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An examination of patient-identified goals for treatment in a first-episode program in Chennai, India

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Abstract

Aim—Our objective was to describe the goals identified by patients upon entering a specialized program for treatment of first-episode psychosis (FEP) in Chennai, India.

Methods—68 patients with FEP completed the Goal Attainment section of the Wisconsin Quality of Life – Client Questionnaire upon entry into treatment. Patients were asked to identify a maximum of three treatment goals and rate each identified goal on its importance and the extent of its achievement.

Results—In the order of frequency of endorsement, the primary goals identified pertained to work, family/interpersonal relationships, education, , symptom relief and psychological recovery, living condition, religion, finances, and household responsibilities. All patients identified at least one goal; 41 patients identified two goals; and 11 patients identified three goals.

Conclusion—Individuals with FEP in India present with a range of realistic and reasonable goals. Findings have implications for improving early intervention services in India by targeting patient-identified goals.

Keywords

Early psychosis; goals; psychotic disorders; schizophrenia; treatment

INTRODUCTION

Personal goals play an important role in the attainment of a subjective sense of well-being by lending people a sense of purpose, direction and meaning.[1,2] Psychotherapy research has increasingly focused on the goals of patients.[3] In contrast, an area in which the personal goals of patients have not been accorded the import they merit is psychosis research. This is especially discordant because identifying goals and linking them to treatment is part of best practice guidelines for the treatment of schizophrenia.[4] Several interventions for psychosis

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including psychiatric rehabilitation, cognitive behaviour therapy and social skills training also revolve around the self-reported goals of patients.[5,6]

An important aspect of most specialized treatment programs for first-episode psychosis (FEP) is working on goals that patients identify collaboratively with their case managers.[7,8, 9] The rationale behind this is to promote therapeutic alliance and service engagement. In addition to identifying treatment goals, it is recommended that the importance and level of attainment of these goals, as perceived by the patient, also be evaluated.[10,11] The goals identified by patients can influence quality of life, and perhaps even medication and treatment adherence.[12,13] Yet, few studies have examined the self-identified goals of patients with psychosis.

Patients' ideas of what constitutes recovery may be very different from those subscribed to by clinicians.[14] Understanding the patients' own goals better can help us devise more effective treatment strategies and services and facilitate the attainment of recovery, especially as it is defined by patients.

The objectives of the current study were to identify and describe the treatment goals of patients with FEP upon entry into a specialized clinical program in Chennai, India and to investigate how patients themselves evaluate the importance of these goals and the level of their attainment. What makes such research particularly relevant is that there are few studies assessing patient perceptions in India.[15] Patient perspectives must be studied not only because doing so helps make treatment services more responsive to patient-identified needs and goals, but more importantly, because it gives service users a voice.[16]

METHODS

Treatment Setting

This study included participants from the First-Episode Clinic in Chennai which is part of the Schizophrenia Research Foundation (SCARF). SCARF is a non-governmental organization located in the southern Indian metropolis of Chennai and provides mental health services to a non-delineated geographic region. At SCARF, persons with FEP receive intensive case management, psychoeducation, community outreach, family interventions, pharmacological treatment, and close monitoring of symptoms and functioning for over two years. Most of the First-Episode Clinic's patients are recruited through the outpatient clinic at SCARF, where services are provided largely free of charge.

Inclusion and Exclusion Criteria

Inclusion criteria were (1) a DSM-IV[17] diagnosis of a schizophrenia-spectrum psychotic disorder (schizophrenia, schizophreniform disorder, schizoaffective disorder, delusional disorder, and psychosis not otherwise specified), (2) patients must not have received previous antipsychotic therapy for more than 30 days, and (3) patients must be willing and able to provide informed consent for participation in assessments. Exclusion criteria were (1) a history of organic mental disorder such as epilepsy, and (2) a primary diagnosis of mood disorder or substance-induced psychosis.

Assessment Protocol

Ethics approval was obtained for the use of a comprehensive assessment protocol in the first-episode clinic at SCARF. This report uses data from some of the assessments in this protocol. A shortened version of the Circumstances of Onset and Relapse Schedule (CORS[18–20]) was used to estimate the duration of untreated psychosis (DUP). DUP was defined as the time (in weeks) between the onset of the presenting psychotic episode and the

commencement of continuous antipsychotic treatment. The Positive and Negative Syndrome Scale (PANSS[21]), an instrument well-established in psychiatric research in India[22–25], was used to assess symptoms upon entry. This 30-item instrument yields scores for overall psychopathology, positive symptoms of psychosis, negative symptoms of psychosis, and general psychopathology.

To assess goals, the Goal Attainment section of the Wisconsin Quality of Life – Client Questionnaire[26] was used. The main question in this section is "What do you hope to accomplish as a result of your mental health treatment? Please write below up to 3 goals". The patient is then instructed to rank each identified goal in terms of its importance and level of attainment on a 1 to 10 scale with 1 being "not at all important" or "not at all achieved" and 10 being "extremely important" or "completely achieved". This section was self-administered when possible. In other cases, patients were assisted by a trained research assistant who clarified doubts, read questions aloud, and/or wrote down responses.

Data analysis

For purposes of analysis, patient-identified goals were grouped into thematic categories independently by the first author and two research assistants. As a second step, a final list of thematic categories (N = 8) was arrived at by consensus between these three raters. Finally, the patient-identified goals were re-sorted into one of the eight categories separately by the three raters. The mean percent agreement was 96.11%. Where there was lack of agreement, the goal was sorted into the category that was chosen by two out of the three raters. The frequency of endorsement of each of these categories was calculated for the first, second and third goals listed. The self-rated importance of and level of attainment with respect to each thematic goal category was also evaluated by using the mean, standard deviation and minimum and maximum ratings. Chi-square analyses and t-tests were used to establish if gender, age and DUP had any impact on the frequency distribution and importance and attainment ratings of patient-identified goals.

RESULTS

Out of 93 patients screened for eligibility from January 2004 until January 2006, 75 patients met the inclusion criteria; and 73 consented to the assessment protocol. Data were missing for five subjects – four who refused to participate in treatment and one who did not complete the assessment. Complete data were therefore available for 68 patients. Detailed sociodemographic and clinical characteristics are presented in Table 1. Most of the patients recruited were young with the mean and median age being 28.79 and 27, respectively.

All patients identified at least one goal; 41 patients identified two goals; and 11 patients identified three goals. A total of 120 goals were identified by the patients. Eight categories emerged after thematically grouping patient-identified goals. These included: work (e.g., get a job, resume working, join the family business); school (e.g., finish studies, study computer science); close family/interpersonal relationships (e.g., take care of my child, live happily with husband); symptom relief and psychological recovery (e.g., get rid of this anxiety, to have peace of mind); living situation (e.g., to live alone, to go back to own house); religious goals (e.g., to visit a pilgrimage site); financial goals (e.g., to settle my debts); and household responsibilities (e.g., to do my household chores well). Tables 2 and 3 pertain to the first and second goals identified by patients.

As seen in Table 2, a majority of the clients (38.2%) identified an employment-related goal as the primary goal they would like to achieve through treatment. Other goals identified by at least 10% of the sample, in order of frequency of endorsement, were goals pertaining to close family and interpersonal relationships, school, and symptom relief and psychological

recovery. Most of the goals identified were perceived as being very important by the patients, with the mean level of importance ranging from 8.46 to 10. Almost all patients felt that they had not achieved or achieved to a very limited extent their primary goal, with the mean level of achievement ranging from 1.75 to 4.91.

As seen in Table 3, goals pertaining to close family or interpersonal relationships and employment were also the patients' most frequently identified second goals. Again, patients generally rated their second goal highly in terms of importance (means ranging from 8.33 to 9.8) and low in terms of attainment (means ranging from 2.78 to 4).

With respect to the third goal, six clients identified a goal pertaining to their close family (importance: Mean = 9.5, SD = .55; attainment: Mean = 2.33, SD = 1.97). Two clients identified job-related goals (importance: Mean = 10, SD = 0; attainment: Mean = 3, SD = 2.83). Two other clients identified religion-related goals (importance: Mean = 7, SD = 1.41; attainment: Mean = 4, SD = 0). One client listed an educational objective (10 and 1 for importance and achievement, respectively).

Do patient characteristics influence goals?

Chi-square analyses were used to evaluate if gender, age (less or more than the median of 27 years) and DUP (less or more than the median of 8 weeks) had any impact on the frequency distribution of the goals pertaining to work and close family that were most frequently identified as the first goal.

With respect to work, gender and DUP had no impact ($\chi^2(1) = 0.59$, $p = 0.44$ and χ^2 (1) = 0.13, p = 0.72, respectively); younger patients were more likely to report their top goal as being work-related ($\chi^2(1) = 5.31$, $p = 0.02$). With respect to goals involving close family, DUP had no impact ($\chi^2(1) = 0.02$, $p = 0.88$); women and older patients were more likely to endorse close family-related goals as their top goal (χ^2 (1) = 6.31, $p = 0.01$ and χ^2 (1) = 6.37, $p = 0$ .01, respectively).

There were no differences in importance and attainment ratings of work-related goals based on gender ($t(23.03) = 1.4$, $p = 0.18$ and $t(21.31) = 0.4$, $p = 0.69$, respectively), age ($t(12.55) = 0.75$, $p = 0.47$ and $t(13.17) = 0.75$, $p = 0.47$, respectively) and DUP ($t(20.45) = 0.53$, $p = 0.60$ and $t(22.41) = 0.81$, $p = 0.43$, respectively). Similarly, gender ($t(1.05) = -0.45$, $p = 0.73$ and $t(1.17) = 0.99$, $p = 0.48$, respectively), age ($t(6.56) = 0.86$, $p = 0.42$ and $t(9.14) = -1.13$, $p = 0.29$, respectively) and DUP ($t(10.06) = 0.24$, $p = 0.81$ and $t(10.66) = -0.67$, $p = 0.52$, respectively) did not influence importance and attainment ratings of goals pertaining to close family/interpersonal relationships.

Patients who identified more than one goal (N =26) did not differ from patients who identified only one goal (N = 42) in terms of gender ($\chi^2(1) = 0.55$, p = 0.46), DUP ($t(42.03) = 1.56$, $p = 0.13$), positive ($t(59.73) = 0.52$, $p = 0.61$) and negative ($t(60.47) = 0.35$, $p = 0.73$) symptoms. Of note, older patients ($t(35.96) = -2.52$, $p = 0.02$) and patients with a higher age at onset ($t(33.9) = -2.44$, $p = 0.02$) were more likely to report more than one goal.

DISCUSSION

Our main finding is that patients with first-episode psychosis enter treatment with specific goals that they can easily and clearly identify. None of the goals were unrealistic or stemmed from delusions. As would be expected in the general population, age and gender had a slight impact on the type of goals identified by FEP patients. Patients who were older at the time of onset of the illness and at entry were more likely to identify more than one goal. Further, all patients reported most goals as being very important to them and as being

attained only to a low degree. Therefore, it might be most beneficial to patients if their self-reported goals are targeted in treatment.

The second important finding from the study is that a significant proportion of FEP patients in India have goals pertaining to employment at the very outset of treatment. Several clients also identified starting or returning to school as their treatment goal, and the frequency of this goal category could be higher in specialized early intervention programs catering to patients from a fixed age range (e.g., 14 to 30).

To some extent, the preoccupation with returning to or commencing work in our Indian patient sample may be a matter of necessity. The non-availability of welfare benefits and the paucity of organized employment services to facilitate the entry or re-entry of patients into the job market make it essential for patients to work to support themselves and their families. To a great extent, however, this goal is likely a reflection of the desire to recover and be fully functional. This is borne out by research demonstrating that a majority of patients with first-episode psychosis, regardless of sociocultural context, desire to be engaged in meaningful activities such as a job, school or volunteer work.[27,28]

Thus, our study suggests that returning to or starting work/school must be part of the dialogue between clinicians and patients early in the course of treatment. Such practice would be consistent with the international consensus statement[29] on “supporting young people with psychosis in education, training, and employment” developed by the International First Episode Vocational Recovery (iFEVR) group.

Patients in this study also frequently endorsed interpersonal/close family-related goals. This is consistent with research[27, 30–33] documenting the importance of meaningful social relationships and roles in the recovery experiences of adults with psychosis. This may particularly be the case in India as most persons with psychosis live with their families. [34]

At the beginning of treatment, clinicians often tend to primarily focus on symptom remission, a goal identified by only 7 out of 68 patients. Patients on the other hand identified goals covering a range of other psychosocial domains such as work, family/interpersonal relationships, school, finances etc. This lack of congruence between the goals of clinicians and the goals of patients may contribute to service disengagement or a feeling among patients of not being understood. Systematically identifying patient goals, tailoring treatment around these goals and frequently assessing the extent of their achievement may have significant implications for improving service engagement and service satisfaction. Further, a motivational interviewing framework (a detailed discussion of which is beyond the scope of this article) could be used to link patient-identified goals to treatment and medication adherence.[35,36]

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TABLE 1

Sociodemographic and clinical characteristics (N = 68).

Age at entry, Mean (SD), Minimum-Maximum		28.79 (9.86), 15–60
Duration of untreated psychosis (weeks), Mean (SD)		25.62 (75.17) Median = 8
Sex (N and %)	Male	30 (44.11%)
	Female	38 (55.88%)
Highest education attained (N and %)	Less than Grade 10	12 (17.65%)
	Grade 10	23 (33.82%)
	High school (Grade 12) diploma	14 (20.59%)
	Bachelors or higher	19 (27.94%)
Marital Status (N and %)	Single, never married	39 (57.35%)
	Married	27 (39.71%)
	Widowed	2 (2.94%)
Primary diagnosis (N and %)	Schizophrenia	40 (58.82%)
	Schizoaffective	15 (22.06%)
	Psychotic Disorder NOS	13 (19.12%)
PANSS Symptom ratings (Mean and SD)	Positive symptoms	19.15(5.9)
	Negative symptoms	17.49 (8.6)
	General Psychopathology	36.4 (7.28)

TABLE 2

Patient-identified first goal: Frequency, Importance and Level of Achievement (N = 68).

Thematic Goal Category	Frequency (%)	Importance		Achievement	
		Mean (SD)	Maximum, Minimum	Mean (SD)	Maximum, Minimum
Work	26 (38.2)	8.73 (1)	7–10	2.58 (1.45)	1–6
Close family/Interpersonal	14 (20.6)	8.46 (1.66)	5–10	4.31 (2.56)	1–9
School	11 (16.2)	9.18 (0.75)	8–10	4.91 (1.76)	2–8
Symptom relief and psychological recovery	7 (10.3)	9 (1.16)	7–10	2.71 (1.11)	2–5
Living situation	5 (7.4)	8.75 (1.26)	7–10	1.75 (0.96)	1–3
Religious	2 (2.9)	9(0)	9–9	2.5(0.71)	2–3
Financial	2 (2.9)	9(0)	9–9	3(1.41)	2–4
Household responsibilities	1 (1.5)	10	N/A	6	N/A

TABLE 3

Patient-identified second goal: Frequency, Importance and Level of Achievement (N = 41).

Thematic Goal Category	Frequency (%)	Importance		Achievement	
		Mean (SD)	Maximum, Minimum	Mean (SD)	Maximum, Minimum
Close family/interpersonal	15 (36.6)	9.8 (0.41)	9–10	3.8 (2.37)	1–10
Work	9 (22)	9 (1.58)	5–10	2.78 (2.18)	1–6
Symptom relief and psychological recovery	8 (19.5)	8.75.(2.82)	2–10	4.38 (2.88)	1–10
Household responsibilities	6 (14.6)	9.33 (0.52)	9–10	3.67 (2.81)	1–9
School	3 (7.3)	8.33 (1.53)	7–10	4 (0)	4–4