

Barriers to Family Resilience in Caregivers of People Who Have Schizophrenia

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Abstract

Purpose: To explore the barriers to family resilience in caregivers of people who have schizophrenia.

Design: A qualitative descriptive approach was used.

Methods: Semistructured interviews were conducted with family caregivers of patients with schizophrenia registered at the psychiatry outpatient unit of a hospital center. Content analysis was performed on audio-recorded and verbatim-transcribed interviews. The consolidated criteria for reporting qualitative research (COREQ) checklist was applied to this study.

Results: A total of 31 family caregivers participated, the majority of whom were female (71%) with an average age of 57.5 years. Most participants lived with and cared for their relative (90.3%). The caregiver role was assumed mostly by mothers (54.8%) and fathers (22.6%). Barriers to family resilience in caregivers of people experiencing schizophrenia broadly fall under five categories: lack of knowledge about the disease, social stigma, expressed emotion, involvement in the relationship, and blame.

Conclusions: In view of the paucity of studies exploring and understanding the barriers to family resilience, this study presents itself as one of the first in this area. There are different barriers to family resilience. This research provides an overview and an understanding of key barriers to family resilience in caregivers of people experiencing schizophrenia.

Clinical Relevance: There is a need for nurses to help families to be resilient. By understanding the barriers to resilience, nurses are able to focus on these factors and help families to remove or reduce their influence.

The increasing deinstitutionalization of patients with mental illness has led family members to assume the role as carers. Caring for a patient who has schizophrenia is challenging. The behavior caused by the disease, as well as all the cultural and social negative connotations, cause tension in the family relationships, which often leads to difficulty in adapting to the caregiver role (Caqueo-Urizar, Rus-Calafell, Urzúa, Escudero, & Gutiérrez-Maldonado, 2015).

In order to continue with their life project, it is necessary for families to develop resilience before this adversity. Resilience is the ability to maintain a stable path of healthy functioning over time as well as the capacity to generate positive emotions and experiences

despite difficult and stressful life experiences (Bonanno, 2004). It is considered the capability to adapt to adverse situations, allowing the family to enhance their internal and external resources, which leads to the development of a psychic construction suitable for social insertion (Rutten et al., 2013). Resilience is not a specific characteristic of a particular person or group but a multidimensional construct that implies the exposure to a significant threat or severe adversity and the ability to make an effective adaptation, despite the potential aggression (Luthar, Cicchetti, & Becker, 2000).

Over the past decade, research has enabled the development of multiple theories that explore the resilience construct. Several studies have been carried out with

variable focus, depending on the population examined and the researcher's discipline (Teahan et al., 2018).

Resilience studies focus on the potential for health promotion, without focusing on pathological aspects. It is a possibility to expand the understanding of the health–disease process centered solely on the person, with an approach that includes the family and the community, articulating the relationships between social, cultural, economic, and political contexts (Eckermann, 2018).

Theoretical resilience frameworks are generally not linked to attempts to measure resilience, since it is difficult to measure people's adaptive capacity, because these capacities involve psychological, cultural, technical, financial, social, and political components (Sturges, 2016).

There is some consensus that resilience may be an intermediate rather than a final outcome, requiring the combination of skills or assets that lead to positive well-being outcomes (Sturges, 2016). Resilience must be seen as a set of psychological phenomena that need to be investigated. It can be triggered and disappear at certain times in life, and can be present in some areas and absent in others (Rutten et al., 2013).

There are factors that can act as facilitators or barriers to resilience, even in the worst circumstances (Melillo & Suárez-Ojeda, 2005). These barriers and facilitators may be different in relation to a range of contexts (Davydov, Stewart, Ritchie, & Chaudieu, 2010). The presence of these factors for one health domain does not by itself imply a role in others. Their specificity regarding specific domains has yet to be clarified (Luthar et al., 2000).

There is a paucity of studies exploring and understanding these factors. This research aims to explore the barriers to family resilience in caregivers of people who have schizophrenia.

Methods

Study Design

The research used a qualitative descriptive design, which enabled an in-depth exploration of barriers to family resilience. The consolidated criteria for reporting qualitative research (COREQ) checklist was applied to this study (Tong, Sainsbury, & Craig, 2007).

Setting

The study setting was a 376-bed metropolitan public hospital center in Portugal that caters to a population of over 250,000 people.

Sampling and Recruitment

The study population consisted of family caregivers of patients with schizophrenia registered at the psychiatry outpatient unit.

The sampling method selection was nonprobabilistic by convenience. The inclusion criteria were outlined as follows: the relative's medical diagnosis was carried out 5 or more years ago; being a family caregiver of the person with schizophrenia for 5 or more years; and literate in Portuguese.

The criteria of 5 years was based on the assumption that for family caregivers to be resilient they need to maintain a stable path of healthy functioning over time, allowing them to enhance their internal and external resources, which leads to the development of a psychic construction suitable for social insertion.

Schizophrenia is relatively chronic in nature. Perceived stress on the family caregivers may decrease over time as they adjust to behavior patterns and relapses over the years, and the caregivers may become more resilient. This situation was identified in caregivers who cared for people with schizophrenia for 5 years or more (El-Ghafari, El-Nabi, & Fathalla, 2018).

All family caregivers of patients with schizophrenia available at the time of data collection that met the inclusion criteria were included to guarantee greater variability of data.

Participants

Of the 31 interviews carried out, the participants were mostly female (71%). The mean age of participants was 57.5 years (range 27–70 years), and the standard deviation was 11.5321 years. Most participants lived with and cared for their relative (90.3%). The role of caregiver was assumed mainly by mothers (54.8%) and fathers (22.6%; Table 1).

Data Collection

All the participants were interviewed in person by the first author (J.B.F.) at the outpatient unit site. On average, each interview lasted approximately 15 min and was audiotaped, transcribed verbatim into textual data by the researchers, anonymized, and later analyzed.

The semistructured interview guide was developed based on the literature review and with input from experts on qualitative research methods. It consists of a set of open-ended questions focusing on the constructs of resilience barriers. Examples of questions used in the guide are as follows: "Are there any

Table 1. Characteristics of the Participants in the Interviews

		n	%
Gender	Female	22	71
	Male	8	29
Household	2	10	32.3
	3	14	45.2
	4	5	16.1
	5	1	3.2
	6	1	3.2
Kinship	Mother	17	54.8
	Father	7	22.6
	Son/daughter	5	16.1
	Brother/sister	2	6.5
Age (years)	Mean	57.5	
	Median	61	
	Mode	62	
	Standard deviation	11.5321	
	Minimum	27	
	Maximum	70	

factors that limit you to overcome the manifestations of your relative's illness?" and "Tell me about a particular situation when you felt unable to cope with it?"

Five pilot interviews were made to test the guide. Subsequently, participants were questioned for feedback to check their perception of how the interview took place. The participants considered that the interview process was sufficiently clear, objective, and comprehensive, and that it did not present questions that could be ambiguous or equivocal. With this feedback, the researchers concluded that the instrument proved to be suitable for this study.

Data Analyses

The process of interview-text analysis was performed by applying qualitative content analysis as described by Bardin (2004), which involved pre-analysis, encoding, categorization, and interpretation of data. This process was followed to identify interesting and important categories that allow answering the research question.

The interview recordings were listened to several times to obtain a general sense. After transcribed verbatim into textual data, the text was divided into meaning units, involving words and phrases on the same topic. Using the participants' own words, codes were assigned to the meaning units. Categories and subcategories were identified based on differences and similarities. Two investigators performed separately the different stages of analysis. To measure intercoder reliability, the percentage of agreement was used. This

method assesses the percentage of agreement between the two coders' decisions when coding the same units of data (Neuendorf, 2017). To obtain the percentage of agreement, the number of coders' consensus decisions was divided by the total number of decisions made by the two coders, resulting in an 80% agreement rate. The differences were resolved by discussion between the researchers.

Ethics and Procedures

Before conducting this study, a research protocol was analyzed and approved by the hospital center's Board of Directors and the Institutional Ethical Review committee (no. 49/2010, protocol 27.10).

All participants signed the informed consent to participate, audio-record the interview, anonymously report, and publish the research data. After the verbatim transcription, all the recorded data were destroyed.

Results

Analysis of interview data revealed several barriers to family resilience that we grouped into categories. Each category is detailed below.

Main Category: Lack of Knowledge About the Disease

Several participants described the lack of knowledge about the disease as a major barrier towards family resilience. They focused on the lack of knowledge to understand the disease, the behavior patterns, and how to relate and help the sick relative. It should be noted that all participants stated that they overcame this limitation with the frequency of psychoeducation and counseling sessions with health professionals. It is extremely important for the family to acquire knowledge about the disease and how to cope with the patient's behaviors and attitudes. This search for knowledge and the beginning of the learning process allows the family to reorganize and have a positive development: "I didn't understand anything about what was happening to him. I never thought that these diseases would do this. . . . We didn't have the knowledge to react to the disease in order to help our son" (P7).

Main Category: Social Stigma

Participants frequently reported social stigma as a barrier towards family resilience. They considered that despite all efforts to reduce stigmatization in this type of disease, it seems that it is not possible to

prevent the family, particularly the parents, to agree with those stereotypes and internalized them by applying them to the self: “I went to school with him and everyone was looking at us just because he is sick, it was the biggest shame of my life. . . . I felt that everyone thought I had done something wrong” (P11).

Main Category: Expressed Emotion

Expressed emotion was also reported by several participants as a barrier towards family resilience. Expressed emotion characterizes the family caregiver's attitude towards the patient. It creates an adverse family environment with dysfunctional interaction patterns that include criticism and hostility: “I screamed a lot at him, I felt revolt and I couldn't stop screaming . . . we couldn't manage his behavior and then we got into conflicts” (P10).

Main Category: Involvement in the Relationship

Two subcategories were identified in this category: noninvolvement and overinvolvement in the relationship. Being in a relationship with others implies dealing with people in an appropriate way according to their needs and to the demands of the situation. It is necessary to mobilize several skills, including perceptual and behavioral flexibilities, which means trying to see the same situation from different angles or aspects and acting accordantly.

Participants reported that living with a schizophrenic patient can be a problematic situation, because of the chronicity and severity of the disease. Faced with many failures, relapses, and therapeutic nonadherence, family members become pessimistic and not involved in the relationship: “My husband was unable to cope with this, their relationship deteriorated, they split up and now they do not speak to each other” (P28).

Likewise, participants also reported that caring for someone implies a burden and it can lead to overinvolvement in the relationship, taking control of the person's decisions and denying them their autonomy: “I don't trust her, she tries to do her life normally, but I need to be involved, to control some aspects and impose restrictions” (P4).

Main Category: Blame

This category consists of two subcategories: self-blame and blames the patient. Some participants reported that they were responsible for the relative's illness. It

seems that they are unable to avoid self-blaming for some educational error or simply as if they were passive carriers of the disease:

He always told me to be firm with them, but I made my mistakes and that was it . . . I am the one to blame. . . . I even told my husband that this must have been something we did.” (P12)

Contrasting with this attitude, other participants blamed the patients for their illness as if it had been triggered by some behavior or attitude:

It must have all started because of bad friends, vagrancy. He always went with a group from the neighbourhood . . . I always warned him, but he never wanted to know . . . I blame him for this.” (P17)

Discussion

Through interviews with the schizophrenic patients' family caregivers, we identified five categories of barriers towards family resilience, namely, lack of knowledge about the disease, social stigma, expressed emotion, involvement in the relationship, and blame.

The barriers frequently described by participants were lack of knowledge about the disease, social stigma, and expressed emotion. This fact may indicate that these barriers in particular may have a predominant impact on family resilience.

It is known that the diagnosis of schizophrenia in the family causes strain in the family relationship. There is a change in their dynamics that leads to a constant adjustment to the manifestations of the disease, often causing family suffering and inappropriate interactions with the patient (Caqueo-Úrizar et al., 2015). The way a family interprets their relative's mental illness influences their care practices, which is an important indicator for the success of the patient's rehabilitation and social reintegration (Glynn, Cohen, Dixon, & Niv, 2006; Sun et al., 2019).

Although the role of caregivers is assumed with some naturalness by the family, the difficulties experienced by accumulating this function require an extra effort, in order to face the difficulties caused by the disease (Mueaer, Deavers, Penn, & Cassisi, 2013; Sun et al., 2019). There are changes in the relationship between the patient and their family, which can result in interpersonal conflicts, expressed emotion, and deterioration of the relationship (Caqueo-Úrizar et al., 2017; Lippi, 2016; Nuralita, Camellia, & Loebis, 2019).

Participants frequently reported expressed emotion as a barrier to family resilience. Previous studies identified that family caregivers with a high level of expressed emotion use inappropriate and inflexible strategies to deal with the difficulties, which are problematic, given that their attitudes regarding the patient are considered an important relapse predictor (Caqueo-Úrizar et al., 2017; Nuralita et al., 2019).

Families of people with mental illness have specific needs, highlighting the need to learn how to relate to the sick person, and to understand the disease and its manifestations. By acquiring knowledge, they will be able to cope with the adverse situation and care for the patient (Grácio, Gonçalves-Pereira, & Leff, 2016; Sin & Norman, 2013).

Regarding social stigma, Corrigan, Larson, and Rüsch (2009) described that to experience stigma, the family member must be aware of and agree with the stereotypes that describe a stigmatized group. Several studies found that the lack of knowledge about the disease led the family to report cases of stigma and to have doubts about the veracity of the diagnosis and the disease (Caqueo-Úrizar et al., 2017; Rezayat, Mohammadi, Fallahi-Khoshknab, & Sharifi, 2019).

Many family caregivers see their social life limited, not only due to the burden of caring for the patient, but also because of the rejection caused by stigma. In addition to feeling ashamed, family caregivers feel guilt for their relative's illness, which leads to the triggering of their own stigma, and the presence of these feelings often leads to avoiding social situations (Rezayat et al., 2019; Sahar & Zaki, 2015).

Across several interviews, barrier involvement emerged from the descriptions of behaviors of non-involvement and overinvolvement in the relationship. One of the aspects that characterize patients with schizophrenia is the absence of social competence, which can be reflected in the absence of basic conversation skills and in the maintenance of relationships, which requires a greater effort from the family in order to maintain the relationship (Chien, Leung, Yeung, & Wong, 2013). In certain cases, the burden leads the family to renounce the role of caregivers. When the family caregivers believe that the patient is unable to solve their problems, this can lead them to take control and make decisions for them. It appears that the burden leads caregivers to restrict patients' autonomy, assuming the decisions for them (Khan, Panday, & Kiran, 2017; Panayiotopoulos, Pavlakis, & Apostolou, 2013). It is necessary to encourage patients to decide for themselves, so that they are integrated into the family environment and learn to face new adversities. It is extremely important that the family give due

value to patients, recognizing their potential and the ability to decide what matters in their lives.

The final category identified was blame, divided into two subcategories: self-blame and blames the patient for having the disease. Several studies have reported that family caregivers often oscillate between these two feelings, even in situations of clinical diagnosis made several years ago. There is an intense feeling of guilt in the family caregivers, especially from parents towards their children, with a greater incidence in mothers. Caregivers may believe that the patient's erratic behavior is caused by something the family has done or has failed to do, which makes them feel guilty about the disease. Among the main causes of attribution of blame, they identified the critical attitude they had towards the patient's behavior, the lack of knowledge about the disease, and the possible genetic component (Cherry, Taylor, Brown, Rigby, & Sellwood, 2017; Wasserman, de Mamani, & Suro, 2012).

Strengths and Limitations

This study is based on 31 interviews, which was considered sufficient for data saturation. Our sample represents a variety in gender, age, kinship, and household. Data were collected by semistructured interview during which participants described their experiences. The interview guide was tested with five pilot interviews. The overall results illuminate variations in family caregivers' perspectives on barriers to family resilience. To enhance credibility, over the analysis process, researchers discussed every step made until consensus was achieved.

As in other qualitative studies reliant on data collection from interviews, there is a possibility that actual reports were different from what participants disclosed. This could be due to the existence of biases that influence the information reported by participants, such as lack of confidence in ensuring anonymity or protection of identity of their values or beliefs. However, trustworthiness in a qualitative study is gained by richness of data, and taking into account that the data were collected from several participants, we consider it unlikely that this has occurred. This study is also limited in terms of its transferability, since the convenience sampling represents greater operational ease, but it results in the inability to make general statements about the population.

Conclusions

In conclusion, this research provides an overview and an understanding of key barriers to family

resilience in caregivers of people experiencing schizophrenia. According to participants' narratives, we identified five categories of barriers towards family resilience, namely, lack of knowledge about the disease, stigma, expressed emotion, involvement in the relationship, and blame.

In view of the paucity of studies exploring and understanding the barriers to family resilience, this study presents as one of the first in this area. Focusing on family caregivers we provide a novel perspective through which we examine the barriers to resilience.

Findings from this study are relevant and can be applied by healthcare professionals to help family caregivers be resilient. There is a need for these professionals to develop a new, more proactive approach when caring for schizophrenic patients' family caregivers. The identification of barriers to family resilience gives an insight into the difficulties experienced by these caregivers, allowing professionals to focus on these factors and to help remove or reduce their influence.

This was the first known study to explore the barriers to family resilience in caregivers of people experiencing schizophrenia. Further research would help to better understand the relations between the barriers identified in this study and family resilience.

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Clinical Resources

- American Psychological Association. Building your resilience. <https://www.apa.org/topics/resilience>
- World Health Organization. Strengthening resilience: A priority shared by Health 2020 and the Sustainable Development Goals. WHO Regional Office for Europe. <https://www.euro.who.int/en/countries/monaco/publications/strengthening-resilience-a-priority-shared-by-health-2020-and-the-sustainable-development-goals-2017>

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