

## Symptoms at Onset in First Episode Schizophrenia: Caregivers Perspectives

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### ABSTRACT

**Background:** Early recognition of symptoms is important in the management of psychosis. Caregivers understanding and attribution of symptoms plays a major role in treatment selection. **Aim:** The aim was to identify the various symptoms cluster recognized by caregivers at illness onset in first episode schizophrenia. **Subjects and Methods:** In a cross-sectional study 40 key caregivers of patients with first episode of Schizophrenia (International Classification of Diseases-10) attending the outpatient services of Schizophrenia Research Foundation were recruited. Caregivers were assessed using a questionnaire adapted from the Psychiatric and Personal History Schedule. **Statistical Analysis:** Principal component (PCP) analysis. **Results:** Caregivers were predominantly women. Parents (58%), siblings (18%), spouse (12%), and children (12%) formed the sample. The caregiver easily recognized depressive symptoms. An analysis was done to analyze symptom data rated on the caregiver questionnaire indicated a four-factor solution. PCP analysis produced a clear depressive, anxious, irritable, and vegetative factor (Eigenvalue >0.05). Caregivers (40%) attributed present lifestyle as causality. The first contact of help in almost half of the sample (45%) was to a psychiatric facility. **Conclusion:** Caregiver's perception about mental illness and ability to identify the four factors has important treatment implications. Studying patterns of help seeking may be a useful strategy in early intervention programs.

**Key words:** Caregivers, first episode, prodrome, schizophrenia

### INTRODUCTION

Research on tracing the trajectory to the first episode of psychoses have identified social withdrawal and mood disturbances as symptoms predominantly noted by families.<sup>[1]</sup> Few families have reported some vulnerability in the patient in terms like being sensitive, shy, having few friends, social awkwardness. Mood symptoms were commonly cited as the initial symptom

experienced (86%) followed by high rates of anxiety (86%), depression (76%), behavioral changes in the form of deterioration in role function (76%), and social withdrawal (72%) by the caregivers of 21 first episode psychosis patients prior to psychosis.<sup>[2]</sup> Comparable results have been reported from the East on young servicemen with first episode psychosis.<sup>[3]</sup> However in India, families tolerance for behavioral abnormality and/

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or disability from the illness is so high that it is often not recognized.<sup>[4]</sup> They misattribute symptoms and behaviors to typical adolescence or to stress. The subtle and nonspecific nature of the initial symptoms makes it difficult to identify, occasionally there is denial on the part of carers to deal with stigma related to mental illness.<sup>[5]</sup> A study done in South India on caregivers belief about the cause of schizophrenia revealed that the current lifestyle was the most commonly cited reason, and supernatural causes were reported by few of them.<sup>[6]</sup> In contrast, a large majority of caregivers (40%) from a rural setting in North India attributed supernatural fears to schizophrenia.<sup>[7]</sup> Studies on help-seeking patterns of psychiatric patients have found that faith healers are the care providers for most of them at first contact. Consultations from nonpsychiatric care providers first and psychiatric services as the later resort results in loss of crucial time in treatment and outcome.<sup>[8]</sup> Despite the progress in awareness of mental health care studying caregivers attribution and early identification of symptoms plays a major role in schizophrenia intervention programs. Keeping this in mind, this study was conceived in key relatives or carers of patients with first-episode schizophrenia.

## SUBJECTS AND METHODS

All key relatives of patients with first episode of schizophrenia (International Classification of Diseases-10) diagnosis attending Schizophrenia Research Foundation (SCARF) outpatient department during the study period.

### Inclusion criteria

- Key relative/caregiver of patients (18–50 years) with a clinical diagnosis of first episode of schizophrenia.
- Key relative or caregiver was defined as a family member living with the patient for minimum 1-year and present during the onset of abnormal behavior and actively involved in patient care.
- Duration of illness <2 years.
- Key caregiver willing to provide informed consent and participate in the study.

### Exclusion criteria

- Caregiver's of patients with a diagnosis other than schizophrenia, duration of illness >2 years
- Patients with no caregiver's
- Caregiver's unwilling to participate in the study
- Key caregiver not fulfilling the definition.

### Tools

- A socio-demographic proforma specifically designed for the purpose of the study will gather information regarding the socio-demographic and illness-related variables.

- A semi-structured questionnaire was used to interview caregivers understanding of Schizophrenia. This tool was adapted from the Psychiatric and Personal History Schedule (PPHS-1, Section C) in which the patient's psychiatric, medical, social, development history, premorbid traits, and the overall adjustment during adolescence is documented from the primary caregiver. The PPHS has been extensively used in the Indian setting.<sup>[9]</sup>

### Ethical clearance

Institutional Ethics Committee clearance was obtained prior to the commencement of the study.

### Study design

Cross-sectional study.

### Study period

Six months.

### Sampling

Serial sampling.

### Procedure

All consenting key caregivers attending the outpatient services of SCARF fulfilling inclusion criteria were screened and recruited for the study. Assessments were completed in a single sitting.

### Data analysis

Analysis of data was done using the Statistical package for Social Sciences (SPSS) version 16 (Chicago, SPSS Inc.). Descriptive statistics and principal components analysis were done on symptoms generated from caregiver questionnaire and four factors with high loading (Eigenvalue >0.5) were generated.

## RESULTS

Forty caregiver's (29.5 years  $\pm$  8.48) predominantly women were recruited. Key relatives included parents, siblings, spouse, and children. The majority of persons were from an urban background, literate, employed and were living in a nuclear household. Table 1 illustrates the most common symptoms identified by the caregivers based on the PPHS interview. Table 2 and Figure 1 depict symptoms as the four factors easily identified by the caregivers using the principal component analysis. Key relatives attributed these reasons-lifestyle (40%), family (17.5%), hereditary (7.5%), fear (7.5%), black magic (5%), destiny (5%), and unknown (22.5%) as causes for change in behavior in the patents. Treatment seeking more with traditional healers and subsequently with psychiatrists was seen in both urban and rural setting.

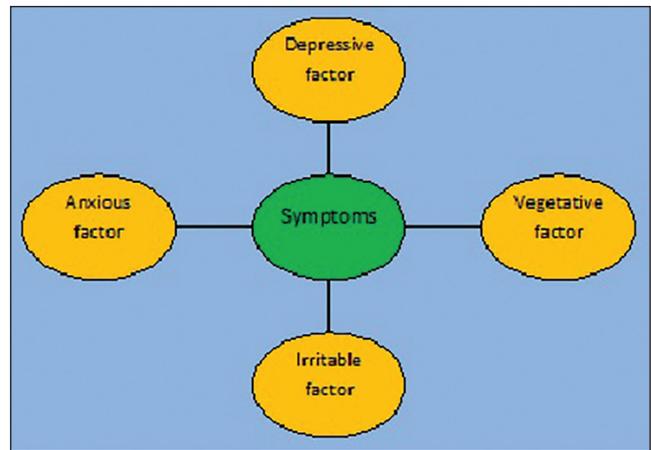
**Table 1: Distribution of symptoms identified by key caregiver based on PPHS (n = 40)**

| Symptoms                      | Frequency | Percentage |
|-------------------------------|-----------|------------|
| Get irritable                 | 17        | 42.5       |
| Look frightened               | 13        | 32.5       |
| Sleep disturbances            | 12        | 30         |
| Look sad                      | 12        | 30         |
| Lose appetite                 | 10        | 25         |
| Avoid company                 | 10        | 25         |
| Neglect of activities         | 9         | 22.5       |
| Lose all interest             | 8         | 20         |
| Aches and pains               | 5         | 12.5       |
| Cause damage                  | 5         | 12.5       |
| Incomprehensible speech       | 5         | 12.5       |
| Excited                       | 4         | 10         |
| Attempt to kill self          | 4         | 10         |
| Excessive religiosity         | 4         | 10         |
| Sweating/palpitations/tremors | 4         | 10         |
| Preoccupied                   | 4         | 10         |
| Crying spells                 | 4         | 10         |
| Preoccupied                   | 4         | 10         |
| Tiredness                     | 2         | 5          |
| Worried                       | 2         | 5          |
| Guilty feeling                | 2         | 5          |
| Assault others                | 1         | 2.5        |
| Spend money                   | 1         | 2.5        |
| No energy                     | 1         | 2.5        |
| Increased appetite            | 1         | 2.5        |
| Withdrawn                     | 1         | 2.5        |
| Excessive                     | 1         | 2.5        |
| Rude                          | 1         | 2.5        |
| Slowness                      | 1         | 2.5        |
| Confused                      | 1         | 2.5        |
| Headache                      | 1         | 2.5        |
| Self-injurious behavior       | 1         | 2.5        |
| Neglect care                  | 1         | 2.5        |
| Decreased libido              | 1         | 2.5        |
| Abusive                       | 1         | 2.5        |
| Boastful talk                 | 1         | 2.5        |
| Suicidal ideas                | 1         | 2.5        |
| Poor concentration            | 1         | 2.5        |

PPHS – Psychiatric and personal history schedule

**DISCUSSION**

Caregivers delineated depressive symptoms more easily, and this finding is consistent with earlier studies. Poor overall adjustment in the pre-psychotic phase as a vulnerability factor is recognized in our study. Key relatives reporting present lifestyle, as the cause of illness is an interesting finding. Most caregivers commented on peer pressure, Internet and gadgets, academic or work expectations causing major changes in lifestyle resulting in psychotic breakdown. The majority of caregivers probably identified the depressive or vegetative symptom cluster easily as a mental illness because sadness, suicidal ideas, lack of interest in activity or aches, and pains were the most recognizable changes in the patient. Symptoms such as irritability, spending money (irritability factor), increased sleep; excessive writing and appearing preoccupied (anxious factor) could be overlooked as “normal” behavior related to stress. However, these symptoms cause concern and families decide to seek psychiatric help.



**Figure 1:** Symptom clusters as types of factor models (principal component analysis)

**Table 2: Factor models highlighted by caregivers (PCP analysis, Eigen value >0.05)**

| Depressive factor             | Anxious/withdrawn factor | Irritable factor      | Vegetative factor  |
|-------------------------------|--------------------------|-----------------------|--------------------|
| Neglect of activities         | Increased sleep          | Excessive religiosity | Lose appetite      |
| Lose all interest             | Increased appetite       | Get irritable         | Disturbed sleep    |
| Assault others                | Withdrawn                | Look frightened       | Suicidal ideas     |
| Attempt to kill self          | Excessive writing        | Persistent thoughts   | Poor concentration |
| Do anything indecent          | Appeared worried         | Spend money           | Decreased libido   |
| Look frightened               | Appeared preoccupied     |                       | Abusive            |
| Look sad                      | Incomprehensible speech  |                       | Avoid company      |
| Aches and pains               |                          |                       |                    |
| Tiredness                     |                          |                       |                    |
| No energy                     |                          |                       |                    |
| Sweating/tremors/palpitations |                          |                       |                    |

PCP – Principal component

Regarding attribution of illness, an equal percentage was unsure or suggested that supernatural causes could be the reasons for the illness. This is not surprising especially in the Indian sub-continent where magico-religious beliefs and caregiver tolerance toward symptoms is high. Therefore, families seek help from faith healers first and consider a psychiatric opinion only later. Although only a few families believed supernatural causes for behavioral change more than half of sample sought help from faith healers. In our sample, key relatives from the urban setting sought help first from a psychiatrist compared to rural caregivers. This difference can be explained based on access to the psychiatric facility, distances to be covered and faith healing being the most accepted form of treatment. This explains how inspire of similar attribution styles, help-seeking patterns differed.

## CONCLUSION

Depressive and vegetative cluster were more commonly present and easily identified symptoms by the caregiver. Anxiety or irritability factors need more recognition. Educating caregivers about the diverse presentations in patients is necessary for early intervention in Schizophrenia. Recognition of symptoms by caregivers and patterns of help seeking is an important facet of early intervention in first-episode patients.

## LIMITATIONS

A prospective study to examine the reliability of the different factors in a larger sample of caregivers will strengthen the findings of the study. A reliable and valid instrument that is culturally sensitive needs to be developed to capture the schizophrenia prodrome.

## Financial support and sponsorship

Nil.

## Conflicts of interest

There are no conflicts of interest.

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