

# Development and feasibility of need-based psychosocial training programme for family caregivers of in-patients with schizophrenia in India

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## ABSTRACT

**Objectives:** To develop and test the feasibility of a need-based psychosocial training programme for family caregivers of in-patients with schizophrenia in India.

**Method:** Six topics for the psychosocial training programme were identified. Each day's programme was based on a theoretical approach and involved a combination of methodologies. A structured questionnaire eliciting comments on each day's topic, content and methodology was given independently to 11 experienced mental health professionals for validation. The final version of the programme based on the feedback given by the experts was pilot tested on a group of six caregivers to check for feasibility.

**Results:** Experts gave an average score of '4' (very much – on a 5 point Likert scale) when asked whether the overall psychosocial programme will achieve its objective of helping the caregiver reduce their burden. They independently approved the theoretical approach and methodology used for each day's topic and suggested many changes. In the pilot study, quantitative and qualitative feedback of the caregivers further endorsed the feasibility and usefulness of the programme.

**Conclusion:** The developed psychosocial training programme was found acceptable to the caregivers of in-patients with schizophrenia.

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## 1. Introduction

Family members of patients with schizophrenia have extensive needs. The major needs of the caregivers include gaining education about the illness, ways of coping with the patient's bizarre and assaultive behaviour, obtaining support, lack of enough opportunities to relieve the burden imposed on them, reducing risks to their own wellbeing and promoting the wellbeing of the mentally ill (Chafetz and Barnes, 1989; Angermeyer et al., 2000; Chien and Norman, 2003). Studies using scales to assess caregiver-needs have focused on specific needs such as educational needs (Chien and Norman, 2003) or on groups of needs such as counseling and support services, education and financial entitlements (Wancata et al., 2006; Barrowclough et al., 1998).

There have been no systematic scientific Indian studies to assess the needs of caregivers; however various opinions have been expressed. Some of the needs opined are the need for

awareness on the nature and outcome of mental illnesses in the community, need for primary psychiatric and other professional treatment, and psychosocial rehabilitation (Goswami, 2006; Janardhan, 2006). Unmet needs of the patients have also been found to be significantly related to caregiver's burden (Cleary et al., 2005). Meeting these needs would help to enhance the level of functioning of the patient (Soloman and Draine, 1994) as well as to decrease the emotional problems of family members (Johnson, 1994).

Needs vary across cultures and hence to develop any programme to cater to the needs of caregivers, an in-depth assessment in a cultural context is essential. Further, schizophrenia outcome in India differs from the West, perhaps due to difference in family values, expectations, expressed emotions, family structure and stigma associated with the illness. In lieu of the above discussion, needs assessment of 30 caregivers of inpatients with schizophrenia, using focus group discussion (FGD) was conducted at NIMHANS, Bangalore (Jagannathan et al., 2011). The main needs of the caregivers that emerged were: (1) managing the behaviour of the patients, (2) managing social-vocational problems of patients, (3) health of the caregivers, (4) education about illness, (5) rehabilitation, and (6) managing sexual and marital problems of patients. These findings provide a

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strong ground for the development of a culturally specific need based psychosocial programme for caregivers of Indian families.

Different psychosocial models have proven to be effective in helping caregivers deal with their family member's illness. Family management interventions such as crisis-oriented family therapy, behaviour family therapy, family psycho-education, multiple family group intervention, relatives groups, and family consultation have shown positive outcomes both for patients and their families (Barbato and D'Avanzo, 2000; Gabi Pitschel-Walz, 2004; Pharoah et al., 2000; Pekkala and Merinder, 2004; Shinde, 2005). However, the significant number of cultural differences discussed above necessitates the development of a culturally suitable need-based intervention package for caregivers to enable them to handle their relative with schizophrenia in the Indian setting.

Unfortunately, there are hardly any research studies which discuss the development and effectiveness of standardized psychosocial programme based on the assessed needs of caregivers of persons suffering from schizophrenia in India. The current paper aims to detail the development of a psychosocial training programme; based on the results of a recently concluded study on the assessed needs of inpatients' family caregivers of persons with schizophrenia.

## 2. Methodology

The study was reviewed and approved by the Institute's Ethics Committee. Written informed consent of the mental health professionals who helped in validation of the programme and family caregivers who participated in the pilot study was obtained. A socio-demographic sheet eliciting information on their age, occupation, monthly income and marital status was filled up by the researcher for both the mental health professionals and family caregivers.

The qualitative research methodology was used to develop and test the feasibility of the psychosocial programme. Qualitative data during the validation phase was collected using the method of in-depth interviews.

The development of the psychosocial programme was conducted in two phases. Phase-1 involved development of the content and methodology for the psychosocial programme. Phase-2 involved face and content validation of the programme. The feasibility of the programme was tested in Phase-3 of the study where the programme was pilot-tested and feedback from the caregivers who participated in the programme was elicited. The process involved in each phase of the development and feasibility testing of the programme is delineated below (Fig. 1):

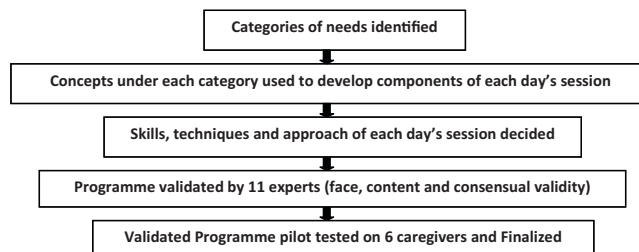


Fig. 1. Process of inductive method of programme development.

### 2.1. Phase-1: programme development

The framework of the psychosocial programme was based on the six broad categories of needs elucidated from the results of the recently concluded study on the assessment of needs of family caregivers of schizophrenia inpatients in India (Jagannathan et al., 2011). Depending on the number of concepts under each category of needs, one or more session was assigned for its discussion. In-depth literature review in conjunction with expert opinion was elicited to decide on the appropriate theoretical approach and methodology to conduct each day's session, covering different needs (category and concepts). The outcome was a 10-day group training programme which addressed the above studied six needs. Each day's programme was based on a theoretical approach, with a combination of techniques and required the caregivers to complete some homework assignments (Table 1).

### 2.2. Phase-2: face and content validation

For the purpose of face and content validation of the programme, in-depth interviews were conducted with the help of a structured interview guide to elicit qualitative comments on each day's topic, content and methodology. Eleven experienced mental health professionals (3 psychiatrists, 3 psychiatric social workers, 2 psychologists and 2 psychiatric nurses and 1 mental health educationalist) were approached individually and the researcher presented the details of the programme to them using the medium of power point presentation. The average number of years of experience (SD) of the experts after their formal qualification was 19.5 (7.7) years. After presenting the details of one day's session, the researcher requested the mental health professionals to fill in their comments in the structured questionnaire on how applicable was the approach used and contents described for that day's session – before proceeding to the next day's session details. Through this methodology of content –

Table 1

Contents of the preliminary 10-day group training programme.

Day	Topic	Approach/model	Content
1	Myths about illness	Psycho-education	11 myths discussed
2	Information about schizophrenia	Psycho-education	Definition, magnitude, identification, symptoms, causes, treatment, relapse prevention, role of family
3	Patient's behaviour	Problem solving	Analyzing patient related problems through problem-solving: advantages–disadvantages approach
4	Socio-occupation	Behaviour modification	Activity scheduling, improving social skills
5	Marital and sexual	SWOT analysis	Weighing the strengths, weakness, opportunities, threats of marital and sexual problems, patient's understanding of marriage/role and responsibilities, laws related to marriage
6	Socio-economic benefits	Psycho-education	Employment, education, social security, affirmative action. Family support groups and laws related to schizophrenia
7	Health of caregivers	Supportive	Managing negative emotions, social support network
8	Health of caregivers	Supportive	Time chart analysis, planning for future, decision making, being physically fit (exercise, diet, sleep)
9	Homework revision	–	–
10	Role play (summary)	–	–

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