

Hermeneutic Phenomenological Approach to the Experiences of the Individuals Living with Schizophrenia: A Qualitative Study

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Abstract

Background: Schizophrenia affects various spheres of life causing so many difficulties and burden, but the studies focusing on the experience of individuals living with schizophrenia with reference to the Tamil Nadu context are sparse. **Material and Methods:** A qualitative interview based on a hermeneutic phenomenological approach was conducted with 10 individuals living with Schizophrenia and was recorded. The responses were transcribed and coded. Based on codes, domains and subdomains were identified. **Results:** Six themes were identified, under which the participant's burden was described. Participants expressed a deep longing for love and care. They were deprived of family's affection. Participants felt economically insecure, which was owing to their unemployment. Participants had many physical complaints including sleep disturbance and fatigue. Participants expressed that they had failing memory, concentration issues, and difficulty in planning. Most of the participants felt isolated by family and kin. They did not participate in much social activities due to the fear of judgment and stigmatization. **Conclusion:** The experience of individuals living with Schizophrenia revealed that they experienced a series of burdens owing to their illness and its impacts that were categorized into various themes including physical, vocational, cognitive, psychological, personal, and social factors.

Keywords: Disease burden, Experiences, Qualitative, Schizophrenia, Tamil Nadu

INTRODUCTION

Schizophrenia is an illness that affects various spheres of an individual's health that includes his mental health, cognition, physical functioning, interpersonal relationship, social participation, and higher executive function.^[1-3]

When considering the global prevalence of individuals living with Schizophrenia, it accounts for up to one percent of the total population, which is about 20 million, and when confined to India, the prevalence accounts for 0.64%, which is about an alarming level of 3.5 million as of 2017.^[4-6]

Individuals living with schizophrenia have a several-fold increased risk of comorbidities ranging from obesity and diabetes mellitus to coronary artery disease and cancer.^[7]

It should be understood that more than half of the individuals living with Schizophrenia in India have certifiable disabilities and occupy more than half of the beds in a psychiatry ward, which accounts for a higher financial burden.^[5,8,9]

Currently, there is no cure available for Schizophrenia. Treatment protocol focuses on overall improvement in

the individual's life and de-institutionalization, thereby reducing the disease burden and providing a symptomatic recovery.^[1,10]

To achieve symptomatic recovery and improve the quality of life and satisfaction of the Individuals living with Schizophrenia, it becomes mandatory to understand their disease burden and other such problems experienced by them from their perspective, which remains a challenge to healthcare professional.^[11]

It is widely accepted that mental health problems are highly associated with social dimensions or community participation, which may include various components such as employment, social networking, housing, finances, leisure activities, health, and well-being along with social interactions.^[12,13]

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Social support and social inclusion can play a major role in de-institutionalization and reducing the economic or health burden and improving the functional outcomes in people living with severe mental illness such as schizophrenia.^[14,15]

There are several studies conducted to understand the perspectives on individuals living with Schizophrenia, but when speaking in terms of regional level, the studies are relatively sparse. It must be understood that the perspectives and disease burden vary with varying levels of social support, regions, lifestyle, and cultural belief.

This study aimed to understand the lived experiences and perspectives on individuals living with Schizophrenia in Tamil Nadu.

METHODS

Aim

This study aimed at exploring the experiences, difficulties, and burdens faced by individuals living with Schizophrenia with respect to the physical, environmental, psychological, personal, and other contextual factors that could significantly affect their quality of life.

Design

Since the aim of the study demanded an exploration and deeper insights of the individuals living with Schizophrenia, a qualitative design was opted and their experiences were gathered through a hermeneutic–phenomenological approach.

Study setting

Participants were recruited from Aadharavu Home, Periyapalayam, Tamil Nadu, India, where individuals living with Schizophrenia from various parts of Tamil Nadu approach comprehensive care.

Ethical considerations

The entire study was in compliance with Helsinki's declaration. Every participant was explained the procedure of the study before the commencement of the study, and written consent was obtained from the participants that clearly stated the aims, needs, benefits, and potential risks involved in the study. The consent also contained details of the researchers, and their purpose for conducting the interview was explained.

Participants were free to walk out at any point of the study. Participants were free to choose if they wanted to attend the interview alone or wanted to be accompanied by a caregiver. All the identification details of the participants were masked during the process of transcription to maintain confidentiality and privacy. The transcribed responses were given to the respective participants to obtain their consent to be used in the study and to obtain feedback.

Participants

For the study, participants were employed based on purposive sampling as it helps in selecting participants aligned with the study design. This helps in capturing a rich and varied

experience of participants. The study aimed at maximum variation sampling to identify a multitude of perspectives, thereby participants were selected from various age groups, backgrounds, and lifestyles. Interviewers were experienced in qualitative research studies and have published qualitative research studies in indexed journals.

Participants were explained about the needs and means of the study. Participants who met the eligibility criteria and were readily willing to participate in the study were recruited.

The eligibility criteria were that the individuals should be diagnosed with Schizophrenia and must be under treatment for at least of about 2 years. The age group was limited from 18 to 65 years for both sexes. Participants who were hospitalized or experienced exacerbations within the last 3 months, who had substance abuse disorder, and those who posed difficulties with comprehension and responding were excluded from the study.

Interview outline

Before the commencement of the study, a semi-structured interview questionnaire for individuals living with Schizophrenia was framed based on the previous studies that were published on this population and was content validated by a panel of four experienced clinical psychologists with a minimum experience of five years.

The interview guide was validated for its accuracy, relevance, evidence of content, and technical quality, and necessary corrections were done based on the suggestions given in the panel discussion with the psychologists.

The interview was focused on their routine, independency, physical health, memory, social life, economic life, interpersonal relationship, self-perception, and emotions.

Data collection

Data were collected through a face-to-face semi-structured interview that was audio-recorded. During the interview, if the participant appeared to be stressed, the interview was stopped and enough time was given to the participant to relax. Following this, the participant was allowed to decide whether to continue with the interview.

The interview was carried on till the point of data saturation. Each interview lasted for a minimum of 30 to 45 minutes. Only the response of the participants who completed the entire interview was selected for the study.

Participants were allowed to choose if they wanted the interview to be conducted in a room or an open environment, with minimal disturbance. At no point in time, the interview was disturbed. Enough time was given to the participants to think and respond. Participants were not interrupted while responding.

The interview session ended with a closing question stating that “We have reached the end of the interview. Is there anything more you'd like to tell me that we have not already discussed? Do you have any questions for me about anything

Table 1: Coding of responses

Open coding	Axial coding	Selective coding
Visual disturbance, Tremors, Body aches, Reduced walking speed, Frequent headaches	Somatic symptoms	Physical factors
Frequent fatigue, Lack of energy, Reduced ADL performance	Energy	
Daytime sleepiness, Disturbed sleep, Dependent on sedatives, Unsatisfied sleep, Excessive sleeping	Sleep	
Work place criticism, Job denial, Unsupportive colleagues	Work environment	Vocational factors
Reduced efficiency, Unable to cope up, Worried about job, Poor planning, Poor execution, Inability to meet deadlines, Loss of focus on a work, Increased absenteeism, Difficulty in multitasking, Constant break form work/education	Work efficiency	
Economically unstable	Economy	
Easily agitated, Anxious about future, Feeling disconnected, Getting lost in thoughts, Loss of emotional control, Quitting tendency, Depressed about present and future, Suicidal ideation, Hyperirritability to sound, Feeling insecure	Emotions	Psychological factors
Difficulty in self-control, Guilt on behaviour, Beating others, Quarrelsome, Constantly changing job, Sedentary behaviour	Behavior	
Disinterest in life, Lack confidence in life, Stressed about life, Loss of hope, Dissatisfaction with life, Lagging behind in life	Perception	
Conversation, Inclusion, Work completion, Food	Pleasure	
Forgetful, Requires assistance	Memory	Cognitive factors
Wandering of thoughts, Absent minded, Frequent distractions, Strained with concentration, Mental strain reducing performance, Difficulty in concentration, Difficulty in grasping information	Concentration	
Isolated by family, Lack of moral support, Feels like burden, Opinions are not validated	Family interactions	Personal factors
Self-isolation, Nobody understands me, Deprived from love and care, Longing for company, Feeling lonely, Feeling of detachment	Interpersonal relationship	
Lack of participation in recreation, Require medical help to cope up,	Self care	
Societal pressure, Afraid of people's judgement	Social interaction	Social factors
Avoid social gatherings, Hesitation to socialise, Social isolation	Social participation	

we discussed?" to ensure that no aspects of the patient's burden were missed out.

To ensure data saturation, a series of steps including purposive sampling, iterative data collection and analysis, and saturation criteria were adopted. Purposive sampling helped us to get a diverse view from participants, through which a wide range of experiences and viewpoints were captured. Following this, data collection and analysis were performed by the iterative approach of qualitative analysis, where the responses were analyzed as initial data alongside which the interview was preceded with the next participants. Through this approach, the emerging themes and codes were constantly compared and contrasted.

Through the codes and themes obtained in an iterative approach, data saturation criteria were established where there were only repetitions of key points and no new themes or codes were generated. The data were coded by two researchers.

Eighteen participants were recruited for the study. Of these, only 10 participants completed the entire interview. The rest of the participants discontinued the interview for reasons such as they felt distressed, they were not willing to disclose their personal problems, or they did not want to discuss their problems.

Data saturation was ensured with the response of the tenth participant. The responses were obtained from six men and four women of age between 23 years and 57 years who had Schizophrenia for a minimum of 3 years to a maximum of 14 years.

Data analysis

The recorded audios were translated into English and transcribed. Care was taken to maintain the core meaning of the response when being translated from vernacular language to English.

The data that were collected systematically through interview were analyzed and coded according to grounded theory analysis. Thus, the process of coding occurred in three stages: open coding, axial coding, and selective coding.

In open coding, the responses were read line by line and were fragmented into highlighted key points and were given a code without changing the meaning of the responses. Following this, axial coding was performed by grouping the open codes according to their similarity. Finally, the axial codes were grouped into core categories in selective coding.

RESULTS

After transcribing the interviews, coding based on grounded theory yielded a total of 16 subthemes that were grouped under six core themes. The core themes included i) physical factors, ii) vocational factors, iii) psychological factors, iv) cognitive factors, v) personal factors, and vi) social factors. Coding of responses with the themes and sub-themes are depicted in [Table 1].

Theme 1: Physical factors

Subtheme 1: Somatic symptoms

Though schizophrenia was primarily considered to be psychiatric

disorder that has a lot to do with mental health, the interview revealed that the participants exhibited an array of physical problems. They had problems such as chronic headache, fatigue, tremors, blurring of vision, and also problem with walking speed though they were able to walk independently.

“My ability to walk, is little bit slow when I compare with my fellow people. If I try to walk fast, I can walk only for a very less duration, like for only about 20 seconds. Then I naturally slow down.”—said a participant.

For the majority of participants, these symptoms were severe enough to interfere with their vocational performance. Few reportedly lost their job owing to their somatic problems. When this aspect was explored in detail, a participant reported that.

“Whenever it starts to shiver, I slow down my work. I used to ask help from others to complete my work. Before my illness, I used to write all day and type all day. But I am unable to do that. I have even lost my job because of that. I made mistakes in typing, typed slow, so I lost my job.”

Subtheme 2: Energy

While few participants denied that they have no difference in energy level, seven of 10 participants accepted that they sure experienced a drop in their energy level after the episodes of schizophrenia.

“I am unable to be active. I can find myself being idle and sedentary for a longer duration. I am not able function actively because I am getting tired easily and not able to concentrate and do a work thus I am unable to function actively.”—responded a participant.

When probed further in this aspect, it was revealed that they were not active as before; in fact, they were unable to be active as before. Even with a few minutes of work, they felt that they had drained out and felt it very difficult to cope with the work.

Subtheme 3: Sleep

When it comes to sleep, there was a range of contrasting responses from the participants. Few participants reported that they have perfect, undisturbed, satisfactory sound sleep with the help of medications.

In contrast, a respondent recorded that *“I have consulted a doctor and have got medicines for sleeping. Even with these tablets I am unable to sleep well. Sleep is not satisfactory. I feel like I want to sleep again.”*

There were also complaints with sleep including oversleeping or excessive sleeping, daytime sleepiness, and disturbed sleep pattern.

Theme 2: Vocational factors

Subtheme 1: Work environment

“Sometimes people criticise me in work with context to my illness and they deny me from getting the job”—a participant recorded.

Participants reported that they were denied from many job opportunities due to the symptoms associated with the illness

and also were criticized by their co-employees that made them feel low and had a disturbing work environment. Sometimes it made them agitated.

On the counterpart, a few respondents stated that they had a lovely workspace where their colleagues were very much understanding and supportive in both emotional aspects and vocational aspects.

A participant recorded, *“My colleagues used to teach me with patience, no matter how many errors I make. They say me that, to make error is nature, we are here to help you. Don't hesitate to voice out.”*

Subtheme 2: Work efficiency

Of all the aspects, work efficiency was the component that was highly affected and remained highly bothersome for almost all the participants of the interview. Few participants felt that they were inefficient to perform a job and often wanted to quit due to their inability, but they had no other option other than to continue the job to meet up their financial needs.

A participant told that *“It's difficult for me to cope-up with job demands. Many times I feel quitting the job. I feel like it's enough. I can't. But then, I have don't have other choice. So I keep these thoughts aside and try to focus on my work though it is difficult.”*

Apart from the lack in their energy level, the other most commonly cited reason for the lack in work performance was their ability to think and perform. They felt it difficult to perform tasks that demanded a higher level of thinking skills, especially when it comes to a complex task. They also had issues in executing the tasks and multitasking. This made them more time-consuming and inefficient candidates when compared to their colleagues.

I am unable to think properly. I am not able to think how to do or plan how I am going to do this. As I am not able to plan, I am unable to execute. So it takes longer for me to do work and other activities. I need to wait and think for some time before doing the work—recorded a Respondent.

While others responded said that, *“Mechanic job itself was difficult for me. Because in that job we have to remove bolts, nuts, engines and gear boxes, etc., removing will be easy. But fixing back and arranging it is difficult. Because we have to plan for it. That was difficult for me.”*

Not just in job aspects, when it comes to student life, schizophrenia did have an impact on the educational aspects too. Students did have problems with facing their deadlines and felt quite inefficient when compared to their previous performance. They require a constant push from the external to finish off the task.

A participant who is currently pursuing her college stated that *“Previously I was a proactive person. I used to complete things before someone expects me to do. But now staffs keep telling me things and I keep forgetting it. More than forgetting, sometimes I am disinterested.”*

Participants reported that they get drained easily so they have taken breaks frequently while working. It must be noted that a few participants decided to quit the job or pursue their jobs after some days as they were unable to cope with the demands. Few reportedly said that they take increased sickness absenteeism.

Subtheme 3: Economy

It was observed that the impact on work efficiency had a direct relationship with their economy. Due to their impaired efficiency in job and job denials, they had to frequently change their job. This made them economically unstable and insecure. This was also a reason for them to doubt their ability and confidence.

This unstable income also had an impact on their family interaction, emotion, and social safety. Participants believed that getting a stable job would fetch them a secure position in the society.

“A good job will would help me to be s`. Economically I would be strong. And working will make feel better and make me feel active”—reported a participant.

Theme 3: Psychological factors

Subtheme 1: Emotions

“I shout at my colleagues. It was actually without any reason and had happened without my control. I was unable to control my mood swings”—an individual living with schizophrenia.

When explored about their emotions, participants showed a spectrum of emotional responses, which include explosion of agitation, sudden wave of depression, dejection, anxiety, and loneliness.

Participants explained that they used to get easily agitated for simple or no reasons. Participants used to shout at others out of anger, especially when others did not listen to them. Sudden noises were more than enough to provoke them. They have little control over themselves and their emotions. When they are provoked, their nature becomes violent and they either scold or physically assault the opponent. When probed on this aspect a participant responded.

“Even for silly reasons I get angry. If there is any small noise in my house or street or other house, sounds like putting the plates, all these simple things irritated me much. I used to scold my parents when I get angry. If they don't listen to me, I would beat them.”

Depression owing to the illness and the impact of illness cannot be overseen. Participants are so much depressed due to their incapacities, lack of love, and deprivation of care. Few participants explained that they quite often wanted to end their life so that they can be free once and for all. They felt there was no one there to understand them.

“I get suicidal ideations. I have expressed it to my mother. My mother is aged. She is about 65. She did not understand. She is unable to understand. It was that point of time I fell in love with a girl and she also broke up. So, there is no one for me to share.”—a participant responded.

Participants said that most of the time they get themselves lost in thoughts like “why these had happened?”, “when will I become better?”, “when will my life be back to normal?” and they get more depressed by these thoughts as they ultimately had no answers.

Subtheme 2: Behavior

Many participants exhibited a tendency to quit. Behavior to quit was used as a mechanism to escape from responsibilities. They felt they were not capable of fulfilling the duties or it was too heavy to bear. They further explained that extending the deadlines or postponing the commitments would give them some sought of relief. When further probed, a student participant responded.

“Sometimes, I feel like I have to quit college also. Or I think I require more time. I feel like I have to take a backseat and take up my exams 6 months later. But I don't know. I am double minded. I don't want to do it, but I want to do it.”

Excessive mood swings and agitation seem to have highly influenced their behavior as they have almost lost their patience. Few people reported that their anger was one of the reasons to shift their job quite often. They thought that would help them, but unfortunately, their behavior did not change so they kept on changing the workplace.

“I used to get angry. I will show my anger in my work place. I used to speak like, I will not work, you go and work for your company. Then, I went to my dad's office and I had extreme anger issues in my dad's office too. So, I stopped working there also.”

In the instant of anger, participants used to behave violently that they either indulge in a verbal quarrel or physical assault, be it their colleagues or friends or family, but they reported that whatever they did was merely out of their control. They further added that no matter how much they try to control their anger and emotions, it all ended in vain.

Participants extended that, after such incidents, they feel very much worried and guilty for the way that they behaved with their fellow people. They always wanted to apologize for how they behaved with others.

Subtheme 3: Perception

“What's more left in my life? I want to achieve something. But I am aged and almost nearing my retirement. Then I won't even get this job. Then no one would respect that. But I have to accept that.”—answered a respondent.

Most of the participants expressed their life was lonely, which made them lose hope in life. They explained that their way of seeing life has completely changed after the episodes of schizophrenia. Their economic insecurity and lack of care from the family were emphasized as a reason for this.

Few participants explained that they were left all alone and that when they lose the job no one is going to take care of them. They have lost interest and hope in life.

They felt they were disconnected from the world. They were much stressed and dissatisfied with the life they lead. They spend most of the time thinking that when their life will be back to normal. When probed on this aspect, a participant responded that

“Even though I want to, I don't feel I am completely connected to the world. I feel like I lag where the world is running right now.”

Subtheme 4: Pleasure

This section of the interview was concerned about the activities or things that would bring them joy and make their mood better. Though there were various answers, the most common answer was the feeling of inclusion. Participants said that they find joy in conversation with others, feeling included in peer group, and spending time with their family.

“I will be happy the day that I get home and spend my time with family like it used to be”—said a participant who was isolated from his family.

Few participants found pleasure and joy in exercise, dance, and praying, and a participant also found pleasure in eating their favorite food. When asked about it, the participant responded that *“Eating makes me happy. Eating the food I like, especially biryani and home-made food, that makes my mood better.”*

Participants not only gained pleasure but also hope through the love and constant support they get from family. They further added that nothing makes them happier than being understood and included by their family.

“My wife is keener on my health. She talks to me about how happily we are going to live in our new home. The constant support and love I get from her makes me happy”—replied a respondent.

It is worth mentioning that few participants found pleasure and happiness in completing the pending works, meeting up expectations, coping with demands, controlling anger, and meeting up deadlines in a work.

Theme 4: Cognitive factors

Subtheme 1: Memory

Memory was highly impacted among these participants. Participants agreed that they do forget things. The tendency to forget did have an impact on their job. They required constant assistance or reminder from the coworker to remind what they are supposed to do.

“I tend to depend on my room mates to remind me things. I forget lot. I need people around me to keep reminding about things like you have this, you have that, etc., I keeping telling my friend that, I forget things, so remind me about this. That is actually very difficult. Even though I make notes, I forget. It is very difficult for me to remember things.”—reported a respondent.

Subtheme 2: Concentration

Participants with schizophrenia exhibited concentration difficulties. They get random thoughts; while working

in essence, they are frequently distracted. This frequent distraction is potent enough to affect their work.

“I have these issues like thoughts getting lost somewhere. I am not efficient in concentrating like before. My mind goes into some random thoughts”—said a participant.

The severity of concentration issues had forced them to take more breaks rendering them inefficient. Participants explained that they get mentally strained when they think a little. This straining made it difficult for them to concentrate further. When probed on this aspect, a participant responded that.

“When I work, I am getting tired and strained. As I get stressed or strained, I start losing my concentration. Due to this problem I had to constantly take breaks from my job and change my jobs quite often.”

Due to issues with concentration, they have lost focus on their work. They also report making many errors in their work, and as a result of this, they required more time to perform a task.

A participant reported that *“I am unable to focus. Now I am working as a gate keeper. I used to write wrongly. I used to make mistakes like writing in-time in out-time and things like that.”*

Theme 5: Personal factors

Subtheme 1: Family interactions

“I don't participate much in decision making. It's not because of discrimination but I self-doubt my abilities. I am unable to think well. And also I am unable to be economically stable. Because I constantly quit my job due to the difficulties and change my job as I require some break in between. This makes me feel insecure and lowers my confidence. So I don't much participate in decision making.”—reported a participant.

Though participants longed for inclusion and company, many of them did not get it. Many participants had issues with interactions. One reason was that their family members did not respect their opinions or they were not given space to voice just because the participants did not have a stable income and mindset.

The other reason was that participants restricted themselves from interactions and decision-making. This was because they self-doubted their abilities to decide and they felt inferior because of their economic stability.

In contrast, there were participants who were given enough space and confidence in the family to interact and participate in important decision-making of family happenings. Their family gave them the upper hand in coping.

However, it should be understood that a few participants felt more insecure in the family and were almost deserted by relatives once their parents passed away. Participants expressed a deep sense of grief while conveying the message that the family members looked at us as a burden. When probed on this aspect, a participant responded that.

"I felt secured until my parents were alive. Once they passed away, my brother left me. They saw me as burden. Once my parents left, my brother did not want to take responsibility for me. He told me that, 'I have my family so I cannot take care of you. You are a single man so you go, work and earn for yourself'."

Subtheme 2: Interpersonal relationship

"When I was in the beginning stage of schizophrenia, a few of my friends left me, telling that I can't handle all this in my friendship. It is very difficult for me to handle a person with schizophrenia and all. That was quite disheartening for me"—said a participant.

Like the other domains, this particular domain had contrasting responses. Few experience their interpersonal relationship to be a supportive one, while few consider it to be dreadful. Few participants longed for a company, while the counterpart wanted to spend time alone.

Few participants expressed that they wanted a company for them to share and care. They longed and craved affection of which they were deprived for so long. When this domain was explored, a participant responded that.

"I want someone to accompany me. My mind thinks it needs a friend nearby. Previously I used to go alone but now I don't wish to."

Many participants hesitated to be vocal about their problems due to the fear of being judged or deserted, but in contrast few participants said that explaining their problems to the colleagues proved to be helpful. It helped the colleagues to understand the difficulties and problems faced by the participants, and from then on, they proved to be supportive of the participants rather than being just discriminative. A participant said that.

"They are much understanding. Initially they didn't understand why I am getting easily agitated but now after knowing my situation, they are much understanding and supportive."

Subtheme 3: Self-care coping

Many participants reported that they have little control over themselves, their emotions, and their health. When questioned about how they take care of themselves and cope with their problems, most of the participants depended on medical help.

"It's very difficult to handle myself. It gets too much, I keep thinking too much that I sometimes I have to reach up to counsellors or psychiatrists near me. They give some ideas that clears up my mind a little. Otherwise alone I will not be able to do."—reported by a respondent.

In contrary, there were participants who absolutely had no idea on how to manage their health issues and emotional imbalance. When probed on this aspect, a participant replied that *"I don't even know what to do. When I think about these, I am getting more stressed."*

Theme 6: Social factors

Subtheme 1: Social pressure

"I feel like I have lot of pressure from the society. I find it very difficult to explain people like how I am"—said a participant.

Few participants reported that they do face a role burden from society. Being a part of society, they were expected to fulfill certain responsibilities, but owing to their illness and the difficulties they face, they are unable to cope with the expected duties that get them more stressed and make them feel more pressurized.

They also feel anxious about how people would perceive them, if they fail to meet or live up to their expectations. They are feared of being judged by society.

Subtheme 2: Social participation

"I myself have a hesitation to socialise. Sometimes I am afraid that I might be judged. I try to go to family and relative function. But I am unable to overcome the hesitation. I lack confidence in social interaction because I get irritated at times for no reason"—a response of an individual living with schizophrenia.

Few participants expressed that they love to get along in social gatherings while few contradicted it. Most participants recorded that they do not socialize much. When probed on this aspect, they gave so many reasons. A few of them were fear of being judged by others, isolated by society, socially discriminated against by society, uncontrollable anger issues, lack of confidence, love to be alone, and hesitation to get along.

They were worried about being isolated by society and not actively participating in functions, but they added that they were left with no other choice. A participant added that.

"For the past few years I don't participate in family functions and I don't talk much. I am not talking to anyone, family members or friends due to my illness."

DISCUSSION

Our study aimed to understand the lived experiences of individuals living with Schizophrenia in the context of Tamil Nadu culture and environment wherein ten individuals were interviewed.

As explained in a systematic review on the disease burden of individuals living with Schizophrenia by Benedicto Crespo-Facorro *et al.*, the participants of the current study also experienced difficulties in maintaining interpersonal relationships and stable employment. They also felt it hard when it comes to social participation and interaction. Participants were afraid of the social stigma attached to their illness, which accounted for self-isolation.^[16-18]

Participants experienced fatigue quite often along with body aches. They also expressed that they have impaired memory power and that they were unable to retain or grasp information. They were unable to concentrate on work-related activities

for a long period of time, which became a reason for their unemployment.^[19]

Participants also reported that their failing memory was so severe that they required someone to remind them of the things that they were supposed to do, including basic tasks such as taking medicine to complex job-oriented tasks.

From the responses, it can be observed that almost all the respondents of the study had difficulties in coping with the impacts of their illness, especially when it comes to their emotion. They even expressed that they felt guilty for the way they behave with others in rage. This is in contrast with the results of the study conducted by Iyus Yosep *et al.*^[6] wherein they found that Individuals living with Schizophrenia in Indonesia was able to find helpful coping strategies to deal with their emotions.

Participants of the study express a deep longing for love, support, and care, especially from their family. It must be understood that involving family in treatment provides better outcomes in the treatment of Schizophrenia, thus making family education an inevitable part of treatment. This avoids discrimination and improves a sense of security.^[1,20,21]

Participant's difficulty in planning how to perform a task and difficulty in executing a task and impaired thought process in general account for the involvement of the lateral prefrontal cortex.^[22]

Due to various reasons including stigmatization, somatic problems, self-isolation, discrimination, inferiority complex, and economic instability, the majority of the participants reported that they do not participate in any of the sports activities, recreation, social gatherings, and function. This can have a greater impact on patient's autonomy and further add up to their burden.^[23]

Participants experienced sleep disturbances. Either they experienced insomnia or oversleeping habit. They were highly dependent on medicines for sleep. Few participants also experienced daytime sleepiness. This might be a reason for their inactiveness and lack of motive to participate in activities, and it can further worsen their condition.^[24]

The gradual cognitive decline, stigmatization, loss of touch with reality, deprivation from love and care, economic instability, increased institutionalization, sleep disorders, hallucinations, and other disorders became a major reason for the increased suicidal thoughts among the participants.^[25]

As explained in several studies, the major problem faced by individuals living with Schizophrenia is that they are socially excluded by the community, owing to various reasons including stigma leading to poor social networking and lack of social support, which is one major cause of poor coping mechanism of individuals living with Schizophrenia in Tamil Nadu.^[14,26]

Thus, it becomes important for psychiatrists, community workers, social health workers, and other healthcare

stakeholders to create self-help groups, mental health education, and community awareness program with strategies for inclusion according to sociocultural concepts and make the general population understand the community they live in is also the community of individuals living with Schizophrenia.^[27]

Though social inclusion is the basic right of any individual living with mental illness, they are deprived of it. This can be possibly averted by making them participate in the social cognitive rehabilitation program and community-related activities, which not only improves their potential and participation level but also improves their self-esteem and creates and identity for them.^[15,26-28]

Future implications

This study is the first of its kind to explore the perspectives of individuals living with Schizophrenia in reference to the cultural contexts of Tamil Nadu; thus, it could serve as a first step in creating a valid patient-reported outcome measure in this region.

Improving social cognition through tailored community-based rehabilitation and strengthening social networking might prove to be helpful in improving functional outcomes and preventing relapses.

Though many studies have emphasized the physical activity and exercise benefits on the outcomes of Individuals living with Schizophrenia, it is evident from the interview that it has not come to practice in Tamil Nadu. It is important to incorporate physical activity and exercise as a part of the treatment regime to improve the quality of life of the patients.

Caregiver or family education and involving them as part of rehabilitation will not only improve the outcome of the treatment and fasten the discharge but also will improve the acceptance of illness by family members.

Patients are highly dependent on medications for sleep and emotional regulation. Other effective coping strategies and relaxation techniques must be taught to the participants to improve their sleep quality and emotional control. This will reduce their dependence on medicine.

Providing vocational rehabilitation and allocating them in suitable job will help in making them economically stable and providing them a sense of financial security.

Limitations

This study did not address their socioeconomic status and educational status and did not assess gender differences. The study was only based on the perspectives of the individuals living with Schizophrenia. The views of the caregiver or the healthcare provider were not taken into account. Participants were only those who had insight and were outpatients, and the actual burden of hospitalized patients may vary.

CONCLUSION

The experience of individuals living with Schizophrenia

revealed that they experienced a series of burdens owing to their illness and its impacts that were categorized into various themes including physical, vocational, cognitive, psychological, personal, and social factors. A rehabilitation protocol formed based on their burdens involving caregiver education and family involvement as an integral part of the rehabilitation will improve the outcome.

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Ethical consideration

The study was approved by the institutional ethical committee of SRM Medical College Hospital and Research Centre, Kattankulathur (IEC 8314/IEC/2022).

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Conflicts of interest

There are no conflicts of interest.

REFERENCES

- Mohandoss AA. Quality of life in schizophrenic patients: Comparative study from South India. *J Dr. NTR Univ Health Sci* 2017;6:224.
- Denis F, Siu-Paredes F, Maitre Y, Amador G, Rude N. A qualitative study on experiences of persons with schizophrenia in oral-health-related quality of life. *Braz Oral Res* 2021;35:e050. doi: 10.1590/1807-3107bor-2021.vol35.0050.
- Alqahtani A, Kay ES, Hamidian S, Compton M, Diab M. A Quantitative and qualitative analysis of schizophrenia language. *arXiv preprint arXiv: 2201.10430*. 2022.
- Bondre AP, Shrivastava R, Raghuram H, Tugnawat D, Khan A, Gupta S, *et al*. A qualitative exploration of perceived needs and barriers of individuals with schizophrenia, caregivers and clinicians in using mental health applications in Madhya Pradesh, India. *SSM-Mental Health* 2022;2:100063.
- Ranjan LK, Gupta PR, Kiran M, Singh NK. Family care burden and its association with psychological distress among caregivers of chronic patients with schizophrenia. *J Public Health Prim Care* 2022;3:81-5.
- Yosep I, Mediani HS, Lindayani L, Sriati A. How patients with schizophrenia “as a Victim” cope with violence in Indonesia: A qualitative study. *Egypt J Neurol Psychiatry Neurosurg* 2021;57:1-6.
- Oud MJ, Meyboom-de Jong B. Somatic diseases in patients with schizophrenia in general practice: Their prevalence and health care. *BMC Fam Pract* 2009;10:1-9.
- Gater A, Rofail D, Tolley C, Marshall C, Abetz-Webb L, Zarit SH, *et al*. “Sometimes it’s difficult to have a normal life”: Results from a qualitative study exploring caregiver burden in schizophrenia. *Schizophr Res Treatment* 2014;2014:368215.
- Gater A, Rofail D, Marshall C, Tolley C, Abetz-Webb L, Zarit SH, *et al*. Assessing the impact of caring for a person with schizophrenia: Development of the schizophrenia caregiver questionnaire. *Patient* 2015;8:507-20.
- Cadge C, Connor C, Greenfield S. University students’ understanding and perceptions of schizophrenia in the UK: A qualitative study. *BMJ Open* 2019;9:e025813.
- Butcher I, Berry K, Haddock G. Understanding individuals’ subjective experiences of negative symptoms of schizophrenia: A qualitative study. *Br J Clin Psychol* 2020;59:319-34.
- Harandi TF, Taghinasab MM, Nayeri TD. The correlation of social support with mental health: A meta-analysis. *Electron Physician* 2017;9:5212-22.
- Gardner A, Folia K, Killackey E, Cotton S. The social inclusion of young people with serious mental illness: A narrative review of the literature and suggested future directions. *Aust N Z J Psychiatry* 2019;53:15-26.
- Seo MK, Lee MH. Effects of community-based programs on integration into the mental health and non-mental health communities. *Healthcare (Basel)* 2021;9:1181.
- Varga E, Endre S, Bugya T, Tényi T, Herold R. Community-based psychosocial treatment has an impact on social processing and functional outcome in schizophrenia. *Front Psychiatry* 2018;9:247.
- Crespo-Facorro B, Such P, Nylander AG, Madera J, Resemann HK, Worthington E, *et al*. The burden of disease in early schizophrenia—a systematic literature review. *Curr Med Res Opin* 2021;37:109-21.
- Desalegn D, Girma S, Abdeta T. Quality of life and its association with psychiatric symptoms and socio-demographic characteristics among people with schizophrenia: A hospital-based cross-sectional study. *Plos One* 2020;15:e0229514.
- Alshowkan A, Curtis J, White Y. Factors affecting the quality of life for people with schizophrenia in Saudi Arabia: A qualitative study. *J Psychiatry* 2015;18:295.
- Kanchanatawan B, Sirivichayakul S, Thika S, Ruxrungtham K, Carvalho AF, Geffard M, *et al*. Physio-somatic symptoms in schizophrenia: Association with depression, anxiety, neurocognitive deficits and the tryptophan catabolite pathway. *Metab Brain Dis* 2017;32:1003-16.
- Peristianto SV. Family Burden of schizophrenic individuals in East Asia: A Scoping Review Protocol; 2022. Available form: <https://osf.io/preprints/3584w/>. [Last accessed on 2023 Aug 19].
- Mouziraji ZE, Mahmoodi-Shan G, Yazdi K, Modanloo M. The paradox of family care for patients with schizophrenia: A qualitative study. *J Nurs Midwifery Sci* 2022;9:211-8.
- Kozlowski-Gibson M. Witnessing life with schizophrenia and anosognosia: A qualitative research study. *J Psychiatry Behav Health Forecast* 2018;1:1007.
- Durgoji S, Muliya KP, Jayarajan D, Chaturvedi SK. Quality of life in schizophrenia: What is important for persons with schizophrenia in India? *Indian J Psychol Med* 2019;41:420-7.
- Batalla-Martín D, Martorell-Poveda MA, Belzunegui-Eraso A, Miralles Garijo E, Del-Cuerpo Serratos A, Valdearcos Perez J, *et al*. The experience of insomnia in patients with schizophrenic disorder: A qualitative study. *Front Psychiatry* 2022;12:2595.
- Millier A, Schmidt U, Angermeyer MC, Chauhan D, Murthy V, Toumi M, *et al*. Humanistic burden in schizophrenia: A literature review. *J Psychiatr Res* 2014;54:85-93.
- Lee MH, Seo MK. Community integration of persons with mental disorders compared with the general population. *Int J Environ Res Public Health* 2020;17:1596.
- Hall T, Kakuma R, Palmer L, Minas H, Martins J, Kermode M. Social inclusion and exclusion of people with mental illness in Timor-Leste: A qualitative investigation with multiple stakeholders. *BMC Public Health* 2019;19:1-3.
- Naslund JA, Bondre A, Torous J, Aschbrenner KA. Social media and mental health: benefits, risks, and opportunities for research and practice. *J Technol Behav Sci* 2020;5:245-57.