrenia patients experience a significant burden, which decreases their quality of life and increases exposed the caregivers and patients to various risks.<sup>[8]</sup> The family caregiver burden affected physical, mental, social relationships, economic status of the family caregivers of schizophrenia patients and leading to a variety of disorders such as depression, anxiety, obsessive–compulsive, and other neurotic disorders.<sup>[9]</sup> Furthermore, they experience anger, guilt feeling, fear, hopelessness, sadness, and negative feelings and attitudes toward the patient.<sup>[10,11]</sup> Most of these evidence comes almost exclusively from researches were done in high-income countries that lead to many added challenges in family caregivers in low- and middle-income countries. Some of these challenges include medical, educational, and social services that are often insufficient. In general, little data are available about experiences of family caregivers in low- and middle-income countries.<sup>[7]</sup> On the other hand, the experiences of family caregivers of psychiatric patients have been well reported, but the differences between countries cannot be ignored because of cultural differences and related factors affect people's view and judgment about mental illness and caregiving and they may cause different experiences in caregivers.<sup>[12]</sup> In addition, although existing scales of family caregiver burden have been used in schizophrenia previously, there is little evidence that the content validity of these scales in this population has been confirmed in line with well-established guidelines for the development and evaluation of self-report scales.<sup>[13]</sup> Therefore, given the little studies on caregiving challenges in Iran, there is a need to understand the caregiving challenges from family caregivers themselves. Hence, the aim of the study is to gain a better understanding of the caregiving burden in family caregivers of patients with schizophrenia in their context and declaration of its related factors.

## Materials and Methods

### Design

This study was conducted using a qualitative research method and content analysis approach in 2018. Qualitative studies are appropriate for the understanding of the phenomena in their context and manifestation of the relations between concepts and behaviors, and the formation and modification of theories.<sup>[14]</sup> Twelve family caregivers of patients with schizophrenia who their patients admitted to the Razi psychiatric hospital in Tehran were selected based on the purposive sampling method. Data were collected based on the family

caregivers' experiences that are providing care of patients at home. The inclusion criteria for participants were as follows: Age between 18 and 65 years, providing care to patients with schizophrenia for at least 1 year, free from any diagnosed physical or psychiatric disorder, and also willingness to participate in this study.

### Data collection

The semi-structured and face-to-face interviews were used for data collection. At first, the family caregivers were asked to explain their experience of a day of caring for their patients. The main questions asked in this study were: "Could you please tell me about your experiences of caring for your patient at home?" and "What challenges do you face during caring of your patients at home?" To follow the family caregivers' thoughts and improve the depth of interviews, branching questions were asked such as "What types of care does the patient need?" and "Which factors make you feel more pressured when caring for your patient?" During the interview, further exploratory and in-depth questions were used to probe the explanations, such as "Can you explain this more?". Interview lengths varied between 25 and 45 min and were conducted in a quiet place that was comfortable for participants, such as in a meeting room. All interviews were tape-recorded and transcribed verbatim after each interview. Data collection and data analysis were performed concurrently and were continued until the theme has emerged, and data saturation was reached. The MAXQDA V 10.0 (VERBI Company; Berlin, Germany) was used for data analyzing.

### Data analysis

Data analysis was performed based on the Graneheim and Lundman method<sup>[15]</sup> including (1) the interviews were transcribed verbatim, (2) each of transcriptions was considered as a unit of analysis and were read several times by researcher to achieve a general understanding of its content, (3) the sentences or entire paragraphs of text were determine as meaning units and primary codes were extracted from them (4) classifying similar preliminary codes in more comprehensive classes and finally, determining the hidden content in the data.

### Trustworthiness

Trustworthiness is an important component in the process of qualitative research. In this regard, credibility, dependability, confirmability, and transferability of data were evaluated base on Guba and Lincoln's criteria.<sup>[16]</sup> To this end, prolonged engagement with the family caregivers lasted for 9 months, and also reading the transcripts several times to take a sense of the whole helped to the credibility of the data. Furthermore, initial codes of interviews were returned to some of the participants to ensure the accuracy of the codes and interpretations as member check. In addition, peer checks

were performed by four faculty members and experts in the field of qualitative research and psychiatric and mental health nursing. In addition, maximum diversity among participants in age, gender, level of education, and marital status is another effort of the researcher to reach of trustworthiness.

### Ethical considerations

This study was approved by the Ethics Committee of the University of Social Welfare and Rehabilitation Sciences under Approval Code No. IR.SWR.REC1396.382. All participants were informed clearly and entirely about the aim of the study and about the reason for using a tape-recorded during the interviews. They were also informed that participation in this study was voluntary, and they could withdraw from the study whenever they wanted. In addition, they were assured that any data were collected anonymously. The written informed consent was obtained from family caregivers prior to any data collection.

### Results

The personal demographic information of the participants is presented in Table 1. The analysis of the collected data from the participants culminated in the extraction of one theme, two main categories, and five subcategories. "Perceived objective burden" developed from the data analysis as a theme. Family caregivers of patients with schizophrenia became engaged in taking responsibility for patient care and help them in doing tasks related to different areas of care. The objective burden of care is the observable aspects of the burden that are perceived by family caregivers. In this study, the perceived objective burden is a reflection of heavy involvement of caregivers and inadequacy provision of mental health services for caregivers.

The main category defined as "Heavy involvement of caregivers" included two subcategories "Numerous caregiving tasks" and "Time-consuming care." The

second main category defined as "Challenges of the healthcare system" comprised three subcategories, including "Neglected educational needs of caregivers," "Ineffective medical and health care services," and "limited access to services" [Table 2].

- 1 Many of the caregivers' experiences implied "Numerous caregiving tasks" and "Time-consuming care" related to "Heavy involvement of caregivers" main category
  - a. According to the family caregivers' experiences, issues include helping the patient to perform self-care activities such as helping the patient in cooking, eating, pay attention to the patient's personal hygiene and grooming, tasks relevant to treatment such as visiting physicians, giving medicine, and protecting the patient from engaging in high-risk behavior such as aggression, violence, substance abuse, and high-risk sexual behaviors implied as issues related to "Numerous caregiving tasks" subcategory. One of the family caregiver's statements is as follows: "I have to do everything for my son. He cannot do anything on his own. I have to supervise on everything from eating to taking medicine" (participant no. 1). Another family caregiver asserted that: "I have to take her medication on time and not let him go out to do evil. I always must protect him from unhealthy sexual behaviors, drug abuse, substance abuse, and alcohol drinking" (participant no. 3)
  - b. Family caregivers reported some experiences, including full-time care for the patient, consuming a lot of time for caring for the patient, and caring for many years, which were related to the "Time-consuming care" subcategory. One of the family caregiver's statements is as follows: "Can you imagine how many years I've been taking care of him? He is my first child; now suppose for yourself how many years I've been looking after him?" (participant no. 4). Also, one of the family caregivers expressed:

**Table 1: Personal demographic information of family caregivers**

Participant number	Gender	Age	Job	Relation with the patient	Education level
1	Female	65	Homemaker	Patients' mother	Primary school
2	Female	55	Homemaker	Patients' mother	Diploma
3	Female	35	Homemaker	Patients' wife	Diploma
4	Female	57	Maid	Patients' mother	Diploma
5	Female	40	Homemaker	Patients' wife	Middle school
6	Female	50	Homemaker	Patients' mother	Middle school
7	Male	70	Retired government officer	Patients' grandfather	Primary school
8	Female	30	Homemaker	Patients' wife	Middle school
9	Female	34	Employed in a part -time job	Patients' sister	M. S. degree
10	Male	47	Painter	Patients' husband	Primary school
11	Male	60	Retired teacher	Patients' father	B. S. degree
12	Female	47	Homemaker	Patients' wife	Diploma

**Table 2: Theme, main categories, and subcategories obtained from the family caregivers' experiences in caring for patients with schizophrenia**

Theme	Category	Sub-category	Codes	
Perceived objective burden	Heavy involvement of caregivers	Numerous caregiving tasks	Helping the patient perform self-care activities such as eating, personal hygiene, and grooming.	
			Giving medicine, visiting the doctors.	
			Protecting the patient from engaging in high-risk behavior such as aggression, violence, substance abuse, and high-risk sexual behaviors	
	Challenges of the health-care system	Time-consuming care		Full-time care of the patient.
				Caring for many years
		Neglected educational needs of caregivers		Lack of knowledge about the nature of the disorder, methods of treatment, how to provide care for the patient.
				Insufficient awareness in managing the high-risk behavior of the patient.
				Insufficient awareness in dealing with the patient's resistance to treatment
		Ineffective medical and health care services		Disagreement between the medical team on treatment.
				Lack of providing appropriate education by the medical team
Limited access to services		Ineffective treatment.		
		Poor skills of the health-care providers		
		Refusing to hospitalize the patient when needed.		
			Reduced inpatient time.	
			Lack of postdischarge surveillance planning.	
			The shortage of medicine.	
			The shortage of hospital beds in the ward.	
			Insufficient coverage of insurance	

"I have to look after her for 24 h. I can never leave his alone. If I get out of my house, my life will be on fire, the samovar will be on fire, the stove will be on fire, so I can't get out of the house and have to be there for 24 h" (participant no. 1).

2. The main category "Challenges of the healthcare system" includes three subcategories "Neglected educational needs of caregivers," "Ineffective medical and health care services," and "Limited access to services"

a. In the "Neglected educational needs of caregivers" subcategory, the family caregivers mentioned experiences such as lack of knowledge about the nature of the disorder, methods of treatment, how to provide care for the patient at home, insufficient awareness in managing the high-risk behavior of the patient, and in dealing with the patient's resistance to treatment (i.e., not taking medicine and refusing to visit the doctor). In this regard, some of the family caregivers stated:

- i. "When she broke her mobile phone and laptop, I didn't know how to calm her down, how to deal with her, and I had been very afraid" (participant no. 9)
- ii. "The last time, she was hospitalized for 2 months; after discharge, the doctor prescribed medicine for 1 month, but she refused to take medicine. We tried every possible way to give her medicine, but we couldn't, we did not know how do we convince her to take her pills" (participant no. 10)
- iii. "I don't know anything about my son's illness, only the doctors said to me that your son

had schizophrenia when I asked them more information, they said to me what makes a difference to you that he has what disease, just know he's sick now" (participant no. 2).

b. In the "Ineffective medical and health care services" subcategory, family caregivers stated some experiences such as the disagreement between the medical team on treatment strategies, ineffective treatment, poor skills of the health care providers in therapeutic communication, and lack of providing appropriate education by the medical team. A family caregiver's experience is:

- i. "When she was in the hospital, the nurses told her everything I had said to them about her, and she hates me more, the nurses' behavior was unprofessional" (participant no. 9)
- ii. "Some time ago, someone called me from the hospital and asked me to participate in a group therapy session at the hospital. When I went there, the number of family caregivers was there, and everyone spoke for themselves. I couldn't find why I had been invited there" (participant no. 2)
- iii. "The nurses have not helped us so far, when we ask them about illness of my patient and methods of treatment, they don't answer us, they cannot guide us" (participant no. 12).

c. In the subcategory "Limited access to services," some family caregivers reported experiences such as refusing to hospitalize the patient when needed, reduced inpatient time, lack of postdischarge surveillance planning, the shortage of medicine,

the shortage of hospital beds in the ward, and insufficient coverage of insurance. Some of these experiences are:

- i. "We called the social emergency services when his condition worsened, and they took him to various hospitals during the night, but none of them accepted to hospitalize him" (participant no. 12)
- ii. "Each time we hospitalize him, they call us in less than a week and tell us that he is discharged, whereas his status didn't change compared to the 1<sup>st</sup> day of hospitalization" (participant no. 7)
- iii. "When she was admitted to the hospital, we saw many patients sleeping on the floor and when we asked them about these conditions, they said we didn't have any empty bed" (participant no. 6).

## Discussion

The results of the present study revealed that the caregiving experiences include "Heavy involvement of caregivers" and "Challenges of the healthcare system." Caregivers of patients with schizophrenia play various roles. They are responsible for the patient's personal activities (such as taking a bath), medical and health care (medicine monitoring, injections, etc.), chores (cooking, cleaning the house, etc.), and functional tasks (phone calls, coordination, transportation, etc.).<sup>[17]</sup> Caregiving roles are not easy and may affect the personal life of the caregivers, and the accumulation of these tasks imposes a heavy burden on caregivers.<sup>[1]</sup> Millier *et al.* reported that patients suffering from schizophrenia require 24-h home care.<sup>[5]</sup> In addition, Hou *et al.* established that 57.4% of patients with schizophrenia were able to stay at home alone for no more than 3 h.<sup>[6]</sup> The results of the mentioned studies are consistent with the findings of the present study. Hence, it can be stated that "Heavy involvement of caregivers" is one of the effective factors in the burden imposed on the caregivers of patients with schizophrenia. Our findings suggest that family caregivers of schizophrenic patients have multiple responsibilities in the caregiving process and also help patients perform their daily life and self-care activities. In addition, the duration of contact with patient and long-term caregiving are among other factors, influencing the family caregiver burden of schizophrenic patients. Involvement in caregiving and practical support of patients with schizophrenia contribute to the caregiver's burden because they require additional hours and commitment to caregiving activities that often lead the consequences for caregivers such as job loss, social activity decline, restrictions on leisure activities and then caregivers experience heavy burden.

In elucidating the "Challenges of the healthcare system," the results of studies indicate that caregivers possess limited knowledge and awareness regarding the illness, the related coping strategies, and how to deal with and support the patient.<sup>[5,18]</sup> In addition, researchers reported that there is no integration between the caregivers and the medical team.<sup>[18]</sup> In addition, limited access to psychiatric health-care services, lack of knowledge about available services, and shortage of professional personnel<sup>[19-21]</sup> are some other factors that affect caregiving. The results of the studies validate the findings of the present study.

The caregiver's burden in patients with schizophrenia may be influenced not only by caregiving activities of family caregivers but also by challenges in the provision of mental health-care services. In some countries, where mental health-care services are nonexistent and there is no social welfare system, the role of the family caregivers becomes more important. In this status, the shortage of psychiatric beds, inadequate knowledge about mental illness and treatment, and lack of nurses' awareness about the caregiving role are the most important challenges that are experienced by caregivers as burden. In addition, the involvement of family caregivers in policy-making and service planning is very essential for improving mental health services. Health-care providers, especially mental health professionals, should develop more innovative programs for families and involve them as active members of the health care team by assigning specific tasks for them and allocating the necessary resources for performing such tasks. Furthermore, designing and implementing programs such as postdischarge surveillance and home visits can significantly reduce the family caregiver burden and create an opportunity for engaging families in the caregiving process.

## Limitation

One of the limitations of this study is the less generalization of the result, because the different studied populations, availability of social and psychiatric health services, cultural differences and various religious beliefs may be contributed to acquiring different results. In addition, all of the participants in this study were from Tehran, and maybe family caregivers of other cities in Iran with other cultures report different points of view. In addition, because the results of this study are based on a small sample size of family caregivers of patients with schizophrenia that were admitted to the hospital, the generalizability of the findings is limited.

## Conclusion

The result of this study shows that caring for a patient with schizophrenia imposes a heavy burden on family caregivers. Many caregiving tasks of family caregivers and challenges of the healthcare system are the most

important factors related to a perceived burden. This finding could improve psychiatric and mental health nurses' knowledge about factors affecting the burden, and also it could help them in the identification of high-risk caregivers and designing proper family-based intervention. In addition, healthcare systems could use the result of this study and promote their quality of services by providing caregivers training, accessible health-care services and supportive systems such as home-visit nurses, home-help service providers, mutual support group members, other outreach services.

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### Conflicts of interest

There are no conflicts of interest.

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