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Social Factors Affecting Relapse of Severe Mental Illness: A Qualitative Analysis of Healthcare Team's Perceptions

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Abstract

Objectives: Relapse is a challenge for patients with severe mental illness (SMI). The purpose of present study was to explain the health care team's perception of social factors affecting SMI relapse.

Methods: In this qualitative content analysis study, semi-structured interviews have been conducted with 23 members of healthcare team. Content analysis was used to categorize the data.

Results: The social factors affecting the relapse of SMI could be classified in three categories of community-related factors, cultural factors, and family-related factors. The first category included low socioeconomic status, lack of community support for SMI patients, and insufficient awareness of community about SMI. The second category included false beliefs and misconceptions, and negative attitudes towards SMI. The third category also included dysfunctional family and non-supportive family.

Conclusion: In order to deal with cultural misconceptions that lead to the relapse of SMI, it is necessary to implement culture-based interventions to correctly confront negative attitudes and stigmatized beliefs and fight against cultural taboos that govern the phenomenon of SMI relapse in Iran. It seems that the implementation of family-centered interventions for the family of patients with SMI can reduce the burden of family-related factors in disease relapse.

Keywords: Mental illness, patient, healthcare team, relapse, qualitative research

Introduction

It is estimated that 900 million people in the world suffer from mental illnesses.[1] In Iran, the results of a systematic review showed the prevalence of mental illnesses at around 25–31%.[2] It should be acknowledged that mental illnesses are one of the five main causes of disabilities that affect all aspects of patient's life, his family and social system, depriving him of a normal life.[3] Most mental illnesses, including major depressive disorder, schizophrenia and bipolar disorder are classified as severe mental illness (SMI) and have frequent relapses.[4]

Patients with SMI are deprived of continued treatment for several reasons, and experience frequent relapses of the disease, which often require re-hospitalization.[5] Relapse of mental illness disrupts the treatment process and increases the risk of resistance to treatment.[6] In fact, relapse occurs when patient gets sick again after recovery. Relapse of SMI is associated with the appearance of early symptoms and increased risk of suicide for patients. Relapse is a challenge for patients with mental illness, and is associated with a large social burden.[7] This phenomenon is very worrying for patients and their families, because it not only slows down the treatment process, but also creates a heavy economic burden for the individual, family, society and healthcare system. It also reduces social functioning and leads to unemployment and isolation.[8] In addition, the most vulnerable time for families is the time of disease relapse, because at this time, patient needs family support to remain optimistic about the future.[9]

Different statistics have been reported for SMI relapse. For example, it has been reported that 90% of people with bipolar disorder have at least one relapse during their lifetime.[5] It has also been revealed that 60% of patients with major depressive disorder experience a second episode of disease after the first one.[10] In this regard, it has been found that 82% of people with schizophrenia experience a relapse in the first 5 years of treatment, and 78% of them experience a second episode of relapse.[8] Researchers have introduced several factors for the relapse of SMI. Patients with mental illness in China stated that work-related stress and discontinuation of medication are the main reasons for the relapse of their disease.[11] In France, patients who had been ill for more than ten years had a higher risk of disease relapse compared to those who had been ill for less than 5 years.[12] In Ethiopia, patients who had been suffering from bipolar disorder for more than 5 years faced a higher risk of disease relapse.[7] A study in the Republic of Congo showed that low education level, being female, low self-esteem and living in rural areas were among the predictors of mental illness relapse.[13] In Iran, for patients with major depressive disorder, factors such as young age at the onset of disease, living in urban areas, history of mental illness in the family, and history of emotional problems play an important role in their frequent hospitalizations.[14] A review study stated that in major depressive disorder, factors such as high level of depression, high level of poor sleep quality, and irritability will increase the severity of disease relapse.[15]

Literature review indicated that different factors including social factors play a major role in the SMI relapse, and patients in different contexts are at risk of SMI relapse. In Iran, no research has been conducted to identify social factors affecting SMI relapse from the perspective of healthcare team. It has neither been described nor documented in Iran. Identifying the health care team's perception of social factors affecting SMI relapse can be an important step towards prevention and control of its consequences. It seems that health care team's perception of social factors affecting SMI relapse has cultural and conceptual context-based roots. Since Iranian society is one of the societies where patients suffer from SMI relapse and this disease is considered a social issue, one of the ways to identify social factors affecting SMI relapse is to use qualitative research. The purpose of present study was to explain the healthcare team's perception of social factors affecting SMI relapse.

Materials and Methods

Design

In this study, content analysis method was used to identify social factors affecting the relapse of SMI from the perspective of health care team. Content analysis is a method of analyzing written, audio or visual messages about a concept. In conventional content analysis, there is little information about a concept, and the concept under study is identified from the textual data through categories and their names.[16] In the current study, the conventional content analysis method was used.

Setting

The study setting was a comprehensive and dedicated psychiatric center affiliated to Iran University of Medical Science in Tehran, the capital of Iran. This center has five wards, one emergency room and two clinics.

Sampling

Participants were selected by purposeful sampling method. They were selected with maximum variation in terms of age, gender, education level and history of employment in psychiatric ward. The criteria for selecting the participants were: working in the psychiatric department as one of the members of healthcare team, including nurses, psychologists, and psychiatrists, and having witnessed the frequent relapse of SMI. In total, 23 members of healthcare team, including 5 psychiatrists, 4 psychologists and 14 nurses participated in this study. The participants were in the age range of 37–46 years, and 16 of them were women. Nurses and psychologists had bachelor's degrees, but psychiatrists had PhD in psychiatry and 8–15 years of work experience.

Data Collection

The data was collected in the first half of 2021. Data collection method was in-depth, semi-structured and individual interview with the participants, which was conducted by the first author. The researcher attended the inpatient wards in the morning and evening shifts and interviewed the participants in a quiet room, with previous coordination with the head nurse. Each interview took about 40 to 50 minutes. Each person was interviewed once and a total of 23 interviews were conducted. The interviews were recorded using a voice recorder. The main interview questions were: "How do you, as a member of healthcare team, describe the relapse of SMI?" "What social factors do you think affect this relapse?" To obtain more information, probing questions such as: "What do you mean by that?" and "Is there anything else you want to talk about?" or "Can you explain more in this regard", were also used. The interviews continued until data saturation was reached, when no new data was obtained.

Data Analysis

The data collection and analysis were also done at the same time. In order to analyze the data, each interview was recorded and then typed verbatim into a text. The interview text was read several times to get a general understanding and then, semantic units were extracted from them. At the next step, codes were obtained from the semantic units. Then, the codes were replaced in subcategories based on their similarities and differences. Finally, as similar subcategories emerged, the main categories were formed.[17]

Rigor

The criteria of credibility, dependability, confirmability and transferability were used to ensure the rigor of the data.[18] In order to achieve credibility, a constant engagement with the subject and data was maintained, and opinions of research team about the interview process and data analysis were considered. The interview text and findings were also given to some of the participants for confirmation. For data dependability, the opinions of an external observer, as a researcher who was familiar with qualitative research methodology but was not part of the research team, were used, achieving an agreement on the results. For confirmability, all activities were recorded and a report on research process was prepared. For transferability, the results were discussed with two members of healthcare team, who were not part of the study and yet had the same conditions as the participants, and the data were approved by them.

Ethical Considerations

This research was approved by the ethical committee of Iran University of Medical Sciences (IR.IUMS.REC.1399.348). In order to comply with ethical considerations, written informed consent was obtained from the participants. They were informed about the objectives of the research and were told that they can withdraw from the study whenever they want. In addition, to obtain permission for recording of the interviewees' voices, they were also assured about the confidentiality of their personal information.

Results

According to the understanding of healthcare team, the social factors affecting the relapse of SMI could be classified in three categories of community-related factors, cultural factors, and family-related factors. Community-related factors included low socioeconomic status, lack of community support for SMI patients, and insufficient awareness of community about SMI. Cultural factors included false beliefs and misconceptions, and negative attitudes towards SMI. Family-related factors also included dysfunctional family and non-supportive family.

A- Community-related Factors

The participants' statements showed that community-related factors have a significant impact on the recurrence of SMI. In this regard, low socio-economic status, lack of community support for patients with SMI, and insufficient awareness of community about SMI were among the factors that had an effect on the recurrence of SMI.

A-1- Low Socio-economic Status

The participants reported low socio-economic status, which manifests itself as a form of poverty, as one of the important factors in the return of symptoms in SMI patients. In this regard, one of the nurses said: "Social-economic problems, poverty and high prices are among stresses that make a person susceptible to SMI relapse. For example, if a patient who has been diagnosed with SMI lives in a community full of poverty and has no access to facilities for his basic needs, he will get sick again". (Participant (P) 5)

Another nurse added: "Sometimes the relapse is due to financial issues. For example, when patients cannot afford medications and cost of travel and frequent visits to clinic is high for them as they have no money, following treatment is not a priority for them." (P11)

One of the psychiatrists stated: "We have lots of patient who are laborers and head of family, making a living with a very low salary. When they see that they are financially weak, they feel helpless and this causes their disease to relapse. We had many patients with sick note for at least a month, who, after discharge from hospital went back to work straight away due to financial issues, this resulted in incomplete treatment and relapse of their disease". (P18)

A-2- Lack of Community Support for Patients with SMI

According to the participants, lack of community support such as job security can lead to disease relapse. A psychologist in this regard stated: "Many times, continuous hospitalizations cause patients to lose their jobs while they receive no job support, and this causes many problems for them. As a result, they prefer not to be hospitalized, so they experience frequent disease relapse, because their treatment is not complete". (P4)

The participants considered the inappropriate community support of the patients as the reason for their disease relapse. One of the nurses stated: "One of the reasons for disease relapse is the lack of community support, which is also very important. For example, as soon as employers find out that a person applying for job has SMI, they refuse to employ him. In this situation, even though his disease is controlled, he may experience a relapse." (P22)

According to the participants, inducing the sense of being different from others by the community can lead to disease relapse. One of the nurses in this regard said: "In the community, when people realize that someone is suffering from SMI, they don't welcome him in any community gathering or if they do, it is because they pity him, which is even worse. Well, here the patient feels different and the community indirectly conveys to the patient that he is dangerous and has a problem. This in turn makes the patient's condition worse, leading to a disease relapse." (P7)

A-3- Inadequate Awareness of Community about SMI

The community's lack of understanding and awareness of SMI and how to deal with the patient correctly reduces the intervals between disease relapses and decreases acceptance of patients by community. One of the psychiatrists in this regard stated: "Community does not have a proper understanding of SMI, and people do not know what to do when they encounter a SMI patient, so they always treat these patients harshly or reject them, which puts pressure on the patients and causes the symptoms to return again". (P16)

One of the nurses also said: "One of the factors that causes the relapse of disease is the community's lack of awareness of the form and type of SMI, as these patients are not properly understood by the community. People should learn how to treat patients with different behavior and appearance, but the problem is that people do not even recognize the initial signs of SMI, let alone the signs of its relapse". (P12)

B- Cultural Factors

The participants believed that misconceptions, false beliefs and negative attitudes towards SMI are rooted in culture and lead to the relapse of SMI.

B-1- False Beliefs and Misconceptions

The participants referred to false beliefs and misconceptions as one of the factors that affect disease relapse. According to them, the actions that originate from false beliefs cause irrational and non-therapeutic recommendations, and while worsening patients' condition, keep them away from correct treatment. One of the nurses emphasized on the deterioration of patient's condition after visiting the exorcist: "We are faced with cultural misconceptions. For example, a patient with SMI went to visit an exorcist for treatment, and he hit his head so hard to get a demon out of his body! These treatments will not improve patient condition and will cause the disease to relapse". (P20)

In this regard, a psychologist stated that sometimes, patients feel they cannot get help from the treatment team, so they seek inappropriate treatments, such as referring to healers. He also stated: "Patients feel that there is nothing we can do, so they turn to inappropriate and wrong treatments. For example, patients abandon their treatment half way through and visit traditional healers, thinking that they can get a better result by illogical treatment model. But in the end, they experience the relapse of their disease." (P17)

B-2- Negative Attitude towards SMI

The participants referred to negative attitude of the community towards SMI, as well as the stigma and cultural taboo that exists about it. They also considered their role in the disease relapse to be very important. One of the psychiatrists in this regard stated: "There is a stigma towards SMI in our culture, and this stigma constantly creates many negative emotions in patients, all of which can cause incompliance and disruption in the patient's treatment. These factors can cause the disease to relapse". (P14)

One of the nurses stated: "I think there is a taboo about SMI in our culture that compels the patient to hide their disease, making their treatment and follow-up difficult. In this situation, we have to wait for frequent relapse of the disease. False and negative views that exist in the community prevent patients from informing the treatment team about the recurrence of their diseases, and we often find out about these issues very late". (P9)

According to the participants, cultural stigma leads to non-continuation of drug use and disease relapse. One of the nurses in this regard stated: "SMI is considered a negative point in people's lives, and there is a negative and pessimistic view of mental patients from the cultural point of view. I think patients have no motivation to continue taking medication because of the stigma that the culture puts on them. And because of this, disease relapses often occur". (P3)

C- Family-related Factors

The participants referred to the important role that family plays in disease relapse. They considered any disruption in the family life, such as having dysfunctional family or non-supportive family, as the cause of disease relapse.

C-1- Dysfunctional Family

Referring to the role of dysfunctional family caregivers who cannot provide effective care to the patient, a psychiatrist stated: "A schizophrenic patient should be taken care of, but the person who is taking care of the patient is an elderly parent who has high blood pressure, diabetes and back pain, which prevent

him from taking care of the patient. In fact, the person who is supposed to take care of the patient is sick himself and cannot take care of the patient, so the disease will relapse again." (P1)

Participants referred to unfavorable family atmosphere, multiple conflicts and high tension between family members as factors that affect relapse of SMI. One of the nurses said: "Another reason for disease relapse is the unfavorable family atmosphere, an environment that is always full of tension and conflicts. For example, some patients have a strong disagreement with their spouses, or there are severe tensions between the patient's parents, and these tensions lead to the recurrence of the disease". (P15)

One of the psychologists also stated: "There are families that criticize too much or are over-involved. For instance, they impose very strict restrictions on patient, are over protective of the patient, or do not allow the patient to do anything; these factors facilitate the disease relapse". (P21)

C-2- Non-supportive Family

The participants introduced the lack of cooperation and family support for follow-up and continuation of treatment to be the main cause of SMI relapse. A nurse in this regard stated: "Another factor that can be the reason for disease relapse is that, the family has not cooperated with the patient to continue the treatment, or the family does not care about the fact that their patient is like a diabetic patient or a chronic patient who needs follow-up and has to go to hospital regularly for a long time". (P10)

One of the psychiatrists added that lack of family support prevents the patient from receiving timely medication and follow-up treatment, and causes the disease to relapse. He also stated: "If patients don't have proper family support, or if they don't have someone to buy them medicine on time, support them and take them to follow-up visits, they are more likely to experience the disease relapse. For example, we had a patient who was living alone and his whole family was living overseas, so he did not a have good family support, as a result he was admitted to hospital almost 3 times a year". (P2)

Discussion

In this study, according to the understanding of healthcare team, social factors affecting the relapse of SMI included community-related factors, cultural factors, and family-related factors. According to the participants, problems such as poverty, high cost of treatment and low socio-economic status lead to the relapse of SMI. The result of a study in India showed that stressful life events lead to disease relapse in patients with bipolar disorder, and the most important of these life events were financial problems and low income.[19] Similarly, patients with schizophrenia in China who had higher incomes were less likely to experience disease relapse.[20] The participants' statements showed that lack of community support for patient, which comes in the form of lack of job support and security, is one of the factors that affect SMI relapse. In this context, researchers believe that community support may be a protective factor that reduces the risk of disease relapse.[21] The results of a study in Spain showed that one of the factors that prevent the recurrence of SMI is having a job and profession. A job, which is suited to a person's spirit and ability, helps to improve his mental health.[22] In this regard, the results of a study conducted in China showed that patients with schizophrenia who were employed were less likely to experience disease relapse.[20] In addition, according to the understanding of participants in the present study, the community's insufficient awareness of SMI and its recurrence symptoms leads to the continuation of disease relapse.

In order to improve the low socio-economic status of patients, which leads to the disease relapse, it is necessary for these patients to receive financial support. Part of this support can be provided by the government and part of it can be provided by non-governmental organizations and NGOs. Also, in order to improve the community's support of patients and increase the awareness of community about SMI and its recurrence symptoms, it is necessary to improve the level of community's literacy about the patients with SMI and teach people that SMI patients are able to work by relying on their abilities after treatment and should not be rejected by the community.

According to the participants, the patients' cultural misconceptions and the wrong cultural attitude towards SMI lead to relapse of the disease. In this regard, instead of health care team, patients turn to exorcists (a person who tries to remove the cause of the disease, i.e., a genie, by hitting the patient's head) or healers (a person who abuses the religious beliefs of patients and tries to improve the patient's mental health) who are unprofessional and incompetent people, and this leads to continuation of the disease and its recurrence. In addition, the stigma and taboo in community, which is rooted in the culture, cause patients to hide their disease and symptoms that also leads to the disease relapse. In fact, stigma is one of the main factors related to disease relapse in patients with SMI, meaning that it makes it difficult to talk about the disease and its relapse. The results of a study in Uganda showed that stigma increases the risk of disease relapse in patients with SMI.[23] In order to deal with cultural misconceptions that lead to the relapse of SMI, it is necessary to implement culture-based interventions to correctly confront negative attitudes and stigmatized beliefs and fight against cultural taboos that govern the phenomenon of SMI relapse in Iran. Both of these interventions can be provided through the national media.

Other statements of the participants indicated that some family-related factors, such as a family that cannot take care of the patient, a tense family, a family that does not pay attention to the patient's illness, and a family that cannot prevent the relapse of the disease due to its lack of support, are involved in the relapse of SMI. In fact, when families do not support patients, they cannot comply effectively with the treatment, so they will be deprived of treatment. The results of a study in Netherlands showed that non-compliance with treatment protocols is one of the factors that affect SMI relapse.[24] At the same time, in China, patients with schizophrenia who had good treatment compliance were less likely to experience the disease relapse.[20] According to the participants, being alone and living on your own, which is one of the examples of lack of family support, leads to the relapse of SMI. In the same context, a review study found that living alone is a risk factor for disease relapse, compared to living in families that support patient.[25] It seems that the implementation of family-centered interventions for the family of patients with SMI can reduce the burden of family-related factors in disease relapse.

It is recommended to conduct studies with an action research approach to solve the problems caused by the relapse of SMI. It is also recommended that more comprehensive qualitative researches be done in this field.

Our participant recruitment approach and the nature of the present study limited our ability to generalize the presented findings. However, the aim of qualitative researches is not a generalization.

Conclusion

This study is the first qualitative study conducted on social factors affecting the relapse of SMI in Iran. Results of this study classify social factors affecting the relapse of SMI in three categories of community-related factors, cultural factors, and family-related factors. The results of this study can sensitize the healthcare system to these factors in order to prevent the relapse of SMI by implementing community, culture and family-centered interventions.

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Conflict of Interest

None to declare.

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