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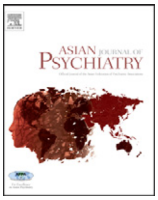

Outcomes that matter: A qualitative study with persons with schizophrenia and their primary caregivers in India

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ABSTRACT

Background: Involving persons with schizophrenia and their families in designing, implementing and evaluating mental health services is increasingly emphasised. However, there is little information on desired outcomes from the perspectives of these stakeholders from low and middle income countries (LMIC).

Aims: To explore and define outcomes desired by persons with schizophrenia and their primary caregivers from their perspectives.

Method: In-depth interviews were held with 32 persons with schizophrenia and 38 primary caregivers presenting for care at one rural and one semi-urban site in India. Participants were asked what changes they desired in the lives of persons affected by the illness and benefits they expected from treatment. Data was analysed using thematic and content analysis.

Results: Eleven outcomes were desired by both groups: symptom control; employment/education; social functioning; activity; fulfilment of duties and responsibilities; independent functioning; cognitive ability; management without medication; reduced side-effects; self-care; and self-determination. Social functioning, employment/education and activity were the most important outcomes for both groups; symptom control and cognitive ability were more important to persons with schizophrenia while independent functioning and fulfilment of duties were more important to caregivers.

Conclusions: Interventions for schizophrenia in India should target both clinical and functional outcomes, addressing the priorities of both affected persons and their caregivers. Their effectiveness needs to be evaluated independently from both perspectives.

1. Introduction

The emergence of the recovery paradigm (Roe, 2001; Liberman et al., 2002) has brought into focus the need for incorporating the views and aspirations of persons with schizophrenia (PwS) in designing, implementing and evaluating mental health care services (Robert et al., 2009). Subjective experiences of the illness and the needs of PwS can affect adherence to interventions and perceptions of care received (Fenton et al., 1997; Kikkert et al., 2006; Pyne et al., 2006). As families are closely involved in caregiving and are considerably affected by the illness (Thara et al., 2003a; Jagannathan et al., 2011), their perspectives are also important. Their involvement may result in better outcomes for PwS and enhance their engagement in and satisfaction with health services (Falloon et al., 1985; Dixon and Lehman, 1995; Chue, 2006). This is particularly true in countries like India, where PwS typically live with their families, and the latter often participate in decision-making regarding health care and treatment compliance (Srinivasan and Thara, 2002; Chatterjee et al., 2009).

Outcome priorities for schizophrenia have been generated from service-user perspectives and that of families and other stakeholders (Fischer et al., 2002; Cradock et al., 2002; Shumway et al., 2003; Rosenheck et al., 2005; Ng et al., 2008, 2011). Desired outcomes generally include symptom remission, reduction of side-effects, employment, independent living, remission without medication, and improved relationships. Studies comparing outcome priorities of individuals and families, however, show

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conflicting results. One study, for example, shows that both groups agree on outcomes that are important, such as relationships and independence (Cradock et al., 2002), while another demonstrates that they differ in their priorities, with families placing a greater emphasis on social relationships and housing independence and PwS, on control of side-effects and work performance (Fischer et al., 2002). Moreover, most of the available literature on desired outcomes comes from high resource countries. This gap in information is a potential barrier to designing and evaluating contextually appropriate services for PwS and their families in low and middle income countries (LMIC).

This paper describes a qualitative study conducted in India which sought to explore and define outcomes in schizophrenia desired by PwS and their primary caregivers. This study was part of the formative phase of a randomised controlled trial designed to evaluate the effectiveness of a community based intervention for schizophrenia in India (Chatterjee et al., 2011).

2. Method

2.1. Participants

We used purposive sampling and selected two sites for our study, one rural and one semi-urban, to maximise the richness and variety of data on desired outcomes. The semi-urban site was Goa (nearly 50% of the population are urban), a small state on the west coast with a population of about 1.4 million. The main sources of employment here include tourism and agriculture. Over 80% of people are literate. The rural site comprised three blocks in the Kancheepuram district of Tamil Nadu (TN) state in south India, where the main source of employment is agriculture and the combined population is over 700,000. Literacy is over 70%. Within each site, we recruited two groups of participants, PwS and primary caregivers, from those presenting for treatment at community mental health clinics (rural site) or psychiatric treatment facilities (semi-urban site) on a first come-first serve basis. PwS were eligible to participate if they met the ICD-10 criteria for schizophrenia and were equal to or above 18 years of age. Psychiatrists in these centres made the diagnosis. The primary caregiver was identified by the PwS and accompanying family members or psychiatrists as the person in the family primarily responsible for meeting emotional, financial and health needs of the PwS.

2.2. Data collection

In-depth Interviews (IDI) were then conducted with PwS and caregivers between September 2008 and July 2009. Participants were asked about their perceptions of the illness and experiences of care received *(What do you think you suffer from? How has the illness affected your life? What benefits have you experienced from treatment?*). Responses to these questions then served as useful probes for eliciting information on desired outcomes in the form of changes they wanted in the lives of the PwS and the benefits they expected from treatment (*Can you tell me what changes you want in your life? What benefits do you seek from treatment?*). Follow-up questions were largely based on what the participants said in response to these open-ended questions and varied from interview to interview: *What sort of changes do you want in ________ [outcome mentioned by participant]?* or *(for changes in specific outcomes mentioned) For which [symptom/side-effect/relationship]?* Persons who did not respond adequately were probed in a modified manner, for example by drawing their attention specifically to areas of impact previously mentioned and probing about whether and in what manner changes were desired in these areas, for example: *You said that you are having _____________ [problem mentioned earlier by participant] how would you define getting better? What changes do you wish to make? For example, do you want your symptoms to change? Which ones? In what way?* We ensured that the probes used were tailored to the specific interview and were in keeping with the established guidelines through rigorous supervision. The interview guides can be found on our website www.sangath.com.

Two research assistants (RAs) at each site conducted the interviews. Before this, they participated in an intensive 3-day workshop on qualitative interviewing methods and underwent subsequent training for 30 days on the use of the guides. Training included lectures, video tapes of interviews, practice sessions with PwS and caregivers, and role plays observed by trainers. Interview guides were translated into local languages (Konkani in Goa and Tamil in TN) by the RAs. They were revised at midpoint taking into consideration researcher experiences and findings from interviews with 12 PwS and 16 caregivers (included in the sample for analysis). The number of questions was reduced, especially in the PwS guide, to reduce burden on participants; there were fewer probes, allowing for more open-ended probing; and words in the local languages that participants did not understand were substituted.

2.3. Procedure

Assent for participation in the study was obtained by the psychiatrists. Those who assented were given informed consent. Written consent was obtained from literate persons and verbal consent was tape recorded for those not literate. Participants who consented were then interviewed either at their homes or at the treatment facility. Each interview was tape recorded and took approximately 45 min. Interviews with PwS and caregivers who were from the same family were carried out simultaneously, in separate, privately enclosed spaces by two independent RAs. Guidelines for transcription and translation were standardised for both sites. Interviews were transcribed and then translated into English within a week. Field notes were stored in a locked cabinet. Audio files and transcriptions were stored in computers and password protected to restrict access to authorised team members.

2.4. Data analysis

All conducted interviews were analysed in NVivo 8 using thematic analysis and content analysis (Miles and Huberman, 1994; Braun and Clarke, 2006; Namey et al., 2007). In the first stage, a coding framework was developed that was based on the research question. This consisted of “master codes” (i.e., abbreviations for the main categories of data expected to emerge from analysis). Examples of master codes were “[o]” for the variable “outcomes”; and “[p]” for PwS or “[c]” for caregivers, to denote respondent group perspectives. The codes in the framework were minimal in order to maximise inductive generation of themes.

In the next stage, raw data was read and re-read repeatedly in order for the coders to become familiar with and get immersed in data. It was then broken down into and summarised as smaller fragments of meaningful information (codes). These were at first descriptive (i.e., paraphrases of words used by the participants themselves) and then interpretative (i.e., words chosen by the coders as more representative of the ‘underlying meanings’ in data). Codes that were similar to one another (reflecting the same meaning) were then grouped together as one category. For example, the desire for doing housework without help was grouped together with other desires of working and earning, and going to the market by oneself, on the key aspect of independence. Next, the category was given a label in the English language that was the closest available approximation to the meaning of the category, and that would most succinctly capture the nuances of