

## Breaking the Barriers: A Qualitative Study of Caregivers' Experience of First Episode Psychosis in a Town in South India

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### ABSTRACT

The onset of psychosis creates profound psychological changes, almost always disturbing, sometimes frightening to the patient as well as to the family members. Relatives play a crucial role in pathways to care of patients with psychosis. In India, with a large population, disproportionate health care system, rampant superstition and high level of stigma towards mental illness, the qualitative paradigms in the research of the experiences of caregivers of persons with first episode of psychosis is extremely important and needs systematic evaluation. **Aims:** We aimed to evaluate the understanding and attribution of symptoms and help seeking processes in care givers of first episode of Psychosis in a town in South India through a qualitative approach. **Materials and Methods:** Qualitative interviews were conducted with sixty one caregivers of people with first episode Psychosis in relation to understanding and attribution of symptoms and help-seeking processes. **Statistics:** Thematic analysis of interview transcripts was conducted. **Results:** Sixty one caregivers were interviewed for the study after excluding eleven caregivers for different reasons. Multiple reasons for delayed help-seeking were found. Myths and misconceptions were a rule rather than exception. Apart from being unaware of symptoms and treatment methods, caregivers described practical difficulties like transportation issues, financial constraints, and difficulty in convincing patient to take treatment. Contact with a psychiatric patient who had got well with treatment and media were effective in early help seeking. **Conclusion:** There is a dire need for more and more community awareness programs to ward off stigma related to mental illness. Targeted interventions addressing the real reasons for stigma is the need of the hour. Utilizing recovered patients in these programs might be beneficial.

**Keywords:** *First Episode Psychosis, Stigma, Help Seeking, Qualitative Study, Caregivers' Experience*

**Key message:** *Stigma prevents timely intervention in first episode psychosis. Misconceptions and myths related to symptoms and treatment of psychosis results in delayed help-seeking. Targeted interventions addressing the real reasons for stigma is the need of the hour. Utilizing recovered patients in these programs might be beneficial.*

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The onset of psychosis creates profound psychological changes, almost always disturbing, sometimes frightening to the patient as well as to the family members (Onwumere et al, 2018). Relatives play a crucial role in pathways to care of patients with psychosis (Valeria Del Vecchio et al, 2005). Many studies from all over the world have tried to look at the explanatory models of Psychosis as understood by caregivers as this can have direct influence on the pathway of care & nature of help seeking. Pathway of care can be defined as the pathway the patient adopts to reach the appropriate treatment center (Sadock et al, 2015). These pathways in case of mental illness are diverse and dependent on multiple factors which include social/cultural/ economic factors, the referral system, the availability/accessibility of mental health services, and the relationship between mental health services and the rest of the disciplines (Lahariya et al, 2010).

Research in India has found that non-health professionals like unqualified medical practitioners and faith healers are commonly involved in pathways to care for people with a first episode of psychosis (Jain et al, 2012) and the pathways involving non-medical professionals are associated with longer DUP (Bechard-Evans et al, 2007). A study from Vellore in India focused more on the knowledge of bio-medical and indigenous beliefs held by people who often seek help from both modern and traditional health systems (Saravanan et al, 2008). It also indicated the need for better understanding of local perceptions of psychosis (Saravanan et al, 2008). A nationwide multicentric study from India concluded that caregivers of patients with schizophrenia experience higher stigma than the caregivers of patients with bipolar disorder and recurrent depressive disorder and this higher stigma is associated with higher psychological morbidity in the caregivers (Grover et al, 2017). In India, with a large population, disproportionate health care system, rampant superstition and high level of stigma towards mental illness, the qualitative paradigms in the research of the experiences of caregivers of persons with first episode of psychosis is extremely important and needs systematic evaluation. Hence we decided to look at caregivers' experiences of onset of psychosis, help seeking process and their belief / knowledge about mental illness through a qualitative approach.

### ***Aims:***

The aim of the study was to evaluate caregivers' understanding and attribution of symptoms at the onset of illness and the help seeking processes, with a qualitative approach in patients with first episode psychosis.

## **METHOD**

The research took place from May 2016 to March 2017 in a Psychiatric hospital located at a district headquarters in South India. Our sample consisted of all newly registered patients fulfilling the inclusion criteria. Participants were recruited through clinical services. Inclusion criteria were subjects of both genders, above the age of 18 years, fulfilling ICD -10 diagnostic criteria for any type of psychotic disorder, consultation with the psychiatrist for the first time, not on any psychotropic drugs with the exception of use of short duration benzodiazepines, giving written informed consent, and willing to spend required time for the interview. Participants were required to understand and speak the local language, i.e., Kannada. The study design was approved by the institutional ethics committee. The interviews were conducted without a time bound framework and on an average, an interview lasted for 2 hours. The interviews were conducted by authors 1 and 2 both having a postgraduate degree in Psychiatry and working in this area since 5 and 12 years respectively.

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The participants narrated their experiences in response to a priming statement, which was fairly open-ended and covered most aspects of disclosure.

Topic guide for semi-structured interviews covered was obtained from an earlier study (Sanna & Nicola, 2011) with permission and with suitable modifications for the cultural setting. The investigators incorporated the modifications keeping in mind their observations in the clinical practice in the current setting. The areas covered included onset of difficulties; respondent's understanding of and responses to symptoms; help-seeking attempts; Additional probes were used to elicit more information as appropriate. All interviews were tape recorded.

### *Statistical Analysis:*

A thematic analytic approach within an interpretative-phenomenological framework was used. Content analysis was used here as a research technique for the objective, systematic and quantitative description of the manifest content of communication. In other words, it breaks usual communication in to more elementary semantic and syntactic structures and calculates frequencies of occurrence. The sample for this analysis may be an audio taped communication which is transcribed and later broken in to clauses for analysis or written narratives. The unit of analysis is often a clause, sentence or paragraph but there are no clear cut guidelines to determine the choice of unit. The categories used for analysis may be predetermined based on the theoretical concern or the data may be allowed to generate their own categories by statistical measures. In the present study the paragraph was the unit of analysis which was further broken up into themes.

We used both deductive and inductive approaches, seeking answers to our initial research questions while also exploring themes that emerged directly from the data. The software used for the analysis was atlas ti version 7.0.83. The responses of the patients for each of the questions were coded using the "codes" option. Families (groups) were created using socio-demographic variables such as gender, marital status, occupation, family size etc. Cross tabulation was done with the codes against each of the variables.

## RESULTS

Seventy two caregivers met the inclusion criteria. However 4 of them failed to give informed consent and 7 of them did not have reliable information. Hence sixty one caregivers were interviewed for the study of which 34 were males and 27 were females. Family history of mental illness was present in 16(24%) of the subjects. The caregivers' socio demographic profile is given in table 1. Duration of untreated psychosis ranged from shortest period of 5 days to longest duration of 8 years (DUP Median- 18months).

*Table no 1 Caregiver Characteristics*

Sociodemographic Parameters	Subgroups	Frequency (Percentage)
Gender	Male	34 (55.75%)
	Female	27 (44.3%)
Age (Years)	16-25	2 (3.3%)
	26-35	11 (18%)
	36-45	21 (34.4%)
	46-55	18 (29.5%)
	56-65	7 (11.5%)
	>66	2 (3.3%)

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<b>Sociodemographic Parameters</b>	<b>Subgroups</b>	<b>Frequency (Percentage)</b>
Education	Upto 5 <sup>th</sup> Std	19 (31.1%)
	6 <sup>th</sup> to 8 <sup>th</sup> Std	20 (32.8%)
	Upto 10 <sup>th</sup> Std	15 (24.6%)
	College and above	7 (11.5%)
Socio economic class	Below Poverty Line	21 (34.43%)
	Above Poverty Line	40 (65.6%)
Residential Status	Rural	39 (63.9 %)
	Urban	22 (36.1%)

The diagnoses of psychotic disorders included: Acute Psychosis (n=13), Schizophrenia (n=17) Psychosis NOS (n=28), Persistent delusional disorder (n=3). The duration of untreated psychosis (DUP) in our study varied from 5 days to 8 years with median duration of psychosis being 18 months. When the median DUP was calculated separately for different socioeconomic groups, there was no significance noted in respect to education, socioeconomic status and residential status of the caregivers. (p>0.05)

Results are organized thematically, describing caregivers' responses to the priming statements related to understanding of symptoms, help seeking processes and caregivers' beliefs related to mental illness and its treatment. (Figure 1) Most of the responses are narration of one caregiver describing the feelings of whole family. Few quotations illustrating major themes are presented in the text.

**Understanding of symptoms and experiences**

Priming statements related to understanding symptoms and experiences included how the caregivers understood and attributed symptoms related to mental illness. It also included their responses to these symptoms.

The majority of caregivers described feelings of being puzzled (n=50), feelings of not knowing what to do (n=25) at the onset of illness. All of them except 2 failed to recognize that these changes in patient were because of any illness let alone mental illness. They said that they never knew about the existence of such an illness or something for which help from health services might be available. Only 2 caregivers recognized it being due to mental illness since they had been in contact with patients who got well after being treated at mental health services. It was noted that 24 of the respondents who were ignorant about these symptoms being due to mental illness had education more than tenth standard. Two of the respondents who recognized the problem as due to mental illness had only primary education but were aware of mental illness because of their past experiences of seeing someone with mental illness.

The attribution of symptoms varied from it being a part of normal reaction to certain happenings (like property dispute, love failures), part of stubbornness in the personality, patient acting deliberately, an external force like evil spirit, God's curse, past sins and black magic. Two of them attributed the symptoms to physical causes (past history of childhood head trauma, recent febrile illness). Some of them (n=10) asked the patient to avoid the stress and to relax and neglect the symptoms in response. The others (n=42) described thinking that symptoms were due to evil spirit and sought immediate religious help. Some patients (n=3)

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were made to stay in the temple for control of problems. They thought these behavioral changes were transient and would resolve without the need for further intervention. These accounts seemed to be linked to longer duration of untreated psychosis.

*"We did not understand what was happening .We were afraid. We thought that this might be due to black magic. We tried to calm her down. We asked her to relax. This did not help. Then we went to astrologer. He asked us to do a 'shantipuja' We thought our relative with whom we had property dispute must have done black magic on her. We were worried."-----Mother of a 24 year old female patient with acute psychosis*

*"We thought it is because of an upsetting message from a girl in mobile phone .We did not understand anything about him having a disease. When he said that somebody is trying to kill him we thought it's really true. His words seemed so real. There was no reason to think it was all his imaginations, something in his head! This broke the marriage which was supposed to happen, hence we were upset. We went to a temple and asked the astrologer. The astrologer gave the coconut and said that he will be alright and within a year that girl's parents will come and give the girl in marriage. He asked our son to go round the sacred tree three times early in the morning. It was all a mess"----- Father of a 26 year old male patient with Persistent Delusional disorder.*

Thus caregivers reported important difficulties in recognizing problems as signs of psychosis. Fluctuation of symptoms during a day or over days caused much confusion regarding deciding whether this was a health problem. For some (n = 12), this was associated with retrospective feelings of frustration or guilt for not having recognized symptoms earlier and thus potentially prolonging the suffering of their family members. These delays were attributed to the vagueness of early symptoms and to lack of awareness of psychosis at individual and community levels. Most of the caregivers (n = 41) described the whole family with the patient withdrawing from their social networks as a response to patient's symptoms.

### Help-seeking processes

Caregivers, described being unaware of problems and the treatment methods available for mental illness. They also described practical difficulties like transportation issues (n=12), financial constraints (n=21), and difficulty in convincing patient to take treatment (n=13). None of them were aware of any legal facilities in the event of patient not agreeing for treatment. Though, many caregivers temporarily acknowledged a need for help, at the same time, they also had denial of problems. The caregivers (n=2) who recognized symptoms as due to mental illness and sought help early either had a mentally ill person in their family members or in the near social vicinity. It was noted that these persons with mental illness in the family or vicinity had good response to treatment and were functioning well.

Physical violence was an important reason to seek help in 17 subjects. Some of them (n=48) who recognized symptoms as due to mental illness though after trying out different ways did not seek help because they thought that treatment was unavailable. They hence preferred religious help. They reported residing in temples for a period ranging from 3 days to 3 months. It was seen that in 20 patients the head of the religious centre (Church Father, Purohith or the God Man-having a possession Trans, Moulvi) after initial rituals suggested the caregiver to take the patient to a psychiatric centre. In all 20 subjects the respondents reported they would not have sought psychiatric help but for 'God's approval'.

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Help seeking for most people (n= 45) was prolonged. The caregivers who acknowledged a need for help, but did not view their difficulties as mental health problems, instigated more general help-seeking. Caregivers noticed uncharacteristic and bizarre behaviors which alerted them to consider taking action, although a majority (n =48) reported that help-seeking was not initiated until a crisis point (patient being highly violent, disinhibited behavior in girls) was reached. Carergivers reported alternative explanations for psychotic symptoms including substance misuse, stress, physical illness, depression, sleep deprivation and religious experiences.

*"We were unaware completely. Hence we went to an astrologer. Pooja didn't work, rather it increased the symptoms because he turned violent after being beaten up by the poojari. We went to a local doctor. He prescribed sleeping pills and told him to relax, not to take tension. When that didn't work, one of the old patients of a psychiatric hospital asked us to consult psychiatrist."-----Mother of a 28 year old male patient with Acute Psychosis.*

*"I was aware of the problem but we required money for the treatment. Taking treatment in nearby places was not an option for this illness. We had to travel quite far. We required at least 3 days, three people to accompany him. It was harvest time that meant lot of work. We could not leave our responsibilities and get him for treatment. What if they suggest staying in the hospital? It meant more money, more days. Though we had realized that this problem was because of mental illness but getting him for the treatment was the biggest problem."----- Wife of a 38 year old male patient with Psychosis nos.*

*"We asked the astrologer. He said patient has some fear in his mind and to remove it he got a talisman and got tied it to him; he spoke to the patient. We did not have any information. Then we read about schizophrenia in a Kannada newspaper, and then we came to know that he must be having the same."-----Father of a 27 year old male patient with Paranoid Schizophrenia.*

### **Beliefs and knowledge about mental health services**

Major theme which emerged in most of the responses were related to stigma (n = 53). The fear of negative reactions to mental illness from relatives and friends (n =49); fears about being labeled 'mad' (n=4), fears about treatment (n=29) which included lifelong treatment, getting addicted to medications, 'shock treatment', getting sleeping pills, becoming dull secondary to treatment. In young unmarried patients, more so in girls the main concern also emerged about marriage if taken treatment for mental illness. It was worrying to see that this stigma and negative beliefs about psychiatric care did not vary across the level of education.

*"We did not want to tell our relatives /village people. We were worried about what they would think of us. We thought this is something which cannot be cured .We felt once a patient, always a patient. We were worried about her being labeled as huchhi (mad). We were worried if she would be given 'shock treatment'. We also thought she might forget everything because of this 'shock treatment'. We were really concerned about her having to take life-long medication." ----- Husband of a 35 year old female patient with Undifferentiated Schizophrenia.*

*"We did not fear others. We knew treatment was important. But we didn't want to tell relatives. She is in her marriage age. You say 'disclose before marriage', but then who will marry her after hearing this? Her own father has studied B.com but still has no knowledge about this .We saw a TV program on this which he did not believe. Even now he is against treating her. He says medicines are going to harm her more than anything. He says it's all in her mind, if she becomes little stronger, no need for*

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*any doctor.” -----Mother of a 22 year old female with Acute Psychosis.*

*“Though we were aware of such hospital, we tried not to go. We asked him to decrease symptoms and be in relaxed mind, because once we start the treatment, may be it will continue for lifelong. He is a business man. We were worried how would his customers react to all this. We also thought about the side effects, his mother has had with the treatment and hence we were worried .We were scared of patient becoming dull and depressed after treatment .There was also the cost factor” -----*

*--- Wife of a 34 year old male with Delusional Disorder.*

*“We have come all the way from Mysore to Shimoga for treatment. If anybody comes to know about this at our place, it's going to be problematic for everything, marriage, studies, our prestige, everything. We knew about mental illness since our uncle had it. It is a lot of suffering.”----- Father of a 24 year old male patient with Acute Psychosis.*

### DISCUSSION

This study took place in a psychiatric hospital at Shimoga district. This centre caters for a diverse patient population.

The duration of untreated psychosis in our study varied from 5 days to 8 years with median duration of psychosis being 18 months. This did not have any correlation with education, socioeconomic and residential status of the patient. Similar to earlier studies, we found treatment delay in first episode psychosis is influenced by multiple, complex factors. We now discuss these factors in the background of the major themes which emerged in the experiential narratives.

#### *Understanding of symptoms and experiences*

It stood out prominently through the narratives that the caregivers had significant difficulties in recognizing symptoms as due to illness let alone mental illness. The experiences revealed significant lack of awareness regarding what symptoms constitute mental illness. It was noted that this lack of awareness did not vary significantly across the level of education, socioeconomic status and residential background. This finding requires further research. The earlier studies from India (Saravanan et al, 2008; Sanna & Nicola, 2011; Faizan et al, 2012) did not explore this issue, however low education, rural background and low socioeconomic status were noted as barriers to seeking mental health care in the pathways of care in these studies. The previous experience of seeing a psychiatric patient had instituted knowledge regarding mental illness. Their successful functioning after treatment prompted two caregivers to bring their patients in to mental health care. This is in accordance with the other study from India wherein they found that the previous patients and their relatives were the important referring agency(Lahariya et al, 2010). In this regard, we need to devise strategies to utilize these previous patients with psychiatric illness, who have recovered well with treatment for community awareness programs.

We noted in our study that there were two patients whose family members read in newspapers about schizophrenia and identified patient's symptoms as due to mental illness. This prompted them to bring them to a psychiatrist. Utilizing media as an effective tool to disseminate awareness, producing scientifically correct and informative programs, articles in print media appear important. These programs/articles need to be easily comprehensible, with case examples so that symptoms of psychosis can be picked up early and easily.

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### *Help seeking*

The narratives related to help seeking revealed unawareness of treatment methods, practical difficulties in help seeking like financial constraints, transportation difficulties and difficulties in getting the patient to care facility. This was similar to earlier findings from Indian studies. ((Lahariya et al, 2010; Becharad-Evans et al, 2007; Saravanan P; Grover et al, 2015) We noted in our study that the caregivers were unaware of any legal facilities like getting a reception order when patient did not agree for treatment. This has not been studied in earlier studies. Being an important factor in increasing DUP, this factor needs substantial consideration. Patient /caregiver benefits available through law would become a reality only if they know about it.

Physical violence identified often as a crisis which required immediate help. However the caregivers did identify retrospectively a period of behavior changes in patients prior to this crisis of violence. In other words though symptoms were noticed they were not given much importance because the patient was non-disturbing. This brings in to discussion the important need to educate the people about the symptoms other than violence which are easily noticeable but often are ignored and thought as not treatment worthy. At the same time, it is important to dispel the myth that all psychiatric patients are violent.

Consultation with Faith healers, religious heads has been identified as major step in pathways to care in psychiatric disorders in India (Campion & Bhugra, 1997; Raguram et al, 2002; Champion and Bhugra, 1997). Our study confirms these findings. Twenty of our patients consulted psychiatrist only after the approval from these religious heads. There has been much debate as to whether this step in the pathways to care needs to be discouraged. While one study (Raguram et al, 2002) reported temple healing to be beneficial, we also have instances such as temples and durgahs keeping mentally ill, chained, and treating them with inhuman practices.

Campion and Bhugra in 1997 studied traditional methods of treatment by religious healers, who are consulted by 45% of mental patients before seeking treatment in a psychiatric clinic in southern India and commented that the medical literature seldom mentions traditional healers despite their importance as the first line of treatment in developing countries. A study from Kuala Lumpur (Phang, 2010) showed that the most common first contact for first-episode psychosis was with traditional healers and authors expressed the potential benefit in management from collaboration with traditional healers. A study (Raguram et al, 2002) from South India reported that traditional community healing resources, including temple healing, are widely used in managing mental illness in India and they suggested that "existing traditional resources may have a role in providing community mental health care." The reasons for preferring faith healing can be trust, easy availability and accessibility, recommendations by the significant others and belief in supernatural causation of illness. (Chadda et al, 2001).

Hence getting psychiatric patient to the psychiatrist without other steps in between may be ideal but not practical in the current Indian scenario. It requires a steady working through the barriers. Hence this also involves creating a network of care where the religious head or a faith healer is seen as an expert in community care and acts as a referrer. It is important to note that the innovative Dava-Dua Program, a fusion of prayer & medicine, launched in Erawadi by Government of Tamil Nadu, India under District mental health program to treat people with mental illness attending durgah, a religious prayer place has been successful.



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(<http://thealtruist.org/dava-dua-program/>) A gradual approach of making population aware of and accepting of the biomedical model of explanations in view of scientific evidences could be tried. We need to device ways how this pathway can be made clearer so that proper psychiatric health care is available to the masses.

### ***Stigma:***

Although the quality and effectiveness of mental health treatments and services have improved greatly over the past 50 years, therapeutic revolutions in psychiatry have not yet been able to reduce stigma. Stigma is a risk factor leading to negative mental health outcomes. It is responsible for treatment seeking delays and reduces the likelihood that a mentally ill patient will receive adequate care. It is evident that delay due to stigma can have devastating consequences. Several studies show that stigma usually arises from lack of awareness, lack of education, lack of perception, and the nature and complications of the mental illness, for example odd behaviors and violence. (Corrigan P, 2004; Arboleda-Florez J, 2012; Thara & Srinivasan, 2000). Stigma related to schizophrenia in India is particularly high (Grover et al, 2017; Thara & Srinivasan, 2000). In general stigma is reported to be associated with illness that manifests with behavioral disturbances or socially odd behavior. As expected this was corroborated by our study. Multiple misconceptions about treatment-concerns about being given sleeping pills, electro convulsive therapy, lifelong treatment and fear of becoming 'dull' after treatment, being labeled as mad were important barriers in seeking help. The concern regarding marriage was foremost for young female patients. The attempts to reduce stigma need to device targeted interventions with innovative techniques to address these specific barriers.

### ***Limitations:***

This study has few limitations. This is a cross sectional study limited to caregivers of persons with first episode psychosis. The sample is not representative of those patients who actually remit spontaneously. Stigma, itself might have been a barrier for caregivers to talk freely in the study despite assurance of confidentiality.

### ***Clinical and research implications:***

The study specifically points out to the different reasons for delay in help seeking and the real reasons for stigma in mental illness in a developing country like India. If these factors are taken into account while devising strategies for tackling stigma, the interventions would be successful.

## **CONCLUSION**

This qualitative study describes the understanding and attribution of symptoms and help seeking processes and beliefs about mental health services of caregivers at the onset of first episode of Psychosis. This study showed that multiple factors like stigma related to illness & treatment, unawareness of symptoms and treatment of mental illness were responsible for delayed help seeking. It was also found that religious beliefs & faith healers had an important role to play in the pathway to care. There is a dire need for more and more community awareness programs to ward off stigma related to mental illness. Targeted interventions addressing the real reasons for stigma is the need of the hour. Utilizing media & recovered patients in these programs might be beneficial.

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### ***Conflict of Interest***

The authors colorfully declare this paper to bear not conflict of interests

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