



ORIGINAL RESEARCH PAPER

Social Work

PERCEPTION OF ILLNESS AMONG PERSONS LIVING WITH SCHIZOPHRENIA

KEY WORDS: Schizophrenia, Lived experience, Perception of illness, Stigma, Symptoms

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ABSTRACT

Lived experiences are the first-hand accounts of an individual on a life event, situation or a phenomenon that they have gone through. There are various theoretical ways of understanding schizophrenia but a subjective experience will provide us with a person centred version which varies from person to person. This paper analyses how the persons living with schizophrenia (PLWS) perceive their illness which is constituted mainly by their lived experiences. The background study of this paper was conducted among ten participants who lived with schizophrenia for a minimum period of five years. Stigma has been seen as major content of these lived experiences of PLWS. The result also showed that lived experiences were influenced by the symptoms of the illness, experiences of stigma, duration of illness. The participants perceived the illness as a 'bad illness', 'illness that everyone hesitates to talk about' and considered as a 'disgrace'.

Introduction

Schizophrenia is a serious mental illness that affects a person in the way he/she thinks, feels, and behaves. The people with schizophrenia will have an altered perception of reality, marked with significant loss of contact with reality. The challenges that this illness post to human beings are in two ways, firstly in the form of a struggle with the symptoms and side effects of the treatment; and secondly it challenges the person with stigma and prejudices, which is the outcome of ignorance and misunderstanding about mental illness¹. The legacy of understandings of mental illness that have come down to us over generations' influence the ways in which we treat who suffer from mental illnesses. Such understandings also underlie assumptions about what mental illness is and how it should be dealt with². Understanding an illness like schizophrenia stand enigmatic in nature; whatever studies had portrayed is just a tip of an iceberg. Various methods have been used to understand different aspects of schizophrenia. Listening to the subjective experiences of persons living with this illness is very effective in understanding about the illness. But we usually fail to hear the voices of such persons. In the mental health field, theoretical understandings may have a powerful effect in limiting the way we look at clients' experiences. So the study on mental illness needs to be subjective in nature. Schizophrenia affects each person in unique way; therefore their experiences will be also different from one another. The studies have noted that the person's subjective experiences have clear relation with the evolution, course and recovery from the illness³. The review of literature in this area has depicted that symptoms and stigma are the major content of the lived experiences and it has shaped their perception of the illness.

The society's reactions towards person living with mental illness denigrate his/ her human worth. The studies have reported their experience of illness as awful or dreadful, an experience such as 'sheer hell'. They experienced feelings of meaninglessness and emptiness due to a passive life created by loss of energy, inability to carryout daily activities⁴. The literature related to life experience of persons with mental illness mainly portrays negative experiences such as stigma, discrimination, prejudice and stereotypes. The reality in global level, experience of being a 'mentally ill' is all about stigma. The problem of representation and identity also figures in the lives of persons living with mental illness just because, they have been given an identity of mad or incapable in the society⁵. Negative representation of mental illness in the media becomes a major reason for the stigma and discrimination due to mental illness⁶.

The literatures also discuss internalization of stigma that affects people's perception of the illness⁷. They are vulnerable

to internal stigma which leads to low self-esteem and creates a barrier towards productive life⁸.

Materials and Methods

The objective of the study was to find out lived experiences of those people living with schizophrenia about their illness. It also studied various factors that shaped their experiences. A qualitative methodology with a case study approach was used for the study in which the participants were ten PLWS. The participants of this study are living with schizophrenia for a minimum duration of five to fifteen years. The participants are in their journey of recovery and not being actively symptomatic; most of them experience the consequences of the illness such as unemployment and social stigma. They are the part of a Day Care Centre which helps them in integrating themselves to society through various activities. All of them are in a period of wellness, even though the symptoms disturb them sometimes, they are still able to manage and overcome them.

Qualitative research methodologies have been found as the most appropriate to portray the voice of the participants and it can contribute in re understanding their perception of illness in a better way. The method used to collect the data was in-depth interviews, an interview guide was used as a tool. The interviews were audio recorded with the consent of participants. The audio records were transcribed and the data has been translated into English from the local language with utmost care. The transcripts of interviews were read line by line and codes were identified. Similar codes were put together under various categories⁹. Verbatim of the participants and data points from word tables were analysed for results.

Results

Perception of the illness

Every participant has perceived the illness in a unique way. The below table will show various responses of participants on their perception of illness.

**Table No. 1
Participant's Perception of Illness**

No. Participants	Perception of the illness
1	<i>Serious effects in life, no one desires this illness</i>
3	<i>Bad illness</i>
4	<i>Humiliating illness and everyone hides</i>
6	<i>Illness of mind, very fearful</i>
7	<i>Bad illness, I hate it</i>
8	<i>Illness of sadness, an illness everyone hesitate to talk about</i>
9	<i>Illness make us slow in everything - activities, communication and relationships</i>

The Perception of the illness is the outcome of their lived experiences over the years. They have their own reasons that gave a meaning to their illness. The participants shared the perceptions as mentioned below,

“An illness that no one desires in the life”

Schizophrenia in particular and generally mental illness has got a 'bad' status among the illnesses. A participant perceived the illness as 'illness that no one desires', this expression refers to the severity, manifestations and the low chances of getting cured. The participants' experience that living with schizophrenia is difficult and challenging and no one should get it in their life time. It shows how much suffering the person has went through.

“Bad illness”

A participant, calls it a 'bad illness' seeing its vicious nature. He experienced how the illness has changed his life. His experiences of observing the people who roam in the street with mental illness made him perceive it in that way. *“The illness makes you a bad person without proper self care, grooming and people talk badly about you”*, he experienced this situation when he had the first episode of illness. He remembers that when his relatives found him in the streets, he was without proper clothing and was lying unclean on the street.

“An illness that creates sadness”

The participants perceive schizophrenia as an illness of sadness. They experienced deep sadness during their course of illness.

“It is very sad that I got this illness. I have seen people roaming on the streets with this illness. Now I am also one among them. But I have my family with me, that is the only difference”

The participants understand the fact that they're not only one who feels this sadness but their family members are also feeling the same. They have seen the burden of their family, sadness and uncertainty in their faces due to unexpected incidents in the life of their beloved ones.

“An illness that people hesitate to talk about”

There is stigma surrounding mental illness. No one even likes to talk about this illness, since it is a shame for them. A participant and her family perceive that the community call their family as an 'ill person's house'. She shared that,

“we know this illness, people are not interested to talk about this. If it is some other disease, even cancer people feel comfortable to talk about it. When we attend a marriage, or a function, this illness is a problem”

This participant experienced the illness as an 'illness everyone hesitated to talk about'. This hesitation is due to stigma prevailing about mental illness. She and her family have faced isolation in family functions where relatives hesitate to interact with her, marriage being delayed as some of them turned down due to her illness.

Symptoms

An illness is manifested through its various symptoms. The study reveals that living with symptoms of schizophrenia is more painful because there is an outward manifestation of the illness. Due to the persistence of the various symptoms, many people observe it and call them 'mad'.

The participants reacted to the symptoms in various ways, *“Disgrace... disgrace on my identity, even a small child can say I am abnormal”*

The pattern of experience of symptom is a feeling of disgrace on the self. The identity is being rejected due to the outward

manifestation of the symptoms, which is in the form of behaviours rather than internal changes.

“I had my tablets in secret, tried to the maximum to behave everything is fine. But the day I performed the namas in the middle of the road, my illness was exposed to entire village.

The participant does not want others to know about his illness, and thus hides the symptoms by attempting to curtail the manifestation of the illness. Despite some success, they also experience failure to mask the illness.

Family history of mental illness is an important factor that influences the lived experiences. In a way, it helps the families in early identification of symptoms. It also affects person's perception of illness by internalizing the negative attributes they have seen in such family history.

Knowledge about schizophrenia constitutes lived experiences in the life of PLWS. Due to the lack of awareness the families misunderstand the symptoms as evil possession and black magic.

Duration of the illness also influenced the lived experiences in a way it shaped their attitude towards life. Those with a long duration of symptoms/illness have developed their own way of dealing with life using coping strategies. The persons with long duration of illness have limited hopes and dreams about life. But the people with a short duration of illness have lot of hope about their future.

Societal attitudes and stigma prevails in the form of labelling; the person or her/his family suffers in their social life due to labelling and negative identity given by the society. This kind of stigma impedes the person living with schizophrenia or his family to attain a job, a good marriage alliance or even a rental house.

Conclusion

Every person living with schizophrenia has lived experiences in different domains of their life. Some of these experiences develop negative attitude towards life and illness and some helps to identify possibilities to achieve goals. Stigma is seen as the major content of lived experiences. In an Indian context, where mental illness is highly stigmatized, the persons with schizophrenia must be given opportunities to be listened at least by the health care professionals. Our approach to such persons must be changed in a way that we conceptualize or understand the illness in their perspective. This approach will help us to support them better and to understand the illness not from a theoretical perspective but from a humanistic perspective.

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