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Black Shadow of Stigma: Lived Experiences of Patients with Psychiatric Disorders on the Consequences of Stigma

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Abstract

Background: Mental illness stigma has undesirable consequences for patients with psychiatric disorders.
Objectives: The current study aimed at understanding the lived experiences of patients with psychiatric disorders on the consequences of stigma.
Methods: Hermeneutic phenomenology was conducted on 12 patients. They were selected from psychiatric hospital clinics in Mashhad.
Results: Black shadow of stigma is one of the main themes in the present work. It consists of seven subthemes including taking refuge in secrecy, academic deadlock, marriage bumps, glass fence of job, the bitter taste of death, cocoon of loneliness, and the narrow circle of friends.
Conclusions: These results call for actions to tackle the stigma in mentally ill people in Iran. The results of this study can help develop interventions and policies to prevent the stigma against people with mental disorders.

Keywords: Hermeneutics, Psychiatric Disorders, Stigma

1. Background

Patients with diagnosis of a psychiatric disorder, known as minority groups, are socially discriminated, stigmatized, and rejected. Discrimination, stigma, and social exclusion are real aspects of living with mental illness whose consequences can lead to loss of opportunities in education, employment, housing, and community (1). These will widely affect not only individuals but also the entire community (2). During the last 2 decades, research has shown that lower moral and character values among the victims of this disease are unavoidable. In fact, this is true of those in ethnic minority groups, or other groups with low self-esteem, as well as members of the majority. Nonetheless, the case is different in people with psychiatric disorders. The nature of these diseases would bring about negative social messages for the individual, as well as limited possibilities for natural communication, prolonged isolation, ignorance, silence, and lack of civil rights (3). They face significant discrimination such as lack of housing and employment, restrictions on the right to vote, to have driving license, or child custody (4). Stigma with psychiatric disorders remains a significant social issue, which is multifaceted and prevalent in today's society, and it is similar to drug addiction, prostitution, and crime (5). Research shows that people with mental disorders are even addressed worse than drug abusers (6). People with psychiatric disorders have been so emotionally hurt that they decided to tell their life stories and share their experiences (7).

2.Objective

Considering the effect of stigma on all aspects of a patient's life and aiming to explore the experiences of patients with psychiatric disorders, the present study aimed at investigating the consequences of stigma.

3. Materials and Methods

This was a phenomenological hermeneutic study. It was also part of a larger study for a doctoral dissertation in nursing to understand the lived experiences of patients with psychiatric disorders on stigmatization. Heidegger's

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philosophy underlies this approach, thus, exploring the lived experience and explaining the meaning of the stigma through the patient's eyes is crucial in this method. Black shadow of stigma is one of the major themes of a patient's stigma experiences (8). The phenomenological approach was appropriate for this study because it pursues the human experiences within the context of people's daily lives. Because each individual is unique, human responses to health and illnesses are different. Based on the humanistic theory in nursing, appropriate nursing intervention could be achieved through interpretation of study results. In fact, most situations need to be understood and interpreted by nurses more than the nursing intervention (9). Nurses need the knowledge on human beings to use it to provide better care to patients (10). The stories of the patients should be explored to realize the inherent experiences that they face in the struggle with their disorder.

3.1. Participants

Participants were selected using selective sampling with maximum variation. The sampling went on until a time when all the 12 patients shared all their experiences of stigma. The participants were selected among the patients with psychiatric disorders who referred to Ibn-e- Sina and 22 Bahman hospital clinics from 2014 to 2015; participation was voluntary. Psychiatrists diagnosed the patients to be in the remission phase of their illness. Participants' profile is presented in Table 1.

3.2. Data Collection

Unstructured interviews, conducted in a quiet room at Ibn-e- Sina and 22 Bahman hospitals, were used to collect data for the present study. In unstructured interviews, the interviewees were encouraged to relate their experiences and describe the events that were important to them. They were encouraged to describe the conditions and express their opinions, and attitudes. According to Bryman (1988), there is the least participants' guidance, and freedom of expression in this method is significant compared to other methods such as focus groups. According to May (2001), unstructured interviews are flexible and do not limit interviews (8). One researcher, who was a psychiatric nursing PhD student and trained in qualitative research, conducted all the interviews. In such interviews, the researcher may start the interview with an open ended-question similar to the following: Would you please tell me about your experience of living with mental illness, or how do you feel about living with a mental illness? The interviewer used probing techniques to clarify some parts of the dialogue and to elicit more data during the interviews. Interviews were carried out on topics preferred by the participants. These interviews lasted between 30 to 110 minutes. Recorded interviews were transcripted as soon as possible.

3.3. Data Analysis

Data were analyzed based on the interpretative method of Diekelmann, Allen, and Tanner (1989) (11). First, to reach a general understanding of each text, all manuscripts from the interviews were read, and interpretational abstracts were written for each text. The first meeting of the research group (1 professor, 1 assistant professor, and 1 PhD candidate) was devoted to discussing the experiences of the several participants. Research lines were obtained from the interpretive guide of the first study, directing interviews and subsequent samples for a deeper understanding. Missing parts or implicitly identified ones were discussed to reach a deeper and richer understand in the follow-up interviews. Then, the implicit meanings or themes, which were extracted from the texts, were confirmed by the researcher to support the formation of categories. At this stage, the research group themes or significant concepts were identified. Moving from each component to the whole text and from the whole to each component in all the interviews was considered. At first, lines of itemized text were read, all codes were recorded, the whole paragraph was read, and then a general theme was obtained. In the next step, the researchers returned to the original texts and group analysis to compare the similarities and differences between the categories. After detecting the main cases, the researcher and the group obtained a shared meaning. According to the basic communication obtained in this step, subsequent interviews and observations were organized and common themes identified. Finally, the text obtained by the research team was reviewed, written, discussed, and interpreted.

3.4. Ethical Considerations

The ethics committee of Mashhad University of Medical Sciences (Ref: 921487) approved the present study. Before the interview, informed consent and voice recording were obtained from all the participants. Moreover, the participants were reminded the right to withdraw from the study at any time. Besides, they were assured of the anonymity of their data.

4. Results

In the present study, participants were 12 patients with psychiatric disorders (OCD, bipolar, depression, schizophrenia, schizoaffective, and borderline personality disorder) aged 21 to 54, with the education levels from primary education to a master's degree. Of them, 6

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Table 1. Participants' Profile

Participants	Sex	Age	Education	Diagnosis	Occupation	Marital Status
1	F	38	diploma	schizoaffective	housewife	divorced
2	F	22	elementary	obsessive-compulsive	housewife	single
3	F	45	junior high	depression	housewife	divorced
4	F	21	university student	bipolar	housewife	single
5	F	31	diploma	bipolar	bookseller	married
6	F	33	junior high	borderline personality disorder	housewife	divorced
7	M	43	drop out university student	schizophrenia	unemployed	single
8	M	48	master	bipolar	teacher	divorced
9	F	36	bachelor's	bipolar	unemployed	single
10	M	54	elementary	bipolar	baker apprentice	divorced
11	M	45	bachelor's	bipolar	dismissed teacher	single
12	M	26	university student	bipolar	unemployed	single

were single, 5 divorced, and 1 married. At the time of the study, 3 participants were employees and the rest were unemployed.

The findings suggest that the negative effects of stigma are widespread and are even more than the disease symptoms. For the participants, the consequences of stigmatization were broad and extensive, affecting important aspects of their lives. These consequences included taking refuge in secrecy, academic deadlock, marriage bumps, glass fence of job, the bitter taste of death, cocoon of loneliness, and the narrow circle of friends. The followings are the participants' quotations:

The summary of subthemes is presented in Table 2.

4.1. Taking Refuge in Secrecy

Making decisions for a person with a psychiatric disorder who has a history of taking medication and hospitalization is difficult. Thus, as a protective strategy when people with the disease talk to others, they try to hide it.

"I was speaking with a lady on a bus, but when I said I was mentally ill, she turned her face to the window and did not speak to me."

Some of the participants who were taking medication considered it a taboo in the eyes of the community, and believed that taking psychiatric medication in the presence of others had caused negative reaction by others.

"One day, my neighbor came to our house, and when I took my medication, she said these psychiatric medications will end your life and cannot be a good thing."

Except for 1 patient, who did not have a history of hospitalization, all participants stated that they had received stigma after others found out about their hospitalization in a psychiatric hospital, which had been a painful experience. It was also found that the number of hospitalizations did not affect stigma and even being admitted to a hospital once would cause the same consequences.

"After I was discharged from the hospital, my mother-in-law said," You're crazy and should be hospitalized in an asylum; you will never recover. My son was Unlucky."

4.2. Academic Deadlock

One of the main objectives of establishing and maintaining supportive relationships with students in their academic environment is to help them understand, investigate, and freely express their emotions and sense of belonging (12).

Stigma has significant effects on education progress of patients with psychiatric disorders. Building stereotypes about people because of mental disorders can lead to active discrimination and withdrawal from activities such as educational opportunities. Participants in this study stated that when they received stigma from their classmates and family members, they could no longer continue their education.

"I wanted to stay in the dormitory, but the students were noisy. I told them to be quiet. In response they said I was crazy and that my hints mad them laugh; after that, I left the university."

Another participant said, "The family does not allow me to continue my education. They told me that I was crazy and shouldn't continue my education."

4.3. Marriage Bumps

Marriage is a great entity in human society, especially in Eastern countries; in these countries, marriage is almost

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Table 2. Summary of the Subthemes and Common Meanings

Major Theme	Subthemes	Common Meanings
Black shadow of Stigma	Taking refuge in secrecy	Forced to hide the disease
		Forced to hide drug consumption
		Forced to hide hospitalization
	Academic deadlock	Compulsory dropout
		Family barriers
		Lack of acceptance at school
	Marriage Bumps	Not selected for marriage
		Being considered incompetent
		Existence of unsuitable people for marriage
	Glass fence of Job	Lack of employment
		Failure to obtain a permanent job
		Getting fired
	The bitter taste of death	Death is better than living with stigma
		Revenge of the stigmatizer
		The only way of Rescue is death
	Cocoon of loneliness	The Hermitage selection
		Compulsory loneliness
		Feeling of loneliness among healthy individuals
	The narrow circle of friends	Relationship with other psychiatric patients
		Being understood by other psychiatric patients
		Rejection by old friends
		Reluctance of healthy people to communicate with psychiatric patients

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mandatory for everyone to reach tranquility (13).

Participants in this study pointed out the conditions for their marriage was not normal, so they were either not proposed to for marriage, or if they were, the suitors had either poor health or were divorced.

"I had a suitor who was paralyzed and could not do any work; and when my father said it was going to be a good marriage, I cried so much."

"My family said I was crazy, no one could match with me. They made me marry a man who had 3 children. My marriage happened out of his first wife's understanding."

4.4. Glass Fence of Job

Not only does working give financial rewards but also it helps social identity, with a sense of progress and self-esteem (14).

Most people would like to have jobs since credibility and competence are considered important. Patients with psychiatric disorders have limited opportunities to find jobs. The employers are not supportive, and the co-workers do not often understand their disease.

Participants in this study reported that in the workplace, when others were informed about their illness, their behavior had changed. For example, they were considered incompetent and had to lower their expectations. Then, patients were mocked and their merits were not considered; and as a result, they were fired.

"I have changed jobs several times. When they realize I'm sick, I had to either leave the job or get paid less."

"They think because I'm sick everything I do is wrong. Once on a welding job, I realized that others do not accept what I say about the place that the pipes must be installed. Other workers said that I was crazy and should shut my mouth."

"After, I went back to work, I endured a terrible environment with colleagues avoiding me, whispering, mocking me. I had to focus on my work."

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4.5. The Bitter Taste of Death

More than 90% of people who commit suicide have a psychiatric disorder (15).

Every 40 seconds a person commits suicide around the world, and about 1 million die per year (16).

Most participants in this study had a history of one or more attempted suicide. They expressed that living with difficulties associated with stigma of psychiatric disorder had put them under so much pressure, leading them to commit suicide.

"Some time ago, I argued with my son and he said he did not like me, and I embarrassed him, and he wished my name was not on him, I thought death was better than this situation, so I took whatever pill we had at home."

"I was hospitalized and my in-laws planned encouraged my husband to remarry. They have said that I was crazy and will not be cured. After I was discharged from the hospital, I saw my husband's second wife was taking my kids, I went to the bathroom and took 300 pills to die."

4.6. Cocoon of Loneliness

Social isolation can be one of the negative consequences of stigma associated with psychiatric disorders. Because of being aware of the negative perceptions of a mentally ill person in a community, patients usually avoid labeling.

This isolation can have a corrupting effect on their psychosocial development, environmental compliance, and improvement, hence, depriving them from social opportunities.

Participants in this study avoided social relations as a coping strategy against receiving stigma, which indeed led to their forced isolation because they are forced to withdraw from others to avoid stigma.

"When they called me crazy, I would Introspect and did not want to see anyone for months. I stayed home and did not go out."

"My friends made fun of me, I had to come home fast. I cried so much when I remembered their words and behavior. I was very isolated, which I enjoyed at first because no one bothered me, but long-term loneliness ruined me."

4.7. The Narrow Circle of Friends

Friendships are an important source of social support through the creation of activities that are not on a system of mutual trust. Rejection by friends feels so hurtful.

Participants in this study reported that as soon as their friends were informed of their disease, they ended the friendship, so the patients, reluctantly, had to socialize with other psychiatric patients.

"Because my friends told me bad things after my illness, I preferred to choose new friends very carefully, and I found friends who would say less negative words."

"If I was not sick , my friends would have been different. Now, my friends are some patients with whom I was hospitalized; and because they are informed of my illness, they do not insult me."

5. Discussion

The results of this study revealed that the consequences of living with stigma of psychiatric disorders have adverse effects on many aspects of life including employment, marriage, education, and communication with others.

Stigma consequences of the illness are among main factors that make people with mental disorders refuse to declare the disease and its related issues. Participants avoid talking about their illness due to the received stigma and the embarrassment related to mental disorders. They spoke about their unwillingness to admit that they are sick, and spoke of the desire to avoid that label.

Many patients received stigma after declaring their illness, and some, kept it a secret because they feared that people would treat them differently.

In the research conducted by Link et al. (1997), most mentally- ill patients pointed out that they were afraid of receiving stigma by others, so they had to hide their disease.

In another study conducted on 48 males with mental illnesses, 57% believed it is good to hide their hospitalization, and 75% said they would not say anything to their future employer (17).

Another adverse outcome of the stigma was on education. Because most psychiatric disorders begin during adolescence and early adulthood, stigma is a barrier to academic achievement. Progress in medicine has made patients with psychiatric disorders able to achieve educational goals. Nonetheless, discrimination and stigma are big threats to their health, success, and achievement. Discrimination and stigmatization lead to a sense of alienation and isolation.

This sense of alienation is caused by unsuccessful interactions in universities, putting the patients at risk of dropping out of university (12). In this regard, participants in the present study received stigma from college classmates, and family, which forced them to not to continue their education. Students said that they had experienced negative reactions such as being insulted and rejected in university settings. The major problem for these patients was to stay at school without stigma. A study conducted by Kahng and Mowbray (2005) revealed that 86% of students would quit

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university. Family plays an important role in supporting these patients. In case of rejection, not only the patient's severity of stigma leads to poor academic performance but also it results in learning disabilities as well as disciplinary problems (18).

One major concern of the participants of this study was related to marriage and its survival. Marriage is important for every person. The main purpose of marriage is to achieve calmness. Consistently, there have been reports of higher levels of mental health because of marriage compared to single patients. Studies show that widows and divorcees have fewer coping strategies and less mental health than the married individuals (19).

Nevertheless, there is an obstacle for people with psychiatric disorders to marry. In this regard, Weiss and colleagues (2001) showed that patients recognized as a mentally ill have barriers to marry plus problems for continuing the marriage. Women are particularly vulnerable to this aspect of social stigma. In addition, matrimonial matters (ie, the ability to marry, the marriage of a family, and the complications of the disease on the current marriage) were anticipated aspects by stigma, which is in line with African studies that have been conducted using the same approach (20).

In line with this study, the research conducted by Galvez et al. (2011) revealed that people with psychiatric disorders had interpersonal problems which led to dissatisfaction in marriage and divorce although these people often marry those who are similar to them (21).

Job is another area which stigma has a large impact on. In the present study, participants stated that work problems are stressful for them and talked about some individuals who lost a job opportunity due to their mental disorder or they were treated with disrespect at work.

A study conducted by Everton and Medina (2008) showed that people with mental illness were employed in marginalized jobs, or employed to do hazardous work. It is reported that people with mental illnesses have little security and less support from the employer in the workplace, and employers often do not understand their disease. In addition, people with mental illnesses reported that the problem greatly reduces the employers' consideration of their qualities, and they are often excluded from the labor force (22).

Stuart (2004) argued that most of the unemployment rate, between 80% and 90%, happened among those reported severely ill. Discrimination in employment was the experience of stigmatization that frequently occurs for them (23).

Patients have reported that after people were informed of their mental illness in the workplace, they change their behavior. For example, they were treated as incompetent or were told to lower their expectations (14).

Suicide is the most serious consequence that occurs in people with psychiatric disorders. From the 12 participants in this study, 10 had attempted suicide due to the stigma of psychiatric disorder, while some of them had done it so many times.

It has been shown that the stigma of a mental illness will lead to a reduction in need for help, difficulty in treatment adherence, reduced self-esteem and hope, social isolation and withdrawal, all of which can contribute to suicide (24).

Stigmatization of patients can not only prevent their treatment but also it will put them at greater risk of suicide. It seems that the best solution for a person who is stigmatized is to commit suicide (25).

Eagles and colleagues (2003) have discussed various interventions to prevent suicide, which suggested that according to the views of patients, the stigma attached to mental disorders should be reduced (26).

One of the most painful consequences of the stigma expressed by most participants was to be forced to withdraw from others to prevent receiving stigma although they had a desire to connect with others and suffered loneliness.

In this regard, Rusch and colleagues (2009) stated if one understands that others want to stigmatize her, (S) he will step down. Although this coping response could avoid stigma experience, it can have negative consequences such as demoralization and unemployment (27).

Another major issue that most participants stated was the loss of friends. After their friends' found out about their illness, they cut relations with the patient or directly stigmatized them. As a result, the patients were forced to communicate with other mentally ill patients.

Wahl (2012) conducted a survey on 1400 psychiatric patients and then interviewed 100 of the respondents. The results revealed that social exclusion frequently occurred to them. They also reported that as soon as people become aware of their disease, they will avoid them. For example, their friends do not continue phone conversations with them, or neighbors would avoid meeting them. All this leads to increased feelings of isolation and alienation from the society (28).

The results of this study revealed that the stigma could have devastating effects on different levels of the patient's life. It is hoped that by understanding the consequences of stigma experiences of patients with psychiatric disorders, we could provide better care to them and relieve their pains regarding the charge of mental health centers, caregivers, the public, and their family.

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5.1. Strengths and Limitations

This study was the first phenomenological research conducted on the psychiatric patients in Iran.

If understanding and proper interpretation of the experiences of patients are present, appropriate interventions will be provided. Therefore, interpretive phenomenological approach was suitable to attain a deep understanding of the patients' experience.

Qualitative research has some inherent limitations. For instance, Results cannot be generalized beyond the group of people whose experiences were present. The study had a small sample in research terms, and therefore, the finding may not represent the views of others. It is important to recognize that the main themes identified in this study are only one interpretation of the data; it is possible that another researcher with different interests, personal characteristics, and theoretical beliefs could have interpreted the transcripts in a different way.

5.2. Implication

The current study provides a framework for a better understanding of the consequences of stigma that the patients experience. This is vital, especially for the mental health staff as they interact with a large number of patients with mental health problems. In addition, based on the findings of this study, patients can be empowered to discover effective ways to cope with stigma. Furthermore, interventions to increase resistance to stigma and reduce its impact may be useful.

5.3. Directions for Future Research

The present study sought to illuminate the general structure of the experience of living with the stigma of any mental illness diagnosis. Another study might explicate the structure of living with the stigma of specific mental illness diagnoses. Participants in this study spontaneously described aspects of a temporal unfolding within their experience of living with psychiatric stigma; the temporal aspects of the experience of living with the stigma of mental illness could be further elucidated by a longitudinal study. A longitudinal study could highlight turning points or significant moments in the unfolding of the experience in ways that were beyond the scope of the present study. It has already been established that mental illness is narrated differently in different cultures, with different associations and varying degrees of stigma. This study focused on the experience of living with psychiatric stigma within the Iranian culture. However, it must be recognized that at the same time that individuals live within the Iranian culture, they also live within other cultures as well, and this leads to the following question: What is the difference in the experience of psychiatric stigma among ethnic cultures, or is there a difference?

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Footnotes

Authors' Contribution: Parvaneh Soodmand conceived and designed the evaluation. Abbas Heydari participated in designing the evaluation. Parvaneh soodmand collected the clinical data. Parvaneh soodmand interpreted the clinical data. Abbas Heydari and Vahid Saadatian revised the interpretation of clinical data. Parvaneh Soodmand drafted the manuscript. Abbas Heydari revised it critically for important intellectual content. All authors read and approve the final manuscript.

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