Evaluation of a community-based rehabilitation model for chronic schizophrenia in rural India

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Background There are no community services for the majority of the estimated 10 million persons with schizophrenia in India. Community-based rehabilitation (CBR) is a model of care which has been widely used for physical disabilities in resource-poor settings.

Aims To compare CBR with out-patient care (OPC) for schizophrenia in a resource-poor setting in India.

Method A longitudinal study of outcome in patients with chronic schizophrenia contrasted CBR with OPC. Outcome measures were assessed using the Positive and Negative Symptom Scale and the modified WHO Disability Assessment Schedule at 12 months.

Results Altogether, 207 participants entered the study, 127 in the CBR group and 80 in the OPC group. Among the 117 fully compliant participants the CBR model was more effective in reducing disability, especially in men. Within the CBR group, compliant participants had significantly better outcomes compared with partially compliant or non-complaint participants ($P<0.001$). Although the subjects in the CBR group were more socially disadvantaged, they had significantly better retention in treatment.

Conclusions The CBR model is a feasible model of care for chronic schizophrenia in resource-poor settings.

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There is a scarcity of information on the effectiveness of strategies for extending care to people with serious mental illness in rural communities in India and in other developing countries (Jacob, 2001). Community-based rehabilitation (CBR) is a form of care that has been implemented in the field of physical disabilities in low-income countries where specialised resources are scarce (Lagerkvist, 1992; Evans *et al*, 2001). This type of care relies on accessibility, cultural sensitivity and community participation in providing services. Similar CBR strategies could be used to meet the complex needs of people with severe mental disorders in underserved settings. This paper describes how such a model was evaluated in a resource-poor region of India.

The mental health programme described here was initiated in partnership with Ashagram ('village of hope'), a non-governmental organisation working towards the rehabilitation of people affected by leprosy. Ashagram's facilities included a 30-bed general hospital, and physiotherapy, prosthetics and income-generation units. The initial focus of the mental health programme was on establishing out-patient facilities at Ashagram; however, preliminary analysis of service utilisation profiles suggested that out-patient care did not reach the most vulnerable sections of the population (Chatterjee & Chatterjee, 1999). To redress these limitations, an attempt was made to adapt the CBR model for use by people with chronic schizophrenia. The content of the intervention was shaped by consultation with patients, families and key persons in the community (further details available from the author upon request). The objective of the study was to compare the effectiveness of CBR with that of out-patient care in the treatment of people with chronic schizophrenia, and to test the hypothesis that CBR would produce superior clinical and disability outcomes compared with standard out-patient care.

METHOD

Setting

The study was conducted in the district of Barwani in the state of Madhya Pradesh. The majority of the population (68%) are indigenous tribespeople. Most inhabitants live in dispersed hamlets (*phalia*) around cultivated land. Each village has a population of 1000–3000 persons. Barwani is one of the poorest areas in India: 53% of the population live below the poverty line. Most villages lack all-season roads, electricity and safe drinking water. The indigenous population are the most socio-economically disadvantaged. Only 15% of the population have access to any health facility within 5 km of their home. Doctors employed in primary health clinics are frequently absent, and private, fee-for-service health professionals (including traditional healers) are usually the only option for treatment. At the time of the study no biomedical mental health facilities existed in Barwani or in the adjoining districts.

Study design

A prospective study design was used which compared CBR and out-patient care for a consecutive series of patients suffering from chronic schizophrenia.

Sample and measures

The recruitment period was from December 1997 to December 1998. The inclusion criterion was a first presentation to the services with a diagnosis of chronic schizophrenia. This diagnosis was established in both groups by a psychiatrist (S.C.) after a clinical interview with the patient and family, using the ICD–10 criteria (World Health Organization, 1992). Chronicity was defined as having suffered from symptoms for at least 2 years prior to recruitment. The CBR group comprised patients living in the designated programme area: this consisted of 66 villages within the Barwani block, with an approximate population of 98 000. The out-patient care group consisted of patients living outside the designated area. The purpose of the study was explained to patients and their families and written informed consent for participation was obtained. For those without reading skills, verbal informed consent was obtained. The Positive and Negative Syndrome Scale (PANSS) for schizophrenia (Kay *et al*, 1987), which has been used in Indian settings (e.g. McCreadie *et al*, 1996), was

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used as a measure of clinical symptoms. The World Health Organization Disability Assessment Schedule (DAS), validated for use in Indian settings (Thara *et al*, 1988), was used to assess social, occupational and behavioural disabilities.

Intervention

The out-patient care model consisted of clinical services provided exclusively at the clinic in Ashagram. After the initial assessment, patients and families were usually seen once a month for follow-up. During these sessions, ongoing drug treatment was reviewed and families were educated about the illness, compliance and recognition of side-effects. Additionally, rehabilitation strategies to enhance the patients' social and occupational functioning were discussed. The CBR model used a three-tiered service-delivery system. At the top was the out-patient care. The second tier employed mental health workers drawn from the local community. After a 60-day training programme they worked with patients, families and the local community in providing services. Each of the mental health workers serviced five or six contiguous villages and carried a case-load of 25–30 patients, including some of the study participants. The third tier consisted of family members and key people in the community who formed the local village health groups (*samitis*). These groups were a forum for the members to plan relevant rehabilitation measures and reduce social exclusion. Important differences between the two models of care are summarised in Table 1. All patients were initially given antipsychotic medication, which in most instances was risperidone (dosage range 2–8 mg); where the risk of non-compliance was significant, depot antipsychotic formulations were used. In addition, during the ongoing reviews with the psychiatrist, adjunctive psychotropic agents were prescribed according to clinical requirements.

Outcomes

Outcomes were assessed at 12 months for all participants, except those in the out-patient care group who had dropped out of care. Since members of their group lived relatively further from Ashagram, it was not feasible to complete these assessments. The primary outcome measures were the changes in PANSS and DAS scores over 12 months; in both measures higher scores indicate increasing clinical severity. Both sets of ratings (baseline and end-point) were completed by an experienced psychiatrist (S.C.), who was not blind to the allocation of participants to the intervention groups.

Analyses

Compliance was assessed as a summary measure based on an interview with the patient and the patient's family at the 12-month review. Patients who had taken their medication for the full 12 months were considered fully compliant; those who had taken it for at least 9 months were considered partially compliant and the remainder were non-compliant. Chi-squared tests for difference in proportions were used to compare the distribution of baseline variables between the CBR and out-patient care groups. Continuous variables were assessed with either the *t*-test (age) or Wilcoxon rank sum test (duration of illness). The effect of intervention group on change in score was assessed by multiple linear regression, including factors that were significantly different at baseline, and baseline value of the score, in the model. Analyses were also stratified by gender. Statistical interaction between gender and intervention group was assessed by including an interaction term for these two variables in the linear regression model. Intention-to-treat and treatment completer analyses were carried out. For the treatment completer analysis two methods were used to estimate the score in non-complaint patients in the out-patient care group. The first method (the conservative scoring method) estimated the final score among non-compliant patients to be the average score in partially compliant out-patient care participants. The second method assumed that there was no change in score among the non-compliant patients. This method is referred to as the 'last observation carried forward' (LOCF) approach (Streiner, 2002). Finally, outcomes for the compliant and partially or non-compliant participants were compared in the CBR group.

RESULTS

Characteristics of the study population

A total of 207 eligible participants were enrolled in the study; 127 lived in the

Table 1 Comparison of interventions

	Community-based rehabilitation	Out-patient care
Contact type	Patients' families, community stakeholders	Patients' family
Frequency	Once a week	Once a month
Location	Home, village, clinic	Clinic
Duration of session (min)	60–90	20–30
Service provided by	Mental health worker, psychiatrist, psychologist, family groups, village *samitis*	Psychiatrist, psychologist
User group meetings	Once every 2 weeks	None
Community group meetings	Once every 4 weeks	None
Links with traditional healers and general practitioners	Strongly encouraged	Neutral
Forms of intervention	Drug treatment, psychoeducation, family counselling, vocational rehabilitation, enhancing social networks, access to social benefits	Drug treatment, psychoeducation, family counselling

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area where CBR was available and 80 lived outside this area, thus falling into the out-patient care group (Fig. 1). The two groups showed marked differences in socio- economic characteristics. Thus, the CBR group were significantly more disadvantaged in terms of literacy, poverty and caste status (Table 2). The two groups were broadly comparable on other demographic and clinical characteristics. However, the CBR group had significantly longer duration of illness and a higher DAS behavioural score.

Comparison of outcomes

Group difference

Compliance was significantly better in the CBR group, where 80 patients (63%) were fully compliant, compared with 37 (46%) in the out-patient care group (P=0.02). The intention-to-treat comparison of outcomes using the conservative scoring approach did not reach statistical significance after adjustment for other confounders (Table 3). However, intention-to-treat analyses using the LOCF approach showed significantly superior changes in score for each outcome among the CBR group (P<0.03; Table 3). Treatment completer analyses showed that clinical and disability outcomes were superior for the CBR group; these differences reached statistical significance for disability (Table 4). The differences were greater for men than for women, and there was evidence of a statistically significant interaction with gender for PANSS positive scores (P=0.03) and PANSS general scores (P=0.07).

Compliance

There was no significant difference in age, economic status or gender between the compliant and non-compliant participants in the CBR group; clinical and disability measures at recruitment were also similar, except that compliant patients had significantly lower PANSS general scores (P=0.04). Compliant patients had significantly greater changes on all measures, and this was true for both men and women (Table 5).

DISCUSSION

This study of community-based rehabilitation for people with chronic schizophrenia in an underresourced rural area in India adds to the scanty evidence base on strategies for caring for people with this disorder in resource-poor settings in developing countries. In such settings, out-patient care is most often the only type of mental health care available; such care, if provided by trained health professionals in an accessible manner, may be an effective way of providing services to a large population. On the other hand, out-patient care is limited by time and staffing constraints in providing care for the psychosocial needs of chronically ill patients. Community-based rehabilitation is a model of community care based on the active participation of people with physical disabilities and their families in rehabilitation that takes specific cognisance of prevailing social, economic and cultural issues. Its use in the area of physical disabilities has been well documented. However, compared with out-patient care, the CBR approach is more intensive in terms of time and resources. This study

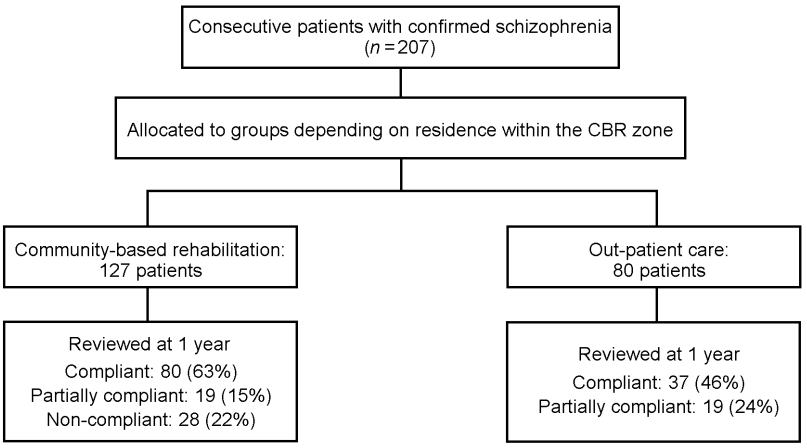

Fig. 1 Study profile (non-compliant subjects in out-patient care were not reviewed). CBR, community-based rehabilitation.

Table 2 Socio-demographic and clinical characteristics of community-based rehabilitation (CBR) and out-patient care (OPC) groups at enrolment

Variable	CBR (n=127)	OPC (n=80)	P for difference
Socio-demographic characteristics			
Age: mean (years)	38.1	36.6	0.3
Male (%)	61	55	0.4
Illiterate (%)	63	44	0.007
Below poverty line (%)	78	33	<0.001
Married (%)	69	61	0.3
Tribal or 'scheduled' castes (%)	97	59	<0.001
Joint family (%)	61	50	0.13
Clinical characteristics			
Paranoid illness (%)	38	48	0.2
Duration: median (years)	8	6.5	0.02
Sudden onset (%)	46	40	0.4
Family history (%)	24	28	0.5
Baseline PANSS scores (mean)			
Positive score	31.8	31.0	0.8
Negative score	33.1	32.9	0.2
Baseline DAS scores (mean)			
Social score	21.8	20.7	0.2
Behavioural score	22.9	21.6	0.05
Occupational score	14.2	13.6	0.1

DAS, Disability Assessment Schedule; PANSS, Positive and Negative Syndrome Scale.

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Table 3 Intention-to-treat analyses comparing community-based rehabilitation (CBR) and out-patient care (OPC) groups

Change in score[3]	CBR (n=127) Mean (95% CI)	OPC (n=80) Mean (95% CI)	Unadjusted P	Adjusted P^1
Conservative method[2]				
PANSS				
Negative	13.9 (12–15)	12.3 (11–13)	0.16	0.91
Positive	15.6 (14–17)	14.1 (13–15)	0.19	0.52
General	26.4 (24–29)	24.6 (23–27)	0.34	0.83
DAS				
Behavioural	9.6 (9–11)	8.6 (8–9)	0.18	0.93
Occupational	6.8 (6–8)	4.7 (4–5)	<0.001	0.08
Social	10.7 (9–12)	8.2 (7–9)	0.005	0.10
Last observation carried forward method				
PANSS				
Negative	13.9 (12–15)	8.8 (7–10)	<0.0001	0.02
Positive	15.6 (14–17)	10.8 (9–13)	0.0003	0.01
General	26.4 (24–29)	18.4 (15–22)	0.0003	0.01
DAS				
Behavioural	9.6 (9–11)	6.3 (5–7)	0.0001	0.02
Occupational	6.8 (6–8)	4.4 (4–5)	0.0001	0.03
Social	10.7 (9–12)	6.7 (5–8)	<0.0001	0.005

DAS, Disability Assessment Scale; PANSS, Positive and Negative Syndrome Scale.
1. Obtained using multiple linear regression to adjust for factors significantly associated with group in Table 2 (illiteracy, poverty, caste and duration of illness).
2. Assumes that non-compliant patients in the OPC group had the same outcome as the partially compliant OPC group.
3. The PANSS and DAS are both scored in line with severity; thus, a positive score indicates an improvement in the outcome being measured.

attempted to adapt the CBR model for use in chronic schizophrenia, and to compare the outcomes with standard out-patient care. The principal finding of the study is that in fully compliant patients CBR is more effective than standard out-patient treatment. However, there was less evidence of effectiveness of the CBR model in the intention-to-treat analyses when a conservative method was used to estimate missing data for non-compliant participants. The differences were statistically significant when using the less conservative LOCF method of estimation of missing data.

Limitations

This study was not a randomised controlled trial, but was the most feasible design in the setting of an actual health service innovation in a remote region. As a consequence, methodological problems such as the potential for observer bias in the ratings could confound the interpretations made. Second, there was no outcome evaluation for the non-compliant out- patient group owing to logistic difficulties. For the intention-to-treat analysis comparing the two interventions, we have used two ways of estimating the outcomes of the missing participants: the LOCF and the conservative assumption that the average end-point scores were the same as those of the partially compliant group in out-patient care. The effect of the latter assumption is likely to overestimate the true effect of the out-patient intervention, as partially compliant patients are likely to have better outcomes than non-compliant patients. The outcome measures used in the study were focused on clinical and disability measures and did not measure changes in important social processes such as social inclusion and stigma, nor other indicators such as violence and self-harm. Finally, there is no estimation of the costs of each model of care. Thus, the study is unable to answer the crucial question of the cost-effectiveness of these two models, which is especially relevant in the light of the fact that CBR is more resource-intensive.

Therapeutic strengths of CBR

The CBR method was more efficient in overcoming the economic, cultural and geographical barriers and was more effective in retaining patients and their families in the programme, as reflected in the significantly better compliance rates. It is plausible to speculate that the mental health workers made a significant contribution by providing a range of services at home. Being members of the local community, they communicated effectively with patients and families, using shared cultural idioms and thus promoting greater adherence to treatment. The mental health workers worked closely with the families and supported them in coping with the appropriate management of the illness. Community-based rehabilitation relies on the engagement of communities in the management of disability. Patients and their families were empowered to become informed partners in the planning and implementation of rehabilitation strategies that were ecologically feasible. The village *samitis* provided broad-based local community support for the programme and made a significant impact by generating a positive social milieu that facilitated recovery. Compliance with prescribed medication and male gender clearly emerged as important variables influencing outcome. Whereas the former factor clearly points to the importance of the role of medication in influencing

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Table 4 Treatment completer analyses comparing community-based rehabilitation (CBR) and out-patient care (OPC) groups

Change in score	Mean (95% CI)	Mean (95% CI)	Adjusted *P*
All compliant patients (CBR: *n*=80; OPC: *n*=37)			
PANSS			
Negative	18.2 (17–20)	12.9 (11–15)	0.06
Positive	20.3 (19–22)	17.8 (16–20)	0.06
General	33.7 (32–36)	29.1 (2–32)	0.12
DAS			
Behavioural	12.8 (12–14)	9.7 (9–11)	0.01
Occupational	9 (8–10)	6.9 (6–8)	0.22
Social	14.1 (13–15)	10.6 (9–12)	0.01
Male patients (CBR: *n*=49; OPC: *n*=18)			
PANSS			
Negative	19.0 (17–21)	13.1 (10–16)	0.002
Positive	20.4 (19–22)	16.1 (14–18)	0.007
General	34.3 (32–37)	26.2 (22–30)	0.0005
DAS			
Behavioural	13.2 (12–14)	9.1 (7–11)	0.0002
Occupational	9.2 (8–10)	6.5 (5–8)	0.001
Social	14.0 (12–16)	10.3 (7–13)	0.02
Female patients (CBR: *n*=31; OPC: *n*=19)			
PANSS			
Negative	17.0 (14–20)	12.8 (11–15)	0.02
Positive	20.2 (18–22)	19.5 (17–22)	0.65
General	33.0 (30–36)	32.0 (28–36)	0.70
DAS			
Behavioural	12.3 (11–14)	10.3 (9–12)	0.05
Occupational	8.6 (7–10)	7.3 (6–8)	0.12
Social	14.5 (13–16)	11.0 (9–13)	0.009

DAS, Disability Assessment Schedule; PANSS, Positive and Negative Syndrome Scale.
1. Obtained using multiple linear regression to adjust for factors significantly associated with group in Table 2 (illiteracy, poverty, caste and duration of illness).

outcomes, we can only speculate that gender-related social and cultural factors could differentially influence the recovery process in men and women. In addition, other ingredients of CBR such as the frequent review process might have influenced the outcome.

Implications for service provision and research

This study has provided preliminary evidence that CBR is a feasible model of rehabilitation for people with schizophrenia even in economically deprived settings, and that outcomes are better, at least for those who are treatment compliant. Since a lack of professional resources is the reality in rural settings in India and other developing countries, the CBR method offers a model which involves active local community participation and low levels of technical expertise to deliver services. Mental health professionals can contribute to enlarging the capacity of existing non-governmental organisations that already operate in such areas to initiate services that draw upon the resources of the community. Emphasising compliance with medication may be a core element of the intervention strategy. In recognition of the limitations of the study reported here, we would recommend a systematic randomised controlled trial, in which communities are randomised into those that receive CBR and those that do not, to study the critical therapeutic ingredients and cost-effectiveness of the CBR model.

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Table 5 Comparison of outcome in the community-based rehabilitation group, compliant *v.* partially or non-compliant patients

Change in score	Compliant (*n*=80) Mean (95% CI)	Partially or non-compliant (*n*=47) Mean (95% CI)	Unadjusted *P*	Adjusted *P*
PANSS				
Negative	18.3 (17–20)	6.5 (4–9)	<0.001	<0.001
Positive	20.3 (19–22)	7.5 (5–10)	<0.001	<0.001
General	33.8 (32–36)	14.0 (9–19)	<0.001	<0.001
DAS				
Behavioural	12.8 (12–14)	4.1 (3–6)	<0.001	<0.001
Occupational	9.0 (8–10)	3.0 (2–4.1)	<0.001	<0.001
Social	14.8 (13–15)	4.8 (3–6)	<0.001	<0.001

DAS, Disability Assessment Schedule; PANSS, Positive and Negative Syndrome Scale.

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CLINICAL IMPLICATIONS

- Community-based rehabilitation (CBR) is a feasible model for the care of people with chronic schizophrenia in resource-poor settings.
- Community-based rehabilitation is associated with better compliance, leading to superior clinical and disability outcomes.
- Medication compliance is a key factor in influencing outcome.

LIMITATIONS

- The study was not a randomised, controlled trial and biases such as observer bias might have influenced the findings.
- The outcomes focused on clinical symptoms and disability; economic and social outcomes and specific therapeutic ingredients of the CBR model were not measured.
- Follow-up data were unobtainable for the non-compliant out-patient group; thus, the outcome for these patients had to be estimated using two different methods.

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