Consumer perceptions of recovery: an Indian perspective

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In many developing countries, including India, the consumer/family movement is still nascent, albeit growing in strength gradually. It is also likely that some of the rather paternalistic treatment settings do not value or seek the opinion of consumers as often as they should be doing. In this context, we undertook at the Schizophrenia Research Foundation (SCARF) a small exploratory study to ascertain consumer perspectives of recovery from schizophrenia.

SCARF is a non-governmental not-for-profit organization which runs outpatient services in urban Chennai, India as well as in rural and semi-urban areas. A brief study on the patients' perspectives on the indicators of recovery was conducted in SCARF outpatient department in Chennai among patients with schizophrenia and schizoaffective disorder. An inclusion criterion was the presence of at least partial insight (i.e., the patient acknowledged having a mental disorder).

Of the 164 patients who fulfilled the entry criteria and who were approached

during a period of 30 working days, 100 gave consent to participate in the study. They were asked open ended questions regarding what they personally considered as indicators of recovery. Then, we submitted them a list of possible indicators of recovery generated on the basis of available literature, consultation with other mental health professionals and prior discussion with 25 patients and their families. Snowballing technique was also used whereby new items generated during the interviews were added to the list for the next interview. The patients were then asked if their recovery had to be "externally validated" by some source such as their family, employer, treating team, or if it was "internal", whereby they only needed to be convinced that they had recovered.

From the interviews, a total of 31 indicators were generated. The most common theme that emerged was the equation of recovery with the absence of symptoms (88% of the respondents) and not having any more relapses (73%). Getting back to their regular lives in terms of functioning (70%) and being able to handle the associated responsibilities (62%) were also deemed important. To 65%, recovery

ery meant not having to take medicines any more. More women (80%) than men responded this way.

Among the respondents, all the students, 71% of the unemployed, 66% of those attending a sheltered workshop at SCARF and 63% of those employed mentioned "holding on to a job" as the most important indicator of recovery. About 35% mentioned getting married and having children as indicators.

Previous work from this centre has underscored the importance of work and occupation in the recovery of patients (1,2). The fact that health insurance in India does not cover mental illness and the state does little in terms of welfare programmes for this group of people makes it critical for many of these patients, specially those from lower economic groups, to find a job to support themselves and their families.

Although personal attributes such as self-efficacy did not figure in the list, they appeared to be quite central to many of the themes which emerged (e.g., statements about efficacy in social and work situations, the need to get on with life, to become independent and to take decisions on one's own).

Patients mentioned internal validation six times more frequently than external validation. In particular, many patients stated that their perception that they were good on the job was more important than the employer's perception.

A heartening feature was that, although the group consisted of primarily chronic patients with a mean duration of illness of about 11 years, none thought that recovery was impossible to achieve and all were able to articulate personalized indicators of recovery.

It is unclear from this study whether our patients viewed mental health service as too paternalistic and felt overwhelmed by a sense of hopelessness and helplessness, as described by Bellack and Drapalski. This needs further research, possibly in varied health care settings. It appears that this sample of patients had a fairly realistic view of recovery and accorded a high premium to social functioning, specially with respect to employment.

References

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