

## Original Article

# Impacts of Informal Caregiving among the Family Caregivers of Patients with Schizophrenia: A Qualitative Study

Zahra Tamizi, Masoud Fallahi, Farahnaz Mohammadi Shahboulaghi<sup>1</sup>, Eesa Mohammadi<sup>2</sup>, Enayatollah Bakhshi, Asghar Dalvandi<sup>3</sup>

Department of Nursing and Biostatistics, University of Social Welfare and Rehabilitation Sciences, <sup>1</sup>Department of Nursing, Iranian Research Center on Aging, University of Social Welfare and Rehabilitation Sciences, <sup>2</sup>Department of Nursing, Faculty of Medical Sciences, Tarbiat Modares University, <sup>3</sup>Department of Nursing and Midwifery, Tehran Medical Sciences Branch, Islamic Azad University, Tehran, Iran

### ORCID:

Zahra Tamizi:  
0000-0003-1430-5481;  
Masoud Fallahi:  
0000-0003-0507-0107;  
Farahnaz Mohammadi  
Shahboulaghi:  
0000-0001-8357-0882;  
Eesa Mohammadi:  
0000-0001-6169-9829;  
Enayatollah Bakhshi:  
0000-0001-8049-0190;  
Asghar Dalvandi:  
0000-0001-8762-7591

## INTRODUCTION

Patients with schizophrenia require long-term care and support.<sup>[1]</sup> Deinstitutionalization policies in the past 60 years have assigned a major portion of the responsibility of caring for patients with schizophrenia to their family caregivers.<sup>[2]</sup> Currently, family caregivers are responsible for providing different care services to patients worldwide.<sup>[3]</sup> Around 20%–50% of patients with schizophrenia in Western countries and 70% of these patients in Asian countries live with their families and

### ABSTRACT

**Background:** Caregiving to patients with schizophrenia is burdensome for family caregivers and has profound effects on them. **Objectives:** This study aimed to explore the impacts of informal caregiving among the family caregivers of patients with schizophrenia. **Methods:** This qualitative study was conducted on a purposive sample of 12 family caregivers of patients with schizophrenia and 3 health-care providers. Semi-structured interviews were held for data collection, and conventional content analysis was used for data analysis. **Results:** Four main subthemes were developed during data analysis, namely threatened health, helplessness, patient abandonment, and personal growth. Together with their eight subcategories, these subthemes were grouped into the main theme of the “Consequences of caregiving burden.” **Conclusion:** Caregiving to patients with schizophrenia imposes heavy burden on family caregivers and has different consequences for them. The findings of this study can improve the knowledge and awareness of mental health and psychiatric nurses about schizophrenia and its consequences for family caregivers and can help them identify family caregivers who are at risk for negative consequences and design proper family-based interventions to reduce the effects of these negative consequences.

**KEYWORDS:** Burden, Family caregiver, Qualitative study, Schizophrenia

are dependent on family caregivers.<sup>[4]</sup> The percentage of patients with schizophrenia who live with their families after hospital discharge is also increasing in Iran and has reached to 65%–75%.<sup>[2]</sup>


**Address for correspondence:** Dr. Asghar Dalvandi, Nursing Department of University of Social Welfare and Rehabilitation Sciences, Kodakyar Ave, Daneshjo Blvd, Evin. E-mail: dalvandiasghar@gmail.com

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Caregiving to patients with schizophrenia is burdensome for family caregivers.<sup>[1]</sup> They should provide different types of services to their patients including financial support and health-care services, supervise their daily activities, and take care of them for 6–9 h a day. Although caregiving may be a positive experience for some family caregivers, it can lead to different negative consequences for them such as physical and mental problems which are called caregiver burden.<sup>[5]</sup>

As a complex concept, caregiver burden has two main components, namely objective burden and subjective burden. Objective burden refers to the tangible effects of caregiving, whereas subjective burden refers to caregivers' perception of care and their assessment of objective burden and includes emotional responses to caregiving experiences.<sup>[5,6]</sup> A study showed that 83%–95% of family caregivers and friends of patients with schizophrenia experience a significant caregiver burden.<sup>[7]</sup>

Caregiver burden is associated with many different consequences and can affect different aspects of life. For instance, it reduces the quality of life, endangers the health of both patients and family caregivers,<sup>[7]</sup> undermines caregivers' ability to take care for their patients,<sup>[8]</sup> and disturbs their daily activities. Family caregivers may also experience problems such as employment-related problems, reduced social interactions and leisure activities, psychological distress, social stigma, poor self-assessment, chronic physical problems, excessive use of psychiatric medications, increased risk of hospitalization, financial strains,<sup>[9]</sup> and family tensions.

A descriptive study into the factors related to caregiver burden among the Taiwanese family caregivers of patients with schizophrenia reported that female caregivers, additional dependent relatives, increased family demands, and decreased sense of coherence significantly contributed to caregiver burden.<sup>[10]</sup> The results of a qualitative study in Iran into caregiver burden in family of patients with schizophrenia that admitted to hospital also came into 11 main themes, namely uncertainty, unawareness, emotional burden, stigma and blame, financial burden, physical burden, restriction of routine activities, disruption of routine activities, troubles with patients' medication adherence, problems with governmental support for health-care services, and dissatisfaction with family, relatives, and acquaintances. That study also reported poor physical and mental health, financial problems, and lack of time for routine activities as the most important problems experienced

by family caregivers.<sup>[2]</sup> Another qualitative study into the subjective experiences of the family caregivers of patients with schizophrenia showed that patients were highly dependent on caring and therapeutic services provided by family caregivers, whereas family caregivers lacked time for themselves and for caregiving to their patients and suffered from physical and mental problems (such as fatigue).<sup>[6]</sup>

Because of the profound effects of caregiver burden on caregivers' physical and mental health, caregiver burden reduction is a key component of the programs for assessing the effectiveness of health-care services.<sup>[6]</sup> Yet, studies showed that caregiver burden is largely neglected<sup>[4]</sup> and is still a major challenge in both developed and developing countries.<sup>[11]</sup> Moreover, limited studies had yet addressed caregiver burden among the family caregivers of patients with schizophrenia. Most studies in this area solely assessed the level of caregiver burden using various measurement instruments. Consequently, there is limited information about the health-care-related needs of patients with schizophrenia and their family caregivers, particularly in Iran, due to factors such as the social stigma associated with mental illnesses.<sup>[2]</sup> The earlier studies also mainly focused on caregivers of patients with schizophrenia and affective disorders who were hospitalized. The present study was designed and conducted to address these gaps. Understanding caregiver burden and its consequences among the family caregivers of patients with mental illnesses such as schizophrenia can facilitate the development and implementation of family-centered nursing care programs to meet family caregivers' and patients' needs.<sup>[10]</sup>

## Objectives

This study aimed to explore the impacts of informal caregiving among the family caregivers of patients with schizophrenia.

## METHODS

### Design, setting and participants

This qualitative study was conducted in 2018–2019 on 15 family caregivers of inpatients and outpatients with schizophrenia, a social worker, a psychiatric nurse, and a hospital discharge staff. They were selected from the psychiatric clinics of Imam Hossein and Razi Psychiatric Hospitals, Tehran, Iran. Participants were purposively selected. Inclusion criteria for family caregivers were an age of 18–65, caregiving to a patient with schizophrenia as a family caregiver for at least 1 year, willingness to participate in the study, and no self-report history of mental, neurological, or cognitive problems.

## Data collection

Fifteen semi-structured interviews were conducted for data collection. The main interview questions were, “Would you please tell me about your experiences of caregiving to your patient?” and “May you please tell me about your challenges in caregiving to your patient?” In order to collect rich data, we also used branching questions such as “What complications did you experience during caregiving to your patient?” and “What difficulties did you experience during caregiving to your patient?” Moreover, probing questions were used to further probe into participants’ experiences. Examples of these questions were, “Can you explain more about this?” “Can you give an example of this?” and “Have you ever been in such situation?” The duration of interviews varied from 25 to 45 min. Interviews were held in a quiet private room in the study setting and were recorded using a voice recorder. Data collection was continued until no new conceptual code was obtained from the interviews and the data were saturated.<sup>[12]</sup>

## Data analysis

Data analysis was concurrently performed with data collection through the five-step conventional qualitative content analysis approach proposed by Graneheim and Lundman.<sup>[13]</sup> First, interviews were immediately transcribed verbatim. Second, each interview transcript was considered as a unit of analysis and was read for several times to gain a comprehensive understanding of its content. Third, sentences and paragraphs related to the impact of caregiving were determined as unit of analysis and were coded as primary codes. Fourth, similar primary codes were grouped into subcategories [Table 1]. Fifth, the latent content of the data was determined through the underlying meaning behind the data.

## Trustworthiness

The four criteria proposed by Lincoln and Guba were used to ensure the trustworthiness of the data. Credibility was maintained through prolonged engagement with the data for 9 months and reading interview transcripts for several times to obtain a sense of the whole. Moreover, through the process of member checking, the primary codes of each interview were provided to some participants to confirm their accuracy. Peer checking was also performed by four experts in qualitative research, psychiatric nursing, and mental health nursing. Accordingly, primary findings were provided to them, their critical comments were received, and necessary modifications were made based on their comments.

Maximum variation sampling (respecting participants’ age, gender, educational level, and marital status) and triangulation (various data source) were also done in order to enhance the trustworthiness of the findings.

A description of the details of research context and the analyzing process was reported as possible. In addition, a researcher makes sure that informants are not identified by quotes from the data.

## Ethical considerations

The study protocol was approved by the Ethics Committee of the University of Social Welfare and Rehabilitation Sciences, Tehran, Iran (code: IR.USWR.REC.1396.382). Participants were informed about the aims and the methods of the study, were ensured of the confidentiality of the study data, and were provided with the right to withdraw from the study. Verbal and written informed consents were obtained from all participants.

## RESULTS

Participants were 11 women and 4 men, whose age mean was 49.26 in the range of 30–70 [Table 2]. Participants’ experiences of the consequences of informal caregiving to patients with schizophrenia were grouped into eight subcategories and the four subthemes of threatened health, helplessness, patient abandonment, and personal growth. These subthemes and their subcategories reflected both negative and positive consequences of caregiving and were grouped under the main theme of the “Consequences of caregiving burden.” The subthemes of the study are explained in what follows together with their subcategories.

### Threatened health

Family caregivers of patients with schizophrenia are at high risk for physical illnesses and psychological distress. They frequently experience deteriorations in their health status due to factors such as stress, depression, and anxiety, and hence, their health is threatened. The two subcategories of this subtheme were poor mental health and physical health problems.

#### Poor mental health

Participants reported the experience of different mental health problems such as impatience, shock, reduced tolerance, unwillingness to do daily activities, lack of good feeling, lack of enjoyment in leisure activities, lack of satisfaction with life, anger at patient’s behaviors, high levels of stress after patient discharge from psychiatric care centers, stress over being alone with the patient at home, and stress related to patient’s acute psychiatric symptoms, mental turmoil, anxiety, and depression.

*When I’m alone with her at home, I’m under a constant stress. My stress declined when she was hospitalized (P. 6).*

#### Physical health problems

Participants had become neglectful toward their own health and experienced physical health problems

**Table 1: The theme, subthemes, and subcategories of the study**

Main theme	Subthemes	Subcategories	Examples of primary codes	Example quotes
Consequences of caregiving burden	Threatened health	Poor mental health	Impatience; reduced tolerance; unwillingness to do daily activities; lack of enjoyment in leisure activities; lack of satisfaction with life	I took care of him for twenty years; but now I've become completely exhausted. My doctor has diagnosed me with depression and has prescribed pills for me (P. 4)
		Physical health problems	Sleep disturbances; fatigue; reduced physical activity	She is awake at nights and doesn't sleep at all. Thus, I also don't sleep because I'm afraid she may harm her sister. I'm very tired (P. 6)
	Helplessness	Loss of control over life	Reduced ability to deal with problems; feeling of being trapped; feeling of loneliness; uncertainty; feeling overwhelmed by the responsibility of patient care	Her illness is so difficult that I can't do anything. I've become completely frustrated. I don't know how to treat her and what bad things will happen to me tomorrow (P. 12)
		The shadow of suffering and sorrow on life	Feelings of loss and grief; despair; suffering from patient's maladaptive behaviors; suffering from living with a patient with schizophrenia	Once, he threatened me with pliers and said that I have relationship with upstairs neighbor. He said that if I don't confess, he will kill me. All of these are psychological torment (P. 3)
		Patient abandonment	Hatred of the patient	Neglecting patient; experiencing problems in marital life; relatives' hatred of the patient; being tired of the patient; being unable to deal with the patient
	Abdicating patient care responsibility		Lack of the acceptance of the patient by the family; giving a wrong address to the hospital reception desk at the time of hospital admission; family members' nonattendance at hospital at the time of hospital discharge; leaving the house and the family	I can't care for her anymore. I've become tired. She should be hospitalized somewhere else and live there for a while (P. 4)
	Personal growth	Dedication	Showing love and affection toward the patient; understanding the patient's intent; increased tolerance; compassion for the patient	It is so difficult for me to see my son has psychiatric illness. But, I love him and have to be patient and care for him as long as he needs care (P. 1)
Empowerment		Internal motivation and commitment for patient care; ability to use self-defense; development of personal abilities over time	I go to psychological counseling and Quran interpretation classes in order to promote my tolerance and patience (P. 4)	

such as sleep disturbances, fatigue, reduced physical activities, pain in the neck, shoulders, back, and legs, hypertension, arthritis, diabetes mellitus, and osteoporosis.

*Last night, he insulted the guests of our neighbor and attacked one of them. They rang our doorbell and complained to me about this. I became nervous and my blood pressure increased (P. 1).*

### Helplessness

Helplessness is a sense of being unable to act or react to a negative situation experienced by family caregivers,

especially during the caregiving process. Sorrow and suffering are among the symptoms of helplessness. This main subtheme included two subcategories, namely loss of control over life and the shadow of suffering and sorrow on life.

#### *Loss of control over life*

Participants reported that they experienced problems such as reduced ability to deal with problems, feeling of being sacrificed and trapped, feeling of loneliness, confusion, uncertainty, and feeling of being overwhelmed by the responsibility of caregiving.



**Table 2: Participants' characteristics**

Number	Gender	Age	Occupation	Duration of care (years)	Kinship with the patient	Educational level
1	Female	65	Housewife	24	Patient's mother	Primary
2	Female	55	Housewife	10	Patient's mother	Diploma
3	Female	35	Housewife	14	Patient's wife	Diploma
4	Female	57	Housewife	20	Patient's mother	Diploma
5	Female	40	Housewife	5	Patient's wife	Secondary
6	Female	50	Housewife	10	Patient's mother	Secondary
7	Female	52	Social worker	-	—	Bachelor's degree
8	Female	47	Hospital nurse	-	—	Bachelor's degree
9	Male	50	Hospital discharge staff	-	—	Diploma
10	Male	70	Retired security staff	6	Patient's grandfather	Primary
11	Female	30	Housewife	4	Patient's wife	Secondary
12	Female	34	Part-time job	3	Patient's sister	Master's degree
13	Male	47	House painter	9	Patient's husband	Primary
14	Male	60	Retired teacher	2	Patient's father	Bachelor's degree
15	Female	47	Housewife	7	Patient's wife	Diploma

*It is for a long time that she is sick. I don't really know when she will get better. I've no idea what to do for her. I'm really concerned for her. I can't leave her alone at home. But, I should go on this way and have no more option (P. 13).*

#### The shadow of suffering and sorrow on life

Participants noted that feelings of loss, grief, despair, and suffering due to patients' maladaptive behaviors throw the shadow of suffering and sorrow on their lives.

*Living with her is a tragedy. It is like a big punishment for me. I have lost myself and have no hope for the future. I've been sunk in a sea of turmoil (P. 12).*

#### Patient abandonment

The burden of caregiving to a patient with schizophrenia can negatively affect family caregivers' quality of life and result in their nonstandard care for their patients and even in the abandonment of them. The patient abandonment subtheme included two subcategories, namely hatred of the patient and abdicating patient care responsibility.

#### Hatred of the patient

The family caregivers of patients with schizophrenia may feel hatred of their patients and hence neglect their patients, experience problems in marital life, feel tired from caregiving, and become unable to deal with their patients.

*I've been living with my mother since my husband's death. Some time ago when my son committed suicide, neither my mother nor the other members of the family worried about him and didn't help me care for him. I individually called the emergency medical service, took him to hospital, and cared for him alone (P. 2).*

#### Abdicating patient care responsibility

Some family caregivers may abdicate the responsibility of patient care by giving a wrong address to hospital reception desk during patient admission to hospital, abandonment of the patient in the hospital, nonattendance at hospital at the time of hospital discharge, leaving the house and the family, and making patient homeless.

*I can't manage her. I tell God thousands of times a day what if her head had hit against something, what if she was mentally retarded, or what if she had another illness such as cancer and then, I could care for her (P. 12).*

*After hospital discharge, when I took the patient to his address, nobody opened the door. When I asked the neighbors, they said that his family had moved elsewhere. I have experienced this situation several times (P. 9).*

*The passage of time makes families more and more tired and makes them leave their patients. Two patients in my ward have experienced this condition. Their families had given wrong addresses to hospital reception staff at the time of their hospital admission. We noticed this at the time of hospital discharge. They are now homeless (P. 8).*

#### Personal growth

Besides its negative consequences, caregiving to patients with schizophrenia may be associated with some positive outcomes such as personal growth. Personal growth is the ongoing process of understanding and developing oneself. It involves improvements in self and behaviors over time and the development of the ability to change. The two subcategories of this subtheme were dedication and empowerment.

#### Dedication

While facing problems, some participants showed love

and affection toward their patients, understood patients' intent, increased their tolerance, resistance, loyalty, and compassion for patients, and devoted themselves to their patients. These behaviors are the characteristics of dedication and personal growth.

*I've experienced great suffering. Sometimes, I ask myself how I can succeed enduring these conditions. I think God has given me an extraordinary power that I can endure these conditions and solve all these problems during caregiving to my son (P. 4).*

### Empowerment

Some participants felt senses of internal motivation and commitment for patient care, had the ability to use self-defense, had developed personal abilities over time, and hence, felt empowered for patient care.

*During the first months after his diagnosis, I just cried; but, I attempted to cope with this problem because I had no more option. Now, my conditions have got so much better and I can better manage the problem. I can defend myself. Now, I make clothes and offer beauty services at home (P. 3).*

## DISCUSSION

Results showed that caregiving to patients with schizophrenia is associated with different consequences for family caregivers. The most important consequence in the present study was threatened health so that participants complained of a variety of physical and mental health problems. In line with this finding, a former study reported that one of the consequences of caregiver burden was "psychological and physical morbidity" which included psychological and physical problems such as impaired immune function and affliction by chronic conditions.<sup>[14]</sup> Another study reported that the family caregivers of patients with schizophrenia did not correctly perform self-assessment, did not adequately engage in physical activity, and suffered from problems such as insomnia, fatigue, and stress.<sup>[6]</sup> Two other studies also reported the history of various chronic conditions such as diabetes mellitus, hypertension, arthritis, and psychiatric disorders as well as the excessive use of psychiatric medications among the family caregivers of patients with schizophrenia.<sup>[9,15]</sup> The violent behaviors of patients with schizophrenia are stressful for their family caregivers and make them prone to different physical and mental health problems,<sup>[4,15]</sup> whereas they are unable to care for themselves.<sup>[6]</sup> Although threatened health is a major problem among the family caregivers of patients with schizophrenia in all communities, there is limited information about the prevalence of these problems among these individuals in Iran, and hence, further studies are recommended in this area.

Helplessness was another main consequence of caregiving burden among the family caregivers of patients with schizophrenia in the present study. Our participants experienced problems such as loss of control over life, suffering, and sorrow. In agreement with these findings, several earlier studies showed that the family caregivers of patients with schizophrenia experienced feeling of being trapped, felt that the responsibility of patient care has been imposed on them,<sup>[16,17]</sup> and had negative feelings such as sadness, sorrow, suffering,<sup>[6,16-18]</sup> loss, and uncertainty.<sup>[1]</sup> Moreover, social isolation caused by the presence of a patient with schizophrenia in the family can lead to feelings of annoyance, discomfort, and suffering.<sup>[16]</sup> These negative feelings are caused by factors such as physical burden, emotional distress, financial problems, social stigma, and lack of knowledge about the disease.<sup>[19]</sup> Helplessness in the present study might have been due to long-term symptoms of schizophrenia and limited perceived professional and social support. Further studies are needed to provide reliable data about the factors contributing to helplessness among the family caregivers of patients with schizophrenia.

The third main subtheme of the present study was patient abandonment with the two subcategories of hatred of the patients and abdicating patient care responsibility. A cross-sectional study showed that 20% of the family members of patients with schizophrenia had abandoned their patients.<sup>[20]</sup> Patient abandonment among the family caregivers of patients with schizophrenia may happen due to limited social and financial support for them, their various care-related responsibilities, their heavy perceived burden of care, the severity of schizophrenia symptoms, and the long-term course of the disease. Further studies are needed to provide more reliable data in this area.

The last main subtheme of the present study was personal growth which consisted of two subcategories, namely dedication and empowerment. In line with these findings, an earlier study showed that the family caregivers of patients with schizophrenia experienced positive consequences such as love for the patient, understanding patient's conditions, ensuring patient safety, satisfaction, patience, and feeling of becoming a better human being.<sup>[6]</sup> Similarly, another study reported positive changes in family caregivers' lives due to interactions with their patients, perceived achievements, satisfaction with caring, and positive care-related experiences.<sup>[19]</sup> There are contradictory results about the positive aspects of caregiving in research. Hence, it can be concluded that more research requires in this area.

This study had some limitations. First, the small sample size of the study can limit the generalizability of its

findings. Therefore, studies with larger samples of the family caregivers of patients with schizophrenia referring to inpatient and outpatient settings are needed to provide more detailed information about the consequences of caregiver burden. This study was conducted in a single city in Iran, i.e., Tehran. Therefore, studies in other cities and on family caregivers from other cultures and ethnicities are recommended.

## CONCLUSION

This study concludes that caregiving to a patient with schizophrenia is very burdensome for family caregivers and causes them negative consequences such as threatened health, helplessness, and patient abandonment. At the same time, it can lead to a positive consequence, i.e., personal growth. Considering the numerous negative consequences of caregiving to a patient with schizophrenia for family caregivers, mental health and psychiatric nurses need to develop their abilities and knowledge to identify family caregivers who are at risk for negative consequences of caregiving and design proper family-based interventions to reduce the effects of these consequences.

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## Conflicts of interest

There are no conflicts of interest.

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