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Experiences of parents and caregivers of children with disability on community-based rehabilitation (CBR) services in Malaysia: A qualitative study

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Abstract

Background: The rehabilitation program for disabled children is provided through community-based rehabilitation (CBR) services by an initiative of the Department of Social Welfare Malaysia. This long-term program needs commitment and compliance, which relates to the quality of services experienced by parents and caregivers. Thus, the purpose of this study was to explore the experiences of the parents and caregivers of disabled children on the CBR services. **Methods:** This qualitative study utilized in-depth interview sessions held from March to May 2015. Fifteen parents and caregivers who had disabled children participating in the CBR program were selected using a purposive sampling method. All recorded conversations were transcribed verbatim and analyzed using Atlas.ti version 8.0. The thematic analysis was used for identifying, analyzing, and reporting the data obtained. The themes that emerged were read, reread, and peer checked until the researcher agreed on the thematic representation of the data. **Results:** Six major themes emerged from this study, including CBR activity, facilities, environment, communication, program impact, and management system. **Conclusion:** The majority of the parents and caregivers had good experiences with CBR services. However, several aspects could be given further attention to improve the CBR quality and to sustain its services for disabled children.

Keywords: caregivers, disabled children, experience, rehabilitation

Introduction

Community-based rehabilitation (CBR) is the main approach by which disabled people in most of the world have any chance of access to rehabilitation services. CBR was first promoted by the World Health Organization (WHO) in the mid-1970s to address the shortage of rehabilitation assistance by providing services in the community with the use of local resources.¹ CBR is useful for situations where resources for rehabilitation are available in the community. CBR was implemented through the combined efforts of people with disabilities, their families and communities, and relevant government and nongovernment agencies in health, education, vocational, social, and other service sectors.^{2,3}

Worldwide, more than 90 countries have implemented the CBR program to cater to people with disabilities in large populations, including Malaysia.^{4,5} Malaysia had implemented the first CBR program since 1984 in Batu Rakit, Terengganu, in collaboration with the Ministry of Health Malaysia. CBR played important roles in providing services for people with disabilities, especially for rural areas, as they have limited access to other

rehabilitation services. For 34 years of providing services, CBR had offered many activities such as individual therapy, group therapy, morning circle, music therapy, gardening therapy, physiotherapy, and occupational therapy to improve and enhance the quality of life of people with disability, their family, and society. CBR program focuses on long-term care and acts as a training center that prepares disabled persons to enroll in special schools and/or employment, and consequently, live in a community with the highest achievable ability.⁶

Over the decades, the development of CBR has been influenced by the concerns of disabled people, current practice, changing understandings of CBR, and emerging evidence from the literature.⁷ CBR activities were linked to positive social outcomes, enhanced social inclusion, quality of life as an outcome measure, family quality of life,⁸ and greater adjustment of people with disabilities. Although CBR was established for 34 years in Malaysia with limited healthcare resources, the effectiveness of its services is questionable. Thus, this study aimed to explore parents' and caregivers' views on CBR services and identify strategies for the provision of services.

Methods

Study Design. This qualitative study utilized in-depth interviews to explore the experiences of the parents and caregivers on CBR services for disabled children. Face-to-face interview sessions were held from March to May 2015.

Study Setting. This study was conducted at the CBR centers and the participants' houses by appointment from three states—Pahang, Terengganu, and Kelantan—until data saturation occurred, which is defined when additional data obtained are repetitive or similar to the previously obtained data.⁹

Participants. This study involved parents and caregivers of disabled children who had experiences in participating in a rehabilitation program conducted under CBR services. The inclusion criteria for this study were parents and caregivers who had disabled children aged below 18 years who participated in a CBR program and understood the Malay language (Bahasa Melayu). Parents and caregivers who had disabled children more than 18 years old and attended private or/and alternative rehabilitation programs more than the CBR program were excluded from this study. The age for exclusion criteria was set up as the majority of the disabled children who participated in the CBR program were aged below 18 years.

Data Collection. During the interview sessions, participant–researcher relationships were established, where the researcher introduced herself, the participants were informed that their participation would be entirely voluntary, and they may reserve their rights to withdraw from the study without penalty. The data were coded, and identifiable characteristics of the participants were kept anonymous, in both the data analysis process and the report, to protect the privacy of the participants. There were seven points, including icebreaking in the interview protocol used to explore parents' and caregiver's experiences. The interviews were conducted in the Malay language by the researcher, while the participants used the east coast Malay dialect. All interviews were recorded using audio recorder apps from a smartphone. All interviewed data were recorded, and the researcher transcribed them into manuscript form. Participants were contacted via phone to clarify any terms, which were not clear or not understood by the researcher as most of the participants spoke in the east coast Malay dialect.

All manuscripts were translated into English and cross-checked with a supervisor who understood Malay and English to prevent any loss of meaning. Thematic analysis was used for identifying, analyzing, and reporting patterns in the data. All audio recorded were transcribed and transformed into a descriptive format and

were checked for completeness of the data. Fifteen audiotapes were analyzed.

Ethical considerations. Ethical issue in this study was addressed. All permission and approval from the Ethics Committee of University Kebangsaan Malaysia (FF-2015-004) and National Medical Research Register (NMRR-15-44-24133) were obtained. This study was also registered with MyResearch (JKMM 100/12/5/2: 2014/281 & JKMM 100/12/5/2/JLD 70) from the Department of Social Welfare for conducting the research on their premises.

Data analysis. The themes that emerged were read and reread until the researcher agreed on the thematic representation of the data. The in-depth interview data were analyzed using Atlas.ti version 8.0, and the themes and subthemes were then illustrated in Figure 1 for experiences shared toward CBR services for the disabled children.

Results

Demographic of participants. All 15 parents and caregivers who had disabled children participated in the CBR program were selected in this study by appointment basis, and the response rate was 100%. The characteristics of all of the participants are shown in Table 1.

Qualitative Data. There were six themes developed from this study: CBR activity, environment, facilities, communication, program impact, and management system. The themes and subthemes are presented in Figure 1.

Table 1. Characteristics of the participants

Criteria	N (%)
States	
Pahang	5
Terengganu	2
Kelantan	8
Type of CBR services	
Center-based	8
Home-based	7
Experience with CBR services (years)	
1–5	6
6–10	8
>10	1

CBR: community-based rehabilitation.

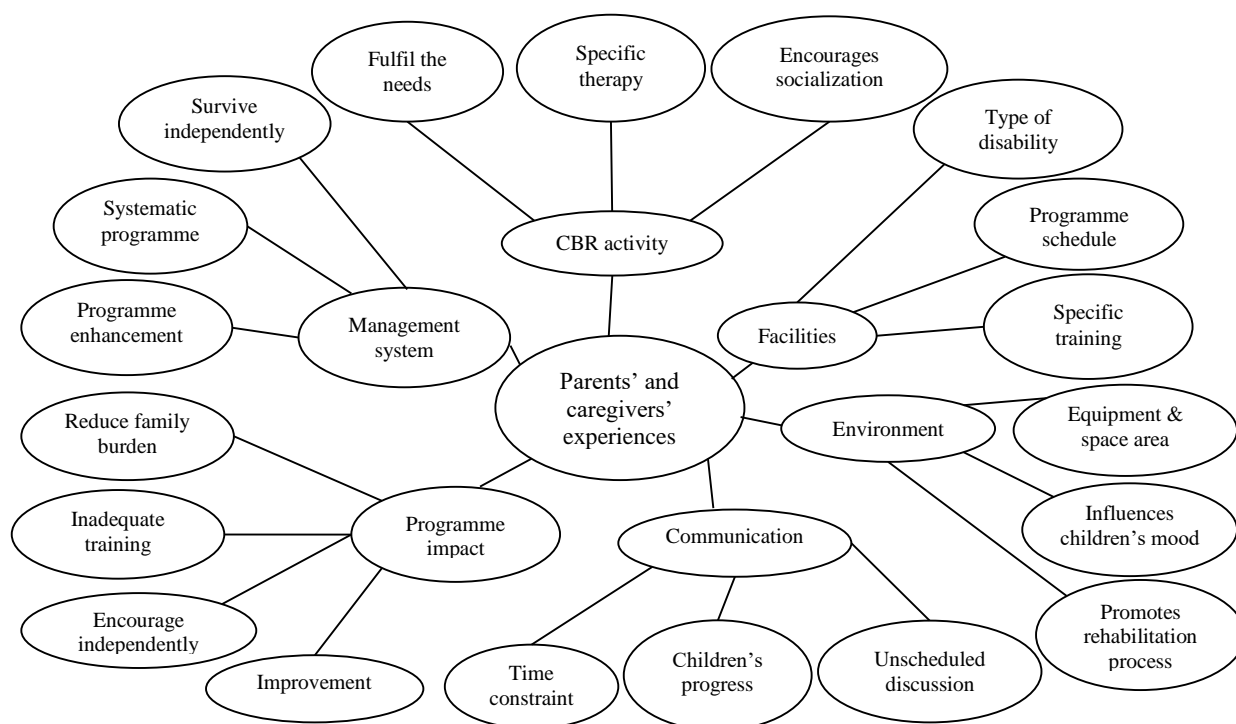


Figure 1. Parents' and caregivers' experiences on the community-based rehabilitation (CBR) program

Theme 1: Community-based rehabilitation activity

Subthemes: Specific therapy, encourages socialization, and fulfills the needs. All participants expressed their views on the rehabilitation activity received by their children, which were more on the ability to perform an activity of daily living (N = 15/15) and physical therapy that encourages independence for their children. However, they felt that the enhancement of the continuity of care and socialization of their children were also needed in the rehabilitation activities. The quotes are as follows:

“Emmm...they (CBR workers) do physio, like a massage” (Participant 1).

“Hmmm...therapy that [he] his received was like an exercise. To strengthen his legs and hands muscle. So that he can stand...hmmm...like that” (Participant 3).

“In CBR center, children can mix around with others...so that [they can] open their mind and they will [be] happy” (Participant 7).

“I didn't aspect more...but as long as he can do daily activity...that's enough for me” (Participant 8).

Theme 2: Environment

Subthemes: Promotes rehabilitation, influences children's mood, and good equipment and space area. Most of the participants believed that the useful

environment provided for further rehabilitation for their children with disabilities had encouraged and motivated parents and caregivers to continue with the therapy provided. The majority of the participants highlighted that the environment helps in promoting the rehabilitation process. Space area, cleanliness, cheerful view, sounds, and location of the centers were emphasized as influencing factors in the rehabilitation process.

“More or less it's helps...contribute to the rehabilitation process” (Participant 1).

“Hmmm...environment okay. Because I emphasized on cleanliness. When there are many children here, we need clean toilet, sink, and many towels. I can see those things are clean and available. So...it's good” (Participant 8).

Nonetheless, a few participants were skeptical about the environment of the CBR center as a rehabilitation center for children with disability:

“Environment...I think the environment not so. Actually, I am not satisfied enough. This center should be more disabled friendly. If like this...it's same like ordinary nursery” (Participant 7).

Theme 3: Facilities

Subthemes: Type of disability, program schedule, and specific training. Facilities also were highlighted as one of the important themes from parents' and caregivers'

views on the CBR services (N = 7/15). The majority of the participants viewed limited facilities in the current CBR system as a major barrier to the provision of long-term rehabilitation to children with disabilities. Professional physiotherapy and specific training for CBR workers were also mentioned in theme facilities because it was considered as one of the facilities offered for CBR service. Inadequate or ill-equipped CBR centers may be a reason for long-term therapy undergone for children with disabilities that may contribute to the economic burden of the family. There were varying types of disabilities that should be catered to differently. Thus, well-equipped CBR center and specific training were also pointed out in improving the service:

“For me, it’s not enough for cleanliness aspect, number of trainers (CBR workers) and physiotherapist” (Participant 11).

“Emmm...lack of facilities. Have to improve it” (Participant 12).

“Emmm...enough...she cannot play much...not same like others...she just exercises (physiotherapy) only...I think is enough” (Participant 2).

“I think...this place is small. Should have large area. So that they (CBR workers) can control them (disabled children)” (Participant 5).

“I think the facilities in this center...same...not so good. Like my child...she is Cerebral Palsy, she need corner chair but she has to share, meaning that not complete facilities” (Participant 7).

Theme 4: Communication

Subthemes: Time constraint, children’s progress, and unscheduled discussion. The issue of communication was also raised. Unscheduled two-way communication between parents and caregivers with CBR workers was found in the majority of parents’ and caregivers’ views (N = 10/15). Although the issue was on children’s progress and continued rehabilitation process at home (N = 9/15), discussions were conducted unofficially, for example, during sending off and fetching children.

“Sometimes...about exercise (physiotherapy) for my child...that’s all” (Participant 2).

“Haaa...during sent and fetched child to CBR center...haaa...asked the CBR workers” (Participant 4).

The participants emphasized that the official session conducted was very minimal (times per year) and usually together with other events, for example, *gotong-royong*.

Limited communication sessions organized may have reduced discussions on further training needs of the children with disabilities, and this may have influenced their rehabilitation process. Quotes related to these subthemes are as follows:

“If have any problem (child’s problem), they (CBR workers) will call me to come to the center. Sometimes, during fetched my child, they (CBR workers) will inform me if there is any problem” (Participant 5).

“Usually unscheduled discussion, but we had meeting once a month...about child’s progress” (Participant 11).

Theme 5: Programme impact

Subthemes: Improvement, encourage independently, inadequate training, and reduce family burden. Several points were highlighted for the outcome of the CBR program. Participants agreed that the CBR activities and the management of CBR centers greatly needed to be well structured to manage long-term rehabilitation for children with disabilities. On the contrary, the majority of the participants emphasized positive feedbacks that the CBR program is a good program for disabled children (N = 12/15) and reduces family burden (N = 6/15), especially for working parents and caregivers. Although there were improvements in children’s progress and encouraged independence (N = 6/15), lack of specific training among CBR workers must be taken into consideration. Improvement in the management of center and activity would give positive impacts on rehabilitation for disabled children. The examples of the quotes are as follows:

“For me, CBR program was good” (Participant 3).

“I think okay because they (CBR center) have many things, like gardening, she can do that independently, here...they teach everything” (Participant 5).

“Actually, I expect from CBR workers, they are okay. But, sometimes they have not enough experience, but they still can handle, so...okay” (Participant 7).

“Yaaa...I think this program helps to reduce my burden in caring of disabled child not for me only but for others parents too and we hope there is more improvement” (Participant 11).

Theme 6: Management System

Subthemes: Program enhancement, systematic program, and survive independently. The majority of

the participants viewed the limited resources in the current CBR center as a major barrier to the provision of long-term rehabilitation to children with disabilities. Implementation of a systematic program that is formal and organized like a school is one of the parents' and caregivers' expectations from the CBR program. Parents and caregivers highlighted that the CBR program encouraged their disabled children to become more independent (N = 9/15). Although there was an improvement in children's progress, other aspects must also be given attention. Program enhancement was also stressed from parents' and caregivers' expectations toward the CBR programs. Many aspects must be considered by the stakeholders for the enhancement of the CBR program, such as program duration, training and motivation, dissemination of program, and skills of the CBR workers. The views are quoted as follows:

“For me...hmmm...CBR create program, then they implement the program effectively. So that, children (disabled children) can reduce their own burden” (Participant 3).

“Emmm...hope that CBR can be more organized and systematic like a school for disabled children that truly emphasize on rehabilitation activity. Can helps from physical and mental aspects” (Participant 10).

Discussion

The CBR services started in the 1970s and established in Malaysia since 1984. Although this well-known program was promoted by the WHO, the qualitative research that explores the perspectives of parents and caregivers toward rehabilitation CBR services is scarce. Views from parents and caregivers are important for sustaining the services, quality improvement, and program benefits for disabled children and their families.

This is the first study that explores the parents' and caregivers' experiences of receiving CBR services in Malaysia. Literature has demonstrated that the rehabilitation of disabled children is long-term care that needs more attention toward the program itself. There were many themes discussed in previous studies. Thematic analysis in the present study resulted in six themes. Nevertheless, in this present study, the researcher wished to highlight on CBR activity, communication, and program impact. All the themes contributed to the parents' and caregivers' experiences on CBR services for their disabled children.

CBR Activity. Generally, rehabilitation can be described as an exercise component. However, rehabilitation involves more than just exercise. The systematic process must be adapted in all the prevention and treatment activities or services that focus on physical impairments,

activity limitations, and individual abilities.¹⁰ Although specific rehabilitation in a community is one of the significant obstacles faced by parents and caregivers of disabled children, especially for working parents, they highlighted that CBR activities fulfilled their disabled child's need in terms of performing a basic activity of daily living, such as eating independently, toileting, and grooming. Despite their “hope,” most of them were realistic about their child's improvement, and they felt satisfied with the program activities. Although some other aspects, such as frequency of the therapy, specific therapy according to the type of disability, and proper schedule for home-based, were also highlighted in the interview. The findings were contrary to previous study that had many mothers being unrealistic about their child improvement and tried to find other treatment when they felt their expectations were not fulfilled.¹¹ The present study findings highlighted that the parents and caregivers of disabled children were very positive and still hoped that their child's health condition will improve based on the abilities observed during the rehabilitation. The CBR activity schedule, which was 4 days per week for center-based and 1 day for home-based, was considered as an acceptable routine as it was very difficult to find childcare with trained workers.¹² The CBR activity was also highlighted to encourage the socialization of disabled children and prevent isolation among them.

Programme impact. Positive outcomes for the family and child were the significant impacts observed from the rehabilitation services.¹³ The findings showed that parents and caregivers expressed their views that the proper CBR program would give a good impact on their child's quality of life. The long-term care needed continuous effective rehabilitation, and improvement in physical and psychosocial functioning was associated with improvement in quality of life, which had resulted from the service utilization.¹⁴ Development of CBR program system to encourage easy service access for parents and caregivers of disabled children was emphasized by previous study in their recommendation for community-based physiotherapy service providers.¹⁵ The system-based approach was also highlighted in a study by another study to evaluate the good impact of rehabilitation services for disabled children.¹⁶

A previous study conducted in Zimbabwe also found improvement in social support, environmental limitation, and outcomes of a rehabilitation program by creating a specific appointment for rehabilitation sessions.¹⁷ This shows that a systematic rehabilitation program has a high impact on the disabled child as well as to the parents and caregivers. Thus, adequate training by the CBR workers should be given attention.

Improvement in the health outcome of a disabled child is such a “gift” for parents and caregivers. This positive sign helps to reduce the family burden from financial and

nonfinancial aspects. Many parents and caregivers had financial constraints to give full commitment to participate in the CBR program with the costs incurred.¹⁸ A study conducted in South Africa also stressed the impact of rehabilitation programs by reducing family burden on the physical stress of parents and caregivers to take care of their disabled child. Positive feedback given by parents and caregivers for the CBR program showed the impact of the rehabilitation programs. Although there were limited trained workers, the CBR program helped in reducing family burden from financial and social aspects because it encourages the independence of the disabled child. Although family burden was reduced with the improvement of the child's health after participating in the CBR program, all the participants in the present study were encouraged to continue on the CBR program as their child and family had benefited from it.

Communication. Effective communication with parents and caregivers of disabled children is highly important. An improper explanation can be related to unmet information relayed and the community services provided to them. Parents and caregivers with disabled children who experienced great emotional stress and dissatisfaction with the disclosure are widespread. Relationships that balanced between consistency, effective communication, and caring are the important issues highlighted in the previous study to consumers using the physiotherapy service.¹⁵ Unscheduled discussions between parents and caregivers was emphasized in the present study that can be related to their dissatisfaction with the program, and hence, they felt demotivated to give commitments. Other literature also stressed the lack of information and community support for parents and caregivers in rehabilitation programs, which possibly delayed optimal rehabilitative care.¹⁸ The findings were concurrent with the study by other researchers that stated mothers felt demotivated and hopeless when unmet with the information they needed.¹⁹ Feeling positive is an important motivation factor emphasized by another study that encouraged cooperation from parents for the treatment of their child's disabilities.¹⁹ Communication concerning a child's condition and family was stressed as an important mediator of service utilization, information of services provided, and program effectiveness as ways in promoting child health and development.²⁰⁻²² This revealed how important proper communication and information are for the parents and caregivers of disabled children.

Preferably, there should be two-way communications between the parents and caregivers and the CBR workers for CBR service,¹⁵ and the discussion should be scheduled and consistent. In this study, although there was limited scheduled communication on a child's progress, the parents and caregivers took initiative by

asking any problems related to their child's condition to the CBR workers.¹⁵ However, the point highlighted was contrary to the previous study, which was conducted among mothers of children with disabilities. Mothers preferred to keep their thoughts than to have discussions to prevent arguments.¹¹ This behavior is influenced by the Malay culture, which is to respect others, especially toward professional authorities. Besides, social support from family and community services similarly is significantly important, where a previous study conducted among parents who took care of their disabled child at home felt isolated, helpless, and rejected when there was no social support from the professionals.²³ Although formal communication between parents and caregivers is very important, informal communication processes often took place when parents and caregivers highly valued professional support by asking their concerns about their child's condition. These views revealed that formal and informal communication were significant in rehabilitation for disabled children.

Time constraints for parents and caregivers to discuss on child's condition may contribute to the limited proper communication process. Nevertheless, a proper communication schedule between the two parties might reduce pressure and stress by giving them knowledge and skills also to enhance the CBR program itself.

Our study had several limitations. Although the recruitment of participants was carefully attempted based on the individual's ability to express their ideas, some participants did not engage adequately in the interview sessions. Several participants had to be encouraged to express their opinion. This had interrupted the natural flow of the sessions and threatened the richness of the data. There were also issues related to dialect (language style related to the states) used in some of the participants, resulting in difficulty in transcribing and interpreting the audio-taped data. Field notes taken during each discussion session has somewhat been useful to complement data obtained from the recorded conversation.

Conclusion

The findings of our study are impactful to the provision of CBR services for the long-term rehabilitation of disabled children. Sustaining the CBR services for decades was a multi-factorial effort, which includes CBR activity, the environment of CBR center, facilities provided, effective communication between parents, caregivers, and CBR workers, the impact of the program offered, and management system. All identified factors provided evidence for better planning and improving the CBR services in the future. Further research that looks into this concern is warranted to guide policies related to the long-term rehabilitation of disabled children in a community setting.

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Conflict of Interest Statement

The authors declare that they have no competing interests.

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