

Perspectives about Illness, Attitudes, and Caregiving Experiences among Siblings of Persons with Schizophrenia: A Qualitative Analysis

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ABSTRACT

Background: Siblings of persons diagnosed with schizophrenia (SPS) are one among the major sources of support for persons with schizophrenia. There is a dearth of psychosocial literature on SPS in India. This qualitative study explored the perspectives about the illness, attitudes, and caregiving experiences of SPS. **Materials and Methods:** Qualitative audio-recorded interviews were conducted with 15 SPS, purposively selected from a tertiary mental health hospital of Southern India. A general inductive approach was adopted to analyze the qualitative data. **Results:** Four broad themes were identified from qualitative data analysis. (1) SPS described several explanatory models of mental illness in terms of causal attributions and treatment care. (2) They had expressed emotion toward their ill siblings, such as criticality, hostility, and emotional over-involvement. (3) They experienced objective and subjective burden while caring for their ill sibling. In spite of all these, (4) they were part of their ill siblings' care in terms of ensuring regular follow-ups and drug adherence and supported their livelihood. They coped up with adaptive as well as maladaptive strategies. **Conclusion:** SPS provide significant support to their affected siblings. However, they do have non-biomedical models of mental illness and negative attitudes toward patients and experience burden. Hence, psychosocial interventions may help SPS while caregiving for their affected siblings.


Key words: Experiences, explanatory models, expressed emotion, siblings, Schizophrenia

Key messages: Siblings of persons with Schizophrenia (SPS) play an important role in the treatment and recovery of their ill siblings. This qualitative study revealed that SPS has non-biomedical models of mental illness and negative attitudes toward their ill siblings, and they experience burden. Personalized interventions are required to address the issues.

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The functional impairment caused by schizophrenia^[1-3] affects the whole family of persons with schizophrenia.^[4,5] More often, the patients in India live with their family members as compared with the patients of western countries.^[6-8] Hence, family members in India are highly involved in caregiving activities.^[6-8] Also, the family caregivers are more engaged in treatment-related decision making of their patients.^[9] These factors expose family members to several challenges from the onset of the illness until the patient's recovery.

Previous studies from India and western countries have reported that caregivers sometimes have supernatural beliefs about mental illness; they attribute illness to social causes and seek non-formal treatment from faith healers.^[10-12] Such illness perspectives with stigmatizing attitudes about mental illness among caregivers may result in a prolonged duration of untreated illness,^[13-15] which could cause a burden for the family caregivers.^[14] Also, they experience emotional problems and are reported to have unmet needs, which have a major impact on their well-being.^[16,17]

The existing literature predominantly highlights the illness beliefs and experiences of parents^[12,18-20] and spouses of patients diagnosed with schizophrenia.^[12,19-21] There has been a growing interest in research with siblings of persons diagnosed with schizophrenia (SPS). Studies have found that they also experience psychosocial consequences of illness, such as poor mental health, poor relationships with their ill siblings, burden, maladaptive coping, and stigma.^[22-24] However, the available studies on SPS are from developed countries and have predominantly reported the outcomes of sisters of persons with schizophrenia. There is a paucity of studies from India and from the Asian subcontinent exploring the SPS' illness perspectives, attitudes, and caregiving experiences.

Persons diagnosed with schizophrenia need long-term family support in their recovery.^[25] However, India has a lack of government-supported aftercare homes for persons with mental illness. Worries may arise when the parents are aged and there are no other family members to look after the patients^[6] In view of this, understanding their issues will help us in designing and providing specific interventions to SPS. Hence, this study aimed to explore the SPS' perspectives about their affected sibling's illness and caregiving experiences.

MATERIALS AND METHODS

Ethical statement

The Human Ethics Committee of National Institute of Mental Health and Neurosciences (NIMHANS), Bengaluru, India, has approved the study related

protocol. Written informed consents were obtained from all the participants prior to the interviews.

Setting and participants

The participants for this study were selected from the Schizophrenia Clinic and outpatient and in-patient departments of Psychiatry, NIMHANS, Bengaluru. The SPS were included in this study if they were a biological sibling of a person diagnosed with schizophrenia (DSM-IV); aged between 18 and 60 years; able to speak English, Kannada, or Telugu; not having any mental illness as per M.I.N.I.-5.0 International Neuropsychiatric Interview,^[26] and found to be not suffering from any medical illness according to a qualified medical professional. In total, 37 subjects were screened for eligibility. Fifteen SPS (Male = 11; Female = 4) who met the inclusion criteria were included in this study. Out of the 15 SPS, 10 were elder siblings, and 5 were younger [Table 1].

Interviews and data collection

To explore the SPS' illness perspectives, attitudes, and caregiver experiences, a semistructured qualitative interview schedule was prepared. This included the sociodemographic profile of the SPS and their ill siblings and open-ended questions. This schedule was face- and content-validated by five mental health professionals who had experience in the field (one psychiatrist, three psychiatric social workers, and one anthropologist) and were not a part of this study. Some of the open-ended questions included were as follows:

- Being a brother/sister of a patient, can you describe your experience?*
- What is your understanding of your brother's/sister's illness?*
- How are you managing your sibling and taking care of yourself?*
- How are you involved in your brother's/sister's care?*

With each question, circular questions were asked, and adequate probes were introduced when participants were not expressive to provide rich data. Each audio-recorded interview lasted for 30–45 min.

Data analysis

The qualitative interviews were transcribed and translated into English text. A general inductive approach to qualitative data analysis was adopted.^[27] The transcripts were read several times to familiarize with the interview content. The qualitative data were managed and analyzed in QDA Miner Lite Version. 1.4.2 (<http://provalisresearch.com/products/qualitative-data-analysis-software/freeware/>). During the initial reading of the transcripts, the small text

Table 1: Sociodemographic Profile of Patients and SPS

Sociodemographic profile		Patients Mean±SD, n (%)	SPS Mean±SD, n (%)
Age in years		30.40±5.42	33±6.72
Gender	Female	3 (20)	4 (26.70)
	Male	12 (80)	11 (73.30)
Sibling status	Elder sibling	-	10 (66.60)
	Younger sibling	-	5 (33.30)
Education (years)		10.26±4.92	11±4.67
Socioeconomic status	Above poverty line family	8 (53.330)	9 (60)
	Below poverty line family	7 (46.66)	6 (40)
Occupational status	Working	3 (20)	14 (93.30)
	Unemployed	12 (80)	1 (6.60)
Marital status	Unmarried	13 (86.70)	6 (40)
	Married	1 (6.70)	9 (60)
	Separated	1 (6.70)	-
Residing together	Yes	-	9 (60)
	No	-	6 (40)
Family type	Joint	-	3 (20)
	Nuclear	-	12 (80)
Caregiver of the patient	No	-	5 (33.30)
	Yes	-	10 (66.70)

SPS=Siblings of persons with schizophrenia; SD=Standard deviation

segments featuring illness perspectives, attitudes, and caregiving experiences of SPS were carefully marked and highlighted, and codes were created. Initial coding was done for five interview transcripts, and the codes were further refined by removing redundant codes, renaming the existing codes, and adding new codes. The coding for the remaining transcripts was completed based on the framework developed from the initial five transcripts. At the analysis of the 14th interview transcript, the codes were saturated, but the coding was completed for all 15 participants. After the coding process, two peer research scholars independently verified the consistency of the codes with the transcripts. The disagreements between the peer research scholars on the codes were resolved with discussion, to reach a consensus. Later, the finalized codes were imported into Microsoft Excel spreadsheet for sorting and grouping. The codes with common features and meaning were grouped and assigned under the overarching themes.

RESULTS

The analysis resulted in the identification of four major themes, such as explanatory models of mental illness, expressed emotion, caregiving experience, and ways of caregiver involvement and coping.

1. Explanatory models of mental illness

Nine out of 15 SPS recalled and described that before consulting mental health professionals, they used to call their affected sibling's illness terms such as "hucchu," "loosu," "paithya" [words for madness in the Kannada language], "thikkalu," and "picchi" [words for madness in the Telugu language]. These terms are highly

widespread and commonly discussed among caregivers in southern parts of India.

"He was behaving very unusually... He was talking to himself and smiling in a way that was totally irrelevant... We thought he has *hucchu* [madness]" (Participant 15, younger brother, 22 years).

"He was fine during the final year of his bachelor's degree. After the exams, he started reporting that he can hear voices... He started suspecting that people around him are stopping him doing well in exams... We thought he is stressed out due to exams and it will resolve after some time... But it did not... Then we realized it was *picchi* [madness]" (Participant nine, elder brother, 42 years).

Causal attributions about the illness are often influenced by close relatives and community people. Some of the important causal factors reported by SPS were black magic, God's curse, and "gaali" [word for possession of evil spirit in the Telugu language]. One SPS narrated that

"He was regularly going to work and earning money. Later he used to tell that he is not interested in work... He was complaining a lot about his co-workers. He used to fight with us for no reason... Then we thought that this is because of *vamachara*" [word for "black magic" in the Kannada language] (Participant 14, younger brother, 31 years).

Before consulting the mental health center, SPS made choices with their families on seeking treatment for their ill sibling based on the existing cultural beliefs in the community. It was a ritual for many SPS to visit “Swamis” [religious priests], religious places such as temples, and “Mantravaadis” [black magicians] at some point of the illness trajectory.

“We did not know where to go initially... Some people told us to take him to temples and perform *poojas* [religious rituals] and some have advised seeking help from black magicians...We visited a few temples...prayed to the God...and even approached *Mantravaadis* [black magicians]... But we lost so much money performing the rituals they suggested” (Participant 12, younger brother, 25 years).

2. Expressed emotion

Expressed emotion (EE) denotes the quality of family interactions or attitude of the family members toward their mentally ill patients that includes the existence of criticality, hostility, and emotional over-involvement. EE is considered to be important indicator of relapse of symptoms of schizophrenia. During the interviews, SPS did exhibit EE toward the patients in the form of criticality and over-involvement.

Owing to a lack of knowledge and increased responsibilities caused predominantly by the negative symptoms or socio-occupational dysfunction, many of the SPS were highly critical toward their patients. Six of them expressed criticality. Some of the SPS reported that

“Yes, he has an illness... But that doesn’t mean that he cannot do anything. He always gives reasons for not doing an activity... It’s frustrating sometimes” (Participant four, an elder brother, 34 years).

“He has improved a lot compared to the earlier times. But still he escapes from work... Being lazy will not help in any way.... There are no days in which we haven’t argued on day-to-day issues” (Participant 13, elder brother, 45 years)

Five of the siblings were over-involved in the care, where they were overprotective toward their siblings. SPS were overcautious and anticipated mistakes. Hence, some of the SPS did not allow their ill siblings to perform their daily routines.

“We know he can manage household finances since he has done Masters in Commerce... But I don’t want to take the risk... Though it is an extra responsibility, I would like to take charge of

the finances myself.” (Participant seven, younger brother, 27 years)

3. Caregiving experience

Eleven of the SPS reported a negative impact of the illness in the form of burden. They experienced both objective as well as the subjective burden due to the severity of the illness and increased responsibilities.

The onset of the illness caused financial burden and increased responsibilities for the SPS, because the patients were having significant socio-occupational dysfunction and were unemployed as reported by the SPS.

“I’m the only earning member now... If he were not suffering from this illness, he would have joined some work... It would have helped to decrease our financial difficulties” (Participant seven, younger brother, 27 years).

“My responsibilities are increased now... He is not at all helping us in any-way. He even refuses to fetch water or shop for groceries” (Participant 12, younger brother, 25 years).

SPS reported that their relationship with the ill sibling has worsened due to the negative symptoms. They also reported that their marital relationship was affected because of their involvement in the caregiving. A few SPS reported that caregiving responsibilities such as follow-up visits and consultations significantly interfered with their daily work.

“He is not like earlier... He doesn’t care about my words... His attitude towards us has definitely worsened” (Participant 4, elder brother, 34 years).

“My husband will not understand the difficulties that my sister is having. Sometimes he stops me from meeting my sister... If I ask for any help with regard to my sister, he won’t talk to me for a few days” (Participant eight, elder sister, 36 years).

SPS reported the subjective burden in the form of grief and started avoiding people due to the embarrassment they faced at the initial stages of their siblings’ illness [self-stigma].

“I never thought that my sister would get mental illness... But when we came to know about it, it was upsetting... We were disturbed”.

(Participant eight, elder sister, 36 years).

“He was doubting the people around him, thinking that they are plotting against him... He used to throw

stones at people and pick up quarrels... Neighbours used to complain about him... It was embarrassing and uncomfortable talking to people about his condition... We were deliberately avoiding them [people]”.

(Participant four, elder brother, 34 years).

4. Ways of caregiving involvement and coping

Despite all these experiences, a majority of the SPS (12 out of 15) were helping their affected siblings in several ways. Most of them were involved in taking ill siblings for follow-up visits and consultations. In addition, they were the major source of support of their ill siblings' livelihood. Some of them reported that

“Though I'm busy with my work, I take my sister for follow-ups... Every time, I take the opportunity to talk to doctors about treatment-related issues of my sister” (Participant 11, elder brother, 28 years)

“Since my sister is separated from her husband and is currently not working, my older brother and I are taking care of her medical expenses as well as daily needs” (Participant six, younger brother, 29 years)

SPS were involved in other important caregiving activities such as supervising the medications and daily activities, guiding other caregivers in the family about managing the patient, motivating the patients to carry out their daily activities, and spending quality time with the patients. They said the following:

“I'm not staying with my sister, but my parents are there with her... I call once in two days, inquire about her condition, and ensure medication intake... Every weekend, I visit my village and spend some quality time with family... If any emergency comes up, I take leave and go there” (Participant 11, an elder brother, 28 years)

SPS reported about the ways of coping with their ill siblings. It included both adaptive and maladaptive coping strategies. They said that

“Keeping myself busy at work helps me to distract my mind from home until evening” (Participant six, younger brother, 29 years)

“I won't share my problems with anyone... I'm not comfortable sharing them.” (Participant 14, younger brother, 31 years)

DISCUSSION

This qualitative study explored the SPS' perspectives about the illness, attitudes, and experiences from the

onset of illness to the ongoing treatment. SPS had their own explanatory models about the patients' illness. During the interviews, most of the SPS expressed some negative attitudes toward their ill siblings. They experienced both objective and subjective caregiver burden. Despite all these psychosocial consequences, they were pro-actively engaged in the care of their ill sibling.

In lower-middle-income countries like India, there are several non-medical belief models about mental illness. At the initial stages of illness, SPS in this study had beliefs that mental illness is a result of previous deeds, black magic, or God's curse. Hence, they sought treatment from religious and faith healers. These findings are in tune with previous studies conducted in Southern India with caregivers of mental illness.^[28,29] Likewise, some studies have also found the high prevalence of non-medical beliefs among patients as well.^[30,31] Some studies had reported similar findings where the persons and their caregivers preferred to seek treatment through these pathways to care before consulting any mental health professionals^[30,31] These kinds of non-psychiatric care may delay the access to early psychiatric care and worsen the symptoms of the illness and the functioning of the patients.^[32,33]

There is a lack of studies exploring the expressed emotion in SPS. This study has found EE among several SPS. This could be because of the negative symptoms of the patients and the SPS' attributions or beliefs about the illness, which are associated with high EE.^[34] Specifically, the controllability attributions are linked with high EE.^[35,36] This suggests that if the family members attribute that the symptoms can be controlled by the patient, it will lead to high EE.^[35,36] Caregivers EE is one of the major indicators of relapse,^[37] and it needs to be addressed with the established interventions.

The results on caregiving experience among SPS are similar to those of previous studies, where SPS experience an objective burden in terms of financial burden; an impact on the relationships with the affected sibling; increased responsibilities and impact on school, work, and recreational activities.^[23,38] In addition, studies had reported similar results with regard to subjective caregiving burdens, such as grief, stigma, anxiety, and distress.^[23,24] Burden among SPS is associated with factors such as the severity of the symptoms or the illness, disturbances on household routine, and medication non-adherence.^[39,40] Further, SPS who attribute that the illness is controllable, feel more burdened than those who feel that their affected siblings cannot control the illness.^[39]

Like other caregivers of schizophrenia patients, SPS do involve in and perform many caregiving activities

regardless of the negative effects of the illness. There are differences with regard to the caregiving activities provided by SPS in this study and the western studies. Some of the previous studies from western countries have shown that SPS predominantly provide emotional support to the affected siblings,^[23,41] that is, in contrast with our study findings, where SPS were found to be actively involved in patient care. They were providing treatment-related support in terms of accompanying the patients to follow-up consultations and support the patient's livelihood. Additionally, they were providing instrumental support, such as supervising medications and patients' daily activities. This is important in long-term care because the SPS outlive the parents. Also, they can share and reduce the burden experienced by other caregivers in the family.

SPS reported their coping strategies. They used both adaptive and maladaptive strategies such as distraction from the affected siblings by involving in or carrying out their regular work and internalizing their feelings. Similar results were found in previous studies.^[24,42] Additionally, previous studies have reported other coping strategies such as getting understanding about the illness by seeking information from professionals, active participation in caregiving, normalizing the situation, maintaining distance, avoidance, grieving, and isolation.^[24,43]

This is the first qualitative study exploring the SPS' perspectives of the illness and caregiving experiences in India. SPS are known to be a high-risk group for mental illness.^[44] Hence, understanding their perspectives about the illness and the caregiver experiences, such as psychological distress, grief, burden, self-stigma, coping, feelings of guilt, fear of the future of their patients, etc., will help in designing specific interventions for SPS. This, in turn, would encourage SPS to be more active in the treatment process and provide long-term social support to their affected sibling.

The findings of the study should be interpreted cautiously, because it has several limitations such as small sample size and the participants being predominantly brothers and from urban backgrounds. Further, similar studies could be conducted with a large sample size with adequate representation of brothers and sisters. It would be interesting to see the comparison of the results with other caregivers of patients with schizophrenia from different social strata.

In conclusion, SPS do have some non-biomedical perspectives of mental illness. Such perspectives may restrict SPS engagement in the treatment process at least during the early course of the illness. Nevertheless, they provide instrumental support to their affected siblings.

They do express some negative attitudes toward the patients and experience both objective and subjective burden. Hence, they may need special attention from the clinicians in terms of understanding their issues and providing need-based psychosocial interventions.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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Conflicts of interest

There are no conflicts of interest.

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