

Caregiving and Help Seeking in First Episode Psychosis: A Qualitative Study

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Abstract The early stages of psychosis pose a frightening and challenging period for their caregivers. In India, the majority of patients with psychosis live with their families, who play an important role in patients' care and treatment. However, their experience in caring persons with psychosis or help-seeking behaviors in the early stages of psychosis is largely unknown. Using a qualitative method, the present study explored the experiences in caring and help-seeking in carers of patients with first episode psychosis. In-depth audiotaped interviews were conducted with 11 carers of patients with first episode nonaffective psychosis. Purposive sampling was used for data collection and content analysis was applied to the data. The major themes explored were sequence of help seeking and faith-healing practices, explanatory model of illness, illness management strategies, financial burden, perceived stress and stigma. Carers experienced shock, disbelief and anxiety about the unexpected behavioural changes in patients during the initial phase. The common pathway to 'help seeking' was faith-healing. It resulted in substantial delays in accessing psychiatric care and drain on family finances. Carers perceived themselves as vulnerable and helpless when patients became violent or demanding, refused to take medicines, experienced sleep disturbance, and remained idle and suspicious. Further, carers were hesitant to seek help due to their stigma attached to

mental illness. Carers' poor understanding and high stigma caused substantial delays in seeking psychiatric treatment. Caregivers experienced high levels of distress and difficulties. Understanding carers' experience and help-seeking behavior may be important for planning and delivery of early intervention services for patients and carers.

Keywords Caregivers · Qualitative study · First episode psychosis

Background

Duration of untreated psychosis is related to poor outcome [1–5]. Most clinical and psychosocial deterioration in psychosis occurs within the first few years of the onset of the illness [6, 7], and hence there is a growing trend for identification and treating psychosis at the early stage [8, 9]. The early stages of psychosis are frightening and challenging experiences for the carers of these patients [10]. Unusual behaviors in a son, daughter or sibling generate emotions such as fear, apprehension, sadness and sometimes guilt and anger in carers [10].

In India, the majority of patients with mental illness live with their families [11], they are the main source of support, [12] and they regularly participate in decision-making regarding health care and treatment compliance [13]. As families are actively involved in care giving for patients, they are very much affected by the illness [14]. More than 75 % of the carers of persons with first episode psychosis (FEP) were at high risk of developing psychiatric illnesses. Further, these carers also showed dysfunction in social role and impairment, especially marked in social and leisure activities [15]. Studying carers' experience and help-seeking behaviours is important in many ways. First, it

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would directly help us to understand the delays in initiating appropriate psychiatric treatment for patients by the carers. Such understanding may be helpful for taking appropriate actions to reduce the duration of untreated psychosis. Second, it would also be helpful in understanding the difficulties of the carers and thereby to offer professional help to alleviate distress.

To the best of our knowledge, in India no studies have explored the carers' experiences for caring a person with FEP. Furthermore, very few studies examined the pathway of mental health care in India [16, 17]. Given this knowledge gap, the current study has been conducted with the aim to explore and document the carers' experiences and help seeking behaviour in carers of patients with FEP.

Methods

We have used a qualitative method based on the rationale that such approaches are more relevant when the variables are not easily identified and the problem needs to be explored in detail [18]. In-depth information may be difficult to collect and convey quantitatively [18]. Carers' unique experiences and treatment pathways of FEP have not been explored, especially in the Indian setting. Hence, we have considered a qualitative approach. This is a part of a larger study which has been reviewed and approved by NIMHANS ethics committee. Informed consent was obtained from each study participants in writing.

Sample

We have recruited 11 carers of patients with FEP for this qualitative study. The study was conducted between 15th May to 30th September 2013, and the carers were recruited from the in-patient and out-patient psychiatric units of National Institute of Mental Health and Neuro-Sciences. (NIMHANS), which is a tertiary mental health care centre located in Bangalore, India. NIMHANS has a 900-bed teaching hospital with training and research facilities in psychiatry and neurosciences. Out of the 11 participants, 7 were recruited from the outpatient and 4 were from inpatient units.

Person with FEP were defined as those diagnosed by a psychiatrist in NIMHANS with any non-affective psychosis of duration less than 5 years. The caregiver was defined a person who is a family member or relative and was actively involved in patient care and living with the patient in the same home. The carers were included in the study if they were at least 18 years or more and could speak Kannada/Tamil/Malayalam or English language. All subjects were free of any major mental or medical illness.

To ensure richness of data collection, purposive sampling techniques was used. This has advantages of obtaining

maximum variation in the selected samples and also would help in documenting heterogeneous and multiple perspectives [19]. Our samples were not strictly representative, but we have selected the samples with the goal of capturing diversity of experiences in care giving and also to understand their unique needs in the specific context.

Data Collection

In-depth interviews were used and each interview was about one and half hour duration which was audio taped. We also used specifically prepared socio-demographic data sheet to collect the personal information of patients and carers.

[Participants were asked open ended questions such as: What did you think when you first observed your family member behaving differently? What kind of support you think is needed for you? What do you find difficult to deal with when you take care of him/her? How did you manage to get treatment for your relative? Who helped you?; How do you feel when you give care to your ill family member? How does care giving affect your everyday life? and so on.]

Carers responses to these questions served as useful probes for eliciting further information on desired outcomes.

Qualitative Data Analysis

We employed directed content analysis technique because it is guided by a more structured process [20]. This type of content analysis using prior research to identified key concepts or variables as initial coding categories [21]. We have adopted this method for two reasons. First, our in-depth interview questions were guided by earlier studies among caregivers although such studies were not done with caregivers of FEP. Second, the text was coded using the predetermined categories wherever possible. Interviews were audio taped and transcribed in English. The researcher verified the transcribed interviews by listening to the audiotape while reviewing the transcript word by word. During this process, all personal identifiers were removed and a code number was assigned to protect confidentiality. The resultant 'clean' transcripts were used in analysis. Initial open coding was conducted on interviews as they are completed and transcribed to categorize key concepts and patterns to the experiences. Each piece of the data is compared and contrasted with other data to build a conceptual understanding of the categories within the phenomenon of interest.

Results

The average age of the patients was 22.3 years (SD \pm 3.6) with a range of 18 to 30 years. Average duration of

psychosis was 33.2 months (SD \pm 12.9) with a range of 6 to 48 months. Average duration of untreated psychosis was 8.33 months (SD \pm 5.4) with range of 1 to 18 months.

The carers had an average age of 48.1 (SD \pm 6.6) with a range of 38 to 60 years. Carers had an average monthly income of 4285.7 Rupees (SD \pm 2998.00) with range of 1,500 to 10,000 Rupees. Refer table 1 for other sociodemographic results of the study participants.

The following themes emerged during the qualitative data analysis.

Sequence of Help Seeking & Faith-Healing Practices

Examining the common pathways to help seeking, the present study suggests that many carers took their ill relatives to faith-healing practitioners. Such faith-healers often performed special rituals, which sometime would proceed to abusive forms of treatment, in some cases inflicting physical harm to patients. Carers were found to turn to mental health services when these procedures did not reduce the symptoms. This caused substantial delays in seeking psychiatric treatment. Such faith-based practices, especially in rural areas, involved significant expenses; therefore by the time they sought treatment at mental health centers, they were often financially drained. The present study reveals that seeking help at mental healthcare center occurs last in the sequence of help seeking process, by which time the family is heavily burdened, drained and compromised financially.

A caregiver mother said:

I took her [patient] into temple and offered prayer when I saw she is very much fearful and not talking to me or other people around. I consulted religious faith-healers and they said that there is an evil spirit in her body that will go away with their 'special poojas'. I have performed all the poojas they have suggested, but nothing worked... for almost one year I have waited.....finally my brother in law advised me to take her to a psychiatrist

A 49 year-old caregiver father said:

I took him [patient] to several faith-healers and performed poojas for almost one year. But his problems got increased and he was not sleeping in the nights. Finally, the faith-healers advised me to consult a doctor for his sleep problem

Another caregiver mother said:

I didn't know what illness it was... I used to go to temple and pray to God to get him [patient] better. I have tried out and visited all temples near my home but he did not get better at all.... Finally, my neighbor

Table 1 Socio-demographic details of the study participants

| Variables | Patients (n = 11) | Caregivers (n = 11) |
|------------------------|----------------------|------------------------|
| Gender | | |
| Male | 8 | 4 |
| Female | 3 | 7 |
| Marital status | | |
| Married | 1 | 8 |
| Unmarried | 10 | – |
| Widowed | – | 2 |
| Separated | – | 1 |
| Education | | |
| Illiterate | 2 | 4 |
| Primary | 1 | 2 |
| High school | 4 | 4 |
| 10th and above | 4 | 1 |
| Occupation | | |
| Regularly working | 2 | 3 |
| Irregular in work | 4 | 2 |
| Not working/unemployed | 5 | 2 |
| Home maker | – | 4 |
| Diagnosis | | |
| Schizophrenia | 8 | – |
| Acute psychosis | 1 | |
| Psychosis NOS | 2 | |

told me about the psychiatric treatment available for this illness. One of her [neighbor's] relative with similar illness had got better with psychiatric treatment from NIMHANS

Families preferred psychiatric care services when patients continued to display problem behaviours even after repeated efforts of faith-healing treatment. It happened usually through opinions and referrals of relatives, neighbours, and in rare cases, by faith-healers themselves. In urban areas, especially among educated middle class families, patients were directly brought to psychiatry hospitals for care.

Explanatory Model of Illness

The findings suggest that carers' perception of illness causation is associated with strong religious belief systems, rituals and practices. In many cases, they believed that God caused this problem for their ill relatives. They preferred religious ways of curing in the form of prayers, worships and poojas. They often sought help from religious leaders and faith-healers for their ill relatives. These faith-healers explained the illness causation in terms of super natural powers or evil spirits. Initially, carers were satisfied

because such explanations underlined their own perception and explanatory model of illness causation. This was more common among carers who are illiterate and from rural areas.

A caregiver mother said:

God gave him [patient] the problem and I hope he would get better with the grace of God. I have offered all the prayers and poojas to get him better

In many of these cases, duration of untreated psychosis was longer because of their lack of awareness about the possible psychiatric treatment for mental illness, myths and misconception which caused substantial delays in seeking help from mental health professionals. However, in some cases, carers who were educated and coming from urban background had comparatively better understanding and explanatory models for their relative's illness.

A caregiver father said:

He [patient] had this problem because his maternal aunt also had similar problems. We have understood about this illness more from the internet. We knew that he is suffering from mental illness which require medicines

Illness Management Strategies

Carers felt vulnerable and helpless when patients became violent; when they showed demanding behaviours, when they refused to take medicines, experienced sleep disturbance, and also when they remained idle and suspicious.

A caregiver mother said:

When he [patient] hurts me, I also hit him back...sometimes I just ignore but nothing has worked so far...

A caregiver father said:

He [patient] is demanding money, mobile phone, watch... last month he hit his mother when she forced him to take medicines

Another caregiver mother said:

She [patient] is not sleeping at night and used to go to toilet frequently...I am also afraid to sleep...what will happen if she leaves the home.

Financial Burden

Carers experienced substantial amount of difficulties in financial aspects of treatment. In many instances, family financial resources are already exhausted due to the amount spent for faith-healing practices. Further, carers were in

their later middle age or early old age, widowed, and with no regular income while some of them were on meagre income like widow's pension, which were likely to contribute to the financial difficulties.

A widowed caregiver mother said:

I find it very hard to spend money for medicines and bus fares for follow-up. Though some medicines are available free of cost, most are not free, for which I have to spend a lot of money. I do not have any regular income other than widow's pension

Another caregiver mother said:

I am not able to go for work and she [patient] would become fearful if I leave...even I am not confident enough to leave her alone...my husband is the only earning member. We have spent lots of money for faith-healing. We have around one lakh rupees (one hundred thousand) loan which needs to be repaid soon. We have spent everything for the treatment and now I don't know what to do

In many cases, carers could not afford the medication and treatment-related expenditures. Many patients were irregular on medication or infrequent for follow-up mainly due to financial difficulties. Further, carers experienced substantial reduction of their family income due to their caregiving roles.

Perceived Stress and Stigma

The present study revealed that carers experienced substantial stress. Some of the distress-provoking situations were perceptions of stigma, concerns and worries about patients' future, and the impact of the illness on the health and wellbeing of carers. Carers had difficulty in help-seeking due to the perceived stigma attached with mental illness.

A widowed mother said about her 18 year old daughter:

I fear people may come to know her illness if I ask help from outside...after all, she [patient] is unmarried [therefore] I am worried about her [marriage] alliance" I took help only from my brother-in-law.

Here, the concerns are centered on possible implication of revealing mental health status of the patient and its impact on patient's future.

In some cases, carers fear about patients' behaviours that reveal mental illness.

I do not go anywhere because she [patient] becomes fearful if I leave the house. I am not confident enough to take her out. She neither talks nor interacts with

others. People will easily understand that she [patient] has mental illness.

It resulted in two difficult situations for carers; first, due to internalized stigma about mental illness, carers feared to take the patients outside the home, thereby restricting patients' physical mobility. On the other hand, carers themselves were not able to go outside the home since they could not leave the patients unattended. It also resulted in irregularity in their work, and thereby affected the family income. Thus, these concerns have reduced the carers physical mobility outside their homes, their social interactions, and also had a negative impact on their family income.

Furthermore, most patients with FEP are in their early adulthood, hence the parents were found to be more concerned and worried about the future of their children. Evidently, the parents of female patients were severely worried about the future of the children, especially after their death. They do not see a bright future for their children since their marriageability is viewed as severely compromised. Patients' illness-related behaviours substantially increased distress in carers. It also resulted in immense psychological and emotional distress in carers.

A caregiver father said:

I have lost sound sleep for the last two years. He [patient] used to go toilet very frequently. I used to wake up each time when he [patient] opened the door to go to the toilet.

It has been suggested that many carers experienced sleep disturbances which was related to the sleep disturbances in patients. In some cases, carers depend on alcohol for their sleep problems. A caregiver father said:

I started drinking alcohol two years back when I was not able to sleep at night... even with alcohol I do not get good sleep. If do not take alcohol, I will go mad.

In some cases, carers feel exhausted and burnt out due to increased caregiving tasks. Such carers also expressed feeling of helplessness and death wishes.

A caregiver mother said:

I have done enough for him and now I cannot do anything more...I feel it was better if I could die, I wish to die [and] I do not feel like living

Discussion

We have conducted this qualitative study to explore the carers experience in caregiving patients with FEP. The study identified major themes such as sequence of help

seeking and faith-healing practices, explanatory model of illness, illness management strategies, and financial burden and perceived stress and stigma.

In line with the earlier studies we have identified that in the sequence of help seeking, many carers of FEP first approached faith healers or religious leaders for patients' treatment [16, 17, 22, 23], and such practices were high among with those carers who were illiterate/less educated and coming from a rural background [22]. We have identified that many carers attributed the causation of illness in terms of religious reasons and superstitious beliefs, which also are in line with earlier studies [22–24]. It has been observed that faith-healing practices caused substantial delays in seeking psychiatric treatment. Many of our patients had long duration of untreated psychosis, which predicts poor outcome [1]. India has a strong religious and cultural belief system which strongly influences health-seeking behaviours and treatment choice of carers [17, 23]. Further, relative shortage of treatment centers and mental health professionals, insufficient psychiatric services in rural areas, poor understanding about mental health and its treatment, myths and misconception, stigma attached with mental illness are other factors which might have led to not seeking any psychiatric treatment [25] and to choose faith-healers for their ill relatives' treatment.

Further, our finding shows that carers experienced substantial difficulties in managing the uncooperative and aggressive behavior of patients. Such difficulties were particularly high among female carers of male patients. Carers adopted different strategies to deal with patients' aggressive behaviours, such as tolerating violence, responding back violently and so on. Carers also compromised their sleep to deal with the behaviours. However, such strategies have not helped them to reduce the problem behaviors in patients. Carers experienced high levels of distress and difficulty. Our finding support a qualitative study conducted in India which identified 'managing illness behavior' was one of the high priority need among carers of schizophrenia [14] and, higher caregiver burden was related to psychopathology [26].

Financial burden was high among carers. They could not go for work due to caregiving, and spent lot of money for faith-healing. In some cases patients were the breadwinners, who stopped working due to the illness. Our finding supports an earlier study which reported that schizophrenia leads to high direct and indirect cost on carers [27]. It should be also noted that many of the carers were either daily wage earners or housewives. Furthermore, in agreement with earlier findings [28–30], carers in this study perceived (internalized) stigma, which not only caused high levels of distress but also restricted their social interaction outside home, and thereby led to poor social

support. It must have also lead to not seeking any psychiatric treatment at the early stages of illness.

Limitations

We have used a qualitative content analysis technique to understand the core themes/categories. But we did not go beyond the content analysis to establish the relationships between the categories. For example, ‘carers’ faith-healing practices’ are mainly due to the result of their ‘explanatory model of illness’. To make it clear, the carers who strongly held the belief that God gave this illness to their son/daughter or those who believed that their son/daughter have evil spirits in their body were often sought faith-healing or religious treatment for mental illness. However, we did not attempt to establish any cause and effect relationship between categories but rather we put them under individual heading to highlight the specific issues. Also, the carers included in this study may not be representative of the overall population of carers of patients with FEP.

Conclusions

Carers experienced high distress, financial difficulties, internalized stigma and adopted poor illness-management strategies. Many caregivers had poor understanding about psychosis and because of which they sought faith-healing/religious treatment which had caused delays in seeking appropriate psychiatric treatment.

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