

GUEST EDITORIAL

**CONSIDERATIONS IN THE QUEST FOR EVIDENCE IN
COMMUNITY BASED REHABILITATION**

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ABSTRACT

This paper seeks to contribute to current debate on evidence-based practice and appropriate models of disability rehabilitation for people with disabilities in developing countries. Based on the authors' experience in, and evaluation of Community Based Rehabilitation (CBR) projects and research, they provide suggestions for utilising different kinds of evidence at different levels of CBR. The paper proposes four considerations. First, at the micro level of individual rehabilitation techniques, it recommends the judicious co-opting of available evidence from conventional evidence sources. Second, at the level of service planning, it suggests the need for conducting major syntheses of CBR evaluation reports for evidence. Third, it proposes the incorporation of values with research in consideration of issues at the model level. Finally, the paper proposes that in the case of CBR and similar approaches, new conceptualisations and methodologies are required in current understandings of evidence-based research and practice, which highlight the voice of people with disabilities, their family members and communities as key sources of evidence-related data.

INTRODUCTION

Common understandings of evidence-based practice usually imply the use of methods that have been selected based on a foundation of repeated comparative studies, using specific, experimental methodologies. If such criteria were applied to CBR practice, it would be necessary to have, among other things, valid and rigorous randomised controlled trials indicating statistically significant effects of CBR relative to other practice models.

Unfortunately, no such research exists. The majority of studies pertaining to CBR are theory papers, opinion articles, service descriptions and service evaluations (1, 2). While these studies have led to constructive debate on processes and issues in CBR; they have not resulted in clear evidence of efficacy, consistent practice directives, or data-informed policy. Despite this, the call for evidence in CBR remains strong. Indeed, the review of CBR, initiated by the WHO (3) identified that increasingly, “*Governments want evidence-based practices, so CBR programmes must be ready to provide evidence*” for the scaling-up of CBR globally. It might be concluded that the current lack of research evidence in CBR may be limiting its recognition, uptake and organisational support. More importantly, the lack of evidence may also be limiting the potential benefit that people with disabilities, their families and communities might derive from more evidence-informed services.

Given the gulf between evidence requirements and the current reality of CBR, we suggest that some consideration of the place and construction of evidence in CBR is warranted. While we agree that substantial evidence is urgently required within the field of CBR, we suggest that discussion on this topic may also be advanced by recognising that evidence has different forms and different applications to various levels of CBR and that there should also be consideration of different ways of determining evidence in CBR. In our opinion there are methodological, practical and philosophical issues that should be explored as CBR seeks to become more evidence based.

LEVELS OF CBR

We suggest that it is important to make a distinction between levels of CBR, recognising that different ‘types of evidence’ may be relevant at different levels. These levels include: (1) discrete CBR practices and techniques, (2) CBR service delivery and (3) the broader CBR model. We also suggest that across these levels, we should also seek to include a key principle underpinning CBR, (4) that of being responsive to the voices of people with disabilities and their communities, as a key source of evidence to inform the development of CBR.

At the level of CBR practices and techniques, there is a need and scope for greater evidence

The first level in our distinction is that of the practical rehabilitation practices and techniques employed in CBR. It is at the level of provision of rehabilitation interventions with individuals

that current understandings of evidence may have greatest application. Unfortunately, as pointed out in a recent detailed review (1), and some general reviews (2), there are few studies in CBR which might be used to contribute to such an evidence base. However, these studies also imply that it may be appropriate for evidence of intervention effectiveness from outside of the field of CBR and CBR publications, to be applied in this setting. We suggest that this may be a fruitful area for further investigation. For example, evidence based practices exist for ulcer prevention and treatment in leprosy rehabilitation (4) and spinal injury rehabilitation (5). Therefore, such practices might be thoughtfully applied to CBR settings, where they are suited to adaptation with low-cost, appropriate technology strategies.

In our opinion, a key priority for CBR organisations which have a clearinghouse or data analysis capacity, should be the investigation of existing databases for evidence-based techniques that may have relevance within community contexts in developing countries. This will not simply be a matter of identifying and 'importing' all evidence based techniques, because on some occasions these may be inconsistent with community based practice, or equally, the implementation of these practices might be compromised by the realities of a community setting (6). In such an undertaking, it will be important to recognise that the context in which much evidence is determined is substantially different from uncontrolled community settings. Further, where evidence-based guidelines arise from economically developed countries, they may be quite prescriptive or bio-medical in nature, and have limited application to developing country settings (7). Conversely, it may be found that in some instances, core values held within the field of CBR (such as commitment to consumer voice, community consultation and cultural relevance) cannot be readily accommodated within certain Western frameworks for evidence (8).

Despite these caveats, we suggest that at the level of specific practices and techniques, where evidence is available and applicable, it should be prudently incorporated into CBR. For this to occur, there is a need for a coordinated research programme which could review available evidence and determine how the resultant evidence-based practices might be co-opted for use in community settings in developing countries.

At the level of CBR service delivery, some new types of evidence are emerging

At the service delivery level, CBR is more than simply a collection of techniques. While CBR projects have much in common, they also reflect considerable diversity. They may

exhibit differences in organisational frameworks, management structures, staffing models and use a variety of practice approaches. This lack of uniformity across CBR initiatives results in significant complexity for attempts to establish an evidence base pertaining to CBR service delivery.

Some recent studies have sought to respond to this challenge by systematically synthesising service level evaluation reports from CBR projects. Such studies, acknowledging that the field of CBR is 'evidence poor' (lacking experimental studies, randomised controlled trials and systematic reviews), have recognised that it is also 'data rich' (having a wealth of evaluations, descriptive analysis and more subjective appraisals). This emerging area of research is seeking to respond to the challenge of making such data relevant as 'evidence' to inform CBR policy and practice (9) and evaluation (10, 11).

These studies are starting to provide a general level of evidence for policy and planning in CBR (rather than specific evidence of effectiveness of CBR interventions). The most evidence-related of these studies (9) systematically synthesised recommendations of 37 CBR project evaluation reports from 22 developing countries. Results of the synthesis indicated that key areas of weakness in CBR practice were in technical, organisational and administrative aspects of management. The study identified shortcomings in strategic leadership, personnel management and CBR training frameworks globally. Based on the evidence of evaluation recommendations, this research noted priorities for enhanced management, organisational, personnel, training and administrative infrastructure in CBR projects. It also identified that for CBR to advance, greater priority must be given to collaboration and linkages at governmental, organisational, political and community levels. Further, this evaluation synthesis revealed consistent concerns regarding the use of income generation in CBR and the way medical and clinical rehabilitation is practised in CBR. In so doing, the synthesis provided an evidence-based critique of issues that require attention in the advancement of CBR.

These findings were partially echoed in another review of evaluations (10) which found that training and training frameworks in CBR were deficient for people with disabilities and CBR workers. These emerging synthesis studies utilise a different type of evidence to inform CBR practice and policy. As a result, more informed, evidence-based CBR services may be developed over time.

At the level of the CBR model, the ‘evidence’ foundation is informed by values as well as evidence

At the model level, CBR has evolved considerably over time (12), it is now recognised that far from being a recipe or blueprint, it is a dynamic concept comprising multiple layers and different strategies, responding to diverse political, cultural and social contexts and different organisational and financial factors. However, the flexibility of CBR does not detract from its usefulness as a model of service delivery.

We suggest that at this level, the recognisable evidence for the CBR model should comprise a mix of principles and values as well as relevant research findings. This is timely, given contemporary definitions of evidence which increasingly include variables such as values (13) and philosophies. Our contention is that at the level of the model, decisions for or against the CBR approach should be informed by values as well as research, and that these values should be acknowledged and actively debated. There are numerous philosophical foundations that can be identified in CBR, many of which are common across all rehabilitation perspectives. We have highlighted a few examples.

First, the historical and philosophical focus of CBR was an attempt to meet the need for adequate and appropriate rehabilitation and disability services for all people in developing countries. CBR then, like other rehabilitation models is based on an understanding of the value of **rights and worth of all individuals** (14). As a result, in recognition of the disadvantage experienced by most people with disabilities, many CBR initiatives seek to enhance their rights and roles in society. **Social empowerment** of people with disabilities, family members and communities is a key value inherent in CBR (15). Again, this value is shared to varying degrees by many rehabilitation models.

The CBR model departs slightly from some other models on the importance it places on values related to community. Where possible, the CBR approach seeks to utilise and build on existing resources, and involve people with disabilities, their families and communities. It may be concluded that CBR programmes aim to be **context-specific**, influenced by social and other factors within the community (16). They provide rehabilitation, training and vocational opportunities and seek to improve integration of people with disabilities into their local communities. The ideal for effective CBR programmes is that persons with

disabilities, their families, the community, community workers and health professionals collaborate to provide services **recognising the value of the local community** (17).

Another value inherent in the CBR model is that of **community participation**. It is maintained that this principle results in greater involvement of family members and local volunteers in the rehabilitation process (18), and less travel and expense for people with disabilities. As a result, family and community members can see what they are achieving, and they can continue to participate in the social, cultural and work life of their community. The value of community participation is also linked to two other values key to CBR. First, **cultural appropriateness** – employing local human resources is more likely to result in culturally appropriate practice (eg. language, religion), and lead to the use of locally-available materials. Second, **cost-effectiveness** – the use of family and community volunteers reduces the dependence on external professionals which decreases service costs and promotes sustainability.

The focus of CBR programmes is usually to support all people with disabilities **across a community** (horizontally), rather than focusing vertically on a specific group or those with a particular disabling condition. This distinction highlights an important values issue that informs choice of model. For example, in the case of working with people with leprosy, practitioners who hold a community-oriented values framework, argue for the integration of leprosy treatments and control programmes into CBR and similar horizontal approaches (19). They express the position that a key to combating social stigma is social and service integration (20). Others who emphasise the values of specialised services prefer a traditional vertical service model for the same reason, to address the social stigma people may experience (21, 22). This highlights our suggestion that at the level of model, values need to be incorporated (along with research) into the evidence debate and decision making.

AN ALTERNATIVE SOURCE OF EVIDENCE THAT MAY INFORM PRACTICES, SERVICE DELIVERY AND THE MODEL OF CBR

Finally, we suggest that a dimension currently under-recognised in the evidence debate is that of the voice of people with disabilities, their family members and communities. Given the philosophical place of CBR (at the local, community level), there is perhaps need for a new conceptualisation of evidence that utilises responsiveness to service-users (listening to

people) as a foundational framework for an evidence base. Indeed, the newly promulgated UN Convention on the Rights of Persons with Disabilities (23) enshrines disabled people's '*full and effective participation and inclusion in society*' as one of its general principles. This should include disabled people's participation in contributing to the evidence base which will shape evidence for service delivery in the future.

Within CBR, there are increasing efforts to ensure that disabled people's voices are heard, at both the individual level and at the collective level. At the individual level, CBR is increasingly adopting the 'social model', which acknowledges the influence of social factors on disabled people's functioning and requires their active participation at all levels. At the collective level, an increasingly rights-based approach to CBR is giving disabled people's organisations (DPOs) a larger role in the initiation, implementation and evaluation of CBR programmes (24). CBR practitioners should therefore collect evidence through participatory methodologies at both of these levels.

In CBR, approaches such as participatory rural appraisal (PRA) are particularly suited to gathering evidence from disabled people and communities in CBR programmes. PRA may be described as a toolbox of research **methods** which are appropriate for communities with low levels of education and little research experience, (e.g. visual and oral methods and use of local materials which allow everyone in the community to participate). However, more importantly, PRA is a **philosophy** by which outside researchers learn from communities and encourage them to take control of the research process. In so doing they can provide information from their perspective which informs CBR service delivery. The challenge is to turn this information into evidence for practice.

While PRA is now commonly used in community development, there are added challenges when used in relation to disability. First of all, disability is rarely if ever, a priority issue for communities, so before collecting evidence from communities on disability issues, there is need for community sensitisation to disability issues. Definitions of 'disability' vary across cultures, and hidden and mild disabilities may not be recognised. Communities may only raise a narrow range of disability-related issues, such as loss of income, and not be aware of other issues such as the psycho-social effects of disability, communication problems or problems facing disabled women.

There are also a number of challenges in carrying out PRA activities with disabled people themselves, since they are often the poorest, most marginalised people in the community. Their marginalisation can exclude them from participatory processes in a number of ways – due to extreme poverty (being unable to participate due to more pressing economic needs), by being ignored or considered unimportant by more powerful people in the community, through communication problems (eg. for people with hearing or learning difficulties), mobility problems, or by being unaccustomed to forming or expressing their opinions.

At the collective level, evidence on CBR programmes can also be gained from disabled people acting through their DPOs. In some countries, DPOs have informed national policy debates on poverty reduction and debt alleviation (25), though however, this may be a long term aspiration for many others. In places where DPOs are relatively newly-established and have limited resources and capacity, genuine representation across gender, disability type, children's issues and rural-urban issues is more limited.

Developing participatory methodologies to gain evidence

How then do CBR programmes go about ensuring community and disabled people's participation in collecting evidence? A CBR organisation in Cambodia, Disability Development Services Pursat (DDSP), piloted methods of enabling illiterate, inexperienced rural disabled people to lead participatory exercises to plan CBR activities (26). The research team of rural disabled people were trained in a range of PRA exercises (mapping, ranking, role-play, household surveys, Venn diagrams, etc.) and carried out surveys of disabled people and their communities in three villages. Many of the lessons learned on participation in planning CBR are also applicable to gathering evidence during a CBR project to inform practice and service delivery.

The disabled research team identified disabled people, using a set of picture cards depicting types of disability to ask villagers how many people in each category of disability there were in the village, and explore incidence of disability. They also identified disabled people's main concerns and potential project priorities through focus-group discussions and individual ranking (using a number of stones to rank importance). This method could also be used to gather evidence on the effectiveness of CBR interventions, or to compare questions of different methods of service delivery, such as service uptake and service effectiveness.

At the collective level of disabled people's participation, CBR programmers should also make efforts to include DPOs in gathering evidence on CBR. While DPOs are weak in many countries, it should be realised that they have 'the right and the responsibility to identify the needs of all people with disabilities, to make their needs known and to promote appropriate measures to address their needs (24). This is the sort of evidence that CBR services should seek, to inform service delivery.

Limitations in participatory methods

Clearly there are limitations to participatory research done by village disabled people. Lack of numeracy skills necessitate additional support, low status and poor self esteem (especially of disabled women) make leadership of activities problematic, limited community development skills may inhibit the generation of village-based solutions. Further, some aspects of research such as the measurement of outcomes usually rely on specific rehabilitation skills and understanding and may best be difficult for people with disabilities and community members without substantial support. Despite these limitations, we suggest that a commitment to 'hearing' the voice of people with disabilities and community members will result in an important source of evidence for CBR.

Similarly, there is considerable scope for bias from data collected by community members (either exaggerating positive effects of a project or intervention to please others, or over-emphasising difficulties in order to persuade the project to continue). While such bias may occur in data collected by organisations and DPOs, it may be particularly evident in any project working with vulnerable and marginalised people.

Due to these potential sources of bias, CBR programmes should always cross-check participatory data gained via disabled people and communities. This cross-checking, or triangulation (27), might take place through: collecting data with a multi-disciplinary team using visual, verbal, group and individual methods, and through using a range of different sources of information (men, women, children, people with different types of disability, with different levels of exposure to the CBR project), with different connections to the CBR project.

CONCLUSION

After nearly 30 years of experience worldwide, CBR is still struggling to gain recognition as a legitimate model of service-provision to disabled people. Its claims that it is an effective,

cost-efficient, sustainable model need to be borne out by evidence. In this regard we have sought to present some considerations, and identify that there are different levels at which to explore different kinds of evidence. First, it was noted that there are promising possibilities for obtaining and incorporating evidence at the direct service-provision and CBR technique level. Second, it was identified that there are encouraging studies emerging for obtaining evidence at the CBR service-level by synthesising evaluation reports and other related documents. Third, the suggestion was raised that the incorporation of values as well as research findings in establishing evidence at the model level may also be a clarifying distinction. Fourth, we suggested that in keeping with underlying values in CBR, creative new methodologies for determining evidence should include participation at the community level, including the service-users themselves, their advocates in DPOs, and local community members. Appropriate research methods, drawn from the experience of the wider community development field, should be included alongside the earlier mentioned evidence strategies to enable the voice of village disabled people to be heard and incorporated into a unique, multifaceted evidence base for the discipline of CBR.

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