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Needs of Indian schizophrenia patients: an exploratory study from India

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Abstract

Background Although there are many studies from the West, no study has evaluated the needs of schizophrenia patients in Indian setting.

Methodology 100 consecutive patients of schizophrenia were assessed on Camberwell Assessment of Needs questionnaire. Same questionnaire was also administered to the caregiver to assess their perception about the needs of the patients.

Results Patients and their caregivers reported 8.12 and 7.13 needs, respectively, more than two-third of which were unmet. The most commonly reported needs by both patients and their caregivers were need for welfare benefits. Besides the welfare benefits, the four most common areas in which patients had needs and required help were—psychotic symptoms, psychological distress, information about the condition and money, whereas four most commonly reported area of needs reported by the caregivers were psychological distress, money, company and intimate relationships. Help provided by the government or non-governmental organizations was negligible.

Conclusions Most of needs of schizophrenia patients are unmet.

Keywords Schizophrenia · Needs

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Introduction

Schizophrenia, in India like the rest of the world, is a major mental health problem. Whether the patient is seen in acute or chronic phase of the illness, the patient and their caregivers exhibit a complex mixture of clinical and social needs. In India, where the population of patients with schizophrenia is sizeable and the resources to cope with this population are meagre, the importance of assessing the needs of the patients cannot be ignored particularly in the context of organisation of services or rehabilitation of the patients.

Needs of mentally ill subjects is a complex concept and accordingly its purpose determines its measurement. According to the Department of Health Social Services Inspectorate [11], need can be defined as the requirement of the individual patient to enable him to achieve, maintain or restore an acceptable level of social independence or quality of life. The assessment of needs provides the link between problems, action and evaluation, and has been put forth as an important dimension in planning, development and appraisal of psychiatric services and psychosocial rehabilitation [4, 6, 7, 16, 30]. Many different instruments have been developed to measure needs and these instruments differ in their content, format and aims. At a practical level these instruments also differ in the time required to complete them, their user friendliness, and the ease with the resulting data on 'need' can be integrated and analysed [12]. Three instruments which have been designed specifically to assess mental heath-care needs are: the Avon Mental Health Measure (AMHM) [3], the Cardinal Needs Schedule (CNS) [20] and the Camberwell Assessment of Needs (CAN) [29]. AMHM is an instrument that empowers the users and assists them in identifying and articulating their own needs. However, it more useful in clinical practice rather than research and one of its major limitations is that it encourages the users to give "open responses"; hence the data gathered cannot be aggregated to a population prospective [3]. On the other hand, CNS has a 'service oriented approach' and was specifically designed for use in research settings. It has a comprehensive battery of assessment scales to gather information from users, professionals and lay carers and measures the extent to which mental health services are failing to provide suitable care. However, the assessment process requires a lot of involvement, and hence it has not been used quite frequently in research settings [20]. CAN was designed to be used in both clinical and research settings. It recognizes the subjective nature of 'need' and emphasizes the importance of gathering information from both service users and staff carers. It is brief, simple to use and can be completed by a member of staff without training [29]. It is one of the commonest scales used to assess the needs of the patients with schizophrenia.

Over the years many studies from the West have assessed the needs in patients with schizophrenia and the mean number of needs reported by patients on Camberwell Assessment of Needs (CAN) has varied from 5.3 to 7.9 [5, 13, 14, 25, 26, 34, 35, 37].

In most studies the majority of needs expressed by the patients were met [25, 26, 37]; however, in some studies unmet needs reflected the mismatch between the demand and the supply. With regard to the type of needs, most consistently reported area of needs by the patients in various studies is the area of psychotic symptoms [5, 13, 18, 25, 26, 37], need for company [5, 13, 25, 26, 37], need for food [13, 25, 26], need of information about the illness [5, 25, 26], assistance in the area of house upkeep/looking after home [5, 25, 26, 37], need in the area of daytime activities [5, 13, 37], help in dealing with psychological distress [37] and need for intimate relations [37].

Consistently reported unmet needs include the areas of daytime activities [21, 25, 26, 37], company [21, 25, 26, 37], intimate relationship [25, 26, 37], information [21, 37], psychological distress [21, 37], physical health [37] and psychotic symptoms [21].

In studies which have assessed the needs from both patients and staff, there is no consistent pattern. In some studies staff reported more needs than patients [25, 26] and in others, patients reported more needs than staff [35]. However, there was no difference in the number of met needs reported by the staff and patients in these studies [25, 26, 35]. In a study which assessed the needs from the staff, the commonly reported needs of the patients as perceived by the staff were in the areas of psychotic symptoms, company, daytime activities, house upkeep, food and information [25, 26] and there was good level of agreement between rating of patients and staff (Kappa >0.8).

Most of the studies have not reported any correlation between number of needs and sociodemographic factors [5, 32]. However, some studies have reported that more needs are expressed by males [6, 23, 25, 26, 36], those who are unemployed [14] and increasing age [16, 21]. In terms of clinical variables, studies suggest that inpatients have more symptoms and more needs compared to the patients in the community [23].

Significant positive correlations have been reported between number of needs and severity of psychopathology [5, 14, 25, 26]. Positive correlations between number of needs and the type of psychopathology have also been reported—viz., disorganization and excitement [14, 25, 26], negative symptoms [14, 32] and affective symptoms [14]. Negative symptoms have also been related to social related needs like interpersonal relationship [23, 25, 26], administration of money, lack of education [25, 26], personal care, safety management, health management, social roles and daytime activities [23].

Only one study from India has till date reported the needs of the Indian psychotic patients. Chadda et al. [8] assessed the treatment and rehabilitation needs of 80 chronic psychiatric patients (schizophrenia, bipolar disorders, unspecified psychosis) and reported that there is need for development of community outreach programme, especially in the geographical locations where no psychiatric services are available, though no structured instrument seems to have been used by these authors.

In India majority of patients with schizophrenia are cared for in the community that to in the setting of the family to which they belong. Studies from our centre have shown that schizophrenia leads to high level of burden and distress in the caregivers of such patients [9, 10, 31]. It has also been shown that more than 95% of the cost of care of schizophrenia is borne by the family [15]. Hence, it is also important to understand the caregiver's perspective of the needs of the patients. Therefore, we felt that we should conduct this study to assess the needs of patients with schizophrenia and needs of the patients as perceived by their caregivers. As data from India on this subject of need assessment are not available, this study should be viewed as an exploratory study that has used a well-known instrument of need assessment from the West. It is hoped that such a study would help in understanding needs of patients in a better way and the data so generated would also aid in meaningful planning of psychosocial rehabilitation.

Materials and methods

The study was carried out at a multi-specialty teaching tertiary-care hospital providing services to a major area of North India. Our department of psychiatry is a general hospital psychiatric unit with inpatient and outpatient facilities in this multi-disciplinary teaching hospital. Although our hospital is a tertiary care centre, patients can walk-in the outpatient clinic on their own without any referrals. Most of the subjects diagnosed with schizophrenia are managed on outpatient basis and only few require admission.

This study is a cross-sectional study and utilises a sample of 100 consecutive schizophrenia patients attending the outpatient services.

Procedure

All the patients with a diagnosis of a psychotic illness were eligible for the study. They were evaluated by one of the consultant psychiatrists [PK, AA and PS (fourth author)] using a semistructured interview and it involved elicitation of information from patients and their caregivers on the following: sociodemographic variables, chief complaints, range of psychopathology, course of symptoms, possible relationship of psychopathology with any organic cause, presence of any comorbid physical illnesses, presence of any substance dependence and its relationship with psychopathology and application of ICD-10 criteria [38] for schizophrenia. Patients with co-morbid psychiatric disorder (life time and current based on history) and physical illnesses (based on physical examination and history) were excluded. Informed consent was obtained from the patients and/or relatives of the patient for participation in the study. However, a count of the excluded subjects was not kept and recruitment in the study was stopped when the desired sample of 100 was obtained. Cross-sectional assessment of psychopathology was done using the Scale for the Assessment of Positive Symptoms (SAPS) [1] and the Scale for the Assessment of Negative Symptoms (SANS) [2]. Needs of the patients, as reported by them and needs of the patients as reported by their caregivers were assessed by using the CAN [29]. CAN was chosen to assess the needs in the current study because it is brief, simple to use, provides information on needs which is subjective in nature and can be completed by a member of staff without training. The instrument was not adapted and was used as such because it was felt by the present investigators that CAN is a comprehensive instrument and as the study is an exploratory study in Indian setting, no adaptation or modifications were needed. It was also felt that using the instrument (CAN) unchanged would give us an opportunity to compare our results with the research findings of the western countries. The assessments of dysfunction [28], social support [24] and family burden [27] were done using instruments as mentioned. The instruments for the measurement of dysfunction, social support and family burden used in this study have been developed in India and are extensively used by researchers in India. The study was approved by the institute ethics committee.

Statistical analysis

The statistical analysis was done using the SPSS software package for windows, version 14.0 (SPSS Inc., Chicago, IL, USA). Descriptive analysis was computed in terms of mean and standard deviation with range for continuous variables and frequency with percentage for ordinal and nominal variables. Correlations between the needs and various sociodemographic variable, clinical variables, burden, social support and dysfunction were studied using the Pearson product moment correlation or Spearman's rank correlation. The agreement between the needs expressed by patients and caregivers was assessed by Cohen's kappa value.

Results

Socio-demographic characteristics of the patients and caregivers

Majority of the subjects with schizophrenia were males (61%) and had mean age of 34.09 (SD 11.0) years. Sixtysix percent of the patients had 10 years or more of formal education, 50% were married, majority (75%) were Hindus and 74% of them came from urban areas. Thirty-nine percent were employed, 30% were unemployed and rest were either home-makers or students. Sixty-one percent of the patients belonged to nuclear family and the rest belonged to joint families. The mean age of onset of the illness of the study sample was 25.62 (SD 6.20) years. More than half of the patients (54%) stayed within a radius of less than 40 km from the hospital.

Among the caregivers who participated in the study as primary caregivers, more than half of them (53%) were parents of the patients. Other caregivers who participated in the study were spouses (30%), sibling (13%) and children (4%). The mean age of the caregivers was 46.76 (SD 13.86) years.

Socio-clinical profile

The mean duration of illness of the subjects was 8.47 (SD 7.1) years. About two-third (67%) of the subjects had diagnosis of paranoid schizophrenia and the rest were non-paranoid in subtype. High scores on social support, dysfunction in all domains and family burden in all spheres indicate that the patients had low social support, were highly dysfunctional and the families carried moderately severe burden of care (Table 1).

Patients perspective of their needs

As per the CAN, the needs of the patients were rated as 0, 1 and 2. If any patients did not respond to the query about the need and it was coded as 9. However for analysis, 9 was recoded as 0. For the areas in which patients reported met or unmet needs, their level of satisfaction with the help received from either formal or informal sources was assessed.

A glance at Table 2 brings out the perspective of the patients in relation to their felt needs. The mean number of needs reported by patients was 8.12 (SD 4.17), of which more than two-third (5.69 \pm 4.00) were unmet needs and only a minority (2.43, SD 2.48) of needs were either met by the caregivers or other agencies. The most commonly reported area of needs by the patients were need for welfare benefits (79%), psychotic symptoms (76%), psychological distress (74%), information about the condition and the treatment (64%), money (60%), company (57%), daytime activities (54%) and intimate relationships (52%). Patients did not feel that they had much needs in the domains of alcohol (5%), safety to self (14%), food (16%), telephone (17%), accommodation (20%) and transport (21%). Other areas of needs of the CAN such as drugs, childcare, sexual expression, safety to others, basic education, self-care, household skills and physical health had moderate rates of endorsement. Important aspect of the needs identified by the patients was that majority of these were not met by either informal or formal services available to them. The main areas of needs where formal or recognized services

 Table 1
 Scores on psychopathology, social support, dysfunction and family burden

Variables	Mean	SD
1. SAPS score (global)	1.98	2.91
2. SANS score (global)	5.14	5.71
3. Social support	47.30	7.54
4. Dysfunction analysis questionnaire sco	res	
Social	65.63	20.21
Vocational	65.00	21.93
Personal	63.89	17.14
Family	65.56	18.88
Cognitive	60.66	17.35
5. Family burden		
Financial	4.75	3.91
Disruption of family routine	4.66	3.58
Disruption of family leisure	3.10	2.84
Disruption of family interaction	3.51	3.32
Effect on health physical of others	0.95	1.34
Effect on mental health of others	1.56	1.40

provided some level of help were psychotic symptoms, psychological distress, information about condition and treatment and physical symptoms. For other areas of needs, family and friends (informal sources) were the main help. However in most areas of reported needs, majority of the subjects were not satisfied by the help received (See Table 2).

Relatives' perspective of the needs

The mean number of needs reported by caregivers was 7.13 (SD 3.86), of which more than two-third (5.05, SD 3.72) were unmet needs and only a minority (2.08, SD 2.10) of needs were met by the caregivers or other agencies. The most commonly reported areas of needs by the caregivers were need for welfare benefits (83%), psychological distress (67%), money (62%), company (50%), intimate relationships (48%), psychotic symptoms (44%), physical health (43%) and information about condition and treatment (43%). In common with areas of needs identified by the patients, the majority of needs identified by the caregivers were not met by either informal or formal services available to them. The relatives did not perceive the patients to have meaningful or pressing needs in the areas of alcohol, safety to others, food, accommodation, drugs, telephone, transport and basic education.

The main areas of needs where the formal services provided some level of help were psychotic symptoms, psychological distress, information about the condition and treatment, and physical symptoms. For other areas of needs, family and friends (informal sources) were the main help. As was the case with the patients, significant proportion of relatives were not satisfied with the help received by the patients in the areas of the needs (See Table 3). The relatives were also partly satisfied by the help provided by the government and the NGOs in the areas of psychotic symptoms, information about the condition and the treatment and physical health. The government and the NGOs were seen to be dismal in providing help with regard to money or welfare benefits.

The relatives also endorsed that although they provided help to the patients, they themselves were not able to meet most of the needs of the patients and particularly so in the areas of accommodation, household skills, intimate relationships, basic education and telephone (Table 3).

Relationship of needs with sociodemographic and socio-clinical profile (Tables 4 and 5)

Correlation analyses were carried out to see the relationship of needs with sociodemographic variables, clinical variables, severity of psychopathology, social support,

Table 2 Needs of the patients as perceived by themselves (N = 100)

Areas of needs	Met needs	Unmet needs	Help received from informal sources			Help received from formal sources			Not satisfied with the help received	
			Low	Moderate	High	No	Low	Moderate	High	N [%] ^b
1. Accommodation	03	17	13	07	_	20	_	_	_	19 [95]
2. Food	06	10	12	04	_	16	_	-	_	15 [93.75]
3. Household skills	17	13	23	07	_	30	-	-	_	27 [90]
4. Self-care	13	15	20	08	-	28	_	-	_	24 [85.71]
5. Daytime activities	11	43	47	07	-	54	_	-	_	54 [100]
6. Physical health	22	20	31	10	01	12	12	13	05	29 [69.04]
7. Psychotic symptoms (care and coping)	17	59	42	28	06	07	15	47	07	55 [72.36]
8. Information about condition and treatment ^a	17	47	46	19	_	07	12	36	10	48 [75.00]
9. Psychological distress	22	52	31	39	04	09	23	38	04	58 [78.37]
10. Safety to self	06	08	11	05	_	14	_	_	_	12 [85.71]
11. Safety to others	02	02	04			04	_	_	_	02 [50]
12. Alcohol	03	02	05		_	05	_	_	_	02 [40]
13. Drugs	04	18	16	05	_	04	04	13	01	16 [72.72]
14. Company	24	33	34	18	05	57	_	_	_	37 [64.91]
15. Intimate relationships	18	34	29	18	05	52	_	_	_	40 [76.92]
16. Sexual Expression	04	24	19	05	04	28	_	_	_	21 [84]
17. Child care	05	19	14	08	02	23	_	_	_	20 [83.33]
18. Basic education	08	17	19	06		25	_	_	_	21 [84]
19. Telephone	09	08	15	02		17	_	-	_	15 [88.23]
20. Transport	07	14	19	02		21	_	_	_	20 [95.23]
21. Money	13	47	36	23	01	59	01	_	_	58 [96.66]
22. Welfare benefits	12	67	00	_	_	67	12	_	_	79 [100]

^a For this area one patient had rating of '9'

^b The figures in the parenthesis represent the lack of satisfaction in the areas of needs, with what ever help being received from formal or informal sources. For each area the denominator was the sum total of met and unmet needs

burden and dysfunction (See Table 4). Among the sociodemographic variables, only gender and family type had correlation with needs. Male patients had more met needs and more total number of needs. Patients belonging to non-nuclear families had more needs. More needs were expressed by patients who had longer duration of illness. Patients with poor social support had more number of unmet needs and total needs. Similarly, compared to nonparanoid subtype, patients of paranoid subtype had more needs. It was also seen that total needs (met and unmet) and unmet needs had positive correlation with burden and level of dysfunction. No other sociodemographic and clinical variables had significant correlation with needs.

Unmet needs and total needs as perceived by relatives also had significant positive correlation with the dysfunction and burden. Patients with poor social support had more number of unmet needs and total needs as perceived by caregivers. However, it was seen that caregivers of younger patients expressed less number of unmet and total needs. Further, caregivers as parents expressed less number of unmet needs. Patients, who had more severe illness measured in terms of SAPS and SANS, had higher number of unmet and total needs (See Table 5).

Agreement between the needs of the patients as perceived by themselves and their relatives

Moderate levels of agreement (0.41–0.60) between the needs as perceived by patients and their relatives in the areas of accommodation, food, alcohol, drugs and transport are evident from Table 6. For other areas, the level of agreement between the patients and relatives was poor.

Discussion

The present study was carried out on a sample of consecutive patients with schizophrenia attending psychiatric services of a tertiary care hospital in north India. These patients had been ill for a considerable period of time and had high scores on psychopathology and dysfunction. They

Table 3 Needs of the patients as perceived by the relatives (N = 100)

Areas of needs	Met needs	Unmet needs	Help received from informal sources			Help received from formal sources			Not satisfied with the help received	
			Low	Moderate	High	No	Low	Moderate	High	N [%] ^b
1. Accommodation	03	11	08	06	_	14	_	_	_	11 [78.57]
2. Food	02	11	10	03	_	13	_	-	_	00
3. Household skills	13	14	11	09	04	27	-	-	_	23 [85.18]
4. Self care	10	21	08	17	05	31	-	-	_	00
5. Daytime activities	08	30	19	16	03	38	-	-	_	00
6. Physical health	18	25	33	08	02	07	13	14	09	31 [72.09]
7. Psychotic symptoms (care and coping)	16	28	18	14	03	07	08	22	08	25 [56.81]
8. Information about condition and treatment ^a	16	27	24	04	-	06	13	18	06	30 [69.76]
9. Psychological distress	19	48	28	34	05	22	08	34	03	00
10. Safety to self	01	07	03	03	02	08	-	-	_	05 [62.5]
11. Safety to others	02	03	02	03	-	05	-	-	_	00
12. Alcohol	03	02	03	02	_	05	-	-	_	03 [60]
13. Drugs	01	14	04	11	-	11	04	-	_	00
14. Company	16	34	08	14	11	50	-	-	_	00
15. Intimate relationships	14	34	25	19	04	48	-	-	_	40 [83.33]
16. Sexual expression	12	13	16	06	03	25	-	-	_	19 [76]
17. Child care	07	23	06	17	07	29	01	-	_	00
18. Basic education	07	15	22	-	-	22	-	-	_	19 [86.36]
19. Telephone	07	12	19	-	-	19	-	-	_	18 [94.73]
20. Transport	05	16	15	06	-	21	-	-	_	00
21. Money	14	48	42	20	_	30	-	-	_	50 [80.64]
22. Welfare benefits	14	69	00	-	_	62	21	-	_	62 [74.69]

^a For this area 1 caregivers had rating of '9'

^b The figures in the parenthesis represent the lack of satisfaction in the areas of needs, with what ever help being received from formal or informal sources. For each area the denominator was the sum total of met and unmet needs

also had low level of perceived social support. Thus, it is apparent that the patients had moderately severe illness. However, the study sample does not claim to represent schizophrenia patients in the community.

The rates of endorsement of various domains of needs by the patients and their relatives make interesting reading. In the context of paucity of resources as well as the general state of economic condition of our country, high rate of endorsement of these needs is understandable.

The mean number of needs reported by patients in our study was 8.12, out of which more than two-third were unmet needs. This is more than the number of needs (5.3–7.9) reported in studies from the West [5, 11, 12, 25, 26, 34, 35, 37]. Further, in contrast to the western literature, where majority of needs expressed by the patients were met [25, 26, 35], in our study about two-third of needs were unmet by available sources. Again, contrary to the findings of a study from the west [25] a higher number of subjects expressed the need for daytime activities in our study. This could be a reflection of the state of services for the care of chronically ill schizophrenia subjects in our country and

almost non-existent system of social services including social security system. At most places in our country, management of such cases involves prescription of psychotropic medications and providing education about the illness. Invariably, rehabilitations issues are not addressed and it is left to the family to take care of these concerns. Need for welfare benefits, the most common need reported by both patients and their caregivers, aptly reflects the low priority given to such concerns in the state policy. This is in contrast to the western literature [33], where need for welfare benefits is not one of the commonly reported needs of the patient.

In western literature, most consistently reported area of needs by the patients is psychotic symptoms [5, 13, 18, 25, 26, 37]. In our study we also found that need for help for psychotic symptoms were among the most commonly reported need by the patients. Our findings of needs in the areas of psychological distress, information (about the condition and the treatment), company, and intimate relationships in more than half of the subjects is in agreement with the western literature [5, 13, 25, 26, 37]. Consistency

Table 4 Correlates of needs of patients as perceived by themselves (N = 100)

	Total met needs	Total unmet needs	Total needs
Gender ^a	-0.212*		-0.227*
Family type ^a			0.198*
Duration of illness			0.201*
Social support		-0.274**	-0.360**
Paranoid subtype ^a			-0.219*
Dysfunction analysis questionnaire	scores		
Vocational		0.294**	0.367**
Personal		0.278**	0.329**
Family		0.288**	0.336**
Cognitive		0.298**	0.361**
Family burden			
Financial		0.351**	0.418**
Disruption of family routine		0.275**	0.268**
Disruption of family leisure		0.330**	0.309**
Disruption of family interaction		0.195	0.203*
Effect on health physical of others		0.339**	0.318**
Effect on mental health of others		0.341**	0.372**
Subjective burden		0.355**	0.406**
Total burden		0.361**	0.378**

^a The values shown in the table are Spearman's rank correlation value, for other variables the values shown in the table are Pearson's product moment correlation values

* P < 0.05 and ** P < 0.01

in the presence of these needs in patients across culture reflects the nature of the disorder and its impact on patient's social life.

The main areas of needs where formal services provided some level of help were psychotic symptoms, psychological distress, information about condition and treatment and physical symptoms. This further suggests that there is lack of rehabilitation facilities in our country and only the treatment needs (i.e. prescription of antipsychotics, information about condition and treatment and physical symptoms) were fulfilled to some extent. For other areas of needs, the family and friends (informal sources) were the main help. This also suggests that the family is the main source of care of schizophrenia patients and bears major burden of care. However, the lack of satisfaction with the help received by majority of the subjects who reported needs in our study is worth noting. This suggests that although family and treating agencies played their part in caring for the patient, there is scope to improve the level of care provided to patients with schizophrenia.

No study from the west has reported the number of needs reported by the relatives as caregivers. We found that mean number of needs reported by caregivers was 7.13, out of which more than two-third were unmet needs and the most commonly reported area of needs by the caregivers were need for welfare benefits, money, psychological distress, company, intimate relationships, psychotic symptoms, physical health and information about condition and treatment. The relatives did not perceive the patients to have meaningful or pressing needs in the areas of food, accommodation, drugs, telephone, transport, basic education, household skills and child care. The relatives also endorsed that although they provided help to the patients, they themselves were not able to meet most of the needs of the patients and particularly so in the areas of accommodation, household skills, intimate relationships, basic education and telephone.

These findings make an appealing reading in the context of our sociocultural milieu and more so as more than half of the caregivers were parents. In our country, it is culturally recognized that it is the moral responsibility of parents to provide a safe environment to their children and to fulfil their emotional and materialistic needs. Accommodation and food were not recognized as frequently expressed needs possibly because of the fact that all our patients lived in the community with their families. Hence, available accommodation and food were thought of as shared facilities and patients or the relatives did not feel independent need of these. The endorsement of the caregivers of lack of satisfaction also suggests that despite their best efforts they are not able to meet the needs of their patients thus underscoring the need to develop good rehabilitation and community-based interventions.

The perception of needs by patients themselves and their caregivers differed to some extent. The need for welfare benefits was identified as the most important need by both the patients and their caregivers. The patients and their relatives also shared the recognition of needs in the domain of psychological distress, money and company of others among the most frequently endorsed needs. However, whereas the patients identified needs of information about the condition and treatment as amongst the top five needs, their relatives did not share this perception. Instead, the relatives identified needs in the areas of intimate relationships as more pressing. This need along with need for company was also perceived to be the common unmet needs by the patients as well but they had assigned somewhat lower priority to these needs. The patients also identified unmet needs in the sphere of daytime activities as one of their most frequently unmet need, a perception that was not shared by their relatives. Thus, it is obvious that the patients and the relatives disagree with regard to unmet needs. In a comparative study of need assessment, Hansson et al. [17] made similar observations though they had compared ratings of needs by key worker and the patients.

Table 5 Correlates of needs of patients as perceived by caregivers (N = 100)

 Table 6
 Agreement between needs as perceived by the patients and relatives

	Total unmet needs	Total needs
Age of patients	-0.222*	-0.209*
Parents ^a	-0.235*	-0.247*
SAPS global	0.380**	0.355**
SANS global	0.367**	0.307**
Social support	-0.208*	-0.233*
Dysfunction analysis questionnaire sco	res	
Social	0.253*	0.244*
Vocational	0.309**	0.340**
Personal	0.289**	0.343**
Family	0.292**	0.318**
Cognitive		0.229*
Family burden		
Financial	0.270*	0.338**
Disruption of family routine	0.424**	0.436**
Disruption of family leisure	0.366**	0.435**
Disruption of family interaction	0.324**	0.391**
Effect on health physical of others	0.305**	0.344**
Effect on mental health of others	0.213*	
Subjective burden	0.361**	0.417**
Total burden	0.390**	0.452**

^a The values shown in the table are Spearman's rank correlation value, for other variables the values shown in the table are Pearson's product moment correlation values

* P < 0.05 and ** P < 0.01

Slade et al. [35] and Middelboe et al. [22] have made similar observations too.

Correlation analysis suggests more needs were expressed by male patients, patients who had longer duration of illness and those who belonged to non-nuclear families. Significantly more number of needs of male patients were met compared to female patients. Caregivers of younger patients expressed less number of unmet and total needs. These correlations can be understood in our socio-cultural background, where males are given preference and usually parents try to meet demands of their male children more often compared to female children. Correlations of more needs with longer duration of illness and presence of less needs in younger patients possibly reflects that as the patients become older and continue to have residual symptoms, they become more burdensome on the caregivers, whose resilience is also on decline with their own increasing age. Hence, the caregivers of older patients express more number of needs. Patients and their caregivers with poor social support had more number of unmet needs and total needs. This suggests that the rehabilitation programmes should be planned with the aim of improving

Areas of needs	Cohen's Kappa
1. Accommodation	0.521
2. Food	0.572
3. Household skills	0.376
4. Self care	0.003
5. Daytime activities	0.272
6. Physical health	0.258
7. Psychotic symptoms (care and coping)	0.321
8. Information about condition and treatment	0.278
9. Psychological distress	0.310
10. Safety to self	0.183
11. Safety to others	0.166
12. Alcohol	0.526
13. Drugs	0.544
14. Company	0.388
15. Intimate relationships	0.278
16. Sexual expression	0.316
17. Child care	0.382
18. Basic education	0.323
19. Telephone	0.399
20. Transport	0.457
21. Money	0.239
22. Welfare benefits	0.340

social support for the patients of schizophrenia. Compared to non-paranoid subtype, patients of paranoid subtype had more needs. This can be understood in the light of relatively more preserved personality in paranoid subjects in contrast to non-paranoid subjects. The total needs and unmet needs expressed by caregivers had correlation with severity of psychopathology. It was also seen that total needs (met and unmet) and unmet needs as expressed by patients or their caregivers had positive correlation with burden and level of dysfunction. This suggests that adequate control of psychopathology, which will also reduce the burden on the caregivers and dysfunction of the patients is a must to reduce the number of needs of patients.

Even though ours is an exploratory study, it does highlight that needs exist and that the government and NGOs are not viewed as satisfactory help providers. This has implication for management of the patients and their psychosocial rehabilitation. The government and the NGOs ought to have inputs that are meaningful and in keeping with the aspirations of the patients and their relatives. The government and NGO's need to develop facilities focusing on the rehabilitation needs of the patients, provide free treatment for the psychotic symptoms and psychological distress which would also decrease the need for the money. These agencies should device mechanisms for employment of mentally ill subjects and should give some monetary help in the form of pension to the mentally ill subjects. In these respects, our study can be helpful by identifying the needs of the patients and their caregivers. In the absence of such supportive measures, constructive management and psychosocial rehabilitation of the patients in India would remain elusive. Amidst various controversies, outcome of schizophrenia has been reported to be better in developing countries like India compared to the western countries [19]; this is despite poor rehabilitation and social service network. Addressing the needs of the patients and caregivers can help organization of services to match the demand and would also give an opportunity to compare the outcome of schizophrenia in comparable settings.

Ours was an exploratory study which evaluated the needs of subjects with schizophrenia using CAN. Results of our study should be interpreted in the light of the fact that we used CAN, which is an instrument developed in the Western set up, in its original form to assess the needs, and this instrument has not been validated in India. Hence, the needs reported by the patients and caregivers are limited to the areas covered by this instrument and in a country like ours, there may be other felt needs which are not addressed to by CAN.

Future studies should evaluate the needs of the patients with schizophrenia in larger sample including subjects living in the community and also those requiring inpatient care. There is a genuine need to develop instruments to evaluate the needs of subjects with schizophrenia especially the rehabilitation and financial needs with particular emphasis on Indian socio-economic-cultural context so that services can be organized according to the requirements of Indian patients and their caregivers.

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References

- 1. Andreasen NC (1983) Scale for the assessment of negative symptoms (SANS). University of Iowa, Iowa City
- 2. Andreasen NC (1984) Scale for the assessment of positive symptoms (SAPS). University of Iowa, Iowa City
- Avon Measure Working Group (1996) The Avon mental health measure. A user centred approach to assessing need. MIND, London
- Barrowclough C, Marshall M, Lockwood A, Quinn J, Sellwood W (1998) Assessing relatives' needs for psychosocial interventions in schizophrenia: a relative's version of the Cardinal Needs Schedule (RCNS). Psychol Med 28:531–542
- Bengtsson-tops A, Hansson L (1999) Clinical and social needs of schizophrenic outpatients living in the community: the

relationship between needs and subjective quality of life. Soc Psychiatry Psychiatr Epidemiol 10:513–518

- Brewin CR, Wing JK, Mangen SP, Brugha TS, Maccarthy B (1987) Principles and practice of measuring needs in the longterm mentally ill: the MRC needs for care assessment. Psychol Med 17:971–981
- Brewin CR (1992) Measuring individual needs for care and services. In: Thornicroft G, Brewin CR, Wing JK (eds) Measuring mental health needs. Gaskell, London, pp 220–236
- Chadda RK, Pradhan SC, Bapna JS, Singhal R, Singh TB (2000) Chronic psychiatric patients: an assessment of treatment and rehabilitation-related needs. Int J Rehabil Res 23:55–58
- Chakrabarti S, Kulhara P (1999) Family burden of caring for people with mental illness. Letter to Editor. Br J Psychiatry 174:463
- Chakrabarti S, Raj L, Kulhara P, Avasthi A, Verma SK (1995) A comparison of the extent and pattern of family burden in affective disorders and schizophrenia. Indian J Psychiatry 37:105–112
- Department of Health Social Services Inspectorate (1991) Care management and assessment: summary of practice guidance. HMSO, London
- Evans S, Greenhalgh J, Connelly J (2000) Selecting a mental health needs assessment scale: guidance on the critical appraisal of standardized measures. J Eval Clin Pract 6:379–393
- Foldemo A, Bogren L (2002) Need assessment and quality of life in outpatients with schizophrenia: a 5-year follow-up study. Scand J Caring Sci 16:393–398
- Grinshpoon A, Ponizovsky AM (2008) The relationships between need profiles, clinical symptoms, functioning and the well-being of inpatients with severe mental disorders. J Eval Clin Pract 14:218–225
- Grover S, Avasthi A, Chakrabarti S, Bhansali A, Kulhara P (2005) Cost of care of schizophrenia: a study of Indian outpatient attenders. Acta Psychiatr Scand 112:54–63
- 16. Hansson L, Bjorkman T, Svensson B (1995) The assessment of needs in psychiatric patients: interrater reliability of the Swedish version of the Camberwell Assessment of Needs instrument and results from a cross-sectional study. Acta Psychiatr Scand 92:285–293
- 17. Hansson L, Vinding HR, Mackeprang T, Sourander A, Werdelin G, Bengtsson-Tops A et al (2001) Comparison of key worker and patient assessment of needs in schizophrenic patients living in the community: a Nordic multicentric study. Acta Psychiatr Scand 103:45–51
- Kovess-Masféty V, Wiersma D, Xavier M, de Almeida JM, Carta MG, Dubuis J et al (2006) Needs for care among patients with schizophrenia in six European countries: a one-year follow-up study. Clin Pract Epidemol Ment Health 2:22
- Kulhara P, Shah R, Grover S (2009) Is the course and outcome of schizophrenia better in the 'developing' world? Asian J Psychiatry 2:55–62
- Marshall M, Lockwood A, Gath A (1995) Social services case management for long term mental disorders: a randomized controlled trial. Lancet 345:409–412
- Middelboe T, Mackeprang T, Hansson L, Werdelin G, Karlsson H, Bjarnason O et al (2001) The Nordic study on schizophrenic patients living in the community. Subjective needs and perceived help. Eur Psychiatry 16:207–214
- 22. Middelboe T, Mackeprang T, Thalsgaard D, Christiansen PB (1998) A housing support programme for the mentally ill: need profile and satisfaction among users. Acta Psychiatr Scand 98:321–327
- 23. Nakanishi M, Setoya Y, Kodaka M, Makino H, Nishimura A, Yamauchi K et al (2007) Symptom dimensions and needs of care among patients with schizophrenia in hospital and the community. Psychiatry Clin Neurosci 61:495–501

- Nehra R, Kulhara P (1987) Development of a scale for the assessment of social support. Initial tryout in Indian setting. Indian J Soc Psychiatry 4:353–359
- 25. Ochoa S, Haro JM, Autonell J, Pendàs A, Teba F, Màrquez M et al (2003) Met and unmet needs of schizophrenia patients in a Spanish sample. Schizophr Bull 29:201–210
- Ochoa S, Haro Jm, Usall J, Autonell J, Vicens E, Asensio F et al (2005) Needs and its relation to symptom dimensions in a sample of outpatients with schizophrenia. Schizophr Res 75:129–134
- Pai S, Kapoor RL (1981) The burden on the family of a psychiatric patient: development of an interview schedule. Br J Psychiatry 138:332–335
- Pershad D, Verma SK, Malhotra A (1985) Measurement of dysfunction and Dysfunction Analysis Questionnaire. National Psychological Corporation, Agra
- 29. Phelan M, Slade M, Thornicroft G, Dunn G, Holloway F, Wykes T et al (1995) The Camberwell Assessment of Need: the validity and reliability of an instrument to assess the needs of people with severe mental illness. Br J Psychiatry 167:589–595
- Pryce IG, Griffiths RD, Gentry RM, Hughes IC, Montague LR, Watkins SE et al (1993) How important is the assessment of social skills in current long-stay in-patients? Br J Psychiatry 162:498–502
- Raj L, Kulhara P, Avasthi A (1991) Social burden of positive and negative schizophrenia. Int J Soc Psychiatry 37:242–250

- 32. Ruggeri M, Leese M, Slade M, Bonizzato P, Fontecedro L, Tansella M (2004) Demographic, clinical, social and service variables associated with higher needs for care in community psychiatric service patients. The South Verona Outcome Project 8. Soc Psychiatry Psychiatr Epidemiol 39:60–68
- Simons L, Petch A (2002) Needs assessment and discharge: a Scottish perspective. J Psychiatr Ment Health Nurs 9:435–445
- 34. Slade M, Phelan M, Thornicroft G, Perkman S (1996) The Camberwell Assessment of Need (CAN): comparison of assessment by staff and patients of the needs of the severely mentally ill. Soc Psychiatry Psychiatr Epidemiol 31:109–113
- 35. Slade M, Phelan M, Thornicroft G (1998) A comparison of needs assessed by staff and by an epidemiologically representative sample of patients with psychosis. Psychol Med 28:543–550
- Usall J, Haro JM, Ochoa S, Márquez M, Araya S (2002) Needs of patients with schizophrenia group. Influence of gender on social outcome in schizophrenia. Acta Psychiatr Scand 106:337–342
- 37. Wiersma D, Nienhuis FJ, Giel R, Slooff CJ (1998) Stability and change in needs of patients with schizophrenic disorders: a 15and 17-year follow-up from first onset of psychosis, and a comparison between 'objective' and 'subjective' assessments of needs for care. Soc Psychiatry Psychiatr Epidemiol 33:49–56
- World Health Organization (1992) Tenth revision of the international classification of diseases and related health problems. Clinical descriptions and diagnostic guidelines. World Health Organization, Geneva