

The evolution of community-based rehabilitation (CBR) programmes: a call for mixed evaluation methodologies

Evidence of
CBR
evaluation
methodologies

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Abstract

Purpose – For the past four decades, there is no evidence of a consensus on the suitable community-based rehabilitation (CBR) evaluation methodologies. To this end, the purpose of this study is to provide a narrative review on CBR evaluations and the potential of photovoice method when used alone and when used in combination with quality of life assessment tools as CBR evaluation methodologies.

Design/methodology/approach – A narrative review was undertaken, but including some aspects of scoping review methodology.

Findings – Thirty-three full-text articles were included for review. Three key findings were an overview of the evolution of CBR evaluation; the use of photovoice method in CBR evaluation and the use of photovoice method in combination with quality of life assessment tools in CBR evaluation.

Research limitations/implications – Photovoice methodology was found to be participatory in nature and as has the potential to elicit the experiences of persons with disabilities. However, photovoice falls short of measuring the quality of life of persons with disabilities, thus will need to be collaborated with another assessment tool. A combination of photovoice and World Health Organization Quality of Life (WHOQOL)-BREF and WHOQOL-Dis assessment has a potential to give an adequate representation of the voices of persons with disabilities and their quality of life.

Originality/value – There is need for changes in CBR evaluation methodologies in response to the evolution of disability models from medical model to human rights model. Thus CBR evaluation methodologies should embrace the diversity among persons with disabilities in interpreting life experiences and quality of life.

Keywords Community-based rehabilitation, Photovoice method, WHOQOL-BREF

Paper type Literature review

Introduction

Community-based rehabilitation (CBR) is a strategy for general community development that addresses the rehabilitation, equalization of opportunities, poverty reduction and social

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inclusion of all persons with disabilities [1]. It is a rights-based and development-oriented approach aimed at improving the quality of life of persons with disabilities in low-income countries. The main aim of CBR is to improve access to services for persons with disabilities in remote rural areas and enhance their quality of life, although the strategy is also utilized in urban areas. Currently, CBR is implemented globally in over 90 countries [2].

The CBR strategy was developed by the World Health Organization (WHO) to be included as part of PHC programs and is accepted as the best way of promoting an efficient way of making services more accessible to persons with disabilities in developing countries and bringing rehabilitation services closer to people with disabilities, especially in low-income countries [3]. As the global implementation of CBR programs increased, the manner in which CBR was conceptualized, initially as a medical care model, evolved in many ways. Other UN agencies, such as the International Labour Organization, United Nations Educational, Scientific and Cultural Organization, United Nations Development Programme and United Nations Children's Fund developed a CBR Joint Position Paper, recognizing the need for a transition to include a multisectorial approach.

Since 2004, the CBR approach has evolved from healthcare service delivery to community development as well as moving toward the social and human rights model of disability [1]. In 2006, with the adoption of the UN Convention on the Rights of Persons with Disabilities (UNCPRD), the human rights model for disability service delivery was adopted. In the same vein, in 2010, WHO adopted the CBR Guidelines [4] which further mandated member states to use the rights-based approach to include the active participation of persons with disabilities. These WHO CBR Guidelines clearly explain CBR as a multisectorial and multidisciplinary approach with five interrelated components including health, education, livelihood, social mobility and empowerment [4]. Currently, CBR does not only focus on the individual's impairments but also addresses experiences of persons with disabilities regarding poverty, reduced opportunities and social exclusion [2].

Researchers have been urged to provide more evidence on the benefits of CBR that can help to convince governments and donors of the potential value and impact of CBR [5]. For the past four decades, there has been some form of CBR evaluation across all countries implementing the program. However, there is currently no evidence of a consensus on the most suitable CBR evaluation methodologies. To this end, this study aimed to provide a narrative review on CBR evaluations and the potential of the photovoice method when used alone and when used in combination with the quality of life assessment tools as primary CBR evaluation methodologies. The main research question was – what value does the photovoice method provide when used alone and when used in combination with the quality of life assessment tools in CBR evaluation?

Methodology

A narrative review was undertaken but included some aspects of the scoping review methodology. Articles were purposively selected from the following databases: PubMed, EBSCOhost including MEDLINE, PsychINFO, Academic Search, Education Source, Health Source and Sage Publication, ScienceDirect and Web of Science. The three search terms used to find the relevant articles were “CBR evaluation methodologies”, “CBR and photovoice” and “photovoice and quality of life assessment tools for persons with disabilities”.

The inclusion criteria were all articles or papers that described CBR evolution, CBR evaluations, photovoice and quality of life assessment tools for persons with disabilities. Articles or papers published from 1995 to 2018 were considered. The search was conducted in July 2018. Articles or papers not in English, grey literature and those for which the full text was not available were excluded. From the articles and papers retrieved from the first round of searches, additional references were identified by a manual search among the cited references.

Results

The initial search yielded 5,564 articles of which 5,514 did not meet the inclusion criteria and 50 were retained for review. The final 33 articles and papers were included for review (Figure 1). The articles and papers included: six discussion papers of CBR evolution and evaluation, four reports on disability CBR programming, seven reviews on CBR monitoring and evaluation, three guidelines/manuals on CBR framework/models for evaluation, three manuals/guidelines on World Health Organization Quality of Life (WHOQOL)-BREF, nine original articles with aspects of CBR monitoring and evaluation and one book chapter on CBR framework/models for evaluation.

A narrative discussion of these results is presented below.

Discussion

This study aimed to investigate CBR evaluations and the potential of the photovoice method when used alone and when used in combination with the quality of life assessment tools as valid methodologies for CBR evaluation. The result and discussion of this narrative review will be presented as follows: an overview of CBR evaluation; the use of the photovoice method in CBR evaluation and the use of the photovoice method in combination with quality of life assessment tools in CBR evaluation.

Overview of CBR evaluation

Early CBR evaluations were conducted when the Training in the Community manual for People with Disabilities was first field-tested [7]. In these early CBR evaluations, the key data

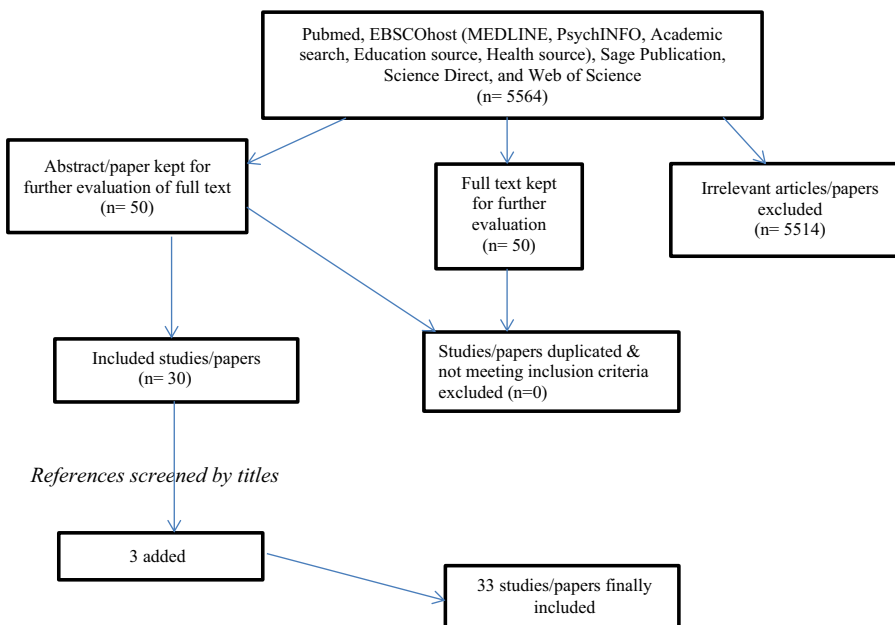


Figure 1.
Flow chart for the
selection of articles

Source(s): Adapted from Moher, Liberati, Tetzlaff, Altman, The PRISMA Group [6]

reported on were consultant visits, training workshops held and the number of stakeholders involved in the training [8]. In subsequent years, more data sets were added regarding the number of people identified with disabilities, the number of people with disabilities who received assistance and the type of assistance [9].

Most of the CBR evaluations were predominantly underpinned by the medical model. However, the CBR Joint Position Paper of 2004 promoted the evolution of the CBR approach from healthcare service delivery to community development as well as the social and human rights model of disability [1]. Further to this, the adoption of the UN Convention on the Rights of Persons with Disabilities in 2006 affirmed the need to uphold human rights by mandating member states to promote and protect the rights of persons with disabilities [1]. In the same vein, the CBR Guidelines [4] added a new rights-based approach to include the active participation of persons with disabilities.

Despite the evolution of CBR evaluation, evidence of its impact remains sparse [10], and does not address the important issue of whether CBR contributes to change [11]. There is a need to explore evaluation methodologies that address the effect of CBR at the individual, family and community level. Such evaluation methodologies should direct the right questions to the right people in the right ways [12]. Most importantly, researchers need to ask persons with disabilities and their families how they perceive CBR in improving their lives [13]. To this end, qualitative and participatory evaluations are required to complement quantitative approaches [14].

Over the years, quantitative methods have allowed for a broad generalization of CBR effectiveness. However, quantitative methods provide solely medically oriented data such as the number of persons with disabilities participating in a CBR program, disability types, assistive devices distributed, etc., but fail to collect data on the experiences of persons with disabilities [13]. Further research has reported limiting or incomplete client records and little information about disability captured by management information systems [13]. The adoption of positivism in quantitative methods has been criticized for generating findings that are descriptive and lack in-depth analysis of issues. Notwithstanding the value of quantitative data to support the CBR program, qualitative data, with respect to experiences of persons with disabilities may provide additional information to enable policymakers to take action that ensures appropriate and adequate support for persons with disabilities. Qualitative research can offer answers on the how and why of CBR benefits and shortfalls [13].

Qualitative methodologies have dominated CBR evaluations including face-to-face interviews and focus group discussions. However, these methodologies have failed to provide evidence on the experiences of persons with disabilities that can potentially reach policymakers. There is a need for other qualitative methods that can be combined with quantitative methods to better capture the effectiveness of a CBR program [15]. The use of mixed methods in CBR program evaluation allows for the triangulation of data which can demonstrate the effectiveness of CBR programs [16].

CBR is a multisectoral and multidisciplinary approach requiring the use of mixed methods in evaluation. Research in CBR evaluation [15] suggests that CBR practitioners should consider using mixed methods and participatory tools to empower persons with disabilities to effectively communicate their needs to program implementers and policymakers. These findings resonate with the World Report on Disability that recommended appropriate tools for research measuring both the experiences of persons with disabilities and their quality of life: “*Measures of the lived experience of disability need to be coupled with measurements of the well-being and quality of life of people with disabilities*” [2].

Notwithstanding the value of the mixed methods approach, one of the unresolved questions in evaluating CBR is – to what extent and how participatory can evaluation be? The ability to answer such questions avoids the trap of falling into tokenistic participation [13].

CBR evaluation tools should include persons with disabilities and their community as a central part of the evaluation [17–19]. Thus, CBR evaluations should not be person-centered but directed at the level of families, service providers and community. Such evaluations should explore these different levels and how they influence each other [13]. Participation of persons with disabilities in CBR evaluations can be informative to implementers and policymakers and can have relevant practical outcomes from the point of view of CBR users. Under the aegis of Article 32 of the UNCRPD, persons with disabilities should be consulted in services in which they are involved [20]. Similarly, some researchers advocated for the use of monitoring systems that are participatory and community-owned to ensure program quality and sustainability [21].

In this review, some researchers proposed the use of various qualitative methods to investigate the experiences of persons with disabilities including focus groups, interviews, document review, questionnaires and nominal groups [19, 22]. However, these methods solely rely on the assumptions and judgments of the researcher, and this often results in information that may not reveal the true picture of the respondents' views [23]. Further, these conventional methods of data collection may also have the effect of instilling a sense of inferiority and resentment in participants as they often view the researcher as the one processing their thoughts [24]. This narrative review identified photovoice methodology as participatory in nature and as having the potential to elicit the experiences of persons with disabilities.

The use of photovoice as an evaluation methodology

Photovoice was identified as embracing participatory principles that include persons with disabilities as the central part of the evaluation and is suited for persons with low literacy rates [25]. In this respect, the photovoice method developed by Wang and Burris [25] appears to have the potential to offer a practical qualitative evaluation tool to elicit the experiences of persons with disabilities with a CBR program. Photovoice is a participatory evaluative tool, commonly used in health research to promote personal and community change for community-based participatory research because of its accuracy in gathering information [26]. Furthermore, photographs captured in photovoice facilitate the interpretation of concerns and enable the promotion of change [25]. When people with disabilities can document their experiences and concerns using photographs, it increases their sense of control of their own lives and instills in them a belief that they can be change agents. It is envisaged that by participating in the study, participants are likely to become more aware of elements of the CBR program, enabling them to educate others about these elements and be more informed about their rights. CBR evaluations need to be conducted in close collaboration with the local community in order to be empowering, and to then be followed by sharing findings and taking action when necessary [15].

Wickenden *et al.* [13] questioned the use of CBR evaluation findings and whether they feed into change. Shumba and Moodley [27] found out that photovoice is a flexible methodology and can enhance community involvement for action and advocacy in highlighting and addressing issues affecting people with disabilities. This can be achieved through adapting the photovoice methodology in line with any disability or CBR framework, for example using the WHO CBR Matrix in data analysis. Further, Shumba and Moodley [28] as part of their study, developed posters for public photo exhibitions to share photographs and findings with the broader community and policymakers to advocate for development and changes to disability policy, legislation and programs. Utilizing photovoice as a research method will enhance the understanding of people with disabilities, enabling them to better articulate their needs. This will help to elicit rich descriptive information and challenges about the everyday lives and social realities of persons with disabilities. Further, photovoice alleviates

the challenge of undertaking a questionnaire-based monitoring and evaluation method for the CBR program, especially in areas with a low literacy rate among persons with disabilities.

On the other hand, caution should be taken when implementing photovoice because of the diversity among persons with a disability, for example, persons who are deaf may require an interpreter. Other challenges that arise with implementing photovoice include strict adherence to ethical issues surrounding photography and human subjects. It is noteworthy that the main aim of the CBR program is to improve the quality of life of persons with disabilities. Thus, photovoice falls short of measuring the quality of life of persons with disabilities and will need to be collaborated with another assessment tool.

The following are photovoice implications for consideration:

- (1) Photovoice is a practical qualitative evaluation tool that can generate social realities of persons with disabilities that are often not accessible to researchers and are sometimes disregarded by family and community members.
- (2) Photovoice can help alleviate the challenge of undertaking a questionnaire-based monitoring and evaluation of the CBR program, especially in areas with low literacy rates among persons with disabilities.
- (3) Photovoice can be utilized to investigate the experiences of persons with disabilities and be adapted to any framework for data collection and analysis e.g. the five components of the WHO CBR Matrix.
- (4) Photovoice can be implemented contextually to suit specific requirements of disability groups. For example, including those persons with mental illness and deaf persons who may require additional reasonable accommodation e.g. deaf persons may require a sign language interpreter.
- (5) Photovoice requires strict adherence to ethical considerations underpinning photographs and human subjects.
- (6) Photovoice will need to be collaborated with another assessment tool to measure the quality of life of persons with disabilities.

The use of the photovoice method in combination with quality of life assessment tools in CBR evaluation

WHO and the World Bank [2] in their World Report on Disability recommended appropriate tools to fill the research gap of simultaneously measuring the experiences of persons with disabilities and their quality of life. The aforementioned argument from the WHO and World Bank [2] proposes mixed methods that place the measurement of quality of life as an additional critical measure to corroborate the elicited experiences of persons with disabilities.

A number of tools have been suggested as suitable in measuring the quality of life of persons with disabilities including the Sickness Impact Profile [29] which measures the impact of disease and impairment on daily activities and behavior; the Nottingham Health Profile [30] which measures perceived health measures; the Medical Outcomes Study SF-36 [31] which measures disability/functional status. While these tools provide a measure of the impact of disease, they do not assess quality of life and many of these tools were developed during a time when the medical model of disability was used. One tool that can effectively be used to measure the quality of life for persons with disabilities and embrace the current human rights model of disability is the WHOQOL instrument [32].

The WHOQOL instrument was developed to assess the “individual’s” perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns [33]. In its development, 15 cultural settings were used, and it was tested in 37 field centers over several years. Language diversity has been adequately embraced by the WHOQOL with 29 language versions available. The WHOQOL instrument has two forms, WHOQOL-100 with 100 questions of assessment and the WHOQOL-BREF with an abbreviated 26 item assessment. The instruments have various domains and subdomains to produce a multidimensional profile of scores. A high correlation was found between domain scores based on the WHOQOL-100 and domain scores calculated using items included in the WHOQOL-BREF. These correlations ranged from .89 (for domain 3) to .95 (for domain 1) [33]. WHOQOL-BREF demonstrated good internal consistency with Cronbach’s alpha values for each of the four domain scores ranging from .66 (for domain 3) to .84 (for domain 1). However, caution should be taken when reading Cronbach’s alpha values for domain 3 as they were based on three scores (i.e. the personal relationships, social support and sexual activity facets), instead of the minimum four generally recommended for assessing internal reliability [33]. To explain the observed variance in the general facet from the WHOQOL-100 assessment, multiple regression was used to determine the contribution made by each domain score. It was concluded that all four WHOQOL-BREF domain scores made a significant contribution to explaining variance observed in the general facet relating to Overall Quality of Life and General Health [33]. The physical health domain contributed the highest and the social relationships domain the least. Thus, it is suggested that when evaluating the overall quality of life, all four domains should be considered [33].

Both the WHOQOL-100 and WHOQOL-BREF have been proposed as having uses in establishing baseline scores in a range of areas, determining changes in a person’s quality of life over the course of interventions, research and policymaking [33]. Measuring the effect of CBR on the quality of life of persons with disabilities over time can help to prioritize areas that need more resources, especially in resource-limited settings [33].

Noteworthy is that the WHO developed an additional module to the WHOQOL-BREF called “WHOQOL-Dis” to measure specific aspects of the quality of life of persons with physical and intellectual disabilities. The WHOQOL-Dis is a measurement option for quality of life and thus recommended joint administration with the WHOQOL-BREF [34]. To this end, researchers can jointly administer the WHOQOL-BREF and WHOQOL-Dis to gain both a generic and an in-depth understanding of the quality of life of persons with disabilities [28]. Thus, a combination of photovoice and WHOQOL-BREF and WHOQOL-Dis assessment has the potential to give an adequate representation of the voices of persons with disabilities and their quality of life. Further, Shumba and Moodley [28], concluded that the WHOQOL-BREF and WHOQOL-Dis can be administered at the end of the photovoice process to depict the convergence and divergence of both the experiences of persons with disabilities and their quality of life regarding CBR.

The following are WHOQOL-BREF implications for consideration:

- (1) WHOQOL-BREF assessment can be utilized to generate milestones in the quality of life of persons with disabilities.
- (2) WHOQOL-BREF assessment may be ineffective for persons with limited literacy levels unless interpretation is provided.
- (3) The combination of photovoice and WHOQOL-BREF assessment provides an integration of the experiences of persons with disabilities on the CBR program and their ultimate quality of life.

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- (4) The combination of the photovoice method and WHOQOL-BREF assessment may be context-specific. For example, including persons with mental illness and visual impairments may require an assistant and brailing of the WHOQOL-BREF. Also, deaf persons may require a sign language interpreter.

Conclusion

The evolution of CBR evaluation as a result of changes in the disability models from a priority health model, to a social and human rights models, calls for changes in CBR evaluation methodologies. The use of mixed methods has been recommended to capture both the experiences and quality of life of persons with disabilities. This resonates with a growing body of CBR literature that calls for a mixed-method approach in CBR evaluative frameworks. Thus, CBR evaluation methodologies should embrace the diversity among persons with disabilities in interpreting life experiences and quality of life. CBR programs built and modified on empirical evidence contribute to the country's health system being strengthened thus improving the quality of life of people with disabilities.

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