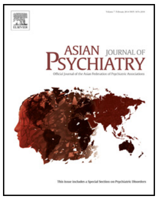
Asian Journal of Psychiatry 17 (2015) 16–23

Contents lists available at ScienceDirect

Asian Journal of Psychiatry

journal homepage: www.elsevier.com/locate/ajp



Assessing the needs of siblings of persons with schizophrenia: A qualitative study from India

Anekal C. Amaresha [*], Boban Joseph, Sri Mahavir Agarwal,
Janardhanan C. Narayanaswamy, Ganesan Venkatasubramanian, Daliboina Muralidhar,
Doddaballapura K. Subbakrishna

Department of Psychiatric Social Work, National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore, 560029, India

A R T I C L E I N F O

Article history:
Received 20 March 2015
Received in revised form 23 June 2015
Accepted 18 July 2015

Keywords:
Siblings
Caregivers
Schizophrenia
Needs

A B S T R A C T

There is a lack of studies on siblings of persons with schizophrenia (SOPS) in Asia. This study aims to explore the needs of SOPS in India. 15 SOPS participated in this qualitative explorative study. All the interviews were audio recorded and later transcribed. Data analysis was carried out using General Inductive Approach. Five themes emerged from the data: managing illness or socio-occupational functioning; follow up services; informational needs; personal needs; and miscellaneous needs. SOPS in India have some distinctive needs. Identifying these needs might help in developing and designing specific psychosocial interventions for better management.

1. Introduction

Schizophrenia is a complex disorder characterized by positive symptoms such as hallucinations and delusions; negative symptoms such as affective flattening, alogia, avolition, anhedonia and apathy, and cognitive deficits. All these symptom domains are associated with socio-occupational dysfunction (Green, 1996; Mueser & McGurk, 2004). The chronicity and the other illness related effects of schizophrenia pose a significant burden on persons suffering from this illness as well as their families (Awad & Voruganti, 2008; Briggs et al., 2008; Lowyck et al., 2004). Literature shows that the family caregivers in India play an important role in the treatment and recovery of the person with severe mental illness (Chadda & Deb, 2013), since a majority of the patients live with their families (Thara & Eaton, 1996; Thara et al., 1994). They take care of the patient's daily activities, supervise medications, and are closely involved in the treatment process by accompanying them for follow-up consultations (Chadda, 2014). In this perspective it is essential to understand and address the issues faced by the families of persons with schizophrenia.

Though schizophrenia affects the whole family, research predominantly identifies the issues of parents and spouses of the patients and a major proportion of participants in psychosocial interventions on caregivers are from these two groups (Chien et al., 2006; Pickett-Schenk et al., 2006; Shor & Birnbaum, 2012; Stephens et al., 2011; Szmukler et al., 2003). The studies on siblings of persons with schizophrenia (SOPS) show that they are also negatively affected by the illness and have suggested that there is a need for psychosocial interventions (Friedrich et al., 1999, 2008; Schmid et al., 2009; Sin et al., 2012). Some of the researchers have argued that SOPS are also important members in the treatment during their siblings' illness trajectory especially when other caregivers are not available (Bowman et al., 2014; Hatfield & Lefley, 2005; Seeman, 2013). In this context it is also necessary to acknowledge their contributions to the recovery of their ill siblings and address their needs. In addition several reviews have established that SOPS are at a high-risk of mental illness (Agnew-Blais & Seidman, 2013; Bora et al., 2014; Smieskova et al., 2013). Thus, understanding their specific needs might help us to formulate psychosocial services.

A recent systematic review identifies the needs of the SOPS in the published literature and highlights some of the limitations in those studies (Amaresha et al., 2014). This review reports of siblings' needs in terms of information; support groups; illness management and rehabilitation for their affected siblings; and help in managing their own psychosocial issues, etc. (Amaresha et

---

[*] Correspondence to: Department of Psychiatric Social Work, First Floor, Dr. M. V. Govindaswamy Centre, National Institute of Mental Health and Neurosciences (NIMHANS) Bangalore-560029, India.
E-mail address: amarmsw@gmail.com (A.C. Amaresha).

http://dx.doi.org/10.1016/j.ajp.2015.07.011
1876-2018/

al., 2014). It also describes some of the limitations in the current literature such as almost all studies being conducted in western countries; participants were predominantly sisters; most of the studies the primary aim was not exploring the psychosocial needs of SOPS; using mailed surveys for needs assessment; analyzing the secondary data of the previous studies and in-adequate reporting of socio-demographic and clinical profile of the participants (Amaresha et al., 2014). Along with these limitations, lack of studies from the Asian sub-continent and the cultural differences with western countries warrants further studies with this population in this region. With this background, we sought to explore the needs of the SOPS with regard to the care taking of patients suffering from schizophrenia attending a tertiary care mental health hospital in Southern India

2. Materials and methods

2.1. Ethical statement

This study is nested in the initial phase of an ongoing doctoral study titled "Efficacy of the psychosocial intervention with siblings of persons with schizophrenia (Clinical Trials Registry India no: CTRI/2014/12/005321)." Ethical approval for this study was obtained from the Human Ethics Committee, National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore, India (NIMH: ES: Ph.D. (PSW): 2011-14:AC). Written informed consents were obtained from the SOPS prior to their participation in the study after a thorough explanation about the study and its procedures.

2.2. Design

This qualitative explorative study used semi-structured face-to-face interviews for data collection and adopted a general inductive approach for data analysis (Thomas, 2006). This approach proposes simple steps in qualitative data analysis, which summarizes large raw textual data into concise results, and establishes clear relationships with research objectives (Thomas, 2006).

2.3. Setting and participants

The study was carried out at the Schizophrenia Clinic, outpatient and in-patient departments of the Department of Psychiatry, NIMHANS, Bangalore. The inclusion criteria for study participants were—a biological brother or sister of a person diagnosed to have schizophrenia (DSM-IV); aged $\geq$18 years; able to converse in either English, Kannada, Tamil, or Telugu; and not having any axis-I psychiatric or medical disorders. We contacted 37 eligible participants during March 2013 to January 2014 and included 15 participants who consented to participate in the study.

2.4. Interviews and data collection

We invited the SOPS, who met the inclusion criteria to participate in the FGDs. However, we could not conduct the FGDs, since the desirable number of participants did not turn up for the FGDs. Hence, we conducted semi-structured face to face interviews with SOPS. The first author (ACA) conducted the interviews. During the initial phase of the interview the socio-demographic details of the SOPS and their affected siblings were collected with a semi-structured questionnaire. The revised Kuppuswamy's Socio-Economic Status scale was used for collecting data on socio-economic status (Kumar et al., 2013). Additionally, we collected the age at onset (AAO) of the illness; duration of untreated psychosis (DUP); duration of illness (DoI); and duration of treatment (DoT) by reviewing affected siblings' case records and interviewing the SOPS. The data on severity of the illness was collected using Clinical Global Impressions-Severity (CGI-S) scale (Busner & Targum, 2007).

The later phase of the interview exclusively focused on exploring the needs of the SOPS. They were asked a few open ended questions in the beginning such as "Can you explain the needs and concerns with regard to you and your sibling? Or what help are you expecting from the treating team with regard to you and your sibling?" If they were unable to give spontaneous subjective responses, then the interviewer assisted them with appropriate probes. For this purpose a checklist was prepared based on the review of literature and in consultation with five mental health professionals. These professionals were not related to the current study and they were from Social Work (3), Psychiatry (1) and Anthropology (1) background. They were selected based on the prior experience in working with families of persons with schizophrenia and having the knowledge of qualitative research methods.

2.5. Data analysis

All the fifteen audio recordings were transcribed into English text and field observation notes were added to this. Later the interview transcripts were imported into and coded with the assistance of Atlas.ti® (Version.7. Scientific Software Development GmbH—http://atlasti.com/) (ATLAS.ti, 2014). Several qualitative researchers recommended that a single person is sufficient to do the analysis if he/she is immersed with the data collection and analysis (Mays & Pope, 1995; Patton, 1999; Pope et al., 2000). Thus, the first author (ACA) was involved in conducting the interviews, transcribing, coding and the data analysis. The general inductive approach (Thomas, 2006) guided the qualitative data analysis. The raw texts were read and reread multiple times to get familiarity with the data. During the coding process the text segments that depicted the needs of SOPS were critically analyzed and codes were created. The initial coding was done for five transcripts and they were revised, refined with new insights and critically checked for the consistency with the transcripts. Based on this primary coding, we created further codings for the rest of the data set. After finishing the coding for the complete data set, it was reviewed again to reduce the redundant codes and identify new codes, which would be meaningful to the topic of interest. These codes were later exported to a Microsoft Excel sheet and critically analyzed, and the relevant themes were named. Later the codes were assigned under the meaningful themes. These codes and themes were discussed with two peer researchers (who are not part of this research) to sort out and cross check the consistency of the codes with assigned themes. The differences were resolved after clarifications and discussion.

The themes were saturated at 12 interviews and we have completed the data analysis for all 15 interviews. The results were described under the broad themes that emerged from the data and were presented as per the hierarchy of needs which was decided based on the number of SOPS emphasized each theme (See Fig. 1. for steps of data analysis). The most illustrative and comprehensive quotes were chosen to describe the main themes. Participants' numbers, age and the relationship were presented along with the quotes.

3. Results

3.1. Socio-demographic characteristics

Table 1 depicts the socio-demographic and clinical characteristics of the 15 SOPS who participated in this study (Brothers = 11 and Sisters = 4) and their ill siblings. The mean age of the SOPS was 33 years and their ill siblings' was 30.40 years.