

# Social Outcome in Clinically Recovered First-Episode Schizophrenia in a Naturalistic, Ten-Year, Follow-Up Study in India

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## Abstract

**Background:** Remission of symptoms and clinical outcome seldom capture real-life outcome in schizophrenia. Measurement of social outcome provides a culturally meaningful indicator of how a patient is performing his or her role after recovery. The present study examined the status of social outcome on multidimensional parameters in a cohort of clinically recovered patients in a ten-year, long-term study of first-episode schizophrenia. **Methods:** First-episode hospitalized patients were recruited for a long-term outcome study. At the ten-year end point, those patients who showed good clinical outcome were assessed on culture-specific parameters of social outcome to find out the true nature of recovery in schizophrenia. **Results:** Sixty-one recovered patients showed differential outcome on various social parameters after ten years. Overall, 52.5% of patients showed good social recovery on all four social parameters. We found that 19 subjects (31.1%) were functioning socially satisfactorily, 10 subjects (16.4%) were productive in day-to-day life, 29 (48.3%) were economically independent, and 11 (18.3%) were satisfied with their education and new skills. **Conclusions:** This study shows that not all patients who show clinical recovery have also improved in social functions on socially relevant parameters. Half of the patients continued to have limitations in the areas of social function (the ability to earn a sufficient income and conform to the expected social role). Social parameters need to be considered in everyday practice when defining outcome status.

**Key Words:** Social Outcome, Clinical Outcome, First-Episode Schizophrenia, Long Term

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## Introduction

Since the beginning of outcome research in schizophrenia, there has been a strong consensus among researchers that capturing the remission of symptoms alone is not enough to reflect relevant outcome. Particularly in long-term outcome, considering information regarding a patient's social situation is vital. Social functions reflect the ability of patients to live in society and how well they are performing their socially expected role (1). Social outcomes are not a new concept. These are commonly used throughout the healthcare systems. Yet, there are some specific reasons for their significance in the field of schizophrenia (2): the disorder is chronic, thus affecting patients lifelong. The symptoms

### Clinical Implications

Social recovery is most likely more significant in terms of providing real-life situations. The level of social recovery is also crucial for care plans for community management. Bringing objectivity and uniformity in clinical practice will provide opportunities from different perspectives. It may help developing strategies to bring patients back to families and society. The present study attempted to study outcome of several key parameters. It shows that no patient recovers if outcome criteria are on multiple dimensions. Approximately half of the patients in our study showed significant social recovery on all social parameters. Clinically recovered patients continue to live with several social challenges. Treatment strategies need to be strengthened so as to help accomplish more successful outcome in schizophrenia. Our study is limited by the high attrition rate from baseline to follow-up. Individuals who were not available at follow-up may have been those who evidenced greater recovery; on the other hand, they may have dropped out of treatment and shown less improvement than our sample. It will be important for future studies to make a greater effort to follow-up with all baseline patients. It also may be important for future research to examine pathways to recovery by measuring, for example, the patient perspective on social and functional recovery.

and the associated distress fluctuate during the course of illness. Thus, assessment of any symptom at a given point of time does not provide a valid picture of the outcome.

One significant characteristic feature of this disorder is “social deterioration,” which mediates the level of functioning. Thus, social and functional outcome become an integral part of recovery.

Longitudinal research has shown that antipsychotic medications can reduce symptoms and prevent relapses. Yet, this improvement is not necessarily linked with an improved social situation. Symptom remission and relapse prevention do not necessarily make patients more productive and functional or help gain employment. These outcomes, therefore, need separate assessments from symptoms.

Healthcare systems require information regarding how a patient is doing in the community. Community level functioning is a better marker of outcome status.

From the public health and stakeholders’ perspective, social outcome is the key evidence for a patient’s return to normalcy. This also becomes important from the perspective of health economics, for research and fund allocations.

Outcome measurements in schizophrenia have evolved considerably. It is argued that, besides symptom remission, outcome is also measured using neurobiological parameters, social and cognitive parameters, as well as with patient-reported measures. Outcome status also needs to match the expectations of families and society at large (3-6). There are significant variations in the outcome of schizophrenia in different parts of the world. More research is required to understand the heterogeneity and determinants of outcome (7, 8). It has been widely acknowledged that patients in developing countries show better outcome (9), but these findings have recently come under scrutiny and results showing good outcome have been challenged (10, 11).

Clinical outcome does not necessarily represent social outcome as well. Only a portion of the patients achieving good clinical outcome also achieve good social and func-

tional outcome, while a small number of patients with good social outcome do not recover in a clinical sense. It has also been stated that recovery in clinical, neurocognition, and social cognition mediates social outcome (12).

The literature has been inconsistent about which parameters represent good social outcome. Specifically, there is a discrepancy between patients, relatives, caregivers and professionals with respect to what constitutes outcome measures, making it difficult to assess the reality of recovery in patients. The reason for the lack of agreement may be due to the limitations of the measurement tools themselves, which are not comprehensive and may measure different aspects of outcome (2).

Additionally, there is no consensus on the parameters of social functioning. Several parameters have been used in various studies, including global functioning, quality of life, patient self-report, relative and caregiver reports, assessment of disability, personal social performance, assessment of skills and learning, social cognition, work, new learning, and employment, among others (13). Further, Meltzer (1995) proposed thirteen different criteria for clinical and social outcome: psychopathology, aggression, suicidality, positive symptoms, negative symptoms, cognition, rehospitalization, extrapyramidal symptoms, compliance, interpersonal social functioning, work-employment, family burden, social burden, and independent living (14).

Different concepts have been used to reflect and summarize social outcomes in people with schizophrenia. These include standard of living, quality of life, social integration, social adaptation, social functioning, social integration, needs for care, and more recently, social inclusion. None of these concepts have been introduced in psychiatry on the basis of a theoretical model. If a theoretical literature existed in psychology and sociology—e.g., for the quality of life concept—it was rarely considered when new concepts were suggested and new assessment tools were designed in psychiatry (15). The reason for introducing a new concept was

commonly the intuitive appeal of the term, which then led to efforts in finding definitions and, subsequently, developing the corresponding assessment tools. There is no universally accepted definition for any of these concepts, and each can be used, and has been used, in various ways, depending on the perspective and interest of whomever is using them. Since the 1980s, researchers have published definitions and taken a pragmatic and often ad hoc approach to developing operationalized methods for the assessment (16, 17); the operationalization usually required some focus and narrowing down of the various potential meanings of the concepts. As a result, all assessment instruments for social concepts have led to disappointment in at least some stakeholder groups because they do not reflect the specific understanding of the concept in the given group. To a different degree, this has happened whenever new concepts of social outcomes have superseded previous concepts. Some books on “quality of life and social function,” the two dominating concepts, were published in the 1990s with limited conceptual and methodological progress since (2).

In the present study we attempted to examine the level of social outcome using multidimensional parameters in a cohort of clinically recovered first-episode patients at the end point of a ten-year follow-up.

## Methods

### Study Site

This study was conducted in a nongovernmental Psychiatric Treatment Centre in Mumbai, India (licensed centre as per Indian Mental Health Act 1987). Ethics permission for this study was obtained from the local independent research ethics board. Appropriate consents were received from all patients.

### Sample and Study Design

A total of 200 patients hospitalized for first-episode schizophrenia was recruited and provided consent. At the ten-year follow-up point, 101 patients were available and these comprised the participants in the present sample. The participants provided consent a second time at the time of the follow-up. The mean age of this sample at baseline was 28.8 years (standard deviation [SD]=8.2; range 17–47) and 74 patients (73.3%) were male. At the end point, the mean age was 39.2 years (SD=7.9; range 22–58). All participants had a minimum of grade 12 education, living in catchments with families, and belonging to the middle-class socioeconomic group. The mean duration of illness prior to treatment was 14.0 (SD=8.0) months. Additional details of the patients at intake and those lost to follow-up are reported elsewhere (18). Forty-nine percent of patients were lost to follow-up during the ten years; although high, this appears

to be a general pattern in early psychosis research (19). Patients available ( $n=101$ ) at the end point of ten years and showing good recovery ( $n=61$ ) as per the Clinical Global Impression Scale (CGIS) were used in the present study to study social outcome. Forty-three of the 61 patients showing clinical recovery (73%) were male.

Patients completed the CGIS at baseline and at follow-up, and 61 patients showed “improvement” or “much improvement” on the CGIS-Improvement subscale. This was a cross-sectional study in a naturalistic clinical setting, which examined the level of social outcome achieved in good outcome patients. We used operationalized criteria for defining good social outcome using a five-point scale to measure parameters of social outcome. We used a measurement scale of 1 to 5, with 1 representing the lowest value and 5 the highest for parameters of social recovery. Parameters used for global social recovery were: 1) social functioning; 2) productivity; 3) economic independence; and, 4) education. Each of these four social parameters was assessed along the 5-point scale. See Table 1 for a detailed description of the social parameters characterized by each point on these scales. These outcome parameters were selected because of their social and clinical relevance; this semi-structured scale has been tested in local conditions and used in other studies (20). We compared the characteristics of patients and treatment variables at baseline and at follow-up. Our criterion for good social outcome was defined as a score greater than or equal to 3 on the social outcome parameters.

### Statistical Methods

The data in this study were analyzed using SAS version 9.1. The number of social parameters considered satisfactory ( $>7$ ) was calculated, and the frequencies and percentages of the social parameters are presented. Thus, our methods and results are descriptive in nature.

## Results

Social parameters assessed at baseline demonstrated 37 (60.7%) patients with satisfactory scores (greater than or equal to 3) on none of the parameters and 24 (39.3%) patients with satisfactory scores on one of the four parameters used in this study. Thus, functioning in these domains was quite poor. The frequencies and percentages of status on social outcomes at the ten-year follow-up are presented in Table 1. Using the criteria of recovery as a score greater than or equal to 3 on these social parameters, 19 subjects (31.1%) are considered to be functioning socially in a satisfactory way, 10 subjects (16.4%) are productive in day-to-day life, 29 (48.3%) are economically independent, and 11 (18.3%) are satisfied with their education. Of the 61 subjects who, based on the CGIS-I, had recovered satisfactorily, only 19.7% were

**Table 1** Social Status of Recovered Subjects at Ten Years of Follow-Up (n=61)

<b>Social Functioning (N=61; score≥3, 73.7%)</b>	<b>N (%)</b>
Withdrawn behavior	0 (0.0%)
Expressed desire of interaction	16 (26.2%)
Definitive evidence of improved functioning	26 (42.6%)
Improvement in functioning and relationship	13 (21.3%)
Functioning with satisfaction	6 (9.8%)
<b>Productivity (N=61; score≥3, 50.8%)</b>	<b>N (%)</b>
Unproductive	13 (21.3%)
Expression of productivity	17 (27.9%)
Occasional productivity	21 (34.4%)
Productive with support	3 (4.9%)
Productive without support	7 (11.5%)
<b>Economic Independence (N=60; score≥3, 78.3%)</b>	<b>N (%)</b>
Complete dependence	5 (8.3%)
Desire to earn	8 (13.3%)
Attempt with failure	18 (30.0%)
Attempt with success	20 (33.3%)
Satisfactorily independent	9 (15.0%)
<b>Education (N=60; score≥3, 48.3%)</b>	<b>N (%)</b>
Unable to resume	14 (23.3%)
Feels confident but unable to start	17 (28.3%)
Attempt but not sustained	18 (30.0%)
Sustained without satisfaction	2 (3.3%)
Sustained with satisfaction	9 (15.0%)

functioning appropriately on all four social parameters. Half of all patients (47.5%) were functioning to a satisfactory degree on two or less of the four social parameters. Thus, although clinically recovered, many of these patients have not recovered functioning in social domains.

In the domain of social functioning, 45 (73.8%) patients had a score greater than or equal to 3, demonstrating satisfactory functioning. In day-to-day productivity, 31 (50.8%) patients scored greater than or equal to 3, and 47 (77.0%) patients did so on the dimension of economic independence. Finally, satisfactory levels of education were seen in only 29 (47.5%) patients in this sample. See Table 1 for the frequencies of each score on all four parameters.

We compared the social outcomes against age at intake and the duration of illness. The analysis showed that patients who were below the age of 25 at the time of first hospitalization demonstrated poor economic independence as compared to individuals first hospitalized after the age of 25. No other social parameters were significantly predicted by age

at intake or illness duration. Thus, an important consideration when assessing the recovery of patients hospitalized before the age of 25 is whether they have established economic independence.

## Discussion

### Parameters of Social Improvements

Different concepts have been used to reflect and summarize social outcomes in people with schizophrenia. These include standard of living, quality of life, social integration, social adaptation, social functioning, social integration, needs for care, and, more recently, social inclusion. As it is not clear how many parameters require improvement for the designation of good outcome, the three most significant parameters of economic independence, no rehospitalization, and social functioning were considered for the purpose of the present discussion. These parameters are most relevant in the culture where the study was carried out. We found that 19.7% of our sample of clinically recovered patients showed social recovery on all four parameters. Only 4.9% of patients recovered on none of the social parameters. Therefore, it seems that many patients who have evidenced clinical recovery are functioning at least to a satisfactory degree in social domains. At baseline, no patients demonstrated satisfactory functioning in more than one domain, so clearly improvements were made over the ten-year period before follow-up assessment. However, our results also suggest that social recovery is not optimal for many individuals.

Recovery was most common in the domains of social functioning and economic independence, whereas less frequent in day-to-day productivity and education. This suggests not only that social recovery is clearly not a singular construct, but also that programs and rehabilitative interventions should focus on increasing the ability of patients to be productive in their daily life and help them to work toward their education goals. Although economic independence was found to be satisfactory in three-quarters of the sample, we also found that age at intake was related to this parameter; lower age at intake is related to poorer economic independence. This suggests that interventions and programs for youth with schizophrenia, or individuals hospitalized at an early age, should pay special attention to the promotion of economic independence, as this seems to be a frequent problem in this group. Although it has been reported that longer durations of untreated psychosis are associated with poorer outcome (21-23), we did not find this to be the case in our research. As our sample consisted only of clinically recovered patients, this finding may suggest that social recovery remains independent of a patient's duration of untreated psychosis. Clearly, further research is required.



The findings of our research suggest that there is a gross discrepancy between clinical recovery and social recovery. There are unmet needs in recovered patients from a social perspective to allow them to lead independent, functional, productive, and socially interactive lives and also continue to remain free from symptoms. There are three different possibilities which can account for such gaps:

1. the treatment given, mainly being antipsychotic drugs, does not help in improvement of social functioning (24-26);
2. the social and psychological treatments known to work are not available and are not commonly provided. Only a chosen few in specialized programs have access to such treatments. The “treatment as usual,” commonly used in the case of schizophrenia in the community in both developing and developed countries, regrettably still continues to be only pharmacological (27);
3. the illness of schizophrenia by its nature and neurodevelopmental features has social deficits, which are currently beyond the reach of available treatments (28).

We believe that all three reasons continue to contribute in determining the outcome of schizophrenia. It is also clear that focusing only on clinical recovery does not capture real-life outcome; similarly, using a single dimension of social outcome also does not give us the correct indication of a patient's improvement. The social parameters are not mutually exclusive, and these are not perfectly inclusive either. There is a significant amount of overlap, but the quantity of overlap is presently undetermined. Many patients continue to function with residual symptoms, passive suicidal ideas, and even with poor coping abilities. Some others improve very well on symptom parameters, comply well, interact adequately, and have developed good social skills, and yet still remain unproductive and unemployable. It is, therefore, important that a consensus evolves about the number of parameters necessary to measure in order to provide the best estimate of recovery. Again, social outcome measurements should be incorporated in routine clinical work as well as research work involving schizophrenia (29, 30).

## Social Functioning

We observed that 73.8% of patients were able to achieve moderate to satisfactory social functioning. Twenty-six patients did not improve on this dimension. The parameter of social functioning has been crucial for outcome measures; it measures the ability to interact, the level of comfort in the presence of others, initiative, drive, psychomotor function, and continues to be an important feature of patient quality of life. Inability to recover on this parameter may jeopardize

the benefits achieved on other clinical and social parameters. Social functioning also plays a crucial role in an individual's life in terms of gaining productivity and employment. Improved social functioning works as a catalyst for independent living and for performing one's social role in the family structure (31, 32).

## Productivity

The parameter of productivity has not been investigated to a great extent. Normally it is embedded in testing items for global assessments of functioning. It is not the ability to obtain gainful employment that is tested, but it reflects an individual's ability to be active and productive in day-to-day life. To some extent it reflects an individual's “activity of daily living” along with the capacity to respond positively to any social situation that demands thinking, planning, and the execution of a task. In clinical terms, it refers to whether an individual has developed the capacity to do a social task in a given situation. It refers to social productivity rather than economic productivity. In this study, 49% of patients did not show any evidence of productivity in their social life. Only 11% were consistently productive with or without support, and 40% were productive minimally or occasionally. This is yet another social limitation in a cohort that has shown good clinical recovery, possibly suggesting why most of the recovered patients are unable to live an independent life (33-36).

## Economic Independence

Economic independence is one of the most significant and crucial parameters of social outcome. It is not just an ability to gain employment, but it reflects the global capacity to reach out, have employability or be self-employed, and to not depend on financial assistance from any other source for routine day-to-day expenditures. It does not necessarily reflect the ability to take the caretaker role of the family, but remains limited to financial self-sufficiency. Our study found that 15% of patients achieved successful economic independence, 33.3% were attempting economic independence and working toward it with reasonable success, but remained short of complete independence, and another 30% showed consistent attempts to become economically independent but not succeeding in their efforts. Twenty-one percent of patients did not have any success on this parameter and, overall, 78.3% showed a variable degree of success in being economically independent.

Economic independence is a function that transforms individuals' self-esteem, self-worth, and minimizes the sense of liability and disability. Further, this parameter is a crucial reflection of the restoration of functions and expected role, a facilitator to treatment, compliance and self-confidence. It is

a particularly significant parameter for developing countries where social security, unemployment benefits, pensions, disability allowances or family allowances are not available. It is a general indicator of good outcome if a patient of schizophrenia starts working and earning. This parameter is also of cross-cultural significance because, in most of the developed and western world, patients have good financial and housing support from the government. The socioeconomic context of the society plays a central role in the progress of patients. Whether social-financial support is an asset or a liability for recovery of patients continues to be debatable (37, 38).

### Education

The parameter of education does not refer only to formal school-based education. It also refers to the ability for learning, new learning, and skills development. It captures the overall ability to learn, in both academic and nonacademic contexts. For some of the patients who were in schools and colleges at the time of illness, it refers to a successful return to the campus. For others who were either not in formal education, or were employed or were doing manual work, it refers to the restoration of these same skills and the ability to adapt to change in learning new skills. This is a unique outcome parameter which adds to patient's self-esteem, respect, confidence and a sense of being free from the illness. It is also a culturally expected and appreciated measure indicating good outcome (39).

### Limitations

Our study is limited by the high attrition rate from baseline to follow-up. Individuals who were not available at follow-up may have been those who evidenced greater recovery; on the other hand, they may have dropped out of treatment and shown less improvement than our sample. It will be important for future studies to make a greater effort to follow-up with all baseline patients. It also may be important for future research to examine pathways to recovery by measuring, for example, the patient perspective on social and functional recovery.

### Conclusions

Social recovery is most likely more significant in terms of providing real-life situations. The level of social recovery is also crucial for care plans for community management. Bringing objectivity and uniformity in clinical practice will provide opportunities from different perspectives. It may help developing strategies to bring patients back to families and society. The present study attempted to study outcome of several key parameters. It shows that no patient recovers if outcome criteria are on multiple dimensions. Approximately half of the patients in our study showed significant social recovery on all social parameters. Clinically recovered patients

continue to live with several social challenges. Treatment strategies need to be strengthened so as to help accomplish more successful outcome in schizophrenia.

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