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Family caregivers' perspectives on barriers to caring for patients with schizophrenia: A descriptive qualitative study

Masoumeh Asgari[1], Masoomeh Adib[2]*, Nahid Dehghan Nayeri[3], Fatemeh Rezayat[4]

[1]Faculty of Nursing and Midwifery, Guilan University of Medical Sciences, Rasht, Iran
[2]Nursing and Midwifery School of Shahid Beheshti, Guilan University of Medical Sciences, Rasht, Iran
[3]Nursing and Midwifery Care Research Centre, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran
[4]Department of Psychiatric Nursing, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran

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Corresponding Author:
Masoomeh Adib, Nursing and Midwifery School of Shahid Beheshti, Guilan University of Medical Sciences, Rasht, Iran.
E-mail: adib.masoomeh@gums.ac.ir

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ABSTRACT

Background & Aim: Schizophrenia significantly burdens family members when a member of their family is afflicted with this condition. Family caregivers play a pivotal role in providing care and support to individuals experiencing schizophrenia within the community. Therefore, an in-depth study of family caregivers' experiences is crucial for developing effective care quality improvement programs. This study aimed at exploring family caregivers' experiences of the barriers to caregiving to patients with schizophrenia.
Methods & Materials: This study was conducted in 2021–2022 through in-depth semi-structured. The duration of the interviews varied in length from 45 to 90 minutes. Interviews were conducted with sixteen family caregivers of patients with schizophrenia. The conventional content analysis proposed by Graneheim and Lundman was used for data analysis.
Results: The findings can be classified into three primary categories. The category "Inefficiency of Support Resources" encompasses the subcategories of "Inadequate Support by Family Members," "Inadequate Support by the Healthcare System," and "Financial Predicament." The category "Limited Public Knowledge about Psychiatric Disorders" includes the subcategories of "Social Stigmatization" and "Being Social Rejection." Lastly, the category "destructive nature of schizophrenia" encompasses the subcategories of "Gradual Loss of Abilities" and "Gradual Patient Passivity."
Conclusion: Family caregivers encounter various barriers in providing patient care. Thus, they require support from the treatment team and family members, as well as financial and the development of rehabilitation programs. Additionally, involving caregivers in the patient's treatment plan and planning programs to reduce the stigma associated with caregivers is crucial.

Introduction

Mental disorders pose significant healthcare challenges worldwide, with schizophrenia being one of the most prevalent and devastating among them (1). This complex disorder encompasses a wide range of psychiatric conditions that involve difficulty distinguishing between reality and hallucinations. Additionally, individuals with schizophrenia experience deterioration in speech, communication, thinking, affect, and behavior lasting for more than two months (2). The condition affects approximately 1% of the global population across all cultures and has a lifelong prevalence of 0.6%–1.9%(3). Given its chronic nature, caring for individuals with schizophrenia falls significantly on family members, who bear a substantial caregiver burden, especially following deinstitutionalization. As a result, family caregivers encounter various challenges in their caregiving journey. The long-term nature of caregiving is linked to a significant caregiver

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burden, leading to both occupational and functional burnout (4). caregiving responsibilities also have adverse effects on the physical, mental, financial, and social well-being of family caregivers, contributing to various issues such as depression, anxiety, and obsessive-compulsive disorders (5). Additionally, caregivers may experience feelings of anger, fear, despair, negative emotions, and attitudes towards the patient, alongside a sense of guilt (6).

These challenges can have far-reaching consequences, undermining family integrity, reducing the quality of care services, and potentially leading to the recurrence of symptoms. Additionally, they impose heavy financial burdens on both families and governments (7).

In countries with limited resources, such as low- or middle-income countries (LMIC) like Iran, the shortage of community-based services for individuals with PWS and their family caregivers can have a particularly negative impact on their mental health (8).

In Iran, families often take on the responsibility of caring for a schizophrenia patient at home for extended periods, leading to numerous challenges for caregivers. While these challenges have been acknowledged in the literature, they have not been extensively detailed, and understanding the full extent of their experiences remains limited.

The lack of comprehensive support systems for schizophrenia patients and their caregivers can further exacerbate the difficulties they face in providing care and managing the condition. In contrast to numerous studies conducted on family caregivers of schizophrenia patients in various countries, research in Iran has predominantly focused on caregivers of mental patients in general (9, 10). This current study serves a unique purpose and can make valuable contributions to the existing literature in two significant ways.

Firstly, it addresses the gap in the limited literature on this subject in the context of Iran, offering insights into the firsthand experiences and diverse dimensions of problems and barriers faced by families in providing patient care, particularly within the framework of Iranian culture. Secondly, this research can act as a catalyst for policy-makers and officials involved in healthcare and treatment to take note of the current situation faced by caregivers. By highlighting the difficulties faced by these caregivers, it serves as a call to action, prompting the implementation of innovative approaches to improve the conditions of both families and patients.

In the current study, it is essential to gain insight into the experiences of individuals who deal with caregiving for patients with schizophrenia daily. To access these valuable experiences, a qualitative approach is deemed appropriate.

Using a qualitative approach, the study aimed to delve into the experiences of family caregivers and explore the barriers they encounter in their caregiving journey for individuals with schizophrenia, particularly within the context of PWS.

Methods

This qualitative study was conducted between October 2021 and August 2022. The research employed a content analysis approach, which aimed to explore the barriers family caregivers experienced in caregiving for patients with schizophrenia. Content analysis is a valuable method for gaining insights into the perspectives and experiences of participants, allowing for a thorough examination and understanding of the phenomenon under investigation (11).

The study was conducted at Shafa referral psychiatric hospital in Rasht, Iran. The participants in the study were sixteen family caregivers of individuals with PWS. They were purposively selected, ensuring maximum variation in terms of their socio-demographic characteristics. Eligibility criteria for this study included: Caregivers of patients with schizophrenia with a duration of at least two years since the onset of the disease with a history of at least one drug treatment for the patient, either in the psychiatric ward or on an outpatient basis. Caregivers who co-resided with the patient in the same household. Participants needed to be at least eighteen years old. Agreement to participate in the study and provide informed consent for involvement. A definitive diagnosis of schizophrenia for a family member by a qualified psychiatrist based on the criteria of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5).

"Initially, the researchers scheduled interview appointments with each participant and conducted the interviews in Persian at the participant's preferred time. Sixteen semi-structured interviews were carried out to collect the necessary data. Some of the questions asked during the interviews were: 'Could you please elaborate on your experiences of living with a PWS?' and 'What kinds of challenges or barriers did you encounter while coping with your patient?'

Moreover, probing questions like 'How?' and 'Could you please explain further?' were employed to gather more in-depth data.

The interviews took place in a psychologist's room within the study setting and lasted anywhere from 45 to ninety minutes. Participants gave their consent before recording, and the interviews were transcribed verbatim. Data collection continued until no new conceptual codes emerged from the interviews, and the data reached a point of saturation.

Concurrently with data collection, the researchers used conventional content analysis, as proposed by Graneheim and Lundman (14). In the initial step, the first and second authors listened to the audio files of each interview and thoroughly reviewed the transcripts to gain a general understanding of the main ideas presented. The interviews were then transcribed verbatim.

Moving on to the second step, the transcribed data underwent further examination to obtain a holistic perspective of the participants' experiences. In the third step, the last author organized the text (transcribed data) into original codes. Next, in the fourth step, the codes were compared and grouped based on their similarities. In the last step, the categories were defined and abstracted to formulate a theme. The final two steps of the analysis process involved the participation of all researchers involved in the study.

To ensure trustworthiness in the study, the researchers employed four criteria: credibility, dependability, confirmability, and transferability (12).

Credibility was established by engaging extensively with the data and seeking feedback from five participants to validate the alignment of the findings with their experiences. Dependability was ensured by conducting peer checks, where coauthors reviewed and verified the research process and its outcomes. Confirmability was maintained through thorough documentation of all steps taken in the study, making the research process transparent and allowing for an audit trail. To enhance transferability, the researchers included clear quotations from participants' interviews, along with detailed explanations of their characteristics.

This study received approval from the Ethics Committee with the code IR.GUMS.REC.1400.141. Participants were provided with detailed information about the study's purpose and the confidentiality of their data. Before the interviews, informed written consent was obtained from all participants, explicitly stating their agreement to audio recording during the interviews. To ensure confidentiality and privacy, participants' identities were protected by using numerical codes instead of their names.

Results

A total of sixteen family caregivers of individuals with PWS were recruited for this study. The participants' average age was 45 years, and the majority of them were female (60%) and single or divorced (40%). The caregivers' relationships with the patients varied, including being the father, mother, child, sister, or spouse. Their caregiving experience ranged from five to fourteen years (Table 1).

During data analysis, the barriers to caregiving for individuals with PWS were categorized into three main categories: inefficiency of support sources, limited public knowledge about psychiatric disorders, and the destructive nature of schizophrenia (Table 2).

Table 1. Participants' characteristics

No.	Age (Years)	Gender	Marital status	Educational level	family relationship	Occupation	Duration of schizophrenia (Years)	Duration of caregiving (Years)
1	60	Female	Married	Bachelor's	Mother	Housewife	9	13
2	52	Female	Married	Illiterate	Mother	Farmer	12	9
3	42	Female	Single	Master's	Sister	Social worker	15	10
4	55	Female	Single	Associate diploma	Sister	Housewife	17	5
5	37	Male	Single	Bachelor's	Child	Self-employed	20	10
6	30	Male	Single	Bachelor's	Child	Cabinetmaker	15	12
7	65	Female	Married	Bachelor's	Spouse	Housewife	18	12
8	42	Female	Married	Below diploma	Spouse	Tailor	18	14
9	32	Female	Divorced	Bachelor's	Child	Self-employed	16	5
10	24	Female	Single	Student	Child	Housewife	8	8
11	38	Female	Divorced	Diploma	Sister	Housewife	9	11
12	45	Male	Married	Below diploma	Sister	Farmer	10	10
13	70	Male	Divorced	Bachelor's	Father	Retired teacher	8	8
14	36	Male	Married	Bachelor's	Spouse	Self- employed	7	7
15	68	Male	Married	Bachelor's	Brother	Teacher	9	9
16	28	Female	Single	Student	Child	Housewife	12	8

Table 2. The subcategories and categories that emerged from the data analysis

Categories	Subcategories
The inefficiency of support sources	Inadequate support by family members
	Inadequate support by the healthcare system
	Financial predicament
Public limited knowledge about psychiatric disorders	Social stigmatization
	Being socially rejected
Destructive nature of schizophrenia	Gradual loss of abilities
	Gradual passivity of the patient

The inefficiency of support sources

The family caregivers of individuals with PWS receive inadequate support from family members, the healthcare system, and society. Our participants' experiences highlighted that the lack of well-developed support programs for family caregivers leads to the healthcare system's inattention to their problems. Long-term and continuous caregiving to individuals with PWS without receiving sufficient support also results in increased financial strain and burden. This category consists of three subcategories: inadequate support by family members, inadequate support by the healthcare system, and financial predicament.

Inadequate support by family members

Chronicity of schizophrenia, its frequent recurrence episodes, and subsequent frequent hospitalizations of the afflicted patients may make other family members indifferent to patient care, reduce their engagement in it, and hence, lead to the loneliness of the main family caregiver. Negative experiences of patient care, witnessing the awkward symptoms of schizophrenia, and challenges of daily life can also lead to burnout and frustration among family members and reduce their engagement in patient care. Consequently, the main family caregiver of PWS will experience a heavier caregiver burden and more physical and mental health problems and hence may not be able to give quality care. For instance, one participant reflected that the ongoing hospitalizations of their family member with schizophrenia made it difficult for them to maintain regular contact and provide adequate care, causing feelings of guilt and isolation.

"*Everyone in the family should engage in and help with caregiving for these patients. I can't handle all the caregiving tasks on my own. I can't dedicate all my time to caregiving because I have to work and focus on my education and personal life too. Sometimes, my mind is so preoccupied that I miss my bus stop, and I end up getting off at the next one because I'm dealing with so many mental concerns. "(P. 3).*

Another stated:

"*Now my older sister is getting married, and my brother is a veteran, so he can't be involved either. Another brother of mine is indifferent and doesn't keep in touch. That's why I feel like I'm all alone in this." (P. 12)*

Inadequate support by the healthcare system

One of the major concerns expressed by caregivers was the lack of support and information provided by the healthcare system. Many caregivers expected the healthcare professionals to address their supportive and informational needs as they navigated through their family member's illness. However, some caregivers mentioned that they received no information about the role of the treatment team in the process of their family member's disease and after discharge. They hoped for respectful communication and an empathetic approach to listening to their concerns and issues. Unfortunately, due to the mental health system's lack of expected support and attention, they felt abandoned and recognized themselves as the sole supporters of the patient's care.

"I gotta be honest; I don't think the treatment personnel can really help us at all. I mean, what do they even do in that department? Can they actually do something to help me? If they could, I wouldn't be feeling so darn alone right now." (P. 9)

Family caregivers expressed a strong desire to actively participate and be involved in the therapeutic programs, which encompassed shock therapy and non-medicinal treatments, as well as attending meetings related to the treatment process. However, they conveyed their frustration that the treatment team often does not permit them to be part of discussions and decisions concerning the therapy. As one participant remarked:

"It would be great if the family could also have a say in the therapeutic procedures, and family members should be involved in the treatments and therapeutic efforts. Why haven't you informed us about the therapeutic methods or efforts that have been or will be used for my brother until now? It's our absolute right as my mother and I to be part of these discussions and decisions." (P.11)

Financial predicament

Participants reported the high daily living costs, patient hospitalization, and psychiatric medications as a major barriers to caregiving to PWS. They referred to their inability to afford the costs of hospitalization and medications as one of their main concerns and noted that patient disability increased their financial burden and worsened their financial problems. A participant stated that,

"When my father got sick, my mother and I worked on the land, but the cost of medicine and hospitalization was too high. We also have debts to pay "(P. 4).

Financial problems were more severe when the afflicted patient had been the main source of family income before the affliction of schizophrenia. Many PWS may be fathers or mothers responsible for generating family income; hence, their schizophrenia-induced disability reduces their ability to generate income and faces families with financial problems. A participant described their problems after her husband's affliction with schizophrenia as follows:

"After his hospitalization, the doctors informed us that his disease had reached an advanced stage, and he was unable to continue with his job. As a result, our financial situation became extremely dire, and we were left with no money to sustain our livelihood. I, being an illiterate housewife, had no means of earning income to support us" (P. 8).

Public limited knowledge about psychiatric disorders

Participants' experiences revealed that family caregivers of individuals with PWS encounter public misconceptions and inaccurate judgments, largely due to the limited knowledge of the general public about psychiatric disorders. The caregivers shared their experiences of facing biased attitudes from society members due to having a family member with psychosis. This discrimination resulted in a lack of respect from others and elicited feelings of anger and frustration among caregivers. They also mentioned that negative attitudes, stereotypical behaviors, and biased thoughts from acquaintances left them saddened. Consequently, these reactions led to a gradual distancing of society from the caregivers. The two subcategories within this category were identified as social stigmatization and social rejection.

Social stigmatization

Social stigmatization is a major barrier to receiving psychiatric and psychological care services as well as to giving care to PWS. Our participants reported that mockery by others and the notoriety of family members in society gave them a sense of humiliation and embarrassment and eventually led to their social isolation. Moreover, public mistreatment of PWS caregivers upset them and required them to hide their patients' disease to protect their family's respectability. In this regard, some of the family caregivers stated:

"My father uses strange and unusual words which differ from others' words and lead to others' laughing and mockery at him and us. Therefore, his companionship with me embarrassed me in front of my friend " (P. 5).

Being socially rejected

Participants' experiences showed that public misconceptions and misunderstandings about schizophrenia and its symptoms and traditional negative beliefs and attitudes about PWS lead to the social rejection of these patients and their families. People distance themselves from these families, leave them alone, treat them with indifference, are reluctant to communicate with them and do not support them.

"Now, most of my time is spent at home. I am a prisoner in my house, and I will never participate in the activities I used to do in the past. For example, when I go outside my father's house, and someone tells me to take

my daughter home, she is sick. It is a bad thing. I really avoid people "(P.1)

Most participants reported losing their social prestige and status due to living with a PWS, so their relatives and friends did not like to communicate with them. Some participants avoided indoor and outdoor social relationships due to others' inappropriate behaviors, and some of them had broken off their relationships with relatives and friends. Such social self-isolation helped them feel lower stress.

"I gradually lost many of my customers though I had not told anybody about my father's disease. You know that people lose their trust in you and don't work with you if they notice such problems " (P. 6).

Destructive nature of schizophrenia

According to the participants, the destructive nature of schizophrenia was a major barrier to caregiving by family caregivers. Schizophrenia-induced gradual loss of abilities and increased passivity, dependence, and indifference to life significantly increase caregiver burden and act as barriers to caregiving. The two subcategories of this category were gradual loss of abilities and gradual passivity.

Gradual loss of abilities

Before affliction by schizophrenia, individuals have different roles and responsibilities in their families. The destructive nature of schizophrenia negatively affects afflicted patients' abilities to perform their activities and tasks, fulfill their roles and responsibilities, and manage their life affairs. Therefore, the roles of family members, particularly the main family caregiver, may change. Assuming the role of caregiving can change the caregiver's ability to fulfill his/her other roles and cause him/her different role conflicts and role confusion. A patient's spouse said:

"There is no one to perform manly familial affairs such as shopping. We have no income and have financial problems. I have land but couldn't cultivate rice because my husband had to do it as a manly task. We had no money to recruit workers to cultivate rice. Therefore, we rented it to others " (P. 10).

Gradual passivity of the patient

According to the participants, frequent hospitalizations and prolonged stays in psychiatric hospitals make patients get accustomed to institutional life and hence, reduce their ability to perform their personal, familial, and social activities after hospital discharge and turn them into passive individuals. Such passivity significantly increases the caregiver burden. Some participants reported their patients' indifference to their life despite family members' requests for engagement in life affairs.

"After hospital discharge, he did nothing at home and was indifferent to all things. His only help to us was his stay in his room and his non-interference with life affairs. This was his only help. He has become a really useless person. We just know that we have somebody at home that can't rely on him" (P. 8).

"After several hospitalizations, he was completely dependent on me. In my house, I bathe him and feed him myself and wash his clothes myself... " (P. 14)

Discussion

This study aimed to investigate the family caregivers' perspectives on barriers to caring for patients with schizophrenia. One of the barriers to family caregivers was the inefficiency of support sources which consisted of inadequate support by family members, inadequate support by the healthcare system, and financial predicament.

Inadequate support by family members was one of the barriers to the primary family caregivers. This finding is in agreement with the findings of several previous studies (13, 14). The lack of help and support from the other family members and especially the feeling of lack of understanding and empathy and emotional dissatisfaction lead to the gradual process of inner isolation in primary family caregivers. Therefore, primary family caregivers may experience fatigue and frustration, gradually develop indifference to caregiving, give up their care and support. In this regard, it is suggested that policy-makers provide adequate support for primary family caregivers of patients with schizophrenia (15). Therefore, primary family caregivers may experience fatigue and frustration, gradually develop an indifference to caregiving, give up their care and support, and leave the caregiving role**.** In this regard, it is suggested that policy-makers give adequate support to primary family caregivers of patients with schizophrenia.

Inadequate support by the healthcare system was another finding. Participants reported ineffective communication with psychiatrists, psychologists, and nurses as another barrier. The main reasons for healthcare providers' limited support for family caregivers are their heavy workload, shortage of beds in psychiatric hospitals, and caregivers' limited knowledge about healthcare providers' responsibilities in patient management(16). Moreover, our findings showed that the family caregivers of PWS received limited education from healthcare providers about schizophrenia, medications, and medication side effects. Previous studies also reported the same finding (17, 18).

Healthcare providers' attempts to engage family members in the process of patient care can reduce caregiver burden and concerns. However, there is no well-developed plan to support family caregivers and engage them in patient care in Iran (16, 19). Regular home visits and educational programs for healthcare providers about effective communication with family members can be effective in reducing caregiver burden and improving engagement in patient care among family caregivers (20).

The Financial predicament was identified as another subcategory mentioned in the study findings. We also found financial problems among family caregivers as a major barrier to caregiving to PWS. These findings have been reported in other studies (21, 22). These findings highlight the necessity of governmental interventions to financially support PWS and their families.

Limited public knowledge about psychiatric disorders was another finding which includes the subcategories of "social stigmatization" and "Being social rejection."

In this regard, several previous studies reported social stigmatization as a major barrier to caregiving to PWS (10, 23, 24). In fact, negative attitudes and conceptions about psychiatric disorders root in limited public knowledge and are associated with the stigmatization and mockery of the afflicted individuals and their families (10). Moreover, we found that the family caregivers of PWS had negative experiences such as humiliation, embarrassment, and social isolation. These experiences can negatively affect family social prestige and lead to psychological discomfort, despair, and low perceived social support among family caregivers (25).

Social rejection was another barrier. This finding has also been reported in other studies (26, 27). Public negative attitudes towards PWS and social stigmatization of these patients and their families make family members decide to hide their patients' diseases and socially isolate and reject themselves and their patients. Therefore, evidence-based, culturally appropriate education is needed to modify negative stereotypes about PWS and their family members among the general population, healthcare providers, and policy-makers (28).

The final barrier of the present study was the "destructive nature of schizophrenia," which consists of two subcategories of "gradual loss of abilities in the patient" and "gradual passivity of the patient." The progressive and chronic nature of the disease results in patient disability. With the patient's failure to perform tasks, they gradually lose their abilities, even at the simplest level, and become unable to fulfill their previous roles and responsibilities. Eventually, they become completely dependent on caregivers. As a result, caregivers experience significant psychological pressure, hindering appropriate care for the patient. Furthermore, as a result of recurrent hospitalizations, patients gradually become dependent on caregivers and become passive. The patient's passivity and detachment from the life process act as barriers to proper care. Our findings are consistent with other studies in this field (10, 29).

Therefore, a change from the current routine towards planning rehabilitation programs and preparing patients for independent living outside the hospital, at home, and in the community appears to be highly necessary (10, 30)

Although maximum diversity was considered in the sample selection process, it is important to acknowledge that the non-participation of family caregivers from more culturally and socially diverse backgrounds was considered a limitation of this study. Additionally, the participants' varying ethnicities, norms, and values might have influenced their perspectives on caregiving and their responses to the interview questions. The different contexts and settings could potentially impact the applicability and relevance of the study's conclusions.

Conclusion

The present study indicated that family caregivers of patients with schizophrenia face multiple barriers, such as inadequate support resources, lack of comprehensive knowledge about schizophrenia, and the debilitating nature of this disease. In light of these findings, policy-makers should strike a balance between transferring care responsibilities to the family and involving the families in the patient's treatment plan. Implementing a respite care program for caregivers could offer them much-needed relief. Exploring options such as insurance coverage or proposing salary incentives for caregivers could address the financial aspects of caregiving. Enhancing community knowledge about schizophrenia can be achieved through creating short educational teasers. Ultimately, in relation to the debilitating nature of the disease, the development of rehabilitation programs is recommended.

Conflict of interest

The authors declare no conflict of interest.

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