

ORIGINAL ARTICLE

Experience and the meaning of stigma in patients with schizophrenia spectrum disorders and their families: A qualitative study

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Abstract

Aim: This study aimed to explore the experiences of stigma in patients with schizophrenia spectrum disorders and their families.

Methods: This qualitative content analysis study was carried out in 2016–2017 in a psychiatric hospital in Tehran, Iran. A total of 16 patients with schizophrenia spectrum disorders and their families were chosen purposefully. In order to collect the data, unstructured interviews were conducted. For the data analysis, an inductive content analysis approach was used.

Results: The data analysis led to the formation of two categories, “being socially rejected” and “being oppressed by others,” and nine subcategories. In being socially rejected, others do not have a desire to communicate and start or continue cohabitation with the patients and their families and stay at a distance from them with fear. In being oppressed by others, persons behave aggressively with the patients and their families, violate their rights, and humiliate and ridicule them with their incorrect judgment.

Conclusions: Patients with schizophrenia spectrum disorders and their families have the unpleasant and upsetting experiences of stigma. This problem imposes pressures and extreme difficulties on them, besides the difficulties related to the nature and the symptoms of the disorder. The findings reveals the need to develop strategies to help patients and their families effectively encounter stigma.

Key words: qualitative content analysis, schizophrenia spectrum disorders, stigma.

INTRODUCTION

Stigma “will be used to refer to an attribute that is deeply discrediting” and reduces a person “in our minds from a whole and usual person to a tainted, discounted one” (Goffman, 1963, p. 3). The stigma of mental illness as a complex property of psychiatric disorders and their treatment has been proved completely. It applies

especially for patients with schizophrenia (Sibitz, Unger, Woppmann, Zidek, & Amering, 2011) because of their symptoms, disturbed behaviors, and others’ perceptions of their dangerousness (Wong *et al.*, 2009).

More than 21 million persons worldwide are diagnosed with schizophrenia (World Health Organization, 2014) and, in Iran, the 12 month prevalence of primary psychotic disorders (including schizophrenia and schizoaffective) has been reported to be 0.5% (Sharifi *et al.*, 2015). Stigma is the most serious concern for these patients (Momeni & Parvizy, 2013) and its effects are often understood as being heavier and more disturbing than the disorder itself (Koschorke *et al.*, 2014). Stigma

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is not limited to patients, but also affects their family members who are associated with them (Park & Park, 2014). The consequences of stigma on patients and their families include reduced self-confidence and self-esteem, feelings of shame and futility, social exclusion and an inability to enter into the community, reduced psychological well-being, decreased quality of life, sleep disorders, the creation of the disease burden, and not seeking treatment (Koschorke *et al.*; Park & Park; Seekles *et al.*, 2012; Shahveysi, Shoja Shafati, Fadaei, & Doulatshahi, 2007; Wong *et al.*, 2009).

Some studies have been conducted and reported in the field the experiences of stigma in psychiatric patients and their families in different countries (Huang, Jen, & Lien, 2016; Koschorke *et al.*, 2014; Suto *et al.*, 2012). The findings of these studies show the feelings and experiences of patients and their caregivers about stigma and discrimination; however, the experiences of stigma and discrimination are context-dependent (Koschorke *et al.*) and the generalization of results from one country or a particular group to other groups and countries has difficulties (González-Torres, Oraa, Arístegui, Fernández-Rivas, & Guimon, 2007).

In Iran, some quantitative studies have been conducted to determine the prevalence, causes, and components of stigma in psychiatric patients and their families (Nojomi, Malakouti, Ghanean, Joghataei, & Jacobson, 2011; Sadeghi, Kaviani, & Rezaei, 2003; Shahveysi *et al.*, 2007; Tavakoli, Kaviani, Sharifi, Sadeghi, & Fotouhi, 2006; Tavakoli, Sharifi, Taj, & Mohammadi, 2010). Also, some qualitative studies address the experiences of psychiatric patients and their families about the consequences of stigma (Heydari, Saadatian, & Soodmand, 2017; Momeni & Parvizy, 2016); however, the question and the purpose of this study are different from the mentioned studies. Only one study explored the experiences of stigma in the families of patients with bipolar disorder (Shamsaei, Kermanshahi, Vanaki, & Holtforth, 2013); however, according to Link and

Phelan (2013), the situations of stigma depending on the origin of the stigma, the amount of impairment in interpersonal interactions, the duration of the disease, and the degree of a patient's dangerousness for others are different from one another (Link & Phelan). In other words, the reaction of the population to psychiatric patients can vary according to the severity and the type of illness (Nojomi *et al.*). Therefore, previous studies cannot answer the present research question about exploring the experiences of stigma in patients with schizophrenia spectrum disorders and their families. According to the above notes and conclusions and considering the importance of stigma in terms of harm to persons with mental disorders and their friends, families, and communities (Gur, Sener, Kucuk, Cetindag, & Basar, 2012), the researchers went on to explore the experiences of stigma in patients with schizophrenia spectrum disorders and their families with the qualitative content analysis approach.

METHODS

Study design

The aim of this study was to explore the experiences of stigma in patients with schizophrenia spectrum disorders and their families. When there is not enough knowledge about a phenomenon or existing knowledge is not integrated, the inductive content analysis approach is recommended (Elo & Kyngäs, 2008). Thus, considering that there was not enough knowledge about the experiences of stigma in patients with schizophrenia spectrum disorders and their families in the mentioned context, this method was used.

Participants

The participants of this study included seven patients and nine patients' family members (Tables 1–2). The

Table 1 Characteristics of the study's participants

(PATIENTS)							
ID	Diagnosis	Age (years)	Sex	Marital status	Educational level	Occupation	Hospital ward
1	Schizoaffective disorder	55	Male	Single	Diploma	Out of work	Inpatient
2	Schizophrenia disorder	55	Female	Divorced	Bachelor	Unemployed	Inpatient
3	Schizophrenia disorder	40	Male	Divorced	Middle school	Unemployed	Day care
4	Schizophrenia disorder	44	Male	Single	Bachelor	Unemployed	Day care
5	Schizophrenia disorder	43	Male	Divorced	Diploma	Laborer	Day care
6	Schizophrenia disorder	40	Female	Married	Diploma	Housewife	Day care
7	Schizophrenia disorder	55	Male	Married	Diploma	Unemployed	Day care

Table 2 Characteristics of the study participants' (Family members)

ID	Relationship with patient	Age (years)	Educational level	Occupation
8	Mother	57	Elementary school	Housewife
9	Mother	43	High school	Housewife
10	Mother	52	Middle school	Housewife
11	Daughter	22	Undergraduate	Artist
12	Mother	48	Middle school	Housewife
13	Sister	40	Middle school	Housewife
14	Mother	56	High school	Housewife
15	Father	58	Bachelor	Paramedic
16	Brother	31	Diploma	Self-employed

inclusion criteria for the patients were having the diagnosis of schizophrenia or schizoaffective disorder by a psychiatrist (based on the Diagnostic and Statistical Manual of Mental Disorders, 5th edn), partial insight, disease duration of >2 years, history of at least one treatment, interest to participate in the study, experiences of encountering stigma, and the ability to talk about the experiences. The inclusion criteria of the patients' family member were having communication with the patient, >2 years of involvement with the patient's condition, interest in participating in the study, experiences of encountering stigma, and the ability to talk about the experiences. Purposeful sampling was used to select participants with the above criteria from a psychiatric hospital in Tehran, Iran. The researcher reviewed the hospital records in searching for patients and their families who met the inclusion criteria. Then, she contacted them in person or on the phone and, after introducing herself and the research objectives, asked them to be present at a designated time in the hospital if they wished to participate in the research.

Data collection

In order to collect the data, unstructured interviews (Elo *et al.*, 2014) were conducted from July, 2016 to March, 2017. In total, 17 interviews were conducted with 16 participants that lasted between 10 and 90 min. The initial question of the interview was open-ended and included "Please tell me how relatives behaved towards you after they were informed about the disease." After answering the question, based on the purpose and the method of the study, probing questions such as "How?" and "Can you explain more and tell me an experience in this regard?" were asked for events related to the phenomenon. The researcher did not guide the participants to predefined responses and allowed concepts to emerge completely from the data that were

generated by the participants. The interviews were recorded with the permission of the participants and were transcribed verbatim at an appropriate opportunity. Four of the participants did not allow voice recording and therefore conversations were written by the researcher during the interviews. Data collection continued until the development of categories and data saturation.

Data analysis

According to Elo and Kyngäs (2008), the qualitative content analysis process follows three stages: preparation, organizing, and reporting. In the preparation phase, the entire interview was selected as the unit of analysis. The researcher tried to make sense from the data and find out what was happening and gain a sense of the whole. For immersing in the data, the interviews were read several times. In organizing, the researcher did actions, such as open coding, creating categories, and abstraction. In open coding, during reading the interviews, notes were written in them. The written notes were reread and necessary codes were written in the margins to describe all the aspects of the content. Then, the codes were transferred from the margins to a code sheet and subcategories were produced at this stage. After the open coding, the subcategories were classified under the categories with a higher level of abstraction (Elo & Kyngäs). An example of the formation of the categories is shown in Table 3.

Rigor of the study

To increase the accuracy and strength of the study, the researcher used strategies, such as the maximum variation of sampling (as shown in Tables 1–2), prolonged engagement with the data, constant comparative analysis, a member check (presenting the codes of five interviews to the participants for evaluating and confirming), a panel of experts (presenting the interviews, codes, and

Table 3 An example of the formation of categories

Text unit	Code	Subcategory	Category
I invited them (neighbors) to come (home). They told me very bluntly, “No. Because your brother is home, we cannot come” (P11)	Neighbor’s refusal to accept the invitation of the patient’s family	The feeling of being rejected	Being socially rejected
No one comes to my house ... I get sad (P10)	Sadness from others’ not communicating with the patient’s family		
Those younger than me do not greet me and those older than me try not to face me ... They stand beside a shop to avoid greeting me (P1)	Others’ avoidance to face and greet the patient	Being ignored by others	
They looked at me as a criminal’s mother and they did not respond to my greeting (P10)	Not receiving the response of greeting from others		

categories to two nursing faculty members who were experienced in qualitative research), and evidence-based writing (using quotations).

Ethical considerations

This study was approved by the ethical review boards at the authors’ institution. Considerations, such as obtaining permission from the authorities of the research environment, self-introducing and informing the participants about the purpose of the research and the duration of the interview, obtaining informed consent from the participants and their families to participate in the study and voice recording, informing the participants about their autonomy to leave the study, and maintaining data confidentiality by not revealing the name of the participants and using aliases were met.

RESULTS

The data analysis led to the formation of two categories, *being socially rejected* and *being oppressed by others* and nine subcategories (Table 4). In being socially rejected, others do not have a desire to communicate and start or continue cohabitation with the patients and their families and distance themselves from them with fear. In being oppressed by others, persons behave aggressively with the patients and their families, violate their rights, and humiliate and ridicule them with their incorrect judgment.

Being socially rejected

Being socially rejected indicates the feeling of loneliness and takes shape as a result of the unwillingness of

others to communicate with the patients and their families. Persons move away from the patients and their families and avoid helping them in times of need. Being socially rejected is a common sense in all or most of the patients and their families and is characterized and experienced with attributes including *the feeling of being rejected*, *being ignored by others*, *others’ refusal to start or continue cohabitation with the patient*, or *the family member and others’ fear of the patient*.

Feeling of being rejected

The feeling of being rejected is the basis of the concept of being socially rejected and takes form as a result of others’ understanding of the disorder and their behavior with the patients and their families. The patients and their families feel rejected and feel that others are unwilling to communicate with them. It leads to a high

Table 4 The subcategories and categories that emerged from the data analysis

Subcategory	Category
The feeling of being rejected	Being socially rejected
Being ignored by others	
Others’ refusal to start or continue cohabitation with the patient or the family member	
Others’ fear of the patient	Being oppressed by others
Sadness from others’ prying	
Encountering the aggressive behavior of others	
Sadness from the misjudgment of others	
Facing injustice by others	
Being humiliated and ridiculed by others	

level of sadness, frustration, feeling empty and alone, insomnia, the intensification of the illness, and feeling compelled to cope with the mistreatment of others and many difficulties in the patients and their families. This feeling is common for many participants. For example, the young sister of a patient with schizophrenia said:

I invited them (neighbors) to come (home). They told me very bluntly, “No. Because your brother is home, we cannot come.” They have told me frequently, “Because your brother is home, we are not comfortable. We do not come.” You know I often get upset ... I say, “Look, even the neighbors cut off their relations with me.” (P11)

Being ignored by others

Being ignored by others is the second attribute of the concept of being socially rejected. The patients and their families feel that because of the illness, others do not pay attention to them and do not respond to their greetings and their questions correctly. Encountering the ignorance of others causes regret and sadness in the patients and their families; however, they feel they cannot afford an action to improve others' behavior. Being ignored by others is common for many participants. For example, a 55 year old man with schizoaffective disorder said:

Those younger than me do not greet me and those older than me try not to face me ... They stand beside a shop to avoid greeting and friendship with me. (Just next door neighbors) greet me because of their need to adjust their satellite dish ... (As a result of others' disregard) I naturally get upset and I cannot do anything. (P1)

Others' refusal to start or continue cohabitation with the patient or the family member

The third attribute of the concept of being socially rejected that is experienced by many participants is others' refusal to start or continue cohabitation with the patient or the family member. Persons who want to marry one of the patient's family members, after realizing the disorder and the severity of the symptoms, give up their decision as a result of their concern about conditions after the marriage and the need for patient care. In contrast, some patients' wives decide to divorce them after realizing the disorder and its chronic and incurable nature. It in turn causes an inability to accept the divorce, frustration, a high level of sadness, a sense of

failure, the destruction of life, and the recurrence of the disorder in the patients and/or their families. In this regard, a 55 year old woman with schizophrenia said:

My engagement broke down; my marriage broke down because my husband was afraid of the name of mental illness. I was normal; I was so excited about the marriage hall. After he realized (the disease), he asked for a divorce in the next morning. (Laughing) overnight! He never understood me ... I was walking in our house crying (because of the divorce). (P2)

Others' fear of the patient

The fourth attribute of the concept of being socially rejected is others' fear of the patient. The patients and their families feel that others fear them while facing the patient's symptoms and appearance and their feeling of fear is because of the possibility of being injured by the patient. It causes a high level of sadness in the families and they consider others' fear to be unnecessary. Others' fear of the patients is higher when they do not know them. This feeling of fear decreases gradually with their familiarity with the patients. Others' fear of the patients is common for the participants. For example, a 55 year old man with schizoaffective disorder said:

Their early behavior was with the feeling of fear ... After all these steps, it became normal that this human (the patient) has no horns and tail. They do not say and do strange things anymore. (P1)

Being oppressed by others

This concept refers to that the patients' and their families' rights are violated in different situations and they encounter discrimination by others. They feel that others have an inappropriate judgment toward them and behave aggressively with them. Also, the patients and their families encounter others' humiliating and ridiculing behaviors because of the disorder. Being oppressed by others is common for most of the patients and their families and is characterized and experienced with attributes, including *sadness from others' prying, encountering the aggressive behavior of others, sadness from the misjudgment of others, facing injustice by others, and being humiliated and ridiculed by others.*

Sadness from others' prying

The first attribute of the concept of being oppressed by others is sadness from others' prying. The patients and their families feel that others, with asking frequent

questions, want to find out their private issues about the patient's condition. This is while the patients and their families want to hide these issues and are reluctant to provide such information. Others' prying in turn causes a high level of sadness in the patients and their families and they feel unable to respond to such questions. Sadness from others' prying is common for many participants. In this respect, the young daughter of a person with schizophrenia said:

They pry while they know this kind of disease ... I know my younger sister becomes upset from their prying ... They ask irrelevant questions in front of my mom. She is 43 years old and although I know she is sick, I realize that she understands many things but she does not express. She is always very sad. (P8)

Encountering the aggressive behavior of others

Encountering the aggressive behavior of others is the second attribute of the concept of being oppressed by others. The patients and their families feel that others are annoyed by the patient's behaviors that are involuntary and are due to the nature of the disorder. Therefore, the patients and their families frequently encounter others' complaints and protests. Encountering the aggressive behavior of others causes regret, a high level of sadness, and a sense of humiliation in the patients and their families. In addition, the feelings of anger and fear in the patients and their families are the other results of this encountering. Encountering the aggressive behavior of others is common for many participants. For example, the middle-aged mother of a patient with schizophrenia said:

(The patient) broke the lamp. The neighbor complained a lot. I said, "He is ill. What do I do?" He said, "Throw the patient to the madhouse." ... (Encountering others' protests against the patient's behavior) causes me no feelings, except sadness and humiliation. This disorder is much worse than cancer. Sometimes, I wish my child had cancer, all people would regret for him. (P10)

Sadness from the misjudgment of others

The third attribute of the concept of being oppressed by others is sadness from the misjudgment of others. The patients and their families feel that others attribute the disorder's symptoms to their sin penalty or to the patient's drug addiction. In addition, others accuse the families of negligence in the patients' discipline and

accuse the patients of laziness. Others' misjudgments are very difficult for the patients and their families and cause them a high level of sadness and anger. However, they do not have the ability to effectively encounter these judgments. Sadness from the misjudgment of others is common for many participants. For example, the young sister of a patient with schizophrenia said:

Everyone told me that he (the patient) must have used something (a drug) ... In the apartment where we live, neighbors have asked me many times, "Is your brother addicted?" Why do they judge about what they do not know? I really become upset because of their judgment. When I say that he is ill, why do not they accept? I become so sad because of this issue. (P11)

Facing injustice by others

The fourth attribute of the concept of being oppressed by others is facing injustice by others. The patients and their families feel exploited and discriminated by others and that their rights are violated because of the disorder. Moreover, the dependence of some patients on their families, especially at the time of the disorder's severity, provides a context in which the misplaced expectations of the family members toward the patients occur. Facing injustice by others leads to the feeling of the distaste by others in some families and self-blame in some patients. Facing injustice by others is common for many participants. In this respect, a 43 year old man with schizophrenia said:

Because of the illness, I feel my rights have been violated by my family. They discriminate. They ask me to work but give rewards to other family members ... I previously had a bad situation. So, whenever I request my right, they say, "You have just recovered. Do you remember how you were? Do not expect us." They expect me to appreciate their services for the rest of my life ... I feel I myself am guilty. (P9)

Being humiliated and ridiculed by others

Being humiliated and ridiculed by others is the fifth attribute of the concept of being oppressed by others. This concept expresses the feeling of devaluation and low self-esteem in the patients and their families. They feel that others behave with them with disrespect, irony, and sarcasm. In addition, some families feel that others compare the patient with their children and address the patient with inappropriate epithets. Encountering the

humiliation and the ridicule of others is very difficult for the patients and their families and leads to the feelings of inferiority and a high level of sadness in them. Being humiliated and ridiculed by others is common for many participants. For example, the young sister of a patient with schizophrenia said:

They teased him (the patient). When he repeated a word among relatives, it seemed that they liked it and asked him 10–20 times and then laughed ... We got upset because of their behavior with the patient. (P11)

DISCUSSION

The findings of the study revealed that the patients with schizophrenia spectrum disorders and their families have the experiences of *being socially rejected* and *being oppressed by others*. In being socially rejected, others do not have a desire to communicate and start or continue cohabitation with the patients and their families and stay away from them with fear. In being oppressed by others, persons behave aggressively with the patients and their families, violate their rights, and humiliate and ridicule them with their incorrect judgment.

The subconcepts of *the feeling of being rejected* and *others' refusal to start or continue cohabitation with the patient or the family member* in the present study are in line with the subthemes of “the narrow circle of friends” and “marriage bumps” in the study of Heydari *et al.* (2017) about the consequences of stigma in psychiatric patients. These similarities can be related to the common context of the two studies. However, the subconcepts of *being ignored by others* and *others' fear of the patient* and the concept of *being oppressed by others* in the present study are not among the findings of the mentioned study. These differences could be related to the difference between the objectives of the two studies; that is, the present study explored the patients' and their families' experiences of stigma, while the other study focused on the consequences of stigma.

The subconcepts of *the feeling of being rejected*, *others' refusal to start or continue cohabitation with the patient or the family member*, and *facing injustice by others* in the present study are semantically in line with the theme of “rejection and discrimination against the patient” in the study of Momeni and Parvizy (2016) about the consequences of stigma in psychiatric patients' lives. However, the subconcepts of *being ignored by others*, *others' fear of the patient*, *sadness*

from others' prying, *encountering the aggressive behavior of others*, *sadness from the misjudgment of others*, and *being humiliated and ridiculed by others* in the present study were not reported in the mentioned study. Perhaps, the reason for these differences is that in the study by Momeni and Parvizy, in accordance with their study purpose, the attitudes of the participants about the consequences of stigma were explored, while the present study explored the lived experiences of the patients with schizophrenia spectrum disorders and their families.

The subconcepts of *sadness from the misjudgment of others* and *others' fear of the patient* in the present study are consistent with the theme of “negative judgment” in the study of Shamsaei *et al.* (2013) about the experiences of stigma in the families of patients with bipolar disorder. In addition, the subconcept of *the feeling of being rejected* in the present study is semantically in line with the theme of “stigmatization and social isolation” in the mentioned study. However, the subconcepts of *being ignored by others*, *others' refusal to start or continue cohabitation with the patient or the family member*, *sadness from others' prying*, *encountering the aggressive behavior of others*, *facing injustice by others*, and *being humiliated and ridiculed by others* in the present study are not among the findings of Shamsaei *et al.* These differences could be related to differences in the type of illness and the patients' symptoms between the two studies; that is, the type and the severity of symptoms were different between the schizophrenia spectrum disorders and bipolar disorders and it could have led to the differences in the experiences of stigma between the two studies.

The subconcepts of *the feeling of being rejected*, *encountering the aggressive behavior of others*, and *being humiliated and ridiculed by others* in the present study are semantically consistent with the subtheme of “negative reactions” in the study of Koschorke *et al.* (2014) about the experiences of stigma and discrimination in Indian persons with schizophrenia. However, the subconcepts of *being ignored by others*, *others' refusal to start or continue cohabitation with the patient or the family member*, *others' fear of the patient*, *sadness from others' prying*, *sadness from the misjudgment of others*, and *facing injustice by others* were not reported in the mentioned study. These differences could be related to the dependence of stigma on social, cultural, historical, and educational contexts in societies. The sociocultural contexts of Iran and India are different. In India, mental illness is almost exclusively managed at home and it can cause the disorder to stay

hidden from the community members, and as a result, patients and their families encounter a lesser level of diversity of inappropriate behaviors by the community members.

The subconcept of *the feeling of being rejected* in the present study is consistent with the theme of “social stigma” in the study of Suto *et al.* (2012) about the experiences of stigma in patients with bipolar disorder and their families in British Columbia, Canada. However, the subconcepts of *being ignored by others*, *others’ refusal to start or continue cohabitation with the patient or the family member*, and *others’ fear of the patient* and the concept of *being oppressed by others* in the present study were not reported in the mentioned study. These differences might be related to differences in the sociocultural contexts of the societies where the two studies were conducted. In the Iranian culture, holding ceremonies and parties and getting persons informed of each other’s condition are customary and normative. It can lead to others’ prying in patients’ lives and encountering many forms of others’ incorrect behaviors for patients and their families.

CONCLUSION

Patients with schizophrenia spectrum disorders and their families have the unpleasant and upsetting experiences of stigma and it imposes pressures and extreme difficulties on them, besides the difficulties that are related to the nature and the symptoms of the disorder. Although the findings of this study have differences with other studies because of their different purposes and contexts, they confirm and complement the findings of other studies. In general, the findings of the present study that are consistent or inconsistent with other studies reveal a variety of upsetting experiences that increase the burden of the disorder. Therefore, in the first stage, it is necessary for specialists and researchers to design methods or mechanisms that are appropriate to help patients and their families effectively encounter these experiences of stigma. In the second stage, it is necessary for policy-makers and health professionals to provide contexts and make policies for implementing the designed mechanisms and thus reduce the risks that are associated with stigma in patients and their families. In addition, these findings can be used to design an instrument for measuring stigma and its risk factors for patients with schizophrenia spectrum disorders and their families.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

AUTHOR CONTRIBUTIONS

F. R. conducted the study and drafted the manuscript; E. M. supervised the study process and critically reviewed the manuscript; M. F. and V. S. advised on the study process. All the authors read and approved the final manuscript.

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