

COMMUNITY PARTICIPATION IN COMMUNITY-BASED REHABILITATION PROGRAMMES

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ABSTRACT

Central to the community-based rehabilitation (CBR) approach is the concept of community participation. While many projects are based on the CBR approach, it is not evident how many CBR projects indeed use and measure community participation. The purpose of this study was to qualitatively analyse the extent of evaluation of community participation in CBR studies evaluated over the last thirty years. A total of 22 evaluations of CBR projects were carried out. Three studies each from Australia, India, Zimbabwe and two studies each from England, Philippines, Vietnam and one each from Finland, Guyana, Jamaica, Japan, Pakistan, Papua New Guinea, Thailand, and the United States were included in the analysis. From the 22 studies that evaluated CBR, only six evaluated community participation. In the six evaluations that measured community participation, it was found that four documented positive effects of participation, while two showed that community participation did not work, or was inadequate in the project. Community participation as a construct has not been adequately measured by CBR programmes. There is need to measure all dimensions of participation including measurement of the number of people with disabilities reached and quantity and quality of resources generated as a result of community participation. Valid and reliable measures of community participation need to be developed.

INTRODUCTION

Three decades have elapsed since the World Health Organisation (WHO) introduced the community-based rehabilitation (CBR) strategy as part of its goal to accomplish “Health for All by the year 2000”(1). A training manual was produced in 1980 (2) which was revised in 1989 (3) and has now been translated in several languages for use at the village level. In

essence, the primary tenet of CBR is to provide primary care and rehabilitative assistance to persons with disabilities, by using human and other resources already available in their communities. The five basic principles of CBR strategy include:

- Utilisation of available resources in the community.
- Transfer of knowledge about disabilities and skills in rehabilitation to people with disabilities, families and communities.
- Community involvement in planning, decision making, and evaluation.
- Utilisation and strengthening of referral services at district, provincial, and national levels that are able to perform skilled assessments with increasing sophistication, make rehabilitation plans, participate in training and supervision.
- Utilisation of a co-ordinated, multisectoral approach.

Central to the CBR approach is community participation. While many projects are based on CBR approach, it is not evident how many indeed use and measure community participation. Rifkin and Kangere note that there is no agreement among planners on the contribution of community participation in improving the lives of people (4). Some of the arguments that they have identified for inclusion of participation in CBR programmes are that people know what works for them and professionals need to learn from them, people make contributions of resources (money, materials, labour) for these programmes, people become committed to activities that they have developed, and people can develop skills, knowledge and experience that will aid them in their future work. It is against this backdrop that the purpose of this study was to qualitatively analyse the extent of evaluation of community participation in CBR studies evaluated over the last thirty years.

METHODOLOGY

In order to collect the materials for the study a search of MEDLINE database was done. A search of the terms “community based rehabilitation” and “evaluation” in MEDLINE revealed 44 articles of which 22 met the inclusion criteria. The inclusion criteria were publications: (a) in the English language; (b) that dealt with community-based rehabilitation as opposed to institutional based rehabilitation; (c) publications that described any aspect of either a qualitative or quantitative evaluation of a CBR programme and (d) published after 1980. Foreign language publications or publications that did not describe a CBR evaluation were excluded. Also

excluded were publications not in MEDLINE database, professional reports, or other forms of publication.

RESULTS

The studies have been arranged in the order of the year these have been published. The studies are summarised in Table 1. The first study was done in Posio, Finland (5). Using an experimental design, it was found that self-perceived health of the elderly and of disabled persons improved for the experimental group. No changes were found for functional capacity, independence in household tasks, social participation, and leisure activities. The primary costs of rehabilitation were lower for the experimental group, but the secondary costs were the same. Community participation was not measured in the study.

Table 1. Summary of community participation in community-based rehabilitation

Year of Publication	Country	Design	Community Participation related Outcome Measure(s)	Salient findings
1985 ⁵	Finland	Experimental	<ul style="list-style-type: none"> • None 	<ul style="list-style-type: none"> • Community participation not measured
1987 ⁶	Zimbabwe	Post-test only design	<ul style="list-style-type: none"> • Participants' reactions to the programme 	<ul style="list-style-type: none"> • 99% found the programme helpful • 35% gave reasons why the programme was helpful
1988 ⁷	Guyana	Multiple baseline design and qualitative assessments	<ul style="list-style-type: none"> • Attitude of mothers • Participants' reactions to the programme 	<ul style="list-style-type: none"> • 90% of mothers indicated that participation in the programme did not interfere with home chores • Parental attitudes changed significantly after the programme
1988 ^{8,9}	Pakistan	Pre-test Post-test design	<ul style="list-style-type: none"> • None 	<ul style="list-style-type: none"> • Community participation not measured

Year of Publication	Country	Design	Community Participation related Outcome Measure(s)	Salient findings
1992 ¹⁰	Philippines and Zimbabwe	Pre-test Post-test design	<ul style="list-style-type: none"> • None 	<ul style="list-style-type: none"> • Community participation not measured
1992 ¹¹	Jamaica	Post-test only design	<ul style="list-style-type: none"> • None 	<ul style="list-style-type: none"> • Community participation not measured
1992 ¹²	India	Post-test only design	<ul style="list-style-type: none"> • None 	<ul style="list-style-type: none"> • Community participation not measured
1996 ¹³	Zimbabwe	Post-test only design	<ul style="list-style-type: none"> • Community involvement 	<ul style="list-style-type: none"> • No support was found that high community involvement would result in low impact of a child with disability on the caregiver
1998 ¹⁴	England	Post-test only design	<ul style="list-style-type: none"> • None 	<ul style="list-style-type: none"> • Community participation not measured
1998 ¹⁵	India	Post-test only design	<ul style="list-style-type: none"> • None 	<ul style="list-style-type: none"> • Community participation not measured
1998 ¹⁶	Vietnam	Qualitative	<ul style="list-style-type: none"> • None 	<ul style="list-style-type: none"> • Community participation not measured
1998 ¹⁷	United States	Factorial mixed model design	<ul style="list-style-type: none"> • None 	<ul style="list-style-type: none"> • Community participation not measured
1998 ¹⁸	Thailand	Pre-test post-test design	<ul style="list-style-type: none"> • None 	<ul style="list-style-type: none"> • Community participation not measured
2000 ¹⁹	Philippines	Qualitative audit methodology	<ul style="list-style-type: none"> • Access • Collaboration 	<ul style="list-style-type: none"> • Using personal interviews, focus groups, and records review it was found that the CBR programme was perceived as important and accessible • Many members of the

Year of Publication	Country	Design	Community Participation related Outcome Measure(s)	Salient findings
				community were participatory and contributing members
2000 ²⁰ & 2003 ²¹	Australia	Qualitative SWOT analysis	<ol style="list-style-type: none"> 1. Network partnerships 2. Community focus 3. Social cohesion 4. Participation 5. Community control over decision making 6. Trust 	<ul style="list-style-type: none"> • Strengths were identified as: network partnerships, community focus, social cohesion, and trust • Opportunities were identified as: participation and community control over decision making
2001 ²²	Vietnam	Qualitative SWOT analysis	<ul style="list-style-type: none"> • Five tenets of WHO model including community participation. 	<ul style="list-style-type: none"> • Weaknesses regarding community involvement
2002 ²³	Japan	Case control design	<ul style="list-style-type: none"> • None 	<ul style="list-style-type: none"> • Community participation not measured
2002 ²⁴	England	Randomised control trial	<ul style="list-style-type: none"> • None 	<ul style="list-style-type: none"> • Community participation not measured
2003 ²⁵	Australia	Qualitative thematic analysis	<ul style="list-style-type: none"> • None 	<ul style="list-style-type: none"> • Community participation not measured
2003 ²⁶	Papua New Guinea	Survey and qualitative	<ul style="list-style-type: none"> • None 	<ul style="list-style-type: none"> • Community participation not measured
2003 ²⁷	India	Prospective treatment and comparison group design	<ul style="list-style-type: none"> • None 	<ul style="list-style-type: none"> • Community participation not measured
2005 ²⁸	Australia	Prospective repeated measures design	<ul style="list-style-type: none"> • None 	<ul style="list-style-type: none"> • Community participation not measured

The second study was done in four areas of Zimbabwe (6). Using a post-test only design, it was found that a large number of persons with disability (41%) were undiagnosed. Based on the coordinator's rating of the client's progress, it was noted that 16 % demonstrated outstanding progress, 79% steady progress, and 5% showed little or no progress. Except for one, all the 136 participants found the programme helpful. The three contributory aspects found to be important in the programme success were: partnerships with agencies, training in mental handicap, and culturally relevant resource materials.

The third study was done in Guyana (7). The study used a multiple baseline design where three data points were taken over a two month period in the baseline and data was collected using Portage checklist and Griffiths test of development. The study also collected qualitative data on emotional disturbance of mothers, attitude of mothers, parental rating of the child with most other children, and sentence completion to gauge initial responses. The study contacted 815 homes with 4,644 persons and found 33 disabled children (1.85% of the sample of children). On a repeated t-test the Griffiths test revealed statistical significance ($p < 0.01$) and so was significance found on the Portage test. Parents also rated significant improvement in their children. Overall, the CBR approach was found to be successful.

The fourth study was done in a slum area (Kachi Abadi) and a village near Lahore in Pakistan (8, 9). The questionnaire from the WHO manual (2) in a house-to-house survey was used to gauge the prevalence of disability and identifying disabled persons in need of interventions. Community participation was not measured in the study.

The fifth study was an evaluation done in Philippines and Zimbabwe in 1992 (10). The study used a pretest post-test design and found that ability scores after CBR training increased by 78% in Philippines and 93% in Zimbabwe. Community participation was not measured in the study.

The sixth study has been done in Jamaica (11). The study utilised a post-test only design and found that knowledge, attitudes and practices improved in approximately two thirds of the persons with disability. Community participation was not measured in the study.

The seventh study is about Greater Madras Leprosy Treatment and Health Education Scheme (GREMALTES) project done in India (12). The study utilised a post-test only design and found that acceptance about disease had increased among patients. Community participation was not measured in the study.

The eighth study was done in Zimbabwe (13) and interviewed CBR beneficiaries on six variables: (a) traditional beliefs about children with disabilities, (b) impact of a child with disability on the caregiver, (c) community involvement, (d) caregiver's perceived ability to teach the child, (e) attitude toward various health services, and (f) expectations for the future of a disabled child. A significant correlation between appreciation of CBR and attitude toward various health services was found. Also, it was found that perceived ability to teach and expectations for the future of the child had significant correlation. There was no support for the hypothesis that high community involvement in the care of a child with disability, would result in low impact on the caregiver.

The ninth study was done in England (14) and aimed at developing and validating a community outcomes scale for persons with traumatic brain injury. Community participation was not measured in the study.

The tenth study developed and validated a parental attitude scale for parents of disabled children in rural India (15). Community participation was not measured in the study.

The eleventh study is a qualitative account of training methods and their evaluation developed in Vietnam for CBR (16). Community participation was not measured in the study.

The twelfth study was physically based in the United States but entailed a 4-day continuing education training for 308 administrators, professionals and paraprofessionals from several countries (17). Community participation was not measured in the study.

The thirteenth study done in Thailand (18), aimed at examining effectiveness and cost of the CBR programme in a slum after a period of three years. Using a pre-test post-test design, effectiveness of the programme was assessed by measuring walking velocity, pain levels, and reasons for discontinuing the use of the CBR programme. Community participation was not measured in the study.

The fourteenth study was done in the Philippines (19) after seven years of operation and used a qualitative approach of audit where records were reviewed, in-depth personal interviews were conducted with key informants and focus groups discussions were held. It was found that the CBR programme was perceived as important and accessible. The referral systems were functioning well but there was scope for improvement. The clients and their families were satisfied with the services and they were willing to help in the continuation of the

programme. The WHO Training Manual was rated as useful. However, there was scope for improvement in training methods, duration, follow-up, and translation into local language. In terms of community participation, many members of the community were found to be participatory and contributing members.

The fifteenth study was done in Australia and published in 2001 (20) and 2003 (21). It utilised participatory rural appraisal in its planning and conducted qualitative SWOT (Strengths, Weaknesses, Opportunities and Threats) Analysis around 15 identified characteristics. With regard to community participation, it was found that network partnerships, community focus, social cohesion, and a relationship of trust were strengths of the CBR programme. Opportunities identified were participation and community control over decision making.

The sixteenth study was an evaluation done in 2001 in Vietnam (22). A participatory SWOT analysis method was utilised for evaluation. The data were examined against the WHO model. Strengths of the programme were found in three out of five areas, namely, utilisation of available resources, transfer of knowledge about disabilities, and utilisation and strengthening of referral systems. The weaknesses were in the areas of community involvement in planning and decision making and a co-ordinated multi-sectoral approach.

The seventeenth study was done in Japan (23) that compared stroke survivors with controls and found that functional fitness levels were less and varied in stroke survivors. Community participation was not measured in the study.

The eighteenth study looked at traumatic brain injury survivors in England and used a randomised controlled design (24). Community participation was not measured in the study.

The nineteenth study done in Australia looked at qualitatively classifying client goals in CBR programmes with acquired brain injury survivors (25). A taxonomy related to five categories of goals was developed: (a) me and my body, (b) looking after myself, (c) addressing psychosocial issues, (d) relating to others, and (e) services and information. Community participation was not measured in the study.

The twentieth study was done in Papua New Guinea (26) and developed a ten question screening questionnaire for childhood disability and also collected qualitative data from persons with disabilities, to understand their perceptions. Community participation was not measured in the study.

The twenty first study was done in India with persons suffering from chronic schizophrenia (27). Using a prospective treatment and comparison group design, the study found that the CBR model was more effective in reducing disability and within this group the compliant group had better outcomes than partially, or non-compliant individuals. Community participation was not measured in the study.

The final study is from Australia (28), in which a three stage programme was evaluated. In the first stage, practical activities were used to build social skills. In the second stage a 9-day outdoor adventure course was introduced with physically challenging tasks and in the third stage individuals worked on individual goals that they had set. Community participation was not measured in the study.

DISCUSSION

From the twenty-two studies that evaluated CBR, only six evaluated community participation. This shows that researchers have not adequately considered community participation as a significant construct. Community participation is an important component of CBR programmes and needs to be measured in each evaluation.

In the six evaluations that measured community participation it was found that four (6, 7, 19, 20, 21) documented positive effects of participation, while two (13, 22) showed that community participation did not work, or was inadequate in the project. A larger number of studies showed that community participation is desirable in projects. However, the number of studies done is very small to conclude for sure, that community participation always works. More number of studies that measure community participation would need to be conducted, before final judgment can be passed on the utility of community participation.

Of the six programmes that have measured community participation, the most common method to measure has been by gauging the participants' reaction to the programme. While reactions to the programme are important, other dimensions of community participation also need to be measured. Examples of such dimensions include involvement in planning, quantity and quality of planning, role in decision making, involvement of persons with disability, of the poor, and disadvantaged, and ownership of the programme by the community. Mitchell (29) has emphasised a greater role of community involvement in planning, decision making and evaluation of CBR programmes.

Partnerships in CBR programmes are also helpful in reaching a large number of persons with disabilities (30). Only one project (13) has attempted to measure that aspect. CBR projects need to measure such outreach impact. It is important to measure and document how many persons with disability have been reached as a result of involving community members.

In CBR programmes people from the community often make contributions of resources (money, materials, labour) (4). A documentation of these resources is also important, especially if the projects have to become self sustaining. Unfortunately, none of the evaluations have measured this aspect. Future evaluations should make attempts to measure the contribution of resources from the community.

In this review, it was found that there is a deficiency of psychometrically valid and reliable instruments that measure participation in CBR programmes. There is a need to develop measurement tools that measure the multiple facets of participation in the context of CBR projects.

In summary, it can be said that community participation as a construct has not been adequately measured by CBR programmes. There is need to measure all dimensions of participation, including measurement of the number of people with disabilities reached and quantity and quality of resources generated as a result of community participation.

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