

ORIGINAL RESEARCH

Children with Disability in Nepal: New Hope Through CBR?

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ABSTRACT

Purpose: *This study assesses the impact of a community-based rehabilitation (CBR) programme on the quality of life (QoL) of children with disability and their families.*

Methods: *A qualitative approach was applied, using two techniques - a ranking line and semi-structured interviews. Nineteen children (ranging from 4 –18 years of age) were interviewed in their homes located in three villages - Chapakhori, Bokraha and Madesha - in Nepal.*

Results: *Children with disability and their families ranked physical health, psychological health, empowerment and level of independence as the most important factors for their QoL. Of the 19 children, 13 had experienced positive changes in their life and 1 child reported a negative change. The positive changes related mainly to their physical health and functioning. The impact of these changes was felt in the 'social', 'level of independence' and 'empowerment' outcome categories. The children mentioned that they had more friends, experienced less stigma, could go to school and were more hopeful about the future.*

Conclusions: *This CBR programme has brought about changes in the QoL of all children with disability and their families. The majority of them reported a positive impact.*

Key words: *community-based rehabilitation, quality of life, children with disability, impact*

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INTRODUCTION

Times are changing for people with disability. In the last 20 years, the social model has taken over from the medical model as the predominant view regarding disability in high-income societies (Albert, 2004). A rights-based approach has been initiated through the UN Convention on the Rights of Persons with Disabilities (CRPD). Nepal ratified the CRPD in May 2010. The Nepalese constitution (2002) defines disability as 'people who are mentally or physically unable or incompetent to lead a normal life' (Japan International Cooperation Agency, 2002). According to the Department for International Development (2000) disability is both a consequence and a cause of poverty. Nepal was ranked 157 in the Human Development Index in 2011; this implies a 'low level of human development', and the majority of people with a disability in Nepal belong to the poorest group (World Health Organisation, 2011). The Central Bureau for Statistics (2011) stated that only 2% of the Nepalese population has some kind of disability. According to the World Health Organisation (2011) these are all underestimations due to lack of evidence. Research (Panthi, 2004) has shown that 70% of all persons with disability are dependent on the support of their families. According to Hinduism which is the most common religion in Nepal, disability is viewed as a punishment for things a person did wrong in a past life (Lansdown, 2003); a bad karma (Boyce et al, 1999). More than 70% of all people with disability in Nepal live with this stigma, especially in rural areas (Thapa, 2009). The consequences of stigma and lack of awareness are discrimination, exclusion of persons with disabilities from society, education and work, leading to poverty and a lower quality of life (WHO, 2011).

In developing countries, it is often the non-governmental organisations that work to improve the QoL of persons with disabilities and ensure their inclusion in society. In Nepal, the Karuna Foundation (KF) is working to prevent avoidable disabilities in children, and to improve the QoL of children with disability. KF has integrated the rehabilitation of children with disability within a larger programme of community-based health insurance in Nepal. CBR in KF districts is organised according to the CBR matrix (WHO, 2010) and is adjusted to local circumstances (Lansdown, 2003). CBR is carried out by local rehabilitation workers and is planned, implemented and evaluated by the local committee. Children are identified, assessed, and individual plans are formulated with the help of the parents. KF monitors, coaches, facilitates and evaluates the CBR programme from the outside.

Assessing the Impact of the CBR Programme

The hypothesis of the KF organisation is that life for the study population has changed as a result of the CBR interventions. However, there was no independent evidence of this as yet, and the impact of these changes on children's QoL was not known either. Research done by Wood et al (2001) shows that the concept of QoL emerged in an attempt to recognise and understand the importance of the impact of health care interventions on people. Impact is defined as 'the effects of an intervention that can be attributed uniquely to it' (Rossi et al, 1999). An important tool to measure QoL is 'the World Health Organisation's Quality of Life Tool' (WHOQoL), using a quantitative approach (Yadav, 2010). The WHOQoL was adapted to different cultures (Orley, 1993). A Nepali version also exists, which is applicable to the Hindu culture (Brouwers et al, 2011). According to Sakai et al (2009) every culture, gender and age has its own perceptions of health, especially in relation to QoL. Therefore it is important that a measurement tool is validated for the specific target culture and group where it is to be used. According to Eide (2006), validated indicators to measure the impact of a CBR programme are lacking. Thomas and Wirz (2002) studied the outcomes of several CBR evaluation studies and came up with some indicators. These indicators were not validated and are not applicable in this research due to the specific study population, namely children with disability and their families, living in Chapakhori, Bokraha and Madesha in Nepal (Thomas & Wirz, 2002).

OBJECTIVE

This research was conducted to answer the question: "What is the impact of the Karuna Foundation's Community-Based Rehabilitation project on the quality of life of children with a disability and their families living in Madesha, Bhokraha and Chapakhori in Nepal?"

METHODS

A qualitative retrospective cross-sectional study design was used. The main limitations of this study design include its recall bias susceptibility, differences due to age or time effects and unequally distributed confounders that may exist between the children (Verschuren & Doorewaard, 2010). Respondents in this study were asked questions about changes in the preceding 2 years.

The conceptual model of this study (Figure 1) was constructed by combining domains of the WHOQoL (Yadav, 2010) and the WHO CBR matrix (WHO, 2010).

The impact indicator in this study is the **improvement** in QoL. Seven components of quality of life were included:

- 1) **Psychological health** which is about an individual's perception of his / her own image and physical appearance, as well as mental wellbeing.
- 2) **Social** which includes all kinds of personal relationships.
- 3) **Physical health** includes the actual (i.e. medical) and experienced health of a person.
- 4) **Level of independence** includes mobility, activities of daily living, capacity to work or go to school.
- 5) **Religion** comprises personal beliefs (i.e. faith).
- 6) **Environment** is about physical safety and security, accessibility and satisfaction with education, healthcare, transport facilities and home environment.
- 7) **Empowerment** which goes together with inclusion and enabling a person with disability to join the mainstream (WHO, 1997; Murphy, 2000; Velema & Cornielje, 2010).



Figure 1: Conceptual model including seven indicators created by combining domains of the WHOQoL and the WHO CBR matrix.

Study Population and Sampling Method

The study population is defined as: 'Children with disability and their families, living in Chapakhori, Bokraha and Madesha in Nepal'. From the database of KF Nepal, 20 cases were selected, based on the inclusion criteria, and 19 children were interviewed. One child dropped out due to family circumstances.

Inclusion criteria:

- All interviewed children lived in the research area.
- Children with all kinds of disabilities were included.
- They had to be between 4 and 18 years of age.

For children below 10 years, a family member was included in the interview.

Where children were unable to represent themselves due to disability affecting communication, the interview involved a direct family member who could reflect on the experience and impact of CBR on the child.

Data Collection Methods

Two types of data were collected, using a 'ranking line' and 'semi-structured interviews'. The ranking line was used with the purpose of conceptualising QoL according to the children and their families, as well as to gain insight into the changes resulting from CBR. The aim of the semi-structured interviews was to gather detailed information on the impact of CBR based on the outcome of the ranking line assessment.

For the ranking line, 7 posters were made which depicted one of the above components of QoL. The ranking line is used to place all 7 categories in order of importance according to how children and their families experience QoL, and which aspects of their QoL have been changed since taking part in the CBR programme (International Alliance, 2006).

The in-depth interviews, using an interview guide, dealt with the 2 categories that had changed the most in the eyes of the beneficiary. The semi-structured interview guide was based on a Hindi version of the WHOQoL which was earlier used in India (Saxena et al, 1998). Indicators from the WHOQoL-100 (Yadav, 2010) and the WHO CBR matrix (WHO, 2010) were used. Closed-ended questions were translated into open-ended questions. These were reviewed by Nepali KF workers and adapted to suit the children.

The interviews with the children and their families took place within their houses or in their compounds. CBR workers did not attend the interviews so as to prevent response bias which could be caused by the presence of an attending third (influential) person (Sica, 2006). This often produces socially desired answers.

Additionally, interviews were held with the 2 CBR workers who had been dealing with the 19 children from the inception of the study. A specific interview guide was developed for the purpose. Two different translators, who were both Nepali public health workers, helped with the interviews which took place in the health centre. Interviews were recorded with a voice-recorder.

Analysis

This study used an inductive approach to analyse the qualitative evaluation data (Thomas, 2006). The outcomes of the ranking line were written down, and the ranking lines of all children were compared with one another. Interviews were transcribed by the translators. The KF staff double-checked the transcripts to ensure reliability of the translations. Transcripts were analysed by the 'Miles and Huberman framework' (Keith, 2005), using the software 'WeftQDA'. The data collection and analysis yielded a lot of information regarding the children's perceptions of the impact of CBR on their QoL. This information helped in finding answers to the main research question.

Ethical Considerations

Participation by the respondents was on a voluntary basis. Informed consent was given, and they had the right to withdraw from the study at any time. To ensure confidentiality, analysis was done anonymously and personal information was not published. The researcher and first author of this article is an individual independent of Karuna Foundation.

RESULTS

The 19 children were between 4 – 18 years of age, with a mean of 12.6 years. There were 9 girls (47%) and 10 boys. The majority (89%) were Hindu while 11% were Buddhist. Nine children (47%) had a physical disability, 15% had multiple disabilities, 11% had speech disability, 11% had mental disability, 11% hearing disability and 5% a vision disability. Nineteen interviews were held, at which 4 children (21%) were interviewed by themselves. The other 13 interviews (69%) involved one of the parents or parents together with their child. Two interviews (10%) were done with the uncles. The number of years since CBR support was extended to the children ranged from 1.5 – 3 years, with a mean of 2.6 years.

Quality of Life

The ranking line revealed many differences between the perceptions of the children and their families regarding what was important for their QoL. There were no notable similarities for the types of disabilities and the way they conceptualised QoL. Table 1 shows that most children ranked physical health as the most important component for their QoL. Nine children ranked this in the first place, while 10 children mentioned other components as the most important ones. Though nobody ranked the social component as most important, the majority gave it the second rank. The least important component was religion (n=5) or no component at all (n=8).

“We don’t have quality of life; the only thing that matters for us is to survive; that we have enough food and water for the family” (Father of a blind child).

Table 1. Results ranking line: children with a disability conceptualizing quality of life (n=19).

	Physical Health	Psychological Health	Social	Empowerment	Level of independence	Environment	Religion	None
Ranked as most important	9	3	0	2	2	1	1	1
Ranked as second most important	0	2	6	2	4	3	0	2
Ranked as third most important	1	0	5	4	2	1	2	4
Ranked as fourth	0	0	1	3	5	2	2	6
Ranked as fifth	0	2	2	3	0	3	1	8
Ranked as sixth	2	3	2	0	0	2	2	8
Ranked as seventh	3	2	0	1	0	0	5	8

Components that showed a Change

The majority of the children mentioned only 2 or 3 components that had changed due to CBR. Only one child said there was a change in all 7 components. A complete overview of the results can be found in Table 2.

Twelve children mentioned that their physical health changed the most due to CBR. Five of them had indicated a change only in their physical health. There were totally 9 children with a physical disability, 6 of whom said their physical health had changed the most while the other 3 had experienced no change at all in their physical health.

Table 2. Results ranking line: changed indicators due to CBR for children with a disability (n=19).

	Physical Health	Psychological Health	Social	Empowerment	Level of independence	Environment	Religion	None
Ranked as biggest change	12	2	2	2	0	1	0	0
Ranked as second biggest change	1	0	5	0	4	2	1	6
Ranked as third biggest change	0	1	2	2	1	1	0	12
Ranked as fourth	0	0	1	1	0	0	0	17
Ranked as fifth	0	0	0	0	0	0	1	18
Ranked as sixth	0	0	0	0	0	1	0	18
Ranked as seventh	1	0	0	0	0	0	0	18

Impact of the Changes

Various perspectives regarding the impact of CBR emerged during the interviews with the children and their families. Fourteen children experienced a change in physical health. While the impact was positive for 13 of them, 1 child experienced a negative impact.

“CBR provided us physiotherapy services. Before he used to crawl but now he can walk perfectly” (Mother of a child with cerebral palsy).

Ten children said that their social life had improved due to the physical change. They now had friends to play with. The community, and even their own families, showed them more understanding. Three children said they now felt

less of a burden to their family. Children mentioned that they experienced less discrimination and people had stopped teasing them.

“People began to know about the disability and they stopped teasing me” (Child with speech difficulties).

Even though families and children felt they had a better understanding of disability, the CBR worker recorded that 11 families still misunderstood their children, the disability and / or the rehabilitation programme.

“She says everything that we say, she has no brain” (Mother of a child with Down syndrome).

“Her parents are uneducated. It is difficult to bring her parents in positive thinking. They see her as a burden” (CBR worker about this child with Down syndrome).

Some children had started going to school after support from the CBR programme. Earlier, some of them were irregular or had dropped out of school, but now they attended every day. Children mentioned that they felt more confident due to physical changes. They were able to help their families with household work or in the fields, which was felt as a positive impact in their lives. The CBR workers hardly talked about this issue; they did not mention any impact (positive) at all. Seven children explained that they felt more independent from their families, especially in their daily activities and work. This had made 3 children feel more positive about the future.

“As she can speak now, she can help me in buying goods, farming and going to the market. Now I can easily get a husband for her. If she had not spoken then it would be difficult for us to get a husband” (Mother of a child with speech difficulties).

Two-thirds of the children (n=12) said they felt happier now than before CBR. The physical changes in their health had a positive impact. The CBR workers had not noticed this about any of the children.

Four children said that they experienced no change after CBR. After a little probing, 2 of them mentioned that there was some change - one child no longer had epileptic attacks and the other did not salivate any more. However both did not experience any impact as a result of this change. The CBR workers saw no change in either of these cases.

DISCUSSION

This study represents the individual perspectives of 19 children with disability and their families regarding the impact of CBR on their lives. More than half of the children ranked physical health as most important for their QoL; twelve felt that this component had changed the most after CBR. For most of them, the maximum impact was experienced in their social relationships, level of independence and in empowerment.

Ranking of CBR's Impact

The ranking line was a good prelude to the interviews. However, some families had difficulty in understanding the 7 components of the framework. It was interesting to note that 12 children ranked physical health as the component that had changed the most whereas, after questioning during the interviews, 18 children mentioned the same thing. Although the outcome categories were not validated components to conduct an impact assessment, they do have a proven causal relation with CBR and QoL (WHO, 2010; Yadav, 2010).

Changes in the children's lives can also happen due to age, so confounding by age may have occurred (Hartman et al, 2002). To prevent this, the respondents were asked whether the changes were caused by CBR or if they thought there were other factors involved.

Understanding the Real Impact

The World Report on Disability (WHO, 2011) shows that impairments do not necessarily need to result in disability for people. Stigma and discrimination are often the cause of the real disability. This study showed that there were changes in the physical health of all but one of the children. The direct consequence of these changes was a reduction in stigma and discrimination, which was a positive impact mentioned by the children. CBR workers in the study areas did not mention this impact. They were more convinced about the physical changes in the children. For 1 child, the physical change had caused a negative impact. This child claimed that now he had pain, was sadder, felt shy, did not go to school any more and did not play with his friends. In contrast, the CBR worker was positive about the change in this child - he could walk now, had more friends and had his own little shop to make some money. According to the CBR worker, the child

did not understand the importance of the changes in his health. The importance of finding out children's perceptions is shown here. This study found that CBR workers often did not understand perceptions about changes and their impact on the lives of children and their families.

The aim of this study was comparable to that of 3 earlier studies - one conducted in Cambodia (Powell et al, 2002), another in Palestine (Eide, 2006) and one in Botswana (Lundgren-Lindquist & Nordholm, 1996). However, the study methods were different and the countries involved are culturally different from one another. In Palestine, CBR was implemented more than 10 years before the study was conducted (Eide, 2006), whereas in Nepal children had been supported by CBR for 2-3 years. Evaluation after 10 years will show the long-term impact, while only the direct, short-term impact can be seen after 2-3 years. At the same time, over a period of 10 years people may forget their experiences prior to CBR, and the effect of age changes could be more pronounced. The 3 earlier studies were focussed on people of all age groups, while this study aimed to measure the impact on children (i.e. between 4 – 18 years). All the outcomes, in terms of results, were comparable to one another. The studies all showed that CBR had a positive impact on the lives of persons with disabilities. The components used in these studies were a little different; hence the impact areas differed from one another. However they all included physical health, social, QoL and Activities of Daily Living (ADL), and the overall impact was comparable.

Methodological Limitations

Since this study is about individual perspectives and experiences, the results rely on qualitative outcomes. The qualitative approach involved 2 different techniques: a ranking line and semi-structured interviews. The interviews served as a check for the ranking line outcomes, while at the same time they allowed the researcher to go more in-depth into the ranking line outcomes.

The use of a comparison group is helpful to establish the efficacy of a particular intervention. It was not possible in this setting due to ethical considerations. To bridge the gap, a hypothetical comparison question was chosen (i.e. *'What do you think your situation would be at this moment if you never had CBR?'*). This helped to understand some more about the impact (Shalock, 2001). The most common answer was that the child still had no friends to play with and still had no future

perspectives without this CBR. In addition, the CBR workers were also asked their views regarding the impact of CBR on the children.

During the interviews, one of the unequally distributed confounders was the difference in educational levels of the families. In this study, the level of education was not a criterion and was not noted. The study was all about the respondents' experiences and feelings, without taking the knowledge and understanding of disability into account. It has been proven that persons with low educational levels, or no education at all, do know less about health and educated persons have a better health status (Cutler & Lleras-Muney, 2010).

The study population was not a homogenous group; children with different kind of disabilities and of varying ages were included. The number of children with a physical disability was higher in comparison to children with other types of disabilities. To reduce bias due to over-representation of a particular disability group, the researcher ensured that there was at least one child included for each type of disability (Sica, 2006).

CONCLUSION

This study has shown the impact of CBR at the individual levels of children with disability and their families. CBR has brought positive changes in the lives of the majority of the children. The changes were not similar to the impact experienced after CBR. The major changes occurred in physical health, while the impact was mainly experienced on a social level, in empowerment and in the level of independence. Children mentioned that they had more friends, experienced less discrimination, attended school more often and therefore felt more independent and were more positive about their future. Due to this impact, children and their families felt happier and more confident about themselves. These findings emphasise the importance of paying adequate attention to improving the physical health and functioning of children with disabilities.

The CBR workers were more focussed on the physical changes. They did not talk about the impact of those changes, but about problems and misunderstanding. There is a gap in the way that the children with disabilities and their families think, and the way that the CBR workers think. The CBR workers' level of thinking corresponds with the medical model, while children and their families are aligned to a social view.

The KF workers' hypothesis for this study population is supported by the findings: the children and their families experienced changes in their lives due to CBR. In general, a positive personal impact was felt by them all. However there is room for improvement, both in the quality of the CBR work and in the baseline measurement of quality of life.

Recommendations

QoL offers a holistic framework to measure the impact of a CBR programme, but this study shows that QoL is difficult to conceptualise for people as it is both complex and personal. During the interviews, from the many different things that were mentioned, the real impact of CBR on people's lives was revealed. CBR programmes should focus on what is important for the target population; it is therefore recommended that research should be more elaborate and conducted in different settings.

The World Report on Disability (WHO, 2011) points to unmet needs for good rehabilitation services in many countries. It is supported by the findings in this study; at the same time, there are improvements in the study area due to CBR. The authors recommend that the CBR workers be trained in the social model approach by KF. They should be trained to view changes and problems from the children's perspective, from a social perspective and to integrate the social model in their work. Skill training should include ways to create awareness and knowledge among the parents. Additional research is required to gauge the quantum of understanding within families about their child with disability and the importance of rehabilitation.

ACKNOWLEDGEMENT

The authors gratefully acknowledge the support and help provided by B Bajracharya to conduct the study and write this article. They thank all the staff from KF for their support and advice during the researcher's stay in Nepal.

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