

# The Challenges of Caring for an Adult Child with Schizophrenia in the Family: An Analysis of the Lived Experiences of Older Parents

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## Abstract

The present study aimed to investigate the lived experiences of older parents regarding the challenges in caring for adult children with schizophrenia. The current study was conducted on 16 parental (mother or father) caregivers of adult children with schizophrenia using a descriptive phenomenological qualitative approach and Colaizzi's seven-step method. This study follows the Qualitative Research Checklist (COREQ). The findings showed that the parent caregivers' experiences could be classified into two main themes: "burden of care" and "Negative attitude and inefficient performance." The former consisted of three sub-themes including "disrupted social and family interactions," "helplessness and inefficient support," and "challenges of the healthcare system," while the latter had two sub-themes including "Negative attitude and inefficient performance of the caregivers" and "Negative attitude and inefficient performance of families and society." Older parents have to tolerate a significant burden of care due to their age and physical conditions. Improving the knowledge of specialists, the government's redoubled efforts in multifaceted support for patients and caregivers, creating an integrated team of specialists, and accepting and improving public attitudes against stigma and obvious discrimination in society as important priorities in improving the condition of caregivers and patients with schizophrenia were considered.

## Keywords

burden of care, attitude, parents, adult children, schizophrenia, qualitative research

### What do we already know about this topic?

Caregivers of patients with schizophrenia experience numerous mental health problems due to the nature of the disease.

### How does your research contribute to the field?

Examining the lived experiences of caregivers of patients with schizophrenia, especially older parents, has received less attention in Iran. In this study, the experiences of older parents were described. The Burden of care and the traditionally negative attitude of caregivers and society has had an unpleasant effect on the care process.

### What are your research's implications toward theory, practice, or policy?

This study can be an effective step in helping counselors and mental health professionals to design intervention programs to deal with mental health problems, change attitudes and improve the performance of caregivers and people in the community toward patients with schizophrenia. Support and protection of caregivers and patients against stigma and negative attitudes should be the priority of government policies in helping this vulnerable group.

## Introduction

Schizophrenia is a serious mental disorder that affects approximately 24 million people or 1 in 300 people (0.32%) worldwide. Among adults, the rate is 1 in 222 (0.45%).<sup>1</sup> Schizophrenia accompanies intellectual disorders that may

damage the patient's cognitive and behavioral performance.<sup>2</sup> According to the latest estimates reported by the Association for the support of patients with schizophrenia (AHEBBA) in 2016, approximately 750 000 people with schizophrenia were diagnosed in Iran.<sup>3</sup>



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The typical age of onset of schizophrenia is late adolescence and early adulthood.<sup>4</sup> Schizophrenia is considered a disabling disorder due to its relapsing nature, unavoidable negative consequences, and heavy social and medical costs, and is known as a stressful illness for both patients and their families.<sup>5</sup> The negative effects of the disorder on families—particularly the patients' parents—may arise from worries about their child's health and social status, the stigma associated with the illness, and as well as problems resulting from care for a child with chronic and severe disorders.<sup>6</sup>

Caring and supporting such patients are performed by families—particularly children's parents—and are considered significant responsibilities that include both first aid measures and the management and control of the symptoms and disorders associated with the illness.<sup>7</sup> Families often face stressful situations in everyday life, such as the unpredictable, strange, and almost uncontrollable behavior of relatives. External stresses related to the stigma of the illness, families' isolation, and family conflicts in the process of caring are some other problems experienced by the parents.<sup>8</sup> Parental caregivers caring for children with schizophrenia face other problems, such as decreased social engagement, increased disagreements with other family members, and heightened family tensions.<sup>9</sup> Also, studies have shown a positive correlation between the burden of care and increasing age, in other words, Older Parents experience a higher burden of care.<sup>10,11</sup> Parents of an adult child with schizophrenia, who are often in old age,<sup>12</sup> worry about who will take care of their child in the future and after their death; They may not be able to take good care of their child due to physical and age conditions.<sup>13</sup>

Studies have shown that societies differ in terms of the burden of care, and the difference can be up to two times<sup>14,15</sup> While demographic characteristics may explain some of the differences between countries, for a deeper explanation of the burden of care, cultural differences in the evaluation, intervention, and social support, as well as differences in the quantity and quality of mental health care in different countries, should be considered.<sup>14</sup> As a result, more in-depth studies need to be conducted to estimate the aspects of the burden of care and the need for services in various countries and cultures.<sup>16</sup> Therefore, the investigation of such Subjects in Iran seems to be essential due to the importance of their special cultural dimension. In Iran, due to the prevailing collectivist culture in society, family members are more concerned about how others view the family than the negative effect of mental disorders on themselves.<sup>17</sup> Cultural differences may affect the experiences of stigma in the families of psychiatric

patients in areas such as concealment, limitations in work and education, traditional beliefs in society toward patients, and so on.<sup>18</sup> Even the negative attitude of caregivers as one of the cultural aspects can lead to a feeling of failure in patient care.<sup>19</sup>

Awareness of attitudes and performance during the exploration of a particular phenomenon is a very important category, both theoretically and practically. No theory of social behavior can be completed without the integration of performance and attitude, and there is doubt about the possibility of predicting complex social behaviors without being aware of attitudes.<sup>20</sup> Studying attitudes make it necessary to measure them. The way to overcome the differences in people's attitudes and actual behaviors in association with patients with schizophrenia is to assess the discriminations perceived by them or their relatives.<sup>21</sup> In Asian and Latino cultures, the stigma of mental illness affects sufferers and their families because it is seen as an embarrassment and illness for the entire family. In other words, mental illness may be more or less attributable to the entire family.<sup>22</sup> In this regard, a study in Iran showed that 42.6% of Iranian family caregivers had experienced the stigma.<sup>23</sup> A study in China showed that almost 65% of caregivers tried to conceal their family members' illnesses.<sup>24</sup> Another study in India indicated that 21% of caregivers had experienced severe levels of stigma, and 45% of them were reluctant to disclose the condition of their family members.<sup>25</sup> Moreover, empirical findings in China and the United States showed that mental health specialists may show negative attitudes toward their patients.<sup>26,27</sup> This may arise from their problems in interacting with such patients, reflecting the lower social acceptance of people with schizophrenia. Moreover, caregivers' inconvenient performance such as repeated criticisms, extreme interference in the patients' lives, insufficient encouragement, inattention to the process of treatment, and caregivers' negative attitudes to the patients results in many relapses.<sup>19</sup>

The findings of the studies conducted in various countries across the world are somehow similar, though they differ in most cases. The caregiving experience is a cross-cultural concept, and traditional cultural values influence caregivers' perceptions of their caregiving roles. In other words, the meaning of caring is profoundly influenced by cultural and spiritual beliefs.<sup>16,28,29</sup> On the other hand, cultural differences influence people's attitudes and views toward caregiving and patients with schizophrenia and may create varying experiences in caregivers.<sup>30</sup> Most importantly, although family caregivers may have shared experiences, the nature of the parent-child relationship is different because of the role of

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child-rearing and contributing to their independence.<sup>31</sup> Thus, investigating the challenges and attitudes of older parents in caring for an adult child with schizophrenia was a serious research question in the Iranian cultural context.

## Method

### Design

In the present study, the qualitative research method in the form of the descriptive phenomenological approach was used to investigate the meaning of the lived experiences of older parents who were caring for an adult child with schizophrenia. A phenomenology is an approach that can be used to describe phenomena related to the lived experiences of humans.<sup>32</sup> Edmund Husserl's ideas in the early 20th century about how to do science led to the development of the descriptive phenomenological research method. Descriptive phenomenology aims to describe the universal essence as a lived experience, which expresses the true nature of the phenomenon.<sup>33</sup> In this approach, according to the principle of bracketing, researchers should postpone or bracket off their ideas related to scientific or philosophical assumptions, theories, past knowledge about the subject of research, or the understanding of a phenomenon.<sup>34</sup> Also, another principle of Husserl's phenomenology is that researchers should not pay attention to the sociocultural backgrounds of the people being studied.<sup>34,35</sup>

Moreover, due to the direct extraction of information from participants and the lack of use of predetermined classes or existing theories, the present study was inductive in terms of nature.<sup>36</sup> The Consolidated Criteria for Reporting Qualitative Research (COREQ) were used to write this manuscript.<sup>37</sup>

### Participants

Using a purposive sampling technique, 16 parental caregivers of adult children with schizophrenia were selected from the Association for the support of patients with schizophrenia (AHEBBA) and Razi Psychiatric Hospital in Tehran.

Ahebba is a daily educational and rehabilitation center for chronic mental patients, which was established in 2016 in Tehran. In this center, all kinds of medical and counseling services, including doctor, psychologist, and nurse visits; Psychosocial rehabilitation services including occupational therapy, group therapy, social work, psychodrama, music therapy, and art therapy; Professional rehabilitation services include leather, computer, language, pottery, and gardening, as well as sports activities including chess, yoga, ping pong, and hand football, are provided to patients. These services are provided daily to reduce disease recurrence, hospitalization, and behavioral rehabilitation and increase the ability to live independently in society by acquiring social and behavioral skills.

Razi psychiatric hospital is located in the Shahr-e-Ray town of Tehran and was established in 2004. This hospital

was the first rehabilitation hospital in Iran, and it contains modern technology and is the leader in mental health treatment. This center works in cooperation with the university of social welfare and rehabilitation sciences and several therapists such as specialist doctors, psychiatrists, physical medicine doctors, occupational therapists, physiotherapists, and speech therapists provide medical and rehabilitation services to patients and educational services to students. Razi psychiatric hospital currently has 1375 approved beds, which provide services to patients in the form of specialized and sub-specialized treatment and rehabilitation departments.

The selection of 16 people as the sample size was based on data saturation. In qualitative studies, the guiding principle for choosing the sample size is data saturation. In this way, the process of selecting samples continued until no new data emerged during the process of obtaining information; That is, the collected data was a repetition of the previous data. The maximum diversity in terms of sex, educational level, duration of caring experience, job, marital status, and economic status was observed in the sample selection process. Ethical considerations such as explaining the goals of the study, receiving informed written consent forms from the participants, informing them on the manner and goals of using voice recorders, protecting their privacy and identity information, and using numerical codes instead of their full names were observed. Also, as a moral principle, all the authors consider themselves obliged to protect the health of the participants, it should be noted that in the present study, none of the caregivers showed any significant distress or emotional crisis. All ethical considerations were approved by the University of Social Welfare and Rehabilitation Sciences under the Code of Ethics IR.USWR.REC.1398.122.

The following were the study's entry criteria: 1) the caregivers were the patients' parents (only mothers or fathers), 2) the parents participated in the study voluntarily and in an informed way, 3) according to the medical report in the archived files in the medical centers, the parent caregivers had no severe mental or physical disorders during the interviews, 4) the participating parent was the main caregiver and lived with the patient. Before selecting the participants, the researchers made sure that the patients were schizophrenic, based on the doctor's diagnosis sheet available in the patients' files in the treatment and support centers.

### Data Collection

In-depth and semi-structured interviews were held for 60-90 minutes for data collection. Sixteen caregivers were interviewed in quiet and secured rooms. In an in-depth semi-structured interview, the use of open-ended questions encourages depth and vitality, which helps to emerge new concepts, insights, and meanings.<sup>38</sup> The purpose of these types of interviews is to collect information about topics or phenomena of interest to researchers and at the same time important events or experiences in people's lives.<sup>39</sup> In other words, in-depth semi-structured interviews are usually the preferred choice

when dealing with sensitive topics.<sup>40</sup> At the beginning of the interview, questions such as "How did you find out your child had schizophrenia?," "How did you feel when you found out about this?" were used. The interview was followed by questions such as "how do you see a child with schizophrenia?," "What is the view of family and society towards patients with schizophrenia?," "What problems did you face in caring for your child?" and "What did this experience mean to you?" Probe and follow-up questions were also used to better understand the caregivers' perspectives. Before the interview, several meetings were held by the research team regarding the place and time of the research, how to conduct the interviews and the general process of the study. The authors of this research had conducted many studies and gained the necessary experience in the field of qualitative studies. The third author (MF) is a psychiatrist, and the other authors are counseling and psychology specialists. Data collection and interviews were conducted by a doctoral student (the first author) who had received training and experience in qualitative interview workshops and worked closely with schizophrenic patients as a student and intern in psychiatric hospitals. Other authors have visited patients and taught students as therapists in psychiatric centers.

Recording the information was performed using either a voice recorder or a notebook (or both) according to the conditions of each interview and the participants' consent. Moreover, two specialists (MF, MSK) with significant experience in the field of qualitative studies took part in the study and reviewed the quality of the data produced in the interviews during the weekly sessions. The interviewer had no contact with the participants before the study. The general practitioners or social workers of the Medical Center called the eligible interviewees and invited them to the interview sessions. Before conducting the interview, the interviewer explained the purpose of the study to the participants and obtained written informed consent from each of them to participate in the research. The interviews were performed during in-person sessions, just between a caregiver and the interviewer. Participants were encouraged to talk freely about their experiences and raise any topic they wanted. Each interview was recorded and transcribed word-for-word, and numerical codes (rather than the participants' names) were used to record the data during the process of transcription. Regular meetings for data quality control were held by the research team after each interview. Finally, the interview codes were independently extracted by two members (MF, MSK) of the research team, and any differences in data abstraction were resolved by reaching a consensus.

### Data analysis

The data were simultaneously recorded aurally (using a voice recorder) and in a written format. The obtained raw data were coded and classified by the interviewer and two

other members of the research team. Data collection continued until the saturation point was reached. Then, the sub-themes and main themes were extracted from the data. The analysis was performed, and the final classification was achieved by reaching a consensus among the members of the research team. The research team was a multidisciplinary one that included experts from different fields, which was essential to guide the research and improving the validity of the findings. Colaizzi's 7-step method was applied in the process of analysis.<sup>41</sup> The following are the analysis steps: 1) transcribing and repeatedly reading all descriptions and statements made by the participants, 2) extracting significant statements, 3) extracting formulated meanings relevant to the main and preliminary statements, 4) organizing the collection of meanings into clusters of themes, 5) integrating the results to comprehensively describe the investigated phenomenon and form more general clusters, 6) describing the fundamental structure of the phenomenon: present a comprehensive description of the investigated phenomenon, and 7) conducting the final validation of the data by return the findings to the participants and eliminating any vague points.

### Trustworthiness

The evaluation of the accuracy and strength of the data was performed according to Lincoln and Guba four criteria including credibility, dependability, confirmability, and transferability.<sup>42</sup> The validation process was such that before the interview, during the interview, and after the interview, the research team followed each of the criteria that helped to Trustworthiness of the research data. In the following, each of the above four criteria is explained along with the practical cases used in this research.

Credibility: Verification of the results with the participants and long-term involvement with the data. Dependability: Suspending the previous knowledge of the research team in data extraction and decision-making process, conducting research as a team and supervised by experts. Confirmability: maintaining the documents in all stages of research, attempting to obtain other people's views. Transferability: using convenience sampling technique with the maximum variability in terms of education level, sex, marital status, duration of care, and so on.

The supervising experts in the current research consisted of people with expertise in psychiatry, psychology, and counseling who had sufficient expertise in the field of qualitative studies.

### Results

The Demographic characteristics of the caregivers and adult children with schizophrenia are presented in Table 1. The mean age of the participants was 66.75, while the mean age of the patients with schizophrenia was 38.25.

**Table I.** Demographic Characteristics of the Caregiver Interviewees and People Experiencing Schizophrenia (n=16).

Caregivers (parents)		Schizophrenic patients											
Participants	Sex	Age	Job	Marital status	Educational level	Economic status	Duration of caring experience	Sex	Age	Educational level	Marital status	The patient's life situation	Number of hospitalizations
1	Female	72	Homemaker	Deceased spouse	Middle school	Good	23	Male	43	Diploma	Single	Only with mother	6
2	Female	62	Peddler	Deceased spouse	Primary school	Weak	13	Male	40	Middle school	Divorced	Only with mother	<b>More than 10 times</b>
3	Male	79	Retired government officer	Deceased B. S. degree spouse	B. S. degree	Weak	27	Male	47	Diploma	Single	Only with father	
4	Female	64	Homemaker	Married	Middle school	Weak	19	Male	39	Middle school	Single	With family	
5	Female	74	Homemaker	Married	Middle school	Weak	28	Male	49	B. S. degree	Single	With family	
6	Female	63	Homemaker	Married	Primary school	Weak	14	Female	33	Diploma	Single	With family	
7	Female	61	Homemaker	Deceased spouse	Illiterate	Weak	17	Male	37	Primary school	Single	Only with mother	
8	Male	74	Retired—private company	Married	Primary school	Weak	24	Male	44	Diploma	Single	With family	
9	Female	62	Homemaker	Married	Middle school	Average	6	Male	24	Diploma	Single	With family	
10	Female	60	Homemaker	Married	Diploma	Average	6	Male	27	Diploma	Single	With family	
11	Female	67	Maid	Divorced	Middle school	Weak	20	Male	42	Middle school	Single	Only with mother	
12	Male	70	Retired government officer	Married	B. S. degree	Good	13	Female	35	B. S. degree	Single	With family	3
13	Female	66	Retired teacher	Married	Diploma	Good	20	Female	36	Diploma	Single	With family	3
14	Female	71	Tailor	Deceased spouse	Diploma	Average	17	Female	41	B. S. degree	Single	Only with mother	2
15	Female	60	Homemaker	Married	Diploma	Average	21	Male	38	Diploma	Single	With family	4
16	Male	63	Retired—private company	Married	M. S. degree	Average	22	Male	37	Middle school	Divorced	With family	1

**Table 2.** Theme and Sub-Themes Obtained From the Caregivers' Experiences.

Themes	Sub-themes
Theme 1: Burden of care	Disrupted social and family interactions Helplessness and inefficient support Challenges of the healthcare system
Theme 2. Negative attitude and inefficient performance	Negative attitude and inefficient performance of the Caregivers Negative attitude and inefficient performance of families and society

The results of the analysis of the interviews showed that two themes and five sub-themes were obtained from the caregivers' experiences (Table 2).

### **Theme 1. Burden of Care**

The Burden of care is defined as the negative impact of caring for the impaired person to which caregivers feel that their emotional or physical health, social life, and financial situation have suffered. In this research, the burden of care included three sub-themes that will be described below.

#### **Disruption of Social and Family Interactions**

Almost all the caregivers complained about the conflicts they or other family members had with the patients. Violence, physical harm, and family conflicts were the most prevalent codes of the sub-theme.

My husband says we should throw him out or find a job for him so that he may leave the home in the morning and return at night. My child started quarreling and hit me, then escaped from home, he lives in my parent's house, and my husband says, he should not come back. (A 60-year-old female)

We have a lot of disagreements; once, I was in the bedroom when an argument broke out, he was holding me from the back and tried to suffocate me. I fell to the ground gasping for breath; on another occasion, he tried to stab me with a knife, he said that I had killed his mother; he suddenly breaks into nervous episodes. (A 79-year-old male)

Family members usually protest as the caregivers give more attention and care to the ill child. In addition, caregivers conflict with other family members because they must perform caregiving responsibilities alone.

Other children do not understand me and protest, we have conflicts at home, they say that I pay extreme attention to him, that I have spoiled him, they always say why I always tend to him, but I say he is ill, they should not grumble. (A 71-year-old female)

In addition, caregivers have significantly less communication and interaction with their families. The caregivers are mostly isolated, and unable to see their relatives and acquaintances due to patient care.

I see that we have been separated, rejected, the family members have distanced themselves from me, the love between sisters and brothers has waned, and we do not see each other at all, a human being should not be rejected! My daughter cannot visit us even once every six months, even if she comes, he will dismiss her. (A 62-year-old female)

The situation is so grave that I do not like anyone visiting me at home, I do not want to become a topic of conversation anymore, and I have cut my relationships with anyone except my mother and my sister. I couldn't go anywhere, I became isolated like my son. I cannot associate comfortably with my relatives and other people. (A 60-year-old female)

#### **Helplessness and Inefficient Support**

Most caregivers were discontent with the government due to its insufficient support of the patients and their families and believed the existing support measures were negligible and not enough.

The government does nothing for these sick children, and we have received no support. Only the state welfare organization pays us 600 thousand rials a month, but it does not cover even the costs of medications. If government officials were thinking of us, we wouldn't have so many problems. There should be a free place for children to be cared for, where they can be employed and motivated. (A 63-year-old male)

Most caregivers were deprived of the support of their family members or other relatives and acquaintances in addition to the fact that they had lost their spouses or had disabled ones. Thus, they fulfilled their caregiving responsibilities alone.

My husband is lying on the bed and cannot walk. My relatives did not do anything to support me, I am alone. Though his siblings are aware of their brother's illness, they provide no support. (A 74-year-old female)

#### **Challenges of the Healthcare System**

The caregivers did not have sufficient awareness and information about the nature and symptoms of the disease, nor did they receive the necessary training. In many cases, they did not know how to control and manage the risky behaviors that arise from the disease.

Once, he said that he disliked me very much and wanted to kill me; he tied my hand and feet and started to look for a knife. I was crying, and tears were running down my cheeks. I was confused and did not know what to do. (A 64-year-old female)

I was not at all aware of his problem. He had hit me several times, but I did not know how to respond. I'm really confused, and nobody has told us what we should do on those occasions. (A 62-year-old female)

The slow and long processes of hospitalizing the patients, the lack of sufficient beds in hospitals, the lack of caregiving services at the patients' houses, and inadequate insurance coverage were among the main problems stated by the caregivers in this sub-theme.

We took him to the hospital but had to stay there until the next morning, and they did not hospitalize him. They did not cooperate with us, I swear to God that I went there every day of a week and asked them to hospitalize my child, but they said there was no empty bed. (A 64-year-old female)

We receive no service here, but in countries such as the U.S., they send cars to the patients' houses to take them to the hospital. Doctors and nurses visit them at their homes. They are provided with stipends, but we have not even the minimum facilities here. (A 74-year-old male)

Moreover, the caregivers' experiences in this sub-theme included a lack of accurate evaluation and the doctor's inattention to the patient, the prescription of repetitive and ineffective medications, inefficient treatments, and the lack of providing specialized services and sufficient medical information to the patients and their families.

I hospitalized him twice; he became worse and revengeful after that. So hospitalization is useless. You do not see any changes in the quality of the medications because they only increase or decrease their dose, and the drugs are not very effective. (A 60-year-old female)

## **Theme 2. Negative Attitude and Inefficient Performance**

In this study, the meaning of "negative attitude and inefficient performance" is the attitude, belief, and inefficient behaviors that some parents show in caring for an adult child with schizophrenia, and it also refers to the inefficient attitude and performance of the family and society toward patients with schizophrenia and their caregivers. This theme includes two sub-themes that will be explained below.

### **Negative Attitude and Inefficient Performance of the Caregivers**

Some caregivers had negative attitudes toward the patient due to the stress and difficulties during care. They used titles such as "crazy" for these patients and believed that were

brainwashed. Sometimes, the thought of killing the patient came to their minds.

If it was not for the fear of God, I had killed him already. You don't know what I've been through for 47 years, he's crazy; I lose my cool when I see him. He was imprisoned for a while, and his cellmates brainwashed him. (A 79-year-old male)

I tell a person with little experience of caregiving to kill the baby and save herself from a lifetime of imprisonment. This is worse than cancer; when you have cancer, you die 5 or 10 days later. But this illness is not different from the craze. Doctors have to order the abortion of such babies to save a community. (A 74-year-old female)

Some parent caregivers used inefficient methods and strategies to manage their child's illnesses, such as the unreasonable hospitalization of their child in drug rehabilitation clinics, giving additional sleeping pills, and chaining the patient to control them.

I ask his doctor to increase the dosage of his medications so that he can sleep ceaselessly and may not interfere with my affairs and. When he wakes up, stress fills all my body. (A 60-year-old female)

Sometimes his illness gets worse, and I cannot control him or take him to the hospital. So, I tie his hands and feet to avoid being harassed by him. At other times that I have no money to hospitalize him in a hospital or a rehabilitation clinic, I have to give him some sleeping pills so that he may go to sleep. (A 64-year-old female)

### **Negative Attitude and Inefficient Performance of the Family and Society**

Some of the most prevalent problems of parent caregivers include the Lack of understanding of the caregiver by relatives and considering them as blaming for the patient's condition, the lack of accepting the illness, belief in the patient's pretending of illness and the Lack of importance to the patients by society and family members.

No matter how much we explain that he is ill, they do not believe it. My sister blamed me for it; she said, why would I do this to my child, he had no problems. The most significant problem we have is that others do not believe the children are ill. (A 63-year-old female)

None of my family members believe that he is ill. In addition, our acquaintances say he is pretending to be ill. They blame me for this. They say I should not keep him at home and should let him go out and find a job. They do not understand that he is ill and cannot work. (A 74-year-old female)

Many parent caregivers complained about the unreasonable interferences and the disturbances created by other family members and society, such as advice to transfer the patient

to the centers of the welfare organization, hospitalizing the patient and attending to their own lives, and Frequent questions about the patient's condition and behaviors.

My relatives said the child annoyed me a lot, that I had to think a little about myself. In his very presence, they said I should hospitalize him, and they often interfered in our affairs. Even a doctor told me to hospitalize him. He told me—you have a family of your own and have to live your own life. (A 66-year-old female)

The parent caregivers believed that society had a pessimistic attitude toward schizophrenia patients, including staring at them, thinking they were insane, and finding it inconvenient to approach them.

The illness is not perceived well in Iran. For example, people would stare at my daughter strangely when we got on the bus. The norms of behaving with such people are not known to anyone, and many people just stare at them. (A 63-year-old female)

In society, people stare at him, point at him. Whenever a person is afflicted with this problem, they are called crazy. Even my child is called the crazy one by other relatives' children at parties. (A 60-year-old female)

Other problems of the parent caregivers were concealing their child's illnesses, giving medications to them secretly, their unwillingness to accompany their child outside their homes, and their constraints in using the public transportation system.

I am always afraid to take my child out because we have not informed anybody of our child's illness. I do not like him visiting other people's houses because he is taking medications. They sneer at him. I cannot give him his drugs comfortably, so I tell him to go to the kitchen and take his drugs so that nobody can see him. (A 63-year-old female)

## Discussion

Due to the special circumstances of parents, as they approach old age, the current study only focused on parental caregivers. A total of 16 male and female parent caregivers participated in the study. The findings of the study showed that the parent caregivers' lived experiences include two main themes: burden of care and negative attitude and inefficient performance.

### Burden of Care

The main theme of the "burden of care" was extracted from the perceptions of the caregivers, which consisted of three sub-themes "disrupted social and family interactions," "helplessness and inefficient support," and "challenges of the healthcare system." It was found that the parent's social and

family interactions got severely disrupted due to the burden of care. The caregivers and other members of the family system often lived in tension, disagreement, and conflict because of the patient's special conditions. The patients' violence against the caregivers and other members of the family and the subsequent violence by the latter groups against the former turned the atmosphere of the family into a disrupted one. The parent caregivers typically performed the caregiving tasks alone. Thus, not only they were not supported by other family members, but they were also criticized for their caring behavior. In other studies, caregivers in the family system have experienced family conflicts.<sup>28</sup> In addition, the findings of the present study showed that the caregivers' sociability and interaction with others were significantly reduced due to their responsibilities in taking care of the patients, and they were turned into socially isolated people. Moreover, other children in the family did not receive the love of their parents as before, and exclusion and apathy dominated the family members. Other studies have shown that caregivers and family members of patients were afflicted with isolation, feelings of loneliness, disruption of interpersonal relationships, and family conflicts in the process of caring for these patients.<sup>8,43</sup>

"Helplessness and inefficient support" was a sub-theme that imposed a considerable burden on the families and caregivers. The government had a very weak performance in supporting the patients and their families. Parents complained that the government was underperforming, due to a lack of attention to establishing institutions and organizations responsible for caring for the sick, meager financial support, and a lack of adequate health services. In line with the experiences of caregivers in the present study, research on family caregivers in other studies also showed that they received little support, their needs were not being met, and most support measures and services provided to them were superficial and unrealistic.<sup>44</sup> Nonetheless, providing services and support to patients and their families can reduce the burden of care for the parental caregiver to some extent.<sup>12</sup> The parents of the present study, because they were often older adults, in addition to caring for the patient, also faced with factors such as their spouse's illness or death, as well as their illness; Thus, not only they were not supported by their spouses, but they did also not receive any assistance or support from their families and relatives. The lack of support from family and relatives for caregiver parents has also been confirmed in other studies, in one study it was shown that the majority of caregivers did not receive any support from others.<sup>24</sup> The lack of social support directed the parents toward isolation and loneliness, which can lead to more stress and family conflicts, as well as various ailments in them.<sup>45</sup>

The final sub-theme of the burden of care was the "challenges of the healthcare system." The findings showed that the parent caregivers had no sufficient knowledge of the nature and symptoms of the illness and were not skillful enough to deal with the patients' physical violence and risky

behaviors, and had not received any training in this field. Studies have shown that the majority of caregivers had no prior knowledge about the nature of schizophrenia.<sup>46,47</sup> Also, the results of the lived experiences of parent caregivers in caring for an adult child with schizophrenia showed that there is limited access to services such as insufficient insurance coverage, lack of intensive care at home, and lack of beds and institutions for these patients, so these cases can add to the problems of caregivers. Many caregivers had to pass through a lengthy process to hospitalize their children in medical centers. In addition, there was no system of transportation to transport the patients to psychiatric centers. Other research has confirmed that these caregivers have limited access to mental health services.<sup>48,49</sup> Another challenge in the field of the healthcare system for service users (caregivers) is the inefficiency of services provided by specialists. The caregivers complained about the inefficient treatment methods and the lack of providing necessary information to caregivers, prescribing of repetitive and ineffective drugs, and the specialists' inefficient evaluation of the patients. In confirmation of the experiences obtained from caregivers in the present study, in other studies also the experiences of caregivers showed that healthcare workers did not provide adequate training to them about schizophrenia.<sup>50,47</sup> In addition, another study showed that healthcare specialists sometimes had problems interacting with patients with schizophrenia.<sup>26</sup>

### **Negative Attitude and Inefficient Performance**

The next theme emerging from caregivers' experiences was "Negative attitude and inefficient performance" and consisted of "Negative attitude and inefficient performance of the caregivers" and "Negative attitude and inefficient performance of the family and society" as its two sub-themes. Because of the stress of caregiving, some caregivers had negative attitudes toward their ill children, labeling them as "crazy" and believing that they must abort if they are told their baby had schizophrenic. The results of caregivers' experiences in other studies confirmed the caregivers' experiences in the present study, they showed that caregivers had poor knowledge and negative attitudes toward mental illness.<sup>51,52</sup> In explaining these results, the authors note that the aggressive behavior of the mentally ill predicted poor knowledge and negative attitudes of the caregivers toward mental illness. In the present study, this view was also prevalent mostly among the parent caregivers whose children were afflicted with severe schizophrenia and showed aggressive behaviors. Parent caregivers' negative attitudes toward their ill child can arise from several factors. The results of one study showed that parents (typically mothers), caregivers with lower levels of education, older caregivers, and people with long histories of caring had more negative attitudes toward their environments compared to the other members of families.<sup>53</sup> The present study tried to cover these

cases using purposive sampling, though they need to be investigated more accurately and carefully in future studies. Another issue was the caregivers' inconvenient behaviors toward their ill child. They gave the children sleeping pills and unreasonably hospitalized them in irrelevant centers such as drug rehabilitation centers to control and reduce the patients' violent acts. A parent chained the patient to control his violent behavior. The presence of such behaviors in parent caregivers may be due to the negative attitude of caregivers, some demographic variables, and violent behavior in people with severe schizophrenia. The caregivers' inconvenient performance, such as their extreme interference in the patients' lives, repeated criticisms, and inattention to their treatment due to ignorance and negative attitude, lead to a decrease in the mental capabilities of the patients and as well as frequent relapses.<sup>19</sup>

Among other experiences of parent caregivers, which was conceptualized as a sub-theme in the present study, was the Negative attitudes and inefficient performance of families and society toward patients and their caregivers. The parents said that their family members and society not only did not accept the patients' illness and believed that they pretended to be ill, but had no understanding of the caregivers and blamed them as the main source of their child's illness. The insufficient understanding and acceptance of society of the patients may be due to the lack of sufficient knowledge and understanding of the illness, which can also make the caregivers' responsibilities heavier. In confirmation of this finding, a study showed that half of the caregivers felt that there was little awareness of schizophrenia in society.<sup>47</sup> An interesting topic of this sub-theme was the intrusion and interference with the caregivers' responsibilities by their relatives and acquaintances, which had been neglected in most similar studies. For instance, they regularly asked the caregiver to send the patients to the centers of the national welfare organization or hospitalize them so that they might attend to their own lives. Moreover, they repeatedly asked about the patient's condition, and the large scale of such interference was irritating for the caregivers. Unlike individualistic culture, participation in social affairs—whether positively or negatively—is more highlighted in a collectivist culture like Iran. In the current study, the relatives' interferences and intrusions in the process of caregiving were related to the negative side of participation. Another finding derived from the lived experiences of parents' caregivers, which was observed in connection with this sub-theme, was the inappropriate attitude of relatives toward patients. Many people still preserve traditional and age-old attitudes toward patients with schizophrenia (e.g., staring at them and assuming them to be crazy), and the caregivers somehow believed that society did not have a convenient way to behave with such patients. A study conducted in Iran showed that 35% of the patients' family members believed society had negative attitudes toward patients. In the culture of collectivism in Iran, family members are more concerned about how others view

the family than the negative impact of mental disorders on themselves.<sup>17</sup> Ultimately, the stigma associated with the illness was another experience reported by the caregivers. The parents had to hide their children from their relatives and secretly give them their medications because of the social stigma associated with schizophrenia. The relatives' rejection and cold behaviors toward the caregivers and their family members were also found to be associated with the experience of stigma. In a study, it was shown that about half of Iranian caregivers experienced the stigma associated with the illness.<sup>23</sup> Other studies showed that the stigma caused the caregivers to hide their patients from society and isolate themselves.<sup>54</sup> Negative attitudes, discrimination, and disease-related stigma toward caregivers of patients with schizophrenia can be due to courtesy stigma, where prejudice against people with mental illness also extends to their caregivers.<sup>55</sup> Another finding also showed that negative attitudes toward caregivers can be due to caregivers' relationship with the mentally ill.<sup>56</sup>

The current study was one of the few studies in Iran that analyzed the experiences of parent caregivers as to their burden of care and the attitudes and performance of the caregivers, families, and society by implementing the qualitative method. Researchers are recommended to investigate the experiences of caregivers belonging to other cultural groups and examine the factors that influence the inefficient attitudes of caregivers, family members, the public, and even specialists toward patients with schizophrenia on a much larger scale.

## Conclusion

As parents assign great importance to their children and feel responsible for them in the Iranian culture, caring for an adult child with schizophrenia is difficult because of the negligible support mechanisms, the physical condition and older age of parents, and the low acceptance of these patients in society. The family conflicts and disruption of social interactions, the lack of government support, the high costs of treatment, inadequate insurance coverage, and the shortage of rehabilitation specialists created a significant burden of care for the caregivers. In addition, inconvenient behaviors and negative attitudes toward people with schizophrenia by some caregivers and others in the community and the lack of an appropriate psychological training program were some of the other important findings of this study. To improve the condition of caregivers and patients with schizophrenia, the following recommendations are suggested; First: Improving the knowledge, skills, and attitudes of healthcare system professionals to support patients and their caregivers. Second: the need for the government's redoubled efforts in allocating more budgets and financial support, necessary insurance coverage, and providing patients with access to all kinds of available support. Third: serious financial support for caregivers, family counseling

and reduction of family conflicts, and psychological training in the field of management and reduction of high-risk disease symptoms. Fourth: Creating an integrated team of psychiatrists, general practitioners, nurses, social workers, psychologists, and caregivers to help rehabilitate people with schizophrenia. Fifth: Using the knowledge, skills, and experiences of the family as the main pillar in the management of improving the condition of caregivers and patients with schizophrenia. Sixth: higher acceptance of patients in society, improvement of public attitude, promotion of anti-discrimination policies, and provision of comprehensive mental health programs by the government to protect patients and caregivers from negative attitudes, stigma, and obvious discrimination in society.

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## Author Contributions

All authors contributed to the study design. The first author was responsible for coordinating the project, conducting interviews, analyzing primary data, and writing the initial draft of the manuscript. Other authors contributed significantly to the process of conducting the research, initial and final analysis of data, editing, and writing the final draft of the manuscript.

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