Ethics and Community-Based Rehabilitation: Eight Ethical Questions from a Review of the Literature

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ABSTRACT

Purpose: This article reviews the literature regarding ethics and community-based rehabilitation (CBR) with the goal of identifying and analyzing ethical considerations associated with this approach. **Method:** We conducted a critical interpretive review of the academic literature related to CBR in low- and middle-income countries and to indigenous communities in high-income countries. Using an inductive analysis of the collected articles, we identified five key topic areas related to ethical considerations. We then critically appraised this literature and developed eight questions that reflect areas of ethical tension, uncertainty, or debate. **Results:** The five key topic areas are partnerships among stakeholders, respect for culture and local experience, empowerment, accountability, and fairness in programme design. The eight ethical questions are linked to these topics and associated with how CBR practices reflect commitments to equity, respect, inclusion, participation, and social justice. **Conclusion:** Continued engagement with ethical considerations associated with CBR can help to strengthen the foundations of this important and influential approach. It is crucial that all those involved in CBR projects, including physiotherapists, pay careful attention to the development of partnerships that, despite asymmetries among stakeholders, are respectful and effective.

Key Words: ethics; global health; health equity; rehabilitation.

RÉSUMÉ

Objectif : Examiner la littérature portant sur la réadaptation à base communautaire (RBC) et l'éthique afin de répertorier et d'analyser les considérations éthiques liées à cette approche. **Méthode :** Nous avons effectué un examen critique de la littérature universitaire portant sur la RBC dans les pays à faible et moyen revenu et dans les communautés autochtones dans les pays à revenu élevé. Suivant une analyse inductive des articles colligés, nous avons répertorié cinq principaux thèmes liés aux considérations éthiques. Nous avons ensuite évalué la littérature de façon critique et formulé huit questions touchant à des éléments qui font l'objet de tension éthique, d'incertitude ou de débat. **Résultats :** Les cinq thèmes répertoriés sont : partenariats entre les intervenants, respect pour la culture et l'expérience locale, autonomie, responsabilisation et équité dans la conception de programmes. Les huit questions d'ordre éthique se rattachent à ces thèmes et visent à déterminer la mesure dans laquelle les pratiques de RBC sont le reflet d'un souci d'équité, de respect, d'inclusion, de participation et de justice sociale. **Conclusion :** Un souci continu des considérations éthiques liées à la RBC permettra de consolider les assises de cette approche importante et influente. Il est impératif que les intervenants en RBC, y compris les physiothérapeutes, prennent soin de former des partenariats qui, malgré le rapport asymétrique entre les intervenants, sont respectueux et efficaces.

People with disabilities (PWD) are more likely than others to live in poverty, not participate in their communities or in the workforce, and be denied access to basic rights.^{1–3} In many contexts around the world, PWD have limited institutional supports and resources available to them as they seek to meet their daily needs and develop the full range of their capabilities, and recognizing these realities prompted the development of

the community-based rehabilitation (CBR) approach.³ Emerging from a World Health Organization (WHO) proposal after the 1978 International Conference on Primary Health Care and the Declaration of Alma-Ata, it has since become a widespread development practice that aims to support PWD, particularly in settings in which institutional rehabilitation programmes are ineffective or not widely available.⁴ In 2004, the International Labour

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Box 1 Key Topic Areas and Associated Ethical Questions

Key topic area	Associated ethical questions
Partnerships among stakeholders	1. What factors limit the development of effective and respectful partnerships?
Respect for culture and local experience	2. How can CBR implementers who come from outside a local community avoid imposing their own values in a harmful way?
Empowerment	3. Do targeted empowerment efforts result in disempowerment of others?
	4. Can empowerment efforts deflect attention from socio-political barriers?
Accountability	5. How can a more comprehensive and inclusive approach to accountability be promoted in CBR programmes?
Fairness in program design	6. Are CBR programmes sufficiently inclusive?
	7. How can limited CBR resources be used most fairly?
	8. When could reliance on volunteers become exploitative?

CBR = community-based rehabilitation.

Organization; the United Nations Educational, Scientific, and Cultural Organization; and WHO endorsed an updated definition of CBR as “a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities.”^{3(p.2)} Diverse commentators have proposed conceptions of CBR that emphasize elements such as the promotion of human rights,^{5,6} the balancing of fundamental power inequalities,^{7,8} and the fulfillment of basic needs.⁹

Alongside evolving definitions of CBR, there has been a lively discussion of the purpose, principles, and commitments that underlay CBR programmes and practices. Several authors have identified a range of ethical considerations as being important for the CBR model and for the implementation of CBR projects. A key contribution to the analysis of ethical issues in CBR was a 2002 article by Turmusani and colleagues,¹ which canvassed ethical issues for CBR in low- and middle-income countries. Ethical considerations have also been raised by other authors writing about the practice, policy, and politics of CBR, as well as its evidence base.^{10–13} In light of the continued evolution of the CBR movement and ongoing discussions of CBR ethics, we reviewed the academic literature related to CBR to investigate how it addresses ethical considerations.

METHODS

We conducted a critical interpretive review of the CBR literature.¹⁴ Developed to guide literature reviews in the field of bioethics, this approach consists of two elements. A critical interpretive review seeks to “capture the key ideas”^{14(p.525)} in a body of literature to answer a specific research question; it also aims to critically appraise and analyze the collected literature to put forward an argument that advances knowledge of the area of inquiry. Our critical interpretive review was guided by the following question: How are ethical considerations reflected in the CBR literature? For the purposes of our review,

we drew on the notion of moral experience and defined *ethical considerations* to include experiences or situations in which values that individuals deem to be important are being thwarted or realized in everyday life and that are interpreted as falling on the spectrums of right–wrong, good–bad, or just–unjust.¹⁵

We began our review by searching the CINAHL, Medline, Scopus, and Source databases up to 2014. We combined the key word *community-based rehabilitation*, or *CBR*, with the following key words related to ethical considerations: *ethics, ethical, moral, morality, principles, values, power, empowerment, privacy, confidentiality, decision making, human rights, harm, and benefit*. We reviewed the titles and abstracts of the texts identified in this search to assess whether ethical considerations in CBR were or were likely to be addressed in the text and whether they were related to CBR in low- and middle-income countries or among indigenous communities in high-income countries. When the review of an abstract was inconclusive, a team member read the complete text.

Next, we searched the reference lists of all retained articles to identify additional texts that were relevant to our review but had not been identified in the initial database searches. Finally, we conducted targeted web searches for additional articles by authors who were identified as having written on topics related to ethics and CBR, but few texts were added to the review using this strategy. Following these steps, we retained 60 texts for further analysis.

Two team members then reviewed all collected texts while considering the following questions: What implicit or explicit ethical considerations related to CBR are present in this text? How are these ethical considerations discussed by the authors? Using this analysis, we identified 51 texts that offered insight into ethical considerations associated with CBR, and we considered these texts to be primary sources for our analysis.

Following the critical interpretive review approach, we mapped important ideas related to our research question and identified key topic areas related to ethical considerations and CBR. Through this process, we associated texts with partnerships among stakeholders,^{3,5,6,16–29} respect for culture and local experience,^{7,9,18,25,26,28,30–38} empowerment,^{5,7–9,17–19,23,25,28,30,37,39–43} accountability,^{2,5,8,9,17,20,21,23,24,27,30,34,36,40,42,44–47} and fairness in programme design.^{10,11,17,18,20,27,28,30,40,48–58} During our analysis we also considered each topic area in relation to all of the collected texts. After critically appraising the collected literature, we then formulated eight questions that reflect sources of ethical tension, uncertainty, or debate related to CBR. The key topic areas and associated ethical questions are presented in Box 1.

RESULTS

Partnerships among stakeholders

CBR is a complex strategy that requires the engagement of diverse stakeholders, and asymmetrical relations are a common feature of CBR projects.^{5,6,22,27} Stakeholders have different degrees of influence, control of resources, power, autonomy, and dependence.

Stakeholders in CBR extend across community, district, provincial, and national levels.⁵ Groups may also be active stakeholders in CBR processes, notably disabled people's organizations and other non-governmental organizations (NGOs).⁷ This diversity leads to challenges in sharing information⁴⁴ because it may not reach all stakeholders,⁵ a situation that has implications for equity and mutuality in these relationships. Failure to promote strong community partnerships and share information among all stakeholders also impedes community participation and empowerment and can hinder a project's sustainability.^{26,30} Finkenflügel argued that "collecting, aggregating, and dispersing information should be an on-going and translucent part of empowering the stakeholders involved in CBR,"^{5(p.164)} thus promoting more equality and greater transparency in CBR partnerships.

Question 1: What factors limit the development of effective and respectful partnerships?

A variety of factors may limit CBR professionals from developing or embracing more effective partnerships in CBR.⁵ These barriers may include a reluctance by those responsible for initiating CBR projects to cede influence over programmes that they have helped build,¹⁷ perceived time constraints associated with partnership models,⁸ and simple inattention.¹⁷ Given these realities, creating and maintaining partnerships in CBR can be a source of ethical tension, especially when communication is difficult, roles and interests are not clarified, and asymmetries of power are entrenched.

Pande and Dalal described management and decision-making models in CBR as bearing the lingering imprint of institutional approaches to rehabilitation in which

projects follow a "victim-service" model,^{18(p.97)} especially in regard to how success is evaluated. Even if project coordinators seek out community expertise and engage these stakeholders to establish goals, a project may still be judged on its ability to compensate for losses resulting from physical disability. This criterion can function as a predetermined and overarching project goal that may not reflect local realities or priorities—or even align well with CBR philosophy.¹⁸ Turmusani and colleagues¹ reported that people who did not have disabilities and individuals identified as experts often retained control of CBR, and PWD had little to no role in meaningful decision making. Pollard and Sakellariou³⁰ surveyed occupational therapists involved in CBR and found that PWD were included in making decisions about implementing only 7 of 66 programmes; this suggests that there is an important gap between the CBR vision and how it is often practised, and it highlights the extent to which effective and respectful partnerships among stakeholders in many CBR projects may be limited.

Respect for culture and local experience

Demonstrating respect for culture and local knowledge has been described as a key element of the CBR approach; it is crucial in enabling programmes to contribute to vocational and other opportunities for PWD and for supporting local socio-economic development.^{1,31} The success of CBR projects is associated with the degree of integration and grounding in local cultural contexts, and it is linked to how well initiatives serve the needs of a population by supporting, and not undermining, local culture and approaches.^{1,32}

A concern that has been raised with several constructs closely tied to CBR is that they reflect commitments and assumptions associated with Western biomedicine. For example, some commentators have questioned whether individual empowerment programmes, which tend to value independence and individual autonomy, are as relevant in cultural contexts that have a different understanding and conception of self, dependence, and community.^{40,41} This critique is not limited to empowerment, however. Chung and colleagues described traditional Chinese peasant culture as valuing stability and harmony, and they noted that CBR staff from outside a community often struggled to incorporate these values when they were put in charge of implementing a programme.⁷

A range of gaps in local applicability and attention to local needs and traditions have been identified in the CBR literature amid concerns about not considering local contexts when applying approaches that have worked well elsewhere—for example, applying an urban approach to a rural setting.^{31,33} However, a more significant challenge exists for CBR projects as they seek to engage with communities and pay attention to local contexts throughout the planning process and across the life cycle of projects. Chung and colleagues emphasized the

importance of carefully attending to the cultural features of communities because cultural frameworks and values were of critical importance in shaping the ways in which people perceived health, disability, autonomy, family, and relationships.⁷

Particularly challenging questions may arise in relation to gender and respect for local cultural values and traditions. Gender influences inclusion and participation in communities, and women with disabilities face unique disadvantages in contexts in which male-dominated services are provided.¹⁷ Thomas and Thomas⁴⁰ described societies in which disabled women might be integrated into communities of women but had to remain segregated from men. These features may give rise to tensions between promoting rights and equity on the one hand and demonstrating respect for local approaches and culture on the other.

Failure to take note of local values and traditions concerning the notion of disability, rehabilitation, and societal responses to those with impairments can perpetuate negative attitudes and practices toward PWD.^{1,18,30,48}

Question 2: How can CBR implementers who come from outside a local community avoid imposing their own values in a harmful way?

Pollard and Sakellariou³⁰ warned of unduly imposing one's own values on the design and implementation of programmes. This risk is particularly elevated when those leading a CBR project come from outside a community and have insufficient knowledge of the socio-cultural context.^{7,31,39} Furthermore, gaps in knowledge about a project's history and prior decisions are more likely to occur with the high turnover of staff members in many international projects.^{30,39} These situations hamper individual workers from gaining a nuanced understanding of the social and cultural context in which a programme is located. It also suggests the limitations of relying on external CBR workers.³⁰ Those who are involved in a CBR project but who come from outside the community need to recognize the importance of adaptation because the fit of the CBR model varies among cultural contexts.¹ NGOs and their international staff must be attentive to local cultural norms, and they must have sufficient humility to recognize the limits of their understanding of local values to avoid problematically imposing their own priorities, values, or modes of working.^{1,17,30} Although CBR is a holistic practice that appeals to a set of universal values (e.g., ensuring respect for and promoting the rights of PWD across diverse cultures), CBR professionals need to consider how to act on these commitments while demonstrating respect for local cultures.

Empowerment

Empowerment is a key objective associated with CBR projects; it includes efforts to ensure that PWD are recognized as full and valued members of their communities.³⁹

Empowerment in CBR is understood to encompass a wide range of elements. Some authors have related empowerment to improving the legal status of PWD and their access to government services.⁵ Others have primarily associated empowerment with increasing participation in local communities.^{18,41} Still others have suggested that empowerment involves efforts to decrease inequality.⁷ Particular initiatives to promote empowerment, however, may raise ethical concerns because they have the potential for negative consequences or fallout.

Question 3: Do targeted empowerment efforts result in disempowerment of others?

A key ethical consideration associated with empowerment efforts is the possibility of unanticipated negative consequences. In some instances, CBR implementers may design empowerment interventions based on predetermined, externally defined goals that are not well aligned with community needs or preoccupations.¹⁸ As a result, empowerment may be a source of social strain or rupture, or it may be less effective. Empowerment efforts may also be disruptive, even when their goals are fully achieved. This reflects the observation of Kendall and colleagues that "conceptually, the very word 'empowerment' is a paradox."^{19(p.437)} In many instances, power is associated with unequal influence or dependence in relationships. These authors suggested that in some contexts, to "empower" one person or group results in another person or group being disempowered (e.g., to empower PWD can sometimes result in caregivers being disempowered.)¹⁹

CBR programmes may introduce significant changes into the decision-making process for families and caregivers.³⁴ Individual empowerment, with its focus on autonomy and independence, may also disrupt important modes of interdependence and community.¹⁹ Pande and Dalal¹⁸ stressed, however, that the empowerment of the least powerful can benefit all of a community. They noted that there was an implicit connection between personal empowerment and community empowerment and that better integrating PWD into a community had benefits for both individuals and communities as a whole.¹⁸

Question 4: Can empowerment efforts deflect attention from socio-political barriers?

Many empowerment efforts seek to address exclusion by enhancing the capabilities and resourcefulness of PWD. Personal empowerment projects focus on recognizing and promoting PWD's own capacities for development.^{9,18} Such efforts often involve encouraging participants to move past the internalized restraints that diminish their feelings of autonomy and capability. Concerns have been raised when such individually oriented empowerment programmes deflect attention from socio-political factors, which often place much greater limitations on the inclusion of PWD in a community.^{9,18,28,35}

If individual empowerment efforts take precedence over other initiatives, especially social engagement and advocacy to address socio-political barriers to inclusion, inclusion will likely remain elusive.

Accountability

Accountability is an important concern in CBR programmes. It can serve to promote the legitimacy of CBR initiatives and even advance the objective of community empowerment.⁴⁷ Some authors have argued that there is a need for clearer objectives and targets, as well as carefully selected indicators, to judge the effectiveness across CBR settings.^{44,46} Velema and colleagues reported, however, that few CBR programmes develop outcome indicators to demonstrate what impact their interventions have had on improving the lives of PWD; this situation raises concerns about whether programmes are effectively meeting the needs of the individuals and communities they serve.⁴⁵ According to Pande and Dalal,¹⁸ limiting evaluations to more easily quantifiable measures may not advance the greater strategic objectives of a programme; if a CBR programme retains a focus on fulfilling quotas, it will likely ignore other ways to achieve independence for PWD and promote greater social inclusion.

In CBR programmes, accountability is often construed as an obligation to donors and is focused on quantifiable measures over a shorter time frame.^{42,47,48} In contrast, programmes devote less attention to other directions and forms of accountability, including accountability to participants or partner organizations, and to considering the longer term impacts of CBR projects in relation to their missions and objectives.

Question 5: How can a more comprehensive and inclusive approach to accountability be promoted in CBR programmes?

Accountability to donors often appears to crowd out other forms of accountability and limit the reach of who is included in these processes. This situation raises questions about the participation and inclusion of the perceptions and experiences of PWD and other stakeholders. Deepak and Sharma⁴⁸ suggested that CBR programmes are often overly focused on arbitrary targets to represent success, distorting the conceptions of project success and sustainability. They noted that important concepts related to accountability, including community ownership, participatory development, and attention to sustainability and self-reliance, emerged primarily from grassroots organizations in developing countries.⁴⁸ However, these concepts are not always incorporated into current accountability measures. Commentators have argued that accountability in CBR should be a more inclusive and participatory process.^{27,46,48,50} Enhancing the participation of PWD in evaluation and accountability will lead to a more inclusive approach to accountability, and it has been described as a potentially emancipatory experience.^{1,23} Such a widened scope of accountability reflects commitments to equity, solidarity, and inclusion.

In addition to a tendency to focus accountability primarily on donors, other features of CBR projects may constrain accountability efforts. An important characteristic is the funding patterns that are prevalent in CBR. Project funding cycles are often short, leading to limited consideration of the longer term impact of projects and a lack of emphasis on sustainability.²⁰ Including a more comprehensive understanding of accountability in CBR programmes, one that also considers their impact on local communities and the experiences of community partners, is consistent with the broader community engagement approach underlying the CBR model.⁴⁶

Fairness in programme design

CBR was originally developed as a strategy to address the lack of well-adapted and relevant programmes to meet the needs of PWD in low-resource settings.³⁷ Now that CBR is well established in many contexts, other equity concerns have come into focus, including questions related to resource use, reliance on volunteers, and the degree of inclusivity of CBR programmes. Because CBR programmes often operate under severe time and resource constraints, it is all the more important to attend to concerns of fairness.

Question 6: Are CBR programmes sufficiently inclusive?

The scope of CBR projects may raise questions of fairness. Despite the objective to include all PWD, Thomas and Thomas⁴⁰ observed that many CBR projects do not integrate people with more severe disabilities. They associated this disconnect with time pressures and resource limitations in individual projects that encouraged the inclusion of people with milder disabilities.⁴⁰ Lang also suggested that many CBR projects have not emphasized the inclusion of all PWD, leading to a situation in which increased participation was considered a long-term goal rather than an immediate priority.³⁹

Question 7: How can limited CBR resources be used most fairly?

Deciding when and where to implement a CBR programme also raises concerns about fairness, along with questions about how best to use limited resources. There is ongoing debate about what conditions are required for a project to be established in a particular setting, including what amount of community participation is needed.^{17,50} Within projects, questions arise about how to allocate limited resources fairly. Decisions need to be made about how to allocate project resources and how to prioritize different types of programming.^{13,17}

Fairness also arises in ensuring project sustainability because if a programme ends abruptly, and before achieving its objectives, it may leave PWD isolated and in worse conditions than before.^{30,39} Deepak and Sharma described how, in many countries, “programmes of CBR were started with support of international non-governmental organizations ... but these programmes disappeared, when the support from the [international NGOs] stopped.”^{48(p.4)} This reality raises questions about the

sustained involvement of NGOs in particular locales as well as the project models used.

Question 8: When could reliance on volunteers become exploitative?

Volunteers are a key component of CBR programmes, and commentators have suggested that having a large number of volunteers is an indicator of programme success.⁴⁸ On the one hand, having a large number of volunteers reflects effective community engagement, and CBR proposals may promise numerous volunteers to increase their chances of securing financial support.⁴⁸ On the other hand, a large number of volunteers allows resource-challenged programmes to sustain their projects for little to no cost.^{45,48,51} Several authors have raised questions about whether using volunteers in CBR projects risks becoming exploitative. In some settings, unpaid CBR personnel may work under the impression that they will eventually receive a salary.⁴⁸ Brinkmann also questioned this practice, stating that the “strenuous work of CBR workers is compensated in a dubious manner, and in most cases they do not even receive a salary. This happens because of the assumption that CBR can not be implemented without ‘volunteers.’”^{49(p.91)}

The difficult economic situations in many of the locales in which CBR takes place suggest that exploitation may be more of a risk,⁴⁹ especially when family members of PWD are expected to act as volunteers.²⁰ Community participation is crucial for CBR success,^{17,18,49,50} but, to address concerns of exploitation and commit to fairness, programmes need to consider the distribution of burdens and benefits associated with volunteer efforts.

DISCUSSION

CBR was developed to address an important ethical concern related to social justice and equity: the lack of support and services to promote the well-being, and address the needs, of PWD in many contexts. The CBR approach is also closely aligned with a commitment to promote participation and inclusion for PWD. Many of the ethical considerations identified in our review relate to these values and are reflected in questions about who is included in programmes, how partnerships are enacted, the possibility of exploitation, fairness in project design, and missed opportunities to address social barriers or enhance inclusion. Thus, it is not surprising that the ethical considerations identified in our review of the CBR literature largely depart from the issues that are commonly linked to the ethics of rehabilitation in institutional settings in high-resource countries⁵⁹ and that they have more in common with those arising in domains such as community-based and action research.^{60,61}

The ethics of CBR programmes can also be situated in the expanding literature on global health ethics, espe-

cially given the focus that global health ethics places on promoting “the idea of human development beyond that conceived within the narrow, individualistic model of human flourishing”^{62(p.130)} and focusing on solidarity with those who are marginalized or who suffer.⁶³ In accordance with these values, several authors have pushed for CBR actors to take a more active stance in advocating for disability issues and the rights of PWD, draw attention to oppressive social structures, and promote the sustainability of projects by adopting more collaborative and inclusive approaches.^{3,20,28–30}

A primary consideration for CBR ethics is promoting and sustaining effective and respectful partnerships among stakeholders. As has been discussed for community-based and action research, several factors support the development of effective partnerships even when partners have divergent backgrounds and roles: mutual trust, attention to the privilege and position of each partner, humility, acknowledgement of different viewpoints, and a commitment to solidarity.^{64–66} These considerations are equally relevant in the CBR context, including the development of what Iris Marion Young has termed *asymmetrical reciprocity*, which entails recognizing the situated realities of partners, including the asymmetries of life experience, worldview, and opportunity while embodying the commitment to mutual respect, trust, and consideration.^{67(p.49)} Enhanced attention to one’s presuppositions, power, and privilege can help support effective partnerships in CBR.

This moral posture may be especially important for professionals, including physiotherapists, who come from another cultural setting to participate in a CBR project as experts. Rule²² reported how improved relationships resulted when mid-level CBR professionals were given training in how they approached their work with PWD. CBR professionals noted that framing their role as working with PWD, rather than as working for PWD, was a crucial step in beginning to address previously ignored issues of social justice and empowerment. As new partnerships are developed, CBR stakeholders may take inspiration from resources such as the Partnership Assessment Tool, which was developed by the Canadian Coalition for Global Health Research and which encourages a deliberate and transparent approach to discussing the goals, expectations, and responsibilities of all partners.⁶⁸ Careful attention to establishing and nurturing effective and respectful partnerships is an important ethical goal in CBR.

Organizations and teams engaged in CBR will also benefit from creating and maintaining “moral spaces” in their routines and schedules to ensure that ethical reflection takes place, including debriefing and learning from challenging experiences.⁶⁹ Two elements may be particularly valuable for CBR organizations. The first is to maintain a collective memory of these discussions, especially when there is a high turnover of personnel. PWD and other community stakeholders may, in fact,

prove to be the people best placed to provide this continuity. The second element is ensuring that learning about the ethical challenges of CBR and responding to these challenges in specific projects are shared beyond that milieu. Organizations or networks will benefit from creating channels for sharing experiences related to ethical issues across projects and learning from each other's experiences. In turn, leaders of CBR programmes can use these experiences to inform policy development and train new staff. Creating spaces to discuss and respond to ethical issues can allow stakeholders to address considerations that were identified in this review, such as equity in partnerships, respect for local culture and practices, allocating project resources prudently, and ensuring fairness in the distribution of both the benefits and the burdens of a project.

Mirroring discussions in the field of international development more broadly,⁷⁰ attention has also been directed to issues around CBR accountability and the participation of PWD in planning and evaluating CBR programmes. Relying on models of upward accountability to donors has led to critical reflection on these practices in CBR or, as Miles has somewhat caustically phrased it, showing "what a great job we did."^{9(p.94)} This critique connects with concerns that have been expressed about the development of an "audit culture" that is reinforced by a focus on quantification and that could undermine inclusion and attention to project goals that are less quantifiable.⁷¹

Discussing accountability in development organizations, Cavill and Sohail⁷² distinguished between practical and strategic accountability. Practical accountability focuses on the effectiveness of operations and how well services are delivered, thus privileging quantifiable data based on mechanisms such as audits and quality assurance tools. Strategic accountability requires that the overall mission of a programme and the long-term effects of its implementation be taken into account.⁷² Placing more emphasis on strategic accountability in CBR projects can counterbalance the attention given to practical accountability.^{44,47} Doing so will allow for a more engaged and meaningful approach to accountability, one that is consistent with certain core values of CBR—equity, community participation, and inclusion¹—especially when all stakeholders are included in decision-making, evaluation, and accountability practices.

Uncertainty remains about which best practices in CBR projects will ensure that benefits are optimized for PWD and that risks and burdens are minimized.^{2,71} Indeed, the scientific evidence base for CBR remains quite limited, fails to incorporate researchers from low- and middle-income countries, and is mostly descriptive.^{13,21} Expanding the CBR evidence base would help answer questions about how to design and implement programmes that are more effective, responsive, and sustainable and that address the needs of a wide range of PWD. Such research could also deepen the engagement

with, and investigation of, ethical considerations associated with CBR by increasing our knowledge about practices such as the inclusion of all PWD, the roles of stakeholders throughout the life cycle of CBR projects, and the impact of different models of empowerment and advocacy.

Conducting empirical and conceptual research to address the eight questions identified in this review would make a valuable contribution to advancing CBR ethics. Our observations suggest that there is an important role for rehabilitation researchers, including physiotherapy researchers, in conducting research to advance the knowledge of best practices in CBR and developing evidence to guide the implementation of CBR programmes that uphold commitments to social justice and equity.

CONCLUSION

We have identified ethical considerations that have been raised in the CBR literature and proposed various strategies for addressing them. Continued engagement with the ethics of CBR—by CBR researchers, practitioners, and policymakers, as well as PWD and members of disabled people's organizations—will be needed to ensure that the ethical foundations of CBR continue to be refined and strengthened. We have also formulated eight key questions that warrant further exploration and development. In addressing these questions, insight and support can also be drawn from a range of sources, including ethical analysis in fields such as global health, community-based and action research, critical disability studies, and international development.

KEY MESSAGES

What is already known on this topic

Community-based rehabilitation (CBR) is an influential development strategy that promotes rehabilitation, social inclusion, and poverty reduction for people with disabilities. The CBR approach is associated with values that include participation, respect, equity, social justice, and solidarity.

What this study adds

We identified ethical considerations in the CBR literature that were centered around five topics: partnership between stakeholders, respect for local culture and experience, empowerment, accountability, and fairness in programme design. In analyzing these key topic areas, we developed eight questions that reflect areas of ethical tension, debate, or uncertainty that should be further discussed and analyzed with regard to how CBR practices and programmes reflect CBR's underlying ethical commitments. We recommend several approaches to support reflection and discussion of ethics in CBR, including recognition of asymmetrical reciprocity among CBR partners and the creation of moral spaces within organizations and teams.

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