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Qualitative Research

Barriers to Caregiver preparedness from the perspective of family caregivers and healthcare providers of people with schizophrenia: A qualitative study

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Abstract

Objectives: Caring for people with schizophrenia is the most challenging condition for their families. Family caregivers encounter broad-spectrum problems by a lack of caregiving preparedness. Therefore, this study aims to identify the barriers to caregiving preparedness from the perspective of family caregivers and health-care providers of people with schizophrenia.

Methods: Twenty semi-structured interviews were conducted by nine family caregivers and four health-care providers of people with schizophrenia selected by purposive sampling in Iran. After explaining our goals and obtaining permission, we recorded their voices, transcribed them for each session, analyzed them, and evaluated their trustworthiness.

Results: The theme of "*Barriers to caregiver preparedness*" emerged from the data in three main categories: Encountering the crisis of the unknown, mental health inequalities in society, and role confusion.

Conclusion: These findings highlighted the contextual factors that result in family caregivers' unpreparedness. Identifying these factors can help the healthcare providers appraise the caregivers for later interventions and assist the health policymakers in overcoming these barriers.

Keywords: Barriers; caregiver preparedness; family caregivers, and schizophrenia; qualitative research.

Family-centered care is a holistic approach focusing on respectful communication between patients, their family caregivers, and health-care providers.[1] Since the deinstitutionalization movement shifted care from the hospital to the home, this method has become more common. Family caregivers' needs for welfare services, financial assistance, and support increased.[2] In developing countries like Iran, the lack of support and community-based services makes the condition much more exhausting for people with chronic mental illness and their families.[3]

One of the most severe, debilitating, and chronic mental illnesses is schizophrenia. People with schizophrenia suffer from the most challenging symptoms, such as paranoia, disorganized speech or behavior, hallucinations, delusions, and cognitive impairment. These symptoms affect both their lives and their families.[4,5]

Caregiving for people with schizophrenia leads to the loss of social function, changes in communication patterns, creates job problems, and ultimately imposes a heavy burden on families.[6] Overall, families' lack of emotional, financial, and

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personal resources gradually causes expressive failure, guilt, loneliness, and family conflicts in the care process.[7]

However, the more prepared caregivers are, the more resources are available to manage events, and the more positive coping behaviors will occur. These resources include having enough information to prepare for the role, having fewer unmet needs, and focusing on the positive aspects of minimizing psychological distress.[8]

Caregiver preparedness is a suitable concept that overshadows most patient care processes. Caregiver preparedness or perceived preparedness for the caregiving role refers to a transitional phase in which family members must, willingly or unwillingly, be prepared to take on a care role. Family caregivers play a significant role in care, encounter many responsibilities for which they are not sufficiently prepared, and find themselves in problematic situations that may lead to emotional distress and difficulties.[9] Over time, family caregivers tend to become more prepared to handle their responsibilities, due to accumulated knowledge, experience, and awareness of available healthcare services. This increased readiness lessens their sense of being overwhelmed or weighed down by their responsibilities. Health-care networks' ability to offer superior support typically upholds the notion of being well-prepared.[10] Intaput et al.[11] in their qualitative research presents a fresh perspective on the importance of being prepared to provide care for individuals experiencing psychosis. While the mentioned study shows the importance of caregiver preparedness according to the family caregivers, Moudatsou et al.[12] highlighted this issue from the perspective of healthcare providers.

In addition, previous studies explained the related factors to caregiver preparedness. These factors included knowledge and information provision,[13,14] uncertainty,[13] demographic characteristics of the patients and their families,[13–15] support needs,[16] family caregivers' mood,[17] quality of life,[18] capacity and commitment of family caregivers,[19] duration of care,[15,20] resilience,[21] burden,[21,22] role strain,[17] unmet needs,[16,19] organizational culture,[14] available resources,[19] and services,[16,19]

To the best of our knowledge, most of the above studies are quantitative, and few are qualitative. Since caregiver preparedness is a concept that should be explored in the context and the factors related should be discovered in-depth, it is better to use a qualitative method to enrich the results. Although caring for people with psychiatric problems differs from caring for physical problems, most studies were about patients with physical problems such as Parkinson's, stroke, dementia, cancer, and those in need of palliative care.[16,23] Ultimately, the present study investigates the barriers to caregiving preparedness from the perspective of family caregivers, and health-care providers of people with schizophrenia to fill this gap. Knowing the related factors will help the health-care providers prepare the family caregivers with a better method and assist the health policymakers in overcoming obstacles.

What is presently known on this subject?

- Contextual factors include lack of knowledge, inequalities in mental health in society, and role confusion that can lead to a lack of caregiving preparedness.

What does this article add to the existing knowledge?

- Unpreparedness for care can create a lot of challenges for family caregivers; emotional, financial, physical, and social burdens are the most prominent.

What are the implications for practice?

- Health-care professionals and policymakers must pay more attention to the unmet needs of the families of people with schizophrenia to increase their caregiving preparedness.

Materials and Method

Study Design and Setting

The present study is a descriptive qualitative work using the content analysis approach recommended by Graneheim and Lundman (2004) to analyze the data after each interview we had done.[24] Due to COVID-19 pandemic, some participants were selected with schizophrenia Instagram pages due to closed psychiatry departments and reduced hospital visits. Knowledgeable participants were selected based on their ideas shared on posts and asked for an interview with consent. The interviews were done through text/phone (WhatsApp/Instagram) or at a park/hospital. The selected hospital is the focal point for all of hospitalized people with psychiatric problems in Shiraz and surrounding cities in the south of Iran. This hospital features various departments designed to cater to the needs of both male and female patients, including emergency units for both genders as well as a dynamic department devoted to psychiatric issues faced by children and teenagers. In addition, there are specialized departments for electroshock therapy, counseling, occupational therapy, speech therapy, and general clinics. Within this facility, the care and treatment of psychiatric patients are entrusted to a team consisting of psychiatrists, nurses, occupational therapists, psychologists, and speech therapists, each specializing in their respective fields.

Procedure and Participants

Nine family caregivers were recruited by purposive sampling if they met the following inclusion criteria: having experience of caring for someone with schizophrenia who lives with her/him at least the 2nd time of hospitalization, being willing to share experiences, and speaking Persian. In addition, the eligibility prerequisites for participation in the research among health-care providers encompassed fluency in the Persian language and willingness to partake in an interview. Participants chose the time and place of the interview to feel more comfortable. Due to corona conditions and security issues, the researcher did not make an appointment at home.

Data Collection

The data collection method involved a semi-structured in-depth interview with participants using field notes through text / phone (WhatsApp/Instagram) or at a park/hospital. Interview duration varied between 30 and 60 min, depending on participants' willingness. The first author conducted twenty interviews for this study between March 2021 and April 2022. Initially, the interviews were unstructured with general questions. The interviews were individual, and it was tried as much as possible in two sessions where the first session of the main interview and the second session, supplementary interviews, content check and ensuring the correct understanding of the speech of the research participants were taken into consideration. Interviews started with axial and general questions and continued with more specific questions, an example of which was as follows:

For instance, asking family caregivers, what were your expectations as a caregiver when discharging your patient? What kinds of challenges did you face when discharging your patient?, and also asking the health-care providers, What are the inhibiting factors that impede the preparation of care among caregivers of patients who are being discharged? What complaints do you usually face from caregivers in taking care of their patients during follow-up? Based on the findings, the questions were narrowed gradually to clarify the barriers to in-depth, consistent, and transparent data about family caregivers' attitudes toward the factors that affected caregiving preparedness. Then, ask exploratory questions such as, "Tell me more about it; how did you meet your expectations?" "What did you think of it?" Furthermore, "how did you feel?" These questions helped researchers understand the factors better.

Data Analysis

Besides the data collection, the interviews were analyzed based on qualitative content analysis reported by Graneheim and Lundman (2004). First author listened to the voice recorded and transcribed it verbatim after each session of interview. Simultaneously, three researchers read the text several times carefully, then extracted the text related to barriers to caregiver preparedness; summarized it together in one text as a unit of analysis; broke it into the meaning unit; condensed meaning unit; subthemes, and themes. Codes were compared and classified by asking multiple questions. Ultimately, they were brought into the groups according to their similarities and differences.[24]

Trustworthiness of the Data and Findings

This study employed four criteria to assess the data's credibility, conformability, dependability, and transferability. The criteria were based on those developed by Guba and Lincoln.[25] For credibility, the researcher spent prolonged time with nine family caregivers and four health-care providers and read the transcripts several times to understand the meaning. Initial codes of interviews were returned to the participants as a member check to help ensure accuracy. Moreover, for dependability, peer review was done by six expert faculty members in qualitative research and mental health nursing who were not involved in a data analysis. In addition, for confirmability, it was attempted to select the participants with the maximum variance from different groups. Finally, transferability of the data was approved by presenting precise quotes and illustrations, in-depth clarification of the data, and receiving guidance from scientific experts.

Ethical Considerations

The Ethics Committee of Islamic Azad University of Tehran Medical Sciences approved the present study with the code IR.IAU.TMU.REC.1400.143. This study had been approved by the appropriate institutional research ethics committee and performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.[26] Consent forms were obtained from all participants, and they were entitled to withdraw unconditionally at any stage. The principles of anonymity and confidentiality for the participants were respected throughout the study.

Results

Table 1 indicates the demographic characteristics of the participants (Table 1). The mean age of the caregivers was 38.27±9.65, and most were female. In this study, the barriers to caregiver preparedness from the perspective of family caregivers, and health-care providers were identified in three categories: encountering the crisis of the unknown, mental health inequalities in society, and role confusion (Table 2).

The principal theme is barriers to caregiver preparedness. The researcher explained all the categories and subcategories in the following:

Encountering the Crisis of the Unknown

Lack of Awareness of Families

Based on family caregivers' experience, most family members did not know about schizophrenia, its symptoms, and how to manage them during the crisis. As one of them stated,

"*Unfortunately, for the first time, due to my lack of knowledge about this disease, the disease temporarily subsided, but in the next period, it became so severe that suicidal thoughts came to my patient; we took her by force there and admitted her. Nevertheless, if we controlled the first period of the disease, we would get the results faster.*" (Participant 1, brother)

Most participants did not know the importance of medications and their side effects. One of the mothers said:

Table 1. Participants' demographics (n=13)

No	Sex	Age, years	Education level	Occupation	Length of caregiving, years	Relationship of caregivers to care-recipients	Number of patient admissions
1	Male	42	Bachelor	Employed	8	Brother	2
2	Female	23	Bachelor	Employed	10	Child	2
3	Female	40	Associate Degree	Employed	5	Sister	2
4	Female	48	high school	Unemployed	12	Sister	3
5	Male	41	Psychiatrist	Employed	–	–	–
6	Female	35	Master of Psychiatric Nursing	Employed	–	–	–
7	Female	54	High school	Unemployed	6	Sister	2
8	Female	28	Diploma	Unemployed	3	Wife	2
9	Female	47	Diploma	Employed	14	Mother	2
10	Female	54	Diploma	Employed	18	Mother	5
11	Female	44	Diploma	Unemployed	8	Sister	7
12	Female	39	Psychiatrist	Employed	–	–	–
13	Female	37	Occupation therapist	Employed	–	–	–

Table 2. Illustration of subcategories, categories, and a theme

Theme	Category	Subcategory
Barriers to caregiver preparedness	Encountering the crisis of the unknown	Lack of awareness of families Insufficient information resources
	Mental health inequalities in society	Social pressure Health and therapeutic challenges Little attention of policymakers to the problems of mentally ill families
	Role confusion	Escape from the role Experience mourning in a caring role

"His medication was very hypnotic, and he was only 18 years old, so I was unaware of the diseases, and I did not force him to take them." (Participant 9, mother)

In addition, family caregivers did not know how to control their stress and deal with stigma.

"We were completely scared in our house for 2 years because my brother beat us when we were all asleep." For Iranians, it is so that we do not say anything for fear of our reputation. We all jumped up in worry and stress. We were in an awful situation." (Participant 4, sister)

Insufficient Information Resources

Websites, pamphlets or leaflets that explain the illness and treatment, and links to local community resources or support groups are the sources of health information for family caregivers of schizophrenic patients. In this study, many family caregivers complained about the information insufficiency to obtain knowledge in a simple and understandable language. Most caregivers were upset that there was no alert person with whom they could share their problems. As one of them indicated:

"I followed many pages (of Instagram) for schizophrenia. They only say that they are like this or like that. Unfortunately, they do not give any proper solutions. How should we deal with them or what should we do or not do in different situations?" (Participant 7, sister)

Mental Health Inequalities in Society

Social Pressure

Most psychiatric patients and their family caregivers struggle with social pressure. Participants in this study talked about themselves and their family members being ignored by the community. The experiences showed that people still have low awareness of psychiatric illnesses and have a negative attitude toward them, which has led to challenges. As one of the psychiatrists noted below:

"Next is the social and family stigma caregivers have." They hide their patients and do not take them to the doctor until their conditions worsen."(Participant 12, psychiatrist)

In Iran, some people still mention psychiatric patients as crazy and problematic. This belief leads to the isolation of caregivers and patients. One of the caregivers expressed it as follows:

"*I am tired of my loved ones' bad moods, of my husband's criticism. My brother has badly influenced my husband's behavior. Their lack of good manners is disgusting. Honestly, I do not want to be with them like before because of their useless curiosities.*" (Participant 7, sister)

The media greatly influences the culture of the people in a society. The psychiatric illness must be appropriately reflected in the media. One of the caregivers said:

"*Honestly, very little attention has been paid to mental illness in the media, and in my opinion, it has highlighted their disabilities more in Iranian cinema.*" (Participant 2, child)

Health and Therapeutic Challenges

In small cities of Iran, there is no social emergency to transport psychiatric patients, and they must be transported to the hospital by ambulance or taxi at a high cost.

"*He always resists going to the hospital." No social ambulance cooperates with us. We must call an ambulance or 110 or pay three hundred thousand tomans to take him to the hospital by force. It is like a thief and a murderer. That is so awful here.*"(Participant 11, sister)

The experience of caregivers shows that formal education during discharge in care centers was inadequate; patients were abandoned and were not followed up at home after discharge. One of the caregivers stated:

"*No, they did not say anything." Unfortunately, my brother always had nausea, diarrhea, and vomiting after taking medicine, but no one told us anything about its side effects.*"(Participant 3, sister)

Most family caregivers complained about insufficient mental and social rehabilitation services. Both the psychiatric nurse and the occupational therapist agreed on this issue. As they mentioned below:

"*The occupational therapist teaches the patients only to do exercises or, for example, a series of drawings and weaving during hospitalization. However, some patients are eager to keep these at home, and some are not.*" (Participant 6, psychiatric nurse)

"*If I want to explain about the rehabilitation of these patients, in our country, they don't spend their money on the equipment for rehabilitation of the patients in neuropsychological department, they prefer to have space to add two more beds and accommodate two more patients, instead of spending a lot on equipment that they can use. What I am saying is during hospitalization. "Occupational therapy for these patients is available privately in other centers, but it costs a lot and most of the families do not have enough information and do not use them.*" (Participant 13, Occupational Therapist)

Most importantly, health-care providers do not consider or support family caregivers of schizophrenia patients. For this reason, they will be physically and mentally damaged over time and discouraged from caring.

"*They did not teach us anything; for example, until 2 years after his hospitalization, we all jumped out of sleep; they did not sympathize with us and did not say, "Well, your soul is also damaged.*" (Participant 4, sister)

Little Attention by Policymakers to the Problems of Mentally Ill Families

There is no constitution for hiring psychiatric patients in Iran, and as soon as they find out that someone is working with a diagnosis of schizophrenia, they fire him. As one of the participants said:

"*He was working in the information technology department of the company, but when they found out that he was sick, they fired him.*" (Participant 8, wife)

Also, one of the psychiatrists declared:

"*For instance, three percent of individuals with disabilities can participate in employment by government agencies, but psychiatric patients have no such share since they have been labeled mentally ill. For instance, three percent of individuals with disabilities can participate in employment by government agencies, but psychiatric patients have no such share since they have been labeled "mentally ill.*" (Participant 5, psychiatrist)

Family caregivers discussed the lack of insurance coverage for mental health services and medications. One of these caregivers said:

"*Caring for these patients requires money and power; that is why I say money; because the cost of counseling and therapies is so high because of the sanctions situation in Iran; foreign medications are also expensive.*" (Participant 10, mother)

Role Confusion

Escape from the Role

Some caregivers delegate care because they are tired of long-term care and delegate their responsibilities to others due to excessive stress, burdensomeness, and lack of support. One of the psychiatrists described this issue as follows:

"*Maybe they (his family caregivers) wanted to get rid of him by proposing to me, and I am very sad that they didn't tell me the truth from the beginning. I know when he was single, his situation was much worse than now.*" (Participant 8, Wife)

Some caregivers are frustrated and do not follow up on patient care training. As one of them said,

"*I did much research to see if it would work or not? Ever since I found out he would not become well; I have not followed it anymore.*" (Participant 4, sister)

Experience Mourning in a Caring Role

Because patients with schizophrenia often experience the disease at the peak of adolescence and youth, relatives of these patients experience this loss significantly. Participants in this study experienced different emotions in mourning. One of the caregivers said:

"*Do you know what "not to believe" means? I was shocked. I did not believe that my son had this disease for about 4 years, and I went to the hospital just as routine and returned home.*" (Participant 10, mother)

Anger is also one of the family caregiver's reactions. This anger is related to the patient's disabilities and dependence on the family.

"*For example, I gave him money; I told him to go and buy bread." I had given him 140 tomans in the card, and he had returned with a big book; he did not buy bread; I screamed a lot, hitting myself a lot. He was looking at me like this, not defending himself, not saying what was going on, not talking, as if he could not hear my voice at all, as if he was somewhere else, and I was screaming here.*" (Participant 9, mother)

All the caregivers had to accept their caring role, but most experienced unpleasant feelings such as feeling scared, hopeless, hypervigilance, exhaustion, and uncertainty about the future. Finally, all these feelings can lead to depression. As one of the psychiatrists clarified below:

"*I see most caregivers," for example, a depressed mother who had no energy and was mentally disturbed because she had a child who hoped to reach high positions but made her grief and sorrow.*" (Participant 5, psychiatrist)

Discussion

To the best of our knowledge, this is the first qualitative study about barriers to caregiver preparedness in family caregivers of people with schizophrenia. The experience of family caregivers was divided into three categories: encountering the crisis of the unknown, mental health inequalities in society, and role confusion.

Encountering the Crisis of the Unknown

Knowledge is essential to improve the skills of caring for transition to home. With these skills, caregivers can better manage the symptoms and, as a result, control their stress more during crisis times.[27] Lack of knowledge is a common issue in family caregivers of people with schizophrenia. Based on the experience of family caregivers, encountering the crisis of the unknown is the most prominent barrier to caregiver preparedness. Similar to this, in a previous phenomenological study, one of the themes that illustrated a lack of readiness among family caregivers of palliative care patients was the unknown.[28] Consistent with this, Liu et al.[13] showed that caregiver preparedness was positively associated with knowledge of stroke. In developing countries like Iran, psychiatric patients do not have access to supportive and community-based services; therefore, their family caregivers confront inadequate information about their unmet needs.[29]

Mental Health Inequalities in Society

After the diagnosis of schizophrenia and the transfer of patients from the hospital to the community, family caregivers faced many inequalities in mental health that can be considered barriers to preparation. Concerning these findings, a study by Lutz et al.[19] clarified that informal, formal, and financial resources affect caregiver readiness. Informal resources consist of emotional support from the surrounding people. Due to negative views toward psychiatric patients and mental health problems, family caregivers cannot share their troubles with neighbors, friends, and so on.[30] In one of the qualitative studies in Iran, one of the themes from the study was being socially ignored and humiliated by others, which is consistent with the results of the present study.[31] Furthermore, a recent meta-synthesis study on the experience of stigma in families caring for people with schizophrenia confirms the fact that Asian countries such as Iran are more exposed to stigma due to their collectivist culture and their families are more prone to use avoidance mechanisms such as isolation and lack of participation because of their negative attitudes toward psychiatric problems.[32] Moreover, formal resources include support from the health-care system and social support.[19] Because of the cultural weakness and therapeutic challenges, family caregivers in this study could not access their legal resources. Asian traditional beliefs are based on not receiving psychological help from external resources due to stigma and discrimination.[33]

Moreover, Iranian collectivist culture pays attention to social support, which can be helpful against the individualistic culture of Western countries. Nevertheless, because people's opinions are essential in the culture of collectivism, stigma is more likely to occur.[23] Several studies demonstrate that stigma is associated with the family caregiver's burden.[34] One study indicated that care burden and caregiver preparedness are inversely related. In such a way, the higher the care burden, the less caregiver preparedness there will be.[35] The last formal resource reported was financial support, which refers to decreased medical costs for psychiatric patients.[19] The present study also showed that health policymakers paid little attention to the problems of mentally ill families. One of the problems was the lack of insurance coverage, expensive medications, and psychotherapy due to a lack of financial support. Health insurance for people with schizophrenia is essential since schizophrenia is a chronic and long-lasting disease. Health insurance can improve the condition of people with schizophrenia, and reduce the family caregiver's burden.[36]

Another problem is the lack of rehabilitation services like employment for psychiatric patients. One study points to the prioritization of health policymakers in rehabilitation services for people with schizophrenia, such as job and funding allocation to these patients.[37] Health policymakers and most health-care providers focus on the patient's needs. They ignore their caregivers, creating challenges and concerns about unmet needs for the family caregivers.[38] In this study, most family caregivers complained of abandonment and neglect by health-care providers, especially in the educational field. One of the recent studies noted the "neglected educational needs of caregivers" as a challenge to the health-care system.[39] Failure to meet the educational needs of caregivers can repeat a vicious cycle that leads to role confusion in caregivers.

Role Confusion

In line with the findings of this study, Bagnasco et al.[40] in their phenomenological research aimed at investigating the experience of 16 caregivers of patients with chronic obstructive pulmonary disease, identified the theme of "feeling the need to escape" which is consistent with this study. Sometimes caregivers escape from the caregiving role and move on to other favorite roles that give them a social identity. In the meantime, they primarily seek support from friends and relatives as an alternative. Overall, facing a lack of social support from friends and relatives can lead to a chronic sense of sorrow in family caregivers.[41] Furthermore, in the present study, family caregivers noted mourning in such a way that they experienced the feelings of shock, fear, disappointment, frustration, and uncertainty. These persistent unpleasant feelings lead to psychological distress, a sign of family burden.[42] Consequently, the family burden can result in a lack of preparedness to take on the caregiving role.

Limitations and Strengths

This descriptive qualitative study has several limitations. First, most interviews were performed in the virtual and remote mode because of respect to the legal of social space and health safety during the COVID-19 era. The researcher may not interpret the interviews well because most nonverbal cues and body language may be omitted. The second limitation was the caregivers' gender. Most participants in this study were female, which can affect transferability. In most communities, women are responsible for caring for sick family members, which is the same in Iran.[43] The last limitation was the age of family caregivers. Since most interviews were performed virtually, the elderly family caregivers could not participate in our study. Because aged caregivers were more at risk for COVID-19, they did not attend hospitals either. Despite the disadvantages of the virtual interview, this method benefits the stigmatized group like family caregivers of people with schizophrenia. It can protect the interviewee's privacy and does not need to consider the time, place of the interview, and cost.[44] The other strength was selecting the family caregivers with the maximum variance from different groups. All family caregivers were evaluated with various family relationships with the patient.

Implications for Nursing and Health Policy

Based on our findings, knowing the barriers to caregiver preparedness can assist healthcare providers, particularly psychiatric nurses, in appraising the family caregiver's preparedness before discharge; therefore, they can remove the barriers associated with the family and the healthcare environment. This research also helps policymakers with policies on community-based healthcare, funding allocation to rehabilitation services, insurance coverage for therapeutic interventions, and culture-building to reduce stigma.

Conclusion

This is the first qualitative research to identify barriers to caregiver preparedness from the perspective of family caregivers and health-care providers of people with schizophrenia. Our study shows that caregiving to people with schizophrenia is stressful. Family caregivers in this study feel abandoned, particularly for their stigmatized condition. Poor communication with health-care providers was also a considerable issue. To ensure a complete evaluation of all factors related to caregiving preparedness, discharge planning needs to take a comprehensive system-based approach. There is a growing need for health professionals to take a more proactive role in educating and providing assistance to caregivers. In the context of Asian societies, it is crucial for professionals to recognize the cultural expectations faced by women who provide care and to promote increased attention to community-based caregiving. This can be achieved by supporting the training of specialized nurses who can effectively assist families within their local communities. It is imperative that we gain further insight into the experiences of male caregivers, as their perspectives have been largely overlooked in the current body of research on informal caregiving.

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