

Income Generation Programs and Real-World Functioning of Persons with Schizophrenia: Experience from the Thirthahalli Cohort

Low rate of employment is an important contributor to disability associated with schizophrenia.^[1] In India, a large proportion of persons with schizophrenia do not receive vocational rehabilitation services concordant with standards of good clinical practice,^[2] but the course and outcome have been consistently shown to be better than in developed countries.^[3-5] It is possible that in communities, other factors may be operating that may be inherently rehabilitative in nature. For instance, in India, there are income generating programs that are successfully operating in rural communities. Here, we report the role of these programs in vocational rehabilitation of a rural cohort of persons with schizophrenia and present the audit of 50 patients (out of 256) who had utilized these programs.

SETTINGS AND METHODS

Sample for this study was schizophrenia patients under the Community Intervention in Psychotic Disorders (CoInPsyD) program in Thirthahalli taluk. Details of the program are mentioned elsewhere.^[6] Almost all schizophrenia patients of the entire taluk are being identified, treated, and followed-up for the past 12 years. Vocational rehabilitation inputs are limited to the provision of common-sense counseling and guiding patients towards existent employment/vocational avenues. Data for the paper was extracted by reviewing case files and by informal interviews at follow-up. Of the 380 patients in the cohort, 256 were interviewed (Death: 37, Migration: 25, Change of diagnosis: 12, Refusal of consent: 12, Not able to contact: 38). Fifty patients had utilized the below-described programs and were productively employed. The CoInPsyD project was approved by the Institutional Ethics Committee. Written informed consent was obtained from all patients/family members.

1. Income generation Programs:

a. **Mahatma Gandhi National Rural Employment Guarantee Act (MNREGA):** It provides for the enhancement of livelihood security for below the poverty line households in rural areas of the country

by providing at least 100 days of guaranteed wage employment (unskilled manual work) in every financial year. The tasks are executed by gram panchayats, and local developmental works are given priority.^[7]

- b. **Sri Kshetra Dharmasthala Rural Development Program (SKDRDP):** Its objective is “inclusive rural development.” Participants are active in self-help groups (SHGs, 5--6 members) that are income generating. Each day of the week, one member of each group would go to any of the other members’ home and work, for example, in farming. The person is remunerated for the work. Some part of this income is saved. There is an arrangement to give small loans as well from the capital (and interest) accrued.^[8]
- c. **Self-help groups:** There are three of them including (a) Sthree Shakti SHG, (b) Navodaya Grama Vikas Charitable Trust, and (c) Caste-based SHGs. The first one is supported by the state government (loans at subsidized rates for individuals) while the other two are not. The basic format of these SHGs is that from a shared common pool, the needy get loans, which is paid back after the need is fulfilled. The aim is to empower rural women and make them self-reliant. Fifteen to 20 women members from below poverty line families, landless laborers, scheduled castes/tribes, Anganwadi teachers, etc., form the SHGs. SHGs also offer self-employment training and marketing guidance.
- d. **Primary agricultural and credit cooperative society:** This is akin to a bank and is run by the government through gram panchayats. The operation is similar to that of the SHGs mentioned above.

A notable point is that these agencies cater to the entire community and not specifically to those with psychiatric illnesses. Furthermore, though programs (c) and (d) are not directly income-generating, families utilize the financial resources from these projects in order to gainfully employ their wards. Patients will actively contribute by lending themselves to agricultural work.

RESULTS

The mean age of the sample was 39 years, with more females (58%) than males (42%). More than three-fourths of the 50 patients were married (78%), and most of the patients belonged to the lower or lower-middle socioeconomic status (94%). The mean duration of remission was 6.3 years, with the mean time taken to work after remission being 2.1 years. Table 1 summarizes the findings.

Patients had responded well to medications and evidently were asymptomatic for long periods of time. Other anecdotal observations about this patient group included that they had low levels of adverse effects, excellent medication adherence, less negative

symptoms, good pre-morbid functioning, and relatively well-preserved personalities. One-third of the patients were using more than one organization/program for employment. There was no significant correlation between patient's severity of illness or duration of illness and their salary or regularity of attending work.

DISCUSSION

This report shows that about one-fifth of the patients in this cohort were gainfully employed, utilizing income-generating resources available locally. A substantial proportion of others in the cohort were meaningfully occupied through other means as exemplified by our previous report from the same cohort.^[6] This report assessed work functioning at

Table 1: Sociodemographic and occupational details

Sociodemographic and clinical variables	Findings
Sociodemographic Details	
Age [Mean (SD)]	39.0 years (10)
Gender	
Male	21 (42%)
Female	29 (58%)
Marital Status	
Married	78%
Single/separated	22%
Socioeconomic Status	
Lower	58%
Lower Middle	36%
Upper Middle	6%
Mean years of education [Mean (SD)]	6.3 (2.1)
PANSS Positive symptoms score Baseline [Mean (SD)]	15 (1.8)
PANSS Negative symptoms score Baseline [Mean (SD)]	28 (2.1)
Mean duration of illness [Mean (SD)]	139 months (61.0)
Mean duration of remission [Mean (SD)]	6.3 years (2.1)
Time taken to start work after remission [Mean (SD)]	2.1 years (1.2)
Asymptomatic for [Mean (SD)]	6.3 (2.1) years Median=7 years Range: 1-10 year
Occupational Details	
Program Utilized	21 (12 males; 09 females)
MNREGA*	26 (13 males; 13 females)
SKDRDP	21 (03 males; 18 females)
SHGs	Mean: 5,600 Median: 5,000
Average monthly income (INR)	Range: 1,500 to 10,000
Regularity at work	Regular: 41 Irregular: 9 Nil
Any complaints from the employer	Yes (n=50)
Is the patient satisfied with the work performance?	Yes (n=50)
Is the family satisfied with the work performance?	Yes (n=50)
Is the patient satisfied with the salary?	No (n=50)
Future plans	All 50 plan to continue working.

*Numbers do not add up to 50 as some patients were using more than one organization/program for employment. INR=Indian National Rupees, MNREGA=Mahatma Gandhi National Rural Employment Guarantee Act, SHGs=Self Help Groups, SKDRDP=Shree Kshetra Dharmasthala Rural Development Program

the end of 4 (mean) years of follow-up (baseline time differed for every patient differed as and when they got recruited to the cohort. The assessments for the purpose of the above report were done during the year 2011). It showed that there was a significant drop in the scores of “work” domain of the Indian Disability Evaluation and Assessment Scale (IDEAS): The score was 2.2 (SD = 1.6) at baseline and 1.1 (1.2) at follow-up [$t = -9.1$; $P = 0.001$]. The mean total IDEAS score decreased to 1.4 (1.9) from baseline total score of 6.6 (4.8).

Specialized human resources were not necessary to do this kind of rehabilitation work.^[5,9] A medical social worker trained in rehabilitation coordinated this work. He guided patients/families towards employing their ward/s by giving information about various avenues available and the possible ways of contacting the agencies. This method is especially relevant in countries such as India where human resources are meager and specialized interventions are neither affordable nor accessible. Some patients would stop work in between---gently nudging them towards restarting work often resulted in success. However, as noted in our previous papers, rehabilitation work is fraught with many barriers in patients with negative symptoms, inadequate symptomatic recovery, absent/poor insight, or poor treatment adherence. These patients, in particular, require multidisciplinary inputs in more specialized settings and do not yield themselves for the public health strategy of managing schizophrenia.^[6,9,10]

Accredited Social Health Activists (ASHAs) and Village Rehabilitation Workers (VRWs) are potential ground-level workforce for rehabilitation, if they are provided training in psychiatric (including vocational) rehabilitation and continual support. These could be simplified so as to integrate this rehabilitation work with their routine responsibilities. This is in keeping with the philosophy of “community-based rehabilitation” promulgated by the World Health Organization as well.^[11]

Therefore, income generation programs---governmental and non-governmental---that are locally available can be utilized as livelihood opportunities for patients and their families by appropriate guidance from community level workers for rehabilitation.

Often, families themselves took the initiative of employing the patient based on their clinical status. This asset in Indian culture needs to be harnessed by providing all possible support from stake holder agencies. The laws and policies of the land need to align with the needs of the families, besides protecting and supporting patient rights.

The programs were clearly helping in generating additional income for the patients/families; yet, there was dissatisfaction with financial gain. This is understandable, given the gap between requirements and income generated. The mean income as reported was Rs. 5,600/month; this has assisted the families/households in generating additional income but obviously was not satisfying enough for the patients or families. This reflects the scenario prevalent in the lower and middle-income countries in general. Aspiration for more income, although present, did not bother them too much, as denoted by the satisfaction with the quality of life that emerged out of vocational functioning. Similar findings have reported previously as well.^[1,5] Obviously, more qualitative research in these aspects will give us more information on this interesting discrepancy.

An anecdotal finding was an experience of very little stigma from employers by patients. The realization that patients’ work-performance is similar to that of normal people could be one reason for lesser stigma.

The limitations of the study are lack of *a priori* hypothesis; anecdotal observations without systematic measures to evaluate adherence, adverse effects and burden; and retrospectively extracted data.

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Conflicts of interest

There are no conflicts of interest.

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