

"Living in Hell": Experiences of Iranian Families Living with Patients with Schizophrenia

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Research Article

Keywords: Schizophrenia, Family, Qualitative, Experience

Posted Date: August 2nd, 2021

DOI: <https://doi.org/10.21203/rs.3.rs-644478/v1>

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Abstract

Background: In addition to bearing on the patients and public, schizophrenia has a tremendous impact on families and caregivers. Its negative consequence has been studied as a burden. In this study, by doing qualitative analysis, we examined the experiences of Iranian families within the Ardabil, Iran, living with patients with schizophrenia.

Method: This research was a qualitative study, and data collection was done through an in-depth, unstructured interview. Twenty family members of patients with schizophrenia were interviewed, and data were analyzed by the conventional qualitative content analysis.

Results: The major themes of the interviews were classified into 3-level codes. Six subthemes were found in the experiences of patients with schizophrenia families, namely stigma, sense of shame, isolation, need for support, and lack of awareness, and poor quality of life, which were combined and classified into one main category named "living in hell".

Conclusions: The findings showed that schizophrenia has an impressive negative effect on the families' welfare; thus, it highlights the necessity to provide interventions to help them adapt to this disorder. The results also highlight that caring is more demanding for families of long-term disease patients.

Background

Deinstitutionalization brings an era in which most patients with schizophrenia are now being cared for by their families within the communities (Chan, 2011). But Studies showed caregivers experience a high level of burden, and their quality of life decreases (Stanley, Balakrishnan, & Ilangovan, 2017). When caregivers hold all the responsibilities of the patient, they may experience feelings such as anger, shame, and guilt, annoyance, stigma, fear, unimportance, despair and uncertainty, apprehension, pressure, and sadness (Ata & Doğan, 2018). Researchers have studied the burden and complexities of caring for patients with schizophrenia (Attepe Özden & Tuncay, 2018; Karamlou, Borjali, Mottaghipour, & Sadeghi, 2015). In a literature review, caregivers of patients with schizophrenia declared the burden of care could be related to workload, sleep disorder, financial problems, less pressure, time, etc. Stigmatization and social isolation made by neighbors or other contacts can impose a significant part of the care burden, which is referred to it as an "environmental burden" (Millier et al., 2014). As well, the experiences of caregivers of patients with schizophrenia (Krupchanka et al., 2018; Nxumalo & Mchunu, 2017) have been studied earlier. However, we have not found many studies regarding the subjective experiences of families of Iranian patients with schizophrenia. Therefore, more research is warranted to comprehend which features of the experience are more widespread and troublesome in the Iranian context. Therefore, the purpose of this study was to investigate the experiences of family members of patients with schizophrenia in Iran.

Method

Method

Design: This study used a qualitative content analysis method to explain the experiences of family members of patients with schizophrenia in Iran.

Participants: Twenty participants were purposefully selected from an educational hospital affiliated with the Ardabil University of Medical Sciences. It should be noted that the Ardabil province is located northwest of Iran, and the local language of the people within the region is Turkish.

Ethical consideration: Ethical approval for the original study was granted by the Ethics Committee at the University. Written and verbal consent was obtained for the interview, audio recording as well permission for the data to be analyzed and used for original and any subsequent analysis.

Data collection and interviews: Data collection was carried out by applying unstructured, in-depth interviews. A general question explored the same phenomenon: "living with a family member who has been diagnosed with schizophrenia".

The authors' collaboration developed the interview guide, and the literature review helped to determine the list of the topics that were to be covered by the interview guide. Questions included: "Would you please inform me about your experiences of caring for your patient? Would you let me know about any troubles you have encountered while caring for your patient?" Based on the earlier information gained from the interviewees, some other questions were also asked when required to obtain more in-depth data.

One researcher (E.T.) conducted all of the interviews. To make sure the phenomenon under study was entirely explored, two pilot interviews were conducted, audio-recorded, transcribed verbatim and assessed by an independent researcher. Interviews were held in the local language (Turkish), and each interview lasted around 1-hour to complete. During interviews, some notes were also taken to clarify the information collected. All interviews were conducted in a private room in the hospital. The conversations continued up to data saturation when no new themes or categories were identified. The data saturation was confirmed by researchers who were experienced in the qualitative study.

Selection of the participants: Only one primary family member for each patient was interviewed. He or she should be defined as the person: (1) who was considered by the patient as the key caregiver; (2) who provided more than 30% of care to the patient based on a self-reported care workload (3) and his/her care length was more than a year. The participants also fulfilled the following criteria: (1) their age was more than 18 years; and (2) his/her patient met the Classification of Mental Disorders, Fifth Edition (DSM-V) criteria for schizophrenia diagnosed by the first author who was a psychiatrist (P.M). All the participants were verbally informed and signed informed consent.

Analysis: The content analysis method was used to analyze simultaneously with the data collection. The analysis was done by open coding to develop the first categories. Interviews were organized into units, and then they were summarized and changed into codes. The primary codes were categorized based on their differences and similarities, and then secondary codes were developed. At this level, the secondary

codes were discussed and reviewed to achieve major themes that were classified as third-level codes (Denise & Beck, Tatano, 2016).

Rigor: Using a heterogeneous group of participants ensured representing a wide range of perspectives. Pilot testing assured us the interview would obtain appropriate data, and the researcher tried not to influence the interviewees during the meetings. The recordings were transcribed and read several times to catch the entire concept. As well, we offered the subthemes to the participants to check the validity of the findings. The co-author who was an expert in qualitative research (M.K) analyzed the transcripts, and there was a high level of consensus in comparing the results.

Results

Data saturation was obtained at the 20th interview. Participants included seven mothers, three fathers, two sisters, two daughters, one brother, four spouses, and one nephew (table 1). The mean age of the participants was 36 years.

The initial coding of the transcripts led to 870 codes, 17 subthemes, and 6 themes including lack of public awareness, stigma, sense of shame, isolation, poor quality of life, and the need for support which were merged into one main category, namely "living in hell" which was taken from the participants' quotes in the interviews (Table 2).

Living in hell: Dealing with a family member who has schizophrenia was overwhelming, stressful, confusing, frightening, and painful. The caregivers' comments represented the sheer of such feelings:

"I felt hopeless. There was nowhere to turn. It made the next 15 years look like hell", said a spouse.

1. Lack of public awareness: Several participants knew that lack of knowledge about psychiatric disorders is the main reason for the bad behaviors of others and the loss of their social status. This theme had three subthemes including public unawareness, lack of proper marriage opportunities, belief that the disease is inherited.

"People think that we've got a patient who's stupid", said a brother.

Most of the participants stated people believe the disease is inherited; therefore, the patients' relatives do not have the opportunity to get married.

The general public view of psychiatric treatment adds to the stigma experienced by the families of people with schizophrenia.

"When people find out you have a mentally ill family member; I believe they are frightened (that they might get it!)". A mother commented.

A mother who had a daughter with schizophrenia since she was 19, expressed: *"It's like what you can see in the movies: Broken windows, people are tied to their beds, and what can you do? The days are hard and you can tell by the looks of the people walking around there that they are having problems."* As a result, coercive treatment and custodial care is the acceptable way of dealing with individuals with schizophrenia in the eyes of the public.

2. Stigma:

This category groups various situations in which family members have witnessed instances of discrimination based on existing prejudice towards mental illness in their social setting, including close family, and the media which spreads to family. Family members commented again and again, at times, that discrimination was directed at them. They have often heard that the mentally ill individuals have been accused of undesirable traits, such as being lazy, dangerous, and liars which have caused the patients' family members to get upset and cry. For example, a father said: *"When my daughter (other than the patient) is quiet or sad for a moment, her mother-in-law tells her bitterly, maybe you are becoming much like your sister"*.

A father said: *"When my daughter (other than the patient) is quiet or sad for a moment, her mother-in-law tells her bitterly, maybe you are becoming much like your sister"*. A spouse said in this regard: *"When my son had discussed with his classmate, all the class members' had ridiculed him, saying that his father was mad and for several times he escaped from school crying"*.

A daughter talked about stigmatization: *"When someone becomes aware of my mother's sickness, he/she gets bitter at me and changes his/her behavior"*.

3. Sense of shame: The discrimination and ridicule made family members embarrassed. Families highlighted instances when they felt ashamed of being related to a patient with schizophrenia and this led them to self-discrimination often involving concealment. As a result of the embarrassment, shame, and dishonor of having these patients, families did not tend to talk to and tell others about their patients. The shame of the disease in some families was just so annoying that some had changed their residential area.

Subthemes "Hiding the disease" and "fear of superimposition" pointed to this theme.

A mother declared: *"Most of the time, we have to hide the disease because of the shame"*.

A son mentioned. *"I haven't talked about my mother's illness with others, particularly with my friends. I feel embarrassed once anyone talks about her"*.

A mother said: *"When my daughter broke the glasses of the window, the neighbors called the emergency medical service; a day after, my son's colleague asked him about what happened and he lied saying that 'my mother had a heart attack' "*.

4. Isolation: This category is related to the social contact avoidance reactions noticed in the families which contained the subthemes of “fear of people”, “and lack of freedom in communication”. They believed this was because of the limitations and discriminations to which they were exposed. This issue leads families to have constraints in their relationships with others and their public communications. It also causes problems in their social relations.

“My husband is pessimistic about my brother. Many times, he has quarreled with me and my brother about him. My brother never comes to my home and I never go to his home, Sometimes, I see him at my father’s home”, a spouse said.

A daughter said: *“Our neighbors don’t let their kids come to my house and play with my sister, and if they have any work to do with my mother, they do it cautiously”.* Families mentioned numerous experiences in which even the closest family members made blaming remarks. Sometimes, they felt how people avoided them: *“they see you at the supermarket and they avoid you, they don’t speak to you anymore. My own family says that it’s because I spoiled him...”* a mother said. This refers to patients ‘avoiding their relatives because of the internalization of stigma. Many respondents had negative opinions about their disease and attributed it to themselves and their patients. This cycle is not only aggravated by its effects on self-image and identity, but also it decreases their awareness of the civil rights of both the patients themselves and their relatives.

5. Poor quality of life: One of the basic concepts in this study was the poor quality of life because schizophrenia is a chronic disease with no cure and is accompanied by bizarre behaviors such as hallucination, aggression, and lack of understanding. The participants mentioned family problems, disturbances, inefficiencies.” Schizophrenia affects all family relationships, and may even impact relationships within one’s community.

The participants of the study experienced “Loss of family security”, “sorrow”, “academic failure”, and “turmoil in the family” which were concluded in the “poor quality of life”.

A spouse said: *“My husband always carries a knife with him and threatens and hits us if the things are bad with him”.*

A mother mentioned: *“After my daughter’s illness, our life was turned upside down. All members of the family got involved and we have no peace for a second even at night. We can just rest when she is admitted to a hospital”.*

“When my son and his sister quarrel with each other, it causes stress for everyone in the family.”

6. Need for support: Another concept of this research was the families' need for support in caring for patients and themselves which had three subthemes including “financial problems”, “burden of care”, and “need to support”. A son said: *“Several times, we had to stop treatment because of the inability to pay for the treatment costs, which, in turn, worsens my father's condition”.*

Again a mother declared: *“Sometimes, my son’s behavior is so unbearable that I wish death for him”.*

The importance of family and friends was a recurring theme. Family social support was identified as an extremely helpful component in providing crisis intervention and resourceful information, exchanging ideas for coping strategies, and above all, sharing the pain and understanding of having lived through similar life experiences.

“The parents will always have to be parents to this child since he/she will need much more reinforcement and assistance than the other family members. Also, siblings have to be willing to accept some of the responsibility and caring.” A mother said.

Finally, family members explained the vast advantages of family, friend, and social support:

“The biggest help in coping with this situation is discovering that many of our friends have family members with mental illnesses— you don't feel as alone.” A mother said.

Discussion

The results of the content analysis emphasized the significance of understanding the experiences of family members of a patient with schizophrenia. The prevailing theme in the interviews revealed by qualitative analysis was overwhelming feelings. This theme depicted the approach by which the family members talked about and defined their experiences. Moreover, such emotions were powerfully intertwined with the other persistent themes, including stigma, sense of shame, isolation, need for support, lack of awareness, and poor quality of life.

The answers provided by the family members put forward that caring for a family member with schizophrenia not only leads to multidimensional costs in terms of time and energy but also brings about multiple sources of stress for the families' life. This is an expected finding in Iranian families because of the tight bounding of family members who feel a strong responsibility to care for one another as their close interpersonal relations distinguish Iranian families. As a result, sickness in one family member causes a notable burden on the entire family. Also, it would be catastrophic since there are not enough social security services to support these families in Iran (Sharif, Shaygan, & Mani, 2012).

Most of the participants believed there is a lack of public awareness, which causes others to have inappropriate behaviors with them, and, as a result, they lose their social status. Krupchanka et al. (2018) pointed "a general lack of understanding and misconceptions about mental illness" in the experience of stigma and discrimination in families of persons with schizophrenia in the Czech Republic (Krupchanka et al., 2018). Caregivers of people with mental illness experience enormous burdens during providing care for their relatives with mental illness. Therefore, creating community awareness and targeted interventions in the area of treatment access, stigma, financial, and other social support for people with mental illness and their caregivers would help out to reduce these burdens (Ayalew, Workicho, Tesfaye, Hailesilasie, & Abera, 2019).

Another finding of this study was the shame and fear of dishonor in the family members of patients with schizophrenia. The concept of shame was consistent with et al. 's concept of "discomfort to disclose the illness"(Varghese et al., 2017).

According to our findings, the patient's inadequate performance may direct family members to stay away from close social interactions. Additionally, because of other's behaviors with and judgments about the patient and his or her family and being afraid that others will be annoyed with the patients' actions, the families prefer to have limited interaction with others. Moreover, due to little support from society, these families are liable to be overwhelmed by their caregiving duties and become too depleted to be involved in their social network. Mizuno et al. (2013) stated the community still has a deep-rooted prejudice regarding patients with mental illness, and this encourages many families to withdraw themselves from society. The adverse reflection of schizophrenia makes families prone to a sense of guilt. So, the families reluctant to join the family association because they understand the feelings of other families; "they hide their patients from the public eye" (Mizuno, Takataya, Kamizawa, Sakai, & Yamazaki, 2013).

The most important concept of this research was the poor quality of life. The finding that family members reported more debt troubles is in line with the results of other studies (Krupchanka et al., 2018). Dijkxhoorn et al., constructed a multiphase model, naming "The Banyan model of caregiver experiences". The phases are (1) manifestation of symptoms, (2) seeking help, (3) helplessness and attribution, (4) relative control and insight, (5) loss and worries, and (6) finding new meaning (Dijkxhoorn, Padmakar, Jude, Bunders, & Regeer, 2019). This model has derived positive outcomes for caregiving.

One more concept of this research was the families' need for financial, emotional, and spiritual support to either treat schizophrenia or care for the patients. Avcioglu et al. stated siblings of patients with schizophrenia should have the right to use social support, and their problem-focused coping strategies should be reinforced. More to the point, parents should be supported to offer appropriate care for the siblings of patients with schizophrenia (Avcioglu, Karanci, & Soygur, 2019). Sekhavatpour et al. stated Spiritual self-care training can increase the quality of life and can be used as a form of holistic nursing care for mothers with premature infants in neonatal intensive care units (Sekhavatpour et al., 2020).

Limitations

The transferability of the findings of qualitative studies is limited (Kyngäs, Mikkonen, & Kääriäinen, 2020); however, if the context is consistent with the socio-cultural context of the present study, the findings can be extended to other cultures to some extent.

Conclusion

The results of this study put forward that schizophrenia has a significant adverse effect on the patients' families within the Ardabil province of Iran. Therefore, the need to provide interventions to help families to manage this disorder should be stressed. Also, the results underline that caring would be more

demanding for families of patients with long-standing disorders, so nurses might assist families in reinforcing their abilities to care for their patients.

Implications for psychiatric nursing practice: We recommend nursing curriculums be revised to enable future nurses to identify the issue of family burden, so preparing them with skills to plan and implement appropriate interventions to deal with this problem.

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