



Original Article

Family, the nest of suffering: Explanation the lived experiences of clients with psychiatric disorder of family stigma

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Abstract

Introduction: People with psychiatric disorders are recognized as a minority group who are socially considered as discriminated, ridiculed, and rejected. There are many sources of stigma for psychiatric patients, which is the most important of them is family members. Since the impact of family stigma on these patients has many undesirable consequences, the aim of this study is to understand the experiences of psychiatric patients due to the family stigma.

Materials and Methods: This study is a hermeneutic phenomenology. It was performed on twelve clients with a psychiatric disorder who were selected by purposeful sampling method in 2017. During this study, unstructured interviews were used to collect data, and the data analysis process was interpretive phenomenology proposed by Dieckelmann et al. (1989).

Results: "Family, the nest of suffering" is the main theme of this study, which includes three sub-themes: "gray family look", "fear of disclosure", and "hell life", and their common supporting meanings.

Conclusion: Being known as a psychiatric patient in the family makes the patients of this study not count as a dignified human being. Family members also have behaviors such as distance, fear, disgust, ridicule, being ignored and unwilling to live with them. The results of this study can also help to shape interventions and policies to prevent family stigma against the people with psychiatric disorders.

Keywords: Family, Hermeneutics, Psychiatric disorders, Qualitative research, Stigma

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Introduction

The word "stigma" was introduced into the Western dictionary nearly four hundred years ago, and Champers's etymology defined it as a sign of shame and disgrace (1). Stigma was a condition that one person is labeled, so others feel he/she is less valuable (2). The starting point for defining stigma due to psychiatric disorders goes back to Goffman (1963), who

said stigma is a relation or address that profoundly discredits one. Identifying this badge separates and humiliates the individual (3). Research shows that psychiatric disorders are one of the most stigmatizing diseases (4). According to Tse et al. study, stigma is related to development of psychiatric disorders and that lead to more stigma (5). One of the most painful types of stigma from a psychiatric

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patient's perspective is receiving stigma from family (6). The psychiatric patients expect their family members to sympathize with them after they become ill, lessen the suffering of the illness, and when the family understands them and stings "madness" for they are very distressing and unbearable (7). Psychiatric disorders usually cause individuals and families to avoid going to a psychiatrist or psychologist because this can affect marriage, employment, and even the social relationships of the patient's family members. Therefore, families usually prefer to hold this issue within the family as a private matter. Unfortunately, the patient's basic rights are neglected and kept secret by the family members, which causes a cycle of other problems in the families (8).

Studies have shown that patients who receive a label of psychiatric disorder have been explicitly excluded from social and family relationships in their families. By disclosing the type of disorder diagnosed, they are identified in the family as a distrustful person who needs support. Many families prefer family members and friends to be completely unaware about this member (9).

In one study, some patients described that, after receiving a diagnosis of a psychiatric disorder, their status in their families was weakened, thereby no longer being valued or respected for their beliefs. Thus, losing one's credibility by portraying them as insane, brainwashed, and unreliable in their statements can be used as a means of preventing family sharing (10). In Iran, the emphasis is on family relationships. Therefore, when a family member becomes ill and hospitalized, all family members become involved. However, the stigma of psychiatric disorders is still a major problem in many cultures such as Iranian culture. The stigma has many consequences for the individual, the family, and the community (11). In Iran, there has been limited research on the stigma of psychiatric disorders. In a systematic review, Mohammadi et al. showed that most studies on stigma in Iran involve problems such as infertility, hemophilia, Down syndrome, epilepsy, and AIDS (12). However, few studies have been found specifically on stigma in psychiatric disorders, and given the limited number of studies conducted in Iran, information on this topic can be expanded. Furthermore, despite the different ethnicities and the lack of adequate information on psychiatric disorders in Iran, few studies have

been conducted on stigma related to psychiatric disorders (13). They also suggested that further research could help improve this problem in Iran. Therefore, cross-sectional studies with different target groups and interventional studies to reduce stigma can increase basic information and provide valuable results to researchers interested in this field (14).

Therefore, this study was conducted to answer the study question about the meaning of family stigma from the perspective of clients with psychiatric disorders. It is hoped that by understanding clients' experiences with psychiatric disorders of stigma, and designing an anti-stigma program based on the actual needs of these patients, they can be better cared for, and the painful silence of this suffering stroke can be addressed. The findings of this study will be helpful for health care officials, caregivers, the general public, patients' families, and other clients with psychiatric disorders.

Materials and Methods

The present study is an interpretive phenomenological study. The primary method in selecting participants was the goal-based approach. Participants were recruited and coordinated during 11 months of access to eligible participants, data, and saturation. Inclusion criteria included the clients who received a diagnosis of psychiatric disorder, aged 18-65 years, experienced the studied phenomenon, willingness to express their experiences of stigma. Exclusion criteria included requests for abandonment and unwillingness to participate. We used unstructured in-depth interviews to collect data. The data were analyzed using the hermeneutic approach and the method proposed by Dickelmann et al. This method is a seven-step process based on Heidegger's phenomenology, which has a team nature and the steps are as follows: 1. Reading all the interviews and texts to gain a general understanding, 2. Write commentary summaries for each interview, 3. Group analysis of selected texts of interviews and identification and extraction of themes, 4. Return and re-refer to interviewees or participants to explain, clarify, and classify cases of disagreement and inconsistencies in the interpretations presented and writing a comprehensive and comprehensive analysis, 5. Compare and contrast texts (interviews) to identify, identify, and describe common

meanings and functions, and 7. Identifying and extracting fundamental patterns that link the themes and connect them (15). To achieve the validity of the study, the criteria presented by Lincoln and GABA in 1985, namely, acceptability, reliability, transferability, and validity, were considered and used by the research group (16).

Therefore, this study conducted by emphasizing selecting appropriate venues, information sources, and eligible participants, close, accurate, and long-term partnerships and interactions, accurate and long-term, continuous engagement, involving stakeholders in interpretation, adopting teamwork and team-based approaches. The participants were reassured of the validity and accuracy of the

study. For each interview, the researcher explained the field and aim of the study and if the participant was satisfied and signed the consent form, he/she was participated in this study. The researcher committed to stopping recording the interview if the participants did not wish to continue the interview. In addition, participants were free to resign from the study. We were providing feedback to the authorities and participants conducted in compliance with the confidentiality of the names of the participants.

Results

In this study, twelve patients were participated. They aged 21-54 years. Table 1 presents the demographic variables of the clients.

Table 1. Demographic variables of the participants

Participant number	Gender	Psychiatric disorder	Marital status	Age (Year)	Job	Education
Participant 1	Female	Schizoaffective	Divorced	38	Housewife	Diploma
Participant 2	Female	Obsessive-compulsive disorder	Single	22	Housewife	Elementary
Participant 3	Female	Depression	Divorced	45	Housewife	Third grade middle school
Participant 4	Female	Bipolar mood disorder	Single	21	University student	Law student
Participant 5	Female	Bipolar mood disorder	Married	31	Book seller	Diploma
Participant 6	Female	Borderline personality disorder	Divorced	33	Housewife	Third grade middle school
Participant 7	Male	Schizophrenia	Single	43	Unemployed	Dropout student
Participant 8	Male	Bipolar mood disorder	Divorced	48	Teacher	Master
Participant 9	Female	Bipolar mood disorder	Married	36	Unemployed	Graphic engineer
Participant 10	Male	Bipolar mood disorder	Divorced	54	Baker apprentice	Elementary
Participant 11	Male	Bipolar mood disorder	Single	45	Teacher (unemployed)	Bachelor
Participant 12	Male	Bipolar mood disorder	Single	26	Unemployed	Physics university student (Third year)

The "family, the nest of suffering," was a main theme in the experience of the participants, indicating that the family members were repeatedly given the "crazy" nickname to patients. They also stated that illness-related infamy had a negative effect on the quality of the family members' relationship with them so that they were no longer considered by the

family and were viewed as worthless. Clients also shamefully and separated themselves from their families. Some participants expressed frustrating issues with their spouses. It is as if their spouse misbehaved because of the disorder and did not see the client as a spouse. They also said that the family would not allow them to associate with other people for fear of

dishonor. Other things that made life difficult for the clients were being monitored for all their work and being discriminated against and ignored by family members.

The main themes "family, the nest of suffering" have three sub-themes: gray family look, fear of disclosure, and hell life, which are described below (Table 2).

Table 2. The main theme and related sub-themes

The main theme	Sub-themes	Common meanings
Family, the nest of suffering	Gray family look	Adult childlike
		Sealed to the Insane
	Fear of disclosing	Mental illness, a taboo for the family
		Protecting reputation with secrecy
		Life under the microscope of the family
	Hell life	Eater in the family
		High wall of discrimination
		A stranger in the family

"Gray family look", is one of the sub-themes of the main them "family, the nest of suffering". Although interactions in families were highly variable, all participants stated that stigma caused by the disease had a negative impact on their family members' perceptions. They were treated according to their age and social status before becoming ill. However, after the illness, they seemed to the family as an immature child who could not do their work and needed maintenance. Even according to the experiences told by middle-aged people, they were treated like a child, causing a sense of inferiority.

Forty-year-old man- B.Sc.:

"My mom God bless her loved me and looked after me as a baby and her behavior hurt me and made me feel inferior".

Another issue that all clients mentioned was to be seen as crazy in the family look. There are prominent examples of labels or idioms common among people used to describe a person suffering from a psychiatric disorder, such as "mental patient", "insane", and "crazy". Calling them with these titles crush their humanity and induce some misconception that words say who this person is. The clients' experience in this area illustrated that they have repeatedly received the titles from family members, including partners', sisters', brothers, or children's. The remarkable thing about this experience was that they expected more support and understanding from the family after the illness, and the stigma they received from their families was more painful than that of strangers.

Forty-eight year old man- M.Sc.:

"One day my brother was calling my dad, and while the sound was on the speaker, he was going to ask about me and said, "What does that psychic do? Does he still bother you?"

"Fear of disclosing" was one of the other sub-themes discussed in clients' experience from receiving stigma from their families. Participants stated that having a psychiatric patient is a disgraceful stigma that causes family discomfort. Therefore, in such cases, to protect the honor, the family tried to hide the clients and, fearing that this illness would not be disclosed to others, hide him/her at home and even avoided referral to the health system if he/she needed it urgently. So that others are not aware of this patient.

Thirty-eight year old woman- Diploma:

"I was very socially before my illness, and was commutating with friends and neighbors. When I got sick my husband told me not to communicate with people anymore not knowing that you were ill and taking drugs".

Twenty-two year old woman- Elementary grade:

"Whatever I was crying that I'm not well no one paid attention. I was not important to them. They said how they could go to the psychologist? How to answer to people?"

One of the other sub-themes that appeared in the experience of participants was "hell life". Almost the majority of clients complained that life in the family environment was suffocating. Participants claimed to be viewed as a stranger in the family so that they felt a separation wall

between themselves and other members of the family and found themselves behind the wall.

Getting under the magnifying glass of all their actions and behaviors and attributing them to disorders by the family, as expressed in the participants' statements, also made sense in their sentences, limiting their laugh, sleep, staying awake and other behaviors. Moreover, the feelings of being constantly watched and observed were experienced by many clients.

Forty-eight year old man- M.Sc.:

"I would love to sit down and watch my favorite movie, but my dad started arguing about getting up. Why are you awake? You didn't take your pills again. How much do I suffer from your madness?"

Another of the participants' experiences was the discriminatory treatment of the family so that they were treated differently from other people and often negatively.

The experience of some clients was that after the illness, their status in the family had weakened, and no one valued or respected their beliefs or had no status in the family. Participants felt that their family members were humiliated and disregarded for their views, values, and feelings.

Fifty-three year old man- Diploma:

"You don't know how hard it is for a man to humiliate and disrespect him. Before I got sick I used to do a lot of work. I did all of my uncle's military work to be exempt, but after the disease, I wasn't the beet leaf. My sister and her husband came from Mecca, the family didn't take me to see them and told me where to get this crazy".

Forty-five year old man- B.Sc.:

"My sisters changed because of my illness. I was so posted to them that they treated me like the time they were fighting with their kids".

Discussion

The findings of this study showed that for clients, family is a strong source of stigmatization. The family as a constituent subset of society, and its main pillar, embraces existing rules and customs, so it is not out of mind for families to be influenced by community stereotypes and stigmatized clients with psychiatric disorders. The clients in this study received the most important and most painful stigma from family members. On the other hand, the family is the communication

chain of the community, and as the constituent of the body of society, the most important role is to make it normative. Since family members have inappropriate attitudes and behaviors toward clients with psychiatric disorders and do not accept them as useful family members, these beliefs and behaviors are transmitted to the community. Individuals are more likely to believe information through their families received to them. The meaning of these attitudes and behaviors by family to a client with a psychiatric disorder is that the disease has made them worthless and can no longer expect and embarrass the family. The family is a strong support base for a client with a psychiatric disorder to rely on them to cope with the problems of the disease (17), but unfortunately, the families in this study played a protective role and stigmatized them. As a result, the client worsened his/her condition.

In this regard, Karp et al. described grounded theory research on the response of families to "emotion management". They examined the intense emotions surrounding efforts to honor a commitment to care for a family member with a major mental illness. The analysis is based on fifty lengthy interviews with parents, spouses, siblings, and children of individuals diagnosed with depression, manic-depression, or schizophrenia. All of the interviews were tape-recorded and transcribed. As each transcribed interview was scrutinized for themes, it shortly became apparent how central and problematic they considered the issue of managing emotions between themselves and their sick spouse, parent, child, or sibling. Their goal is to explain the kinds of emotions that arise as family members engage in ongoing interpretations of what they owe a spouse, child, parent, brother, or sister in desperate emotional trouble. None of the available programs for computer-assisted coding and analysis of qualitative data were used in this study. Instead, all interviews were closely read, and any materials related to the emotions accompanying duty, obligation, and responsibility were collated in a single data book on that dimension of the data. Based on fifty in-depth interviews, the authors concluded that some families succumb and are convinced that the psychiatric disorder gets worse. In this study, family members saw their patient's relatives as a child who was unpredictable and irresponsible and would not improve in the future (18). A study by Li et al., "experiencing social stigma in people with schizophrenia", to

document and compare the interpersonal experiences of stigma in patients with schizophrenia and patients with diabetes mellitus in Hong Kong was conducted. Four focus groups comprising thirty-one psychiatric out-patients were conducted to formulate a conceptual framework and devise items for examining subjective stigma.

In probing stigma, they asked participants about the attitudes, reactions, and treatment that they perceived to be unfair or prejudicial and believed to be due to their having a psychiatric illness. Based on a thematic analysis of the transcribed responses of the focus groups, a 137-item Psychiatric Stigma Experience Questionnaire (PSEQ), in Chinese, was constructed. The PSEQ was an exploratory tool that covered stigma in work, family, social relationships, and medical treatment. Convenience sampling was used to recruit four-hundred and eighty participants (aged 17-62 years). They included three-hundred and twenty outpatients with schizophrenia (217 men, 103 women) who resided in twenty-eight 'halfway houses' and one-hundred and sixty out-patients with diabetes mellitus (78 men, 82 women) attending a public clinic. Because of the practical difficulty of administering a protracted questionnaire at the diabetes clinic, the researchers used a shortened 28-item version containing salient domains of the stigma. Bivariate analyses were conducted using Chi-squared statistical significance tests and t-tests to examine associations between schizophrenia and stigma experience. Results showed that clients received frequent stigma from parents, siblings, or close relatives. For example, 57.2% of patients with schizophrenia reported that family members considered them extremely violent; more than half of them (53.6%) felt they were hated or disliked by family members, and 59.6% indicated that family members hide the presence of a psychiatric patient in the family. In addition, a very high percentage of clients reported that their family members were unfairly treated (19). Thorneycroft et al., in a study on seven-hundred and thirty-two schizophrenic participants in twenty-seven countries, found that about half of them received discrimination from family members (20). Marrow and Luhrmann, in their research entitled "the zone of social abandonment in cultural geography: On the street in the United States, inside the family in India," examines the spaces across

societies in which persons with severe mental illness lose meaningful social roles and are reduced to "bare life". They compared strategies for managing and treating persons with psychosis across the United States and India and demonstrate that the relative efficiency of state surveillance of populations and availability of public social and psychiatric services, the relative importance of family honor, the extent to which a culture of psychopharmaceutical use has penetrated social life, and other historical features, contribute to circumstances in which disordered Indian persons are more likely to be forcefully "hidden" in domestic space. In contrast, mentally ill persons in the United States are more likely to be expelled to the street (21). In a research conducted by Ciftci et al., "mental health stigma in the Muslim community", they define constructs that comprise stigma, discuss the harmful effects, and present factors that may influence them. In order to better understand mental health stigma in the Muslim community, they focus on intersectional stigma and present literature on the complex relationships among race/ethnicity, gender, class, religion, and health status among Muslims. In addition, they include literature highlighting culturally specific presentations of symptoms and mental health problems. While working with Turkish children with psychiatric disorders, they found that too much shame led to the imprisonment of children at home and prevented them from "going out" in public environments (22).

Conclusion

For the clients of this study, there was nothing more discrediting and disabling than stigmatizing by their family. Being known as a psychiatric patient in the family makes the patients not count as a dignified human beings. They also have behaviors such as distance, fear, disgust, ridicule, being ignored, and being unwilling to live with them. The assignment of the nickname "crazy" by family members, and the "stamp of insanity", creates a painful sense of rejection, as every human being expects sympathy and understanding from his/her family even when suffering the worst diseases. So that patients feel the need for more support, and when viewed as a worthless person, the possible reaction is shame and frustration, and a sense of isolation and alienation. Feeling lost the previous position in the family can also be

reinforced by degrading, over-supporting, or being seen as a child. The meaning of these attitudes and behaviors by family to a client with a psychiatric disorder is that the disease has made them a worthless person who can no longer expect and embarrass the family.

The family is a strong support base for a client with a psychiatric disorder to rely on to cope with their illness problems, but unfortunately, the families in this study played a supportive role and stigmatized them.

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