

# Effectiveness of Community-Based Rehabilitation on the lives of Parents of Children with Cerebral Palsy: A Mixed Method Study in Karnataka, India

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## ABSTRACT

**Purpose:** The study aimed to identify the effects of the CBR programme on parents of children with Cerebral Palsy, living in Karnataka State, India. It also tried to find the challenges and improvements needed to make the CBR programme more effective.

**Method:** A cross-sectional, descriptive study design was used to collect a sample of 100 parents of children with Cerebral Palsy, with GMFCS levels IV and V. The sample was drawn from various communities in Bangalore, Davanagere and Bijapur, where the services of The Association of People with Disability are available. Face-to-face interviews were conducted with the study subjects. Data was analysed by SPSS using descriptive and inferential statistics.

**Results:** It was observed that the CBR programme had a positive effect on parents' health, knowledge, social lives and empowerment. A binary logistic regression was done to find the relationship between health, knowledge, social lives and assistive devices use. A strong association was found between all the areas ( $p=.001$ ) except GMFCS and assistive devices use ( $p=.004$ ) at 95% CI. The odds ratios between them were greater than 1 and showed the strong positive effect of the CBR programme on parents.

**Conclusion:** The CBR programme not only has a positive effect on children with Cerebral Palsy, but also plays an important role in parents' lives. It contributes in a positive way to parents' overall activity.

**Key words:** Cerebral Palsy, CBR, Rehabilitation, GMFCS, Parents

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## INTRODUCTION

People with disability belong to one of the poorest and most marginalised groups in the society, accounting for approximately 15% of the world's population (World Health Organisation, 2011). To decrease the burden for persons with disabilities in low-income countries, the World Health Organisation (WHO) initiated Community-Based Rehabilitation (CBR) four decades ago (Khasnabis et al, 2010). CBR programmes have been recognised as exceptionally successful methods for advancing the rights and opportunities of people with disabilities (Mauro et al, 2014). Despite the fact that people with disabilities in low- and middle-income countries access rehabilitation services primarily via CBR programmes, there is hardly any literature that provides rigorous evaluation (Fuzikawa, 2008; Mauro et al, 2014).

Cerebral Palsy is a common childhood disability and is associated with life-long disability. Children with Cerebral Palsy experience sensory, motor, speech and cognitive impairment (Brannan & Heflinger, 2006; Pakula et al, 2009). The estimated incidence of Cerebral Palsy worldwide is 2 to 2.5 per 1000 live births (Sankar & Mundkur, 2005) and around 3/1000 live births in India (Vyas et al, 2013). Being a developing country, the actual figure might be considerably higher (Vyas et al, 2013). Impairments may lead to various functional limitations which, in turn, may require assistance in activities of daily living throughout the life of an individual with Cerebral Palsy. Some studies show that taking care of a child is part of normal parenthood; however, the excessive demands associated with taking care of a child with a disability may lead to increased burden/ strain.

Negative health outcomes among caregivers associated with their children with a long-term health condition have been reported; for instance, depression, stress, anxiety and low self-efficacy (Murphy et al, 2007; Lee et al, 2009; Cadman et al, 2012). Mothers of children with intellectual disabilities reported lower levels of happiness, self-esteem and self-efficacy than mothers of children without intellectual disabilities (Emerson et al, 2007). In general, the challenges faced by caregivers include psychological issues owing to the demands of caregiving. Furthermore, uncertainties and physical health challenges in parents of children with disabilities emanate from excessive stress and may be related to constantly assisting their children in activities of daily living, and thus add to the mental strain of parents (Tonga & Düger, 2008; Sajedi et al, 2010; Dambi & Jelsma, 2014). Mothers often experience socio-economic challenges (Olaogun et al, 2006; Singogo et al, 2015) as well as marital problems (Vijesh & Sukumaran, 2007; Singogo, et

al, 2015). Apart from social isolation and marital problems, research has found that mothers experienced negative attitudes from family, friends, community members and healthcare professionals (Jette, 2006; Resch et al, 2010; Woodgate et al, 2015). Hence, the challenges faced by caregivers, mainly mothers of children with Cerebral Palsy, could be viewed within a bio-psychosocial model of disability (WHO, 2001; Singogo et al, 2015). It is therefore evident that the quality of life (QoL) of these mothers is negatively affected as a result of caring for their children with Cerebral Palsy (Green, 2003). Thinking about a child with Cerebral Palsy may be overpowering, resulting in distress and anguish as the truth of lost expectations and dreams become evident (Huang et al, 2010).

The level of required assistance depends on the severity of impairments, activity limitations and participation restrictions (Jette, 2006). Physical barriers also serve as major problems. The physical environment creates challenges because of lack of sidewalks, ramps, functioning lifts and small indoor spaces (Edwards & Tsouros, 2006; Evcil, 2009; Singogo et al, 2015).

Implementing CBR programmes in rural and distant zones can be successful in improving the quality of life of people with physical disabilities (Fuzikawa, 2008; Grandisson et al, 2014; Khan et al, 2017). The CBR approach was found effective in overcoming economic, cultural and geographical barriers and was more effective in retaining clients and their families in programmes (Chatterjee et al, 2003). Exploration and assessment of the conditions under which CBR programmes are best for various populations is unquestionably required, with regard to both CBR standards and guidelines for powerful examination and assessment (Grandisson et al, 2014). Carrying out evaluations of CBR programmes is also essential in order to monitor their effectiveness and relevance. Kuipers et al (2008) articulated that without evaluation the effectiveness of CBR is not confirmed, which in turn could affect the integrity of a CBR programme. Since the origination of CBR, there have been an extensive number of CBR evaluations around the world (Chappell & Johannesmeier, 2009).

In a study it was found that apparently CBR has an effect on groups of persons with disability both legitimately and by implication. For instance, direct interventions such as counselling and training of parents of children with disabilities and other family members had an effect on their self-esteem and confidence in dealing with their family member with disability. The study showed that the effectiveness of CBR was not just the result of individual medical rehabilitation interventions, but included aspects of community development, poverty reduction, social inclusion

and equalisation of opportunities, as set out in the joint position paper (WHO, 2005) definition of CBR (Engle et al, 2011). Biggeri et al (2012) stated that “the CBR programme evaluated has a positive effect on access to services and the well-being of persons/children with disability who are particularly deprived on outcomes of interest.”

In a study in India, it was found that the quality of life of most of the parents of children with disability was neither good nor bad. Parents interviewed stated that it could be because they had learned to cope with the situation. The major aspect that had been influenced with the CBR programme were socially related, followed by mental aspects. Most of the guardians were happy with their own well-being. The majority of their concerns were because of lower economic status, lack of attention for the illness/disability of their child and the inaccessible healthcare facilities (Chalipat et al, 2016).

A few studies report that Health Related Quality of Life (HRQOL) of mothers of children with Cerebral Palsy is influenced contrarily (White-Koning et al, 2007; Arnaud et al, 2008). While the HRQOL of mothers is reported to be negatively associated with depression, anxiety, educational status, and functional levels, others assert that there is no correlation between the HRQOL of mothers and functional levels of children with Cerebral Palsy (Ones et al, 2005). A study by Diwan et al (2011) found that 70% of mothers having a child with Cerebral Palsy had a mild to severe depression, and that depression was negatively affecting their HRQOL.

## **Objective**

The focus of the study was to identify the effects of the CBR programme on the lives of parents of children with Cerebral Palsy in five areas namely health, knowledge of parents, social lives, home modification and empowerment of parents. It also tried to find the challenges and improvements needed to make the CBR programme more effective in the future.

## **METHOD**

### **Study Design**

This was a cross-sectional study. Mixed methods (qualitative and quantitative) were employed to achieve the objective.

## Study Setting

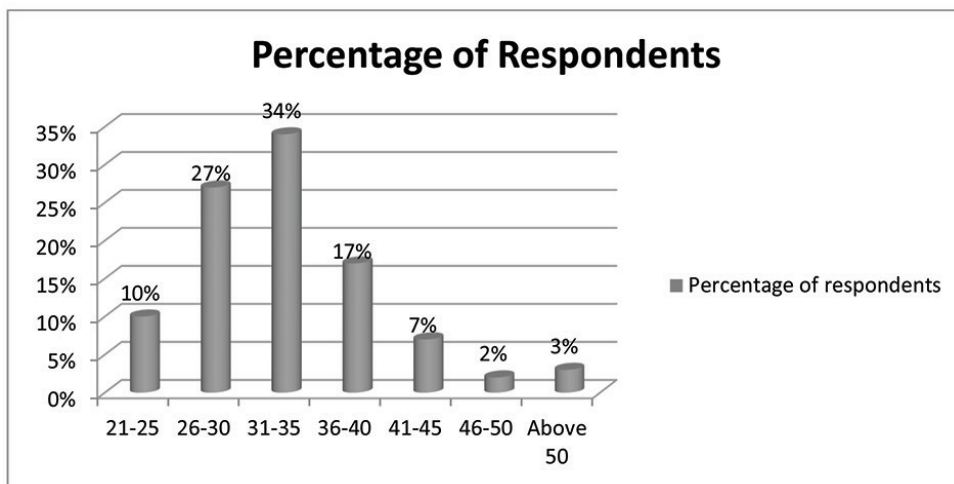
The study was conducted in 3 districts of Karnataka State in India namely Davangere, Bijapur and Bangalore, where The Association of People with Disability (APD) have their network.

## Sample

Parents of children with Cerebral Palsy were the target population. Convenience sampling procedure was used to select the potential participants. This non-probability sampling method included all the parents involved in the CBR programme for more than two years. The sample size consisted of 100 participants.

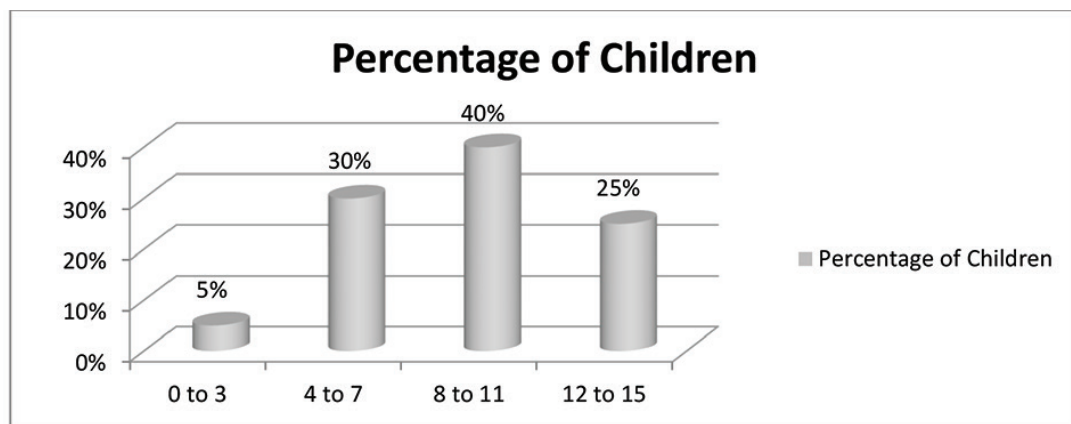
Most of the respondents (34%) were between 31-35 years of age and the smallest group (2%) were in the age group of 46-50 years. The mean age was 33.56 years with a standard deviation of 6.40, ranging from 23-54 years (Figure 1). Among them 92 % were biological mothers and 8 % were biological fathers.

**Figure 1: Percentage of Respondents (parents) according to Age Groups**



Among the 100 children, most (40%) were between 8-11 years of age and the fewest (5%) were in the age group of 0-3 years. The mean age was 8.99 years with a standard deviation of 3.27, ranging from 6 months to 15 years (Figure 2). Of these children, 29 % were of GMFCS level IV whereas 71% were of GMFCS level V.

**Figure 2: Distribution of Children according to Age Group**



### Data Collection

In-depth information about the existing CBR programme was gathered. Data was collected through interviews as well as a questionnaire completed by individual mothers and fathers who were involved in their children's daily activities. Participants were asked to provide information about their health, social wellbeing, and knowledge about their child's disability and how to handle them with appropriate care and empowerment status i.e. the knowledge about their child's disability. They also were asked to make suggestions for the improvement of the CBR programme.

### Study Instrument

The survey questionnaire consisted of 44 questions inquiring about respondents' socio-demographic background, child's disability characteristics, their health, knowledge, social life and empowerment status. It also sought information about the use of assistive device and possible home modifications.

The questionnaire developed for the study was based on a literature review (Grandisson et al, 2014), and had some questions adapted using the following references: WHOQoL-BREF (WHO, 1996), Community Integration Questionnaire (Willer et al, 1993), Burden Scale for Family Caregivers (Graessel et al, 2014), the Zarit Burden Interview (Bédard et al, 2001), Pelvic Floor Impact Questionnaire (PFIQ) -7 (Shirley Ryan Abilitylab, no date). The questionnaire was translated into Kannada, the local language, by a hired professional translator following the standard procedure of linguistic validation. Before data collection was



started, a pilot study was conducted with 5 parents of children with Cerebral Palsy who were attending the CBR programme of the Association of People with Disability (APD). This was done to ensure the face validity of the questionnaire. After reviewing the results of pilot study, changes were made, and the final questionnaire was ready to be employed among the 100 participants of this study.

1. Demographic characteristics: Information pertaining to the participants and their children was collected. Maternal characteristics were defined such as the mother's age, educational attainment, marital status, employment status, occupation, number of family members living in the same household, and socio-economic status. The child's characteristics included age and GMFCS levels.
2. Effects on parent's health, knowledge, social life and empowerment was gathered with an adapted scale, which measures the effectiveness of the CBR programme on the parents in various dimensions. There are 16 items on a five-point Likert-type Scale consisting of four areas: health, knowledge, social life, and empowerment. Items are scored from '1' (low) to '5' (high), with higher scores indicative of greater positive effects of the CBR programme on parents. The Scale demonstrated acceptable reliability (Chronbach's  $\alpha = 0.83$ ) for this sample.
3. Assistive Devices and Modifications: The scale was adopted by the authors using similar scales like QUEST (Version 2.0) (Demer et al, 2000) & ATSurvey-1107, (Massachusetts Rehabilitation Commission, 2006) measured the modifications done in various dimensions. This 10-item five-point Likert-type Scale consists of three areas: home modification, established exercise area and assistive devices. Items are scored from '0' (low) to '4' (high), with higher scores indicative of greater changes in the home environment. The Scale demonstrated acceptable reliability (Chronbach's  $\alpha = 0.77$ ) for this sample.

## Data Analysis

The data collected was reviewed, recorded and entered into the SPSS programme, in order to reduce human error during analysis.

## **Ethical Consideration**

Ethical approval for conducting research was given by the Institutional Review Board (IRB) of Bangladesh Health Professions Institute (BHPI). Prior permission was taken from the Association of People with Disability (APD) to collect data from areas where it functioned. Informed consent forms as well as questionnaires, in both English and Kannada languages, were submitted along with the research proposal.

Informed consent was taken from individual respondents before data collection. The respondents were informed that they did not need to answer any question with which they were not comfortable. No coercion was used, and confidentiality and anonymity of the obtained information was maintained as per the “right to privacy”.

## **RESULTS**

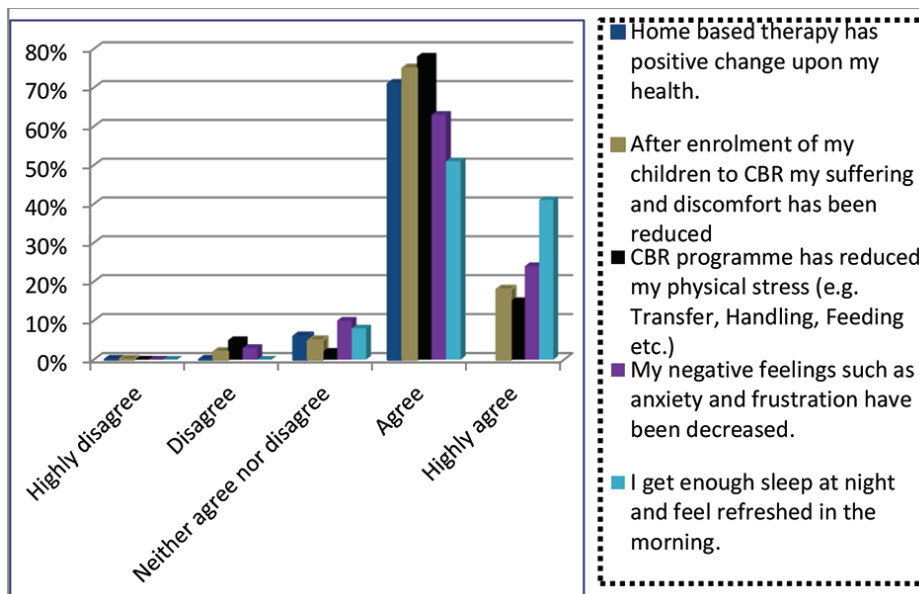
### **I. Effectiveness of CBR**

#### **1. Health**

Out of 100 respondents, 71% agreed that home-based therapy had brought about a positive change to their health, 23% highly agreed and 6% neither agreed nor disagreed. While 75% agreed that after enrolment of their child in the CBR programme their suffering and discomfort were reduced, 18% highly agreed, 5% neither agreed nor disagreed, and 2% disagreed. Again, 78% agreed that the CBR programme had reduced their physical stress (e.g. transfer, handling, feeding, etc.), while 15% highly agreed, 5% disagreed and 2% neither agreed nor disagreed. Around 63% of the respondents agreed that their negative feelings such as anxiety and frustration had decreased after enrolling in the CBR programme, followed by 24% who highly agreed, 10% who neither agreed nor disagreed, and 3% who disagreed with this. While 51% of the respondents agreed that they got enough sleep at night and felt refreshed in the morning, 41% highly agreed and 8% neither agreed nor disagreed with this. From the above frequencies it can be said that the CBR programme had a positive effect upon parents' health (Figure 3).



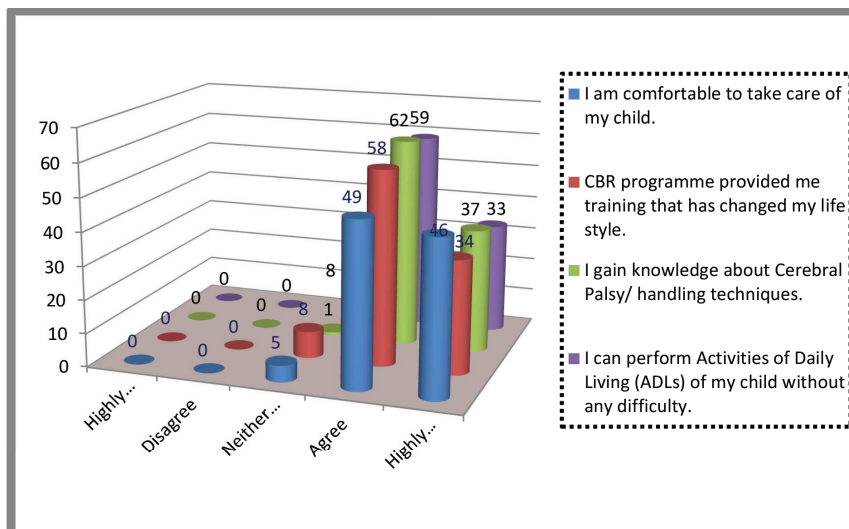
**Figure 3: Health Status of the Parents**



## 2. Knowledge of Parents

While 49% agreed that they were comfortable with taking care of their children after the training, 46% highly agreed and 5% neither agreed nor disagreed. There were 58% who agreed that the training provided by the CBR programme had changed their lifestyle, 34% highly agreed, and 8% neither agreed nor disagreed in response to this question. While 62% agreed that they gained knowledge about Cerebral Palsy and how to handle their child in a therapeutic way, 37% highly agreed and 1% neither agreed nor disagreed with this. Most of the respondents or 59% agreed that they could perform Activities of Daily Living of their children without any difficulty, 33% highly agreed and 8% neither agreed nor disagreed. the above results show that there was a positive effect on knowledge of parents after the CBR programme.

**Figure 4: Frequencies Distribution of Changes in Knowledge of Parents about Cerebral Palsy**



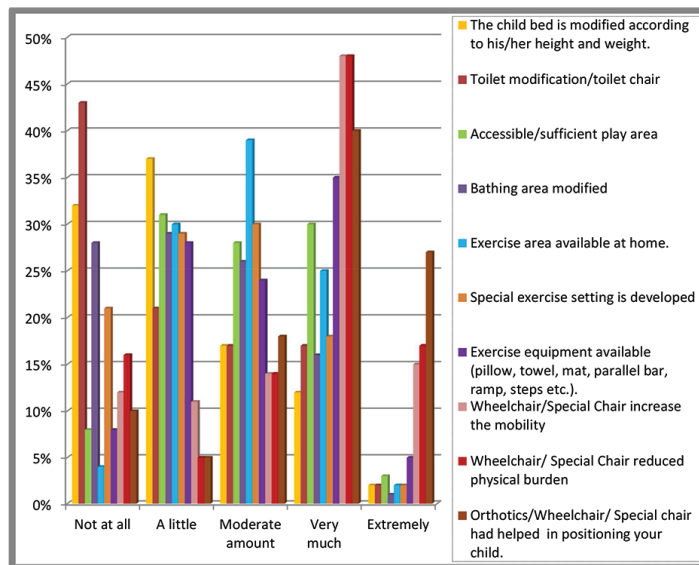
### 3. Social Life

While 60% agreed that the CBR programme made it easier to participate in social activities outside their homes, 27% highly agreed and 13% neither agreed nor disagreed with this. Sixty-eight percent (68%) of parents agreed that their family and society's attitude was positive after the implementation of the CBR programme, 25% highly agreed, 4% disagreed and 3% neither agreed nor disagreed. While 69% agreed that they do not feel neglected by the community members, 23% highly agreed, 5% neither agreed nor disagreed, 2% disagreed and 1% highly disagreed with this. Most of the respondents or 64% agreed that they get necessary time for their own needs and interest, 20% highly agreed, 11% neither agreed nor disagreed, 4% disagreed and only 1% highly disagreed in response to this. It was agreed by 61% of the study population that their social participation has increased (e.g., family gatherings, marriage, religious and social functions, etc.), 31% highly agreed, 6% neither agreed nor disagreed, and 2% disagreed. From these results it may be concluded that the CBR programme had a positive effect on the parents' social lives, although further improvement on this aspect is necessary.

#### 4. Home Modification, Exercise Area and use of Assistive Devices

Among the children, the use of a wheelchair or a special chair increased mobility very much for 48%, extremely for 15% and moderately for 14%. Among the parents, the use of a wheelchair or special chair to transport their child had reduced the physical burden very much for 48%, extremely for 17%, and moderately for 14%. The use of orthotics, a wheelchair, or a special chair had helped in positioning their child very much for 40%, extremely for 27% and moderately for 18%. No major changes were found in home and toilet modifications for the children (Figure 5).

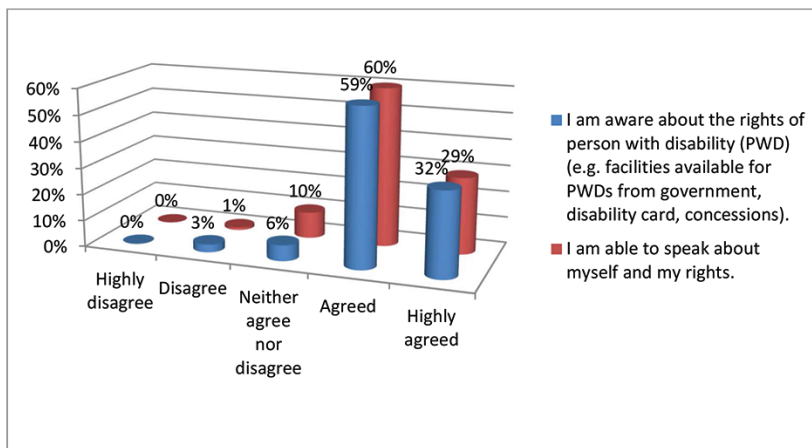
**Figure 5: Distribution of changes in Home Modification, Exercise Area and use of Assistive Devices**



#### 5. Empowerment of Parents

Fifty-nine percent (59%) agreed that they are aware about the rights of people with disabilities (e.g. facilities available for people with disabilities from government, disability card, concessions). 32% highly agreed, six percent neither agreed nor disagreed and three percent disagreed to this question. 60% agreed that they are able to speak about themselves and their rights. 29% highly agreed, 10% neither agreed nor disagreed and only one percent was disagreed to this question.

**Figure 6: Empowerment of parents after CBR implementation.**



## II. Binary Logistic Regression

From the binary logistic regression, it was found that if knowledge changes from poor to good category, the health status increases by  $e^\beta$  unit, odds ratio  $e^\beta = 4.096$ .

It was also found that odds of good social life status are 6.14 times that of good health status, i.e., if the health status improves from poor to good, then social life improves by 6.14 times.

Odds of good social life status are 11.11 times that of good knowledge status. If knowledge changes from poor to good category, social life status will increase by 11 times.

Odds of the use of assistive device are 3.62 times that of GMFCS level. If GMFCS changes from IV to V category, use of assistive devices will increase by 3.62 times.

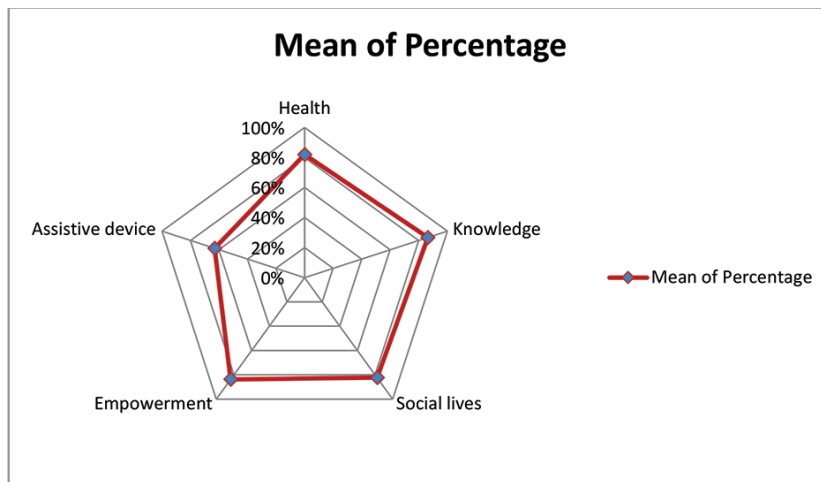
**Table 4: Binary Logistic Regression between Domains**

S.N	Domains		B	S.E	Wald	df	Sig.	Exp(B)
1.	Health vs. Knowledge	Step 1 <sup>a</sup> Knowledge(1)	1.414	.427	10.946	1	.001	4.111
		Constant	-2.317	.681	11.574	1	.001	.099

2.	Health vs. Social lives	Step 1 <sup>a</sup>	Health	1.815	.485	14.008	1	.000	6.142
			Constant	-3.586	.821	19.077	1	.000	.028
3.	Knowledge vs. Social Lives	Step 1 <sup>a</sup>	Knowledge	2.408	.552	18.996	1	.000	11.109
			Constant	-4.648	.984	22.299	1	.000	0.10
4.	GMFCS vs. Assistive device	Step 1 <sup>a</sup>	GMFCS	1.288	.462	7.752	1	.005	3.624
			Constant	-5.358	2.162	6.139	1	.013	.005

### III. Radar Graph

**Figure 7: Radar Graph for Means of Health, Knowledge, Empowerment, Social Lives and Assistive Devices**



Radar chart is a graphical way to compare data by displaying data in a "web-like" form. Since it resembles a spider web it is also known as a spider chart/graph. It is usually applied to evaluate multiple alternatives based on multiple criteria.

In the current study, the means of Health (82%), Knowledge (86.4%), Social Lives (82.32%), Empowerment (83.70%) and Assistive Device (63.08%) were put in the radar graph to draw a conclusion. Based on the Graph, it can be seen that Assistive

Devices has the lowest mean, which indicates that this area needs prioritisation in the near future, followed by Health of parents.

The reason for low effectiveness could be the lack of service, accessible houses and roads, and lack of awareness among the groups.

#### IV. Qualitative Results

##### Theme 1: Main Caregiver

Most of the respondents in this study were mothers (92%) and 8% were fathers. Usually, fathers are not as involved in taking care of a child as mothers. Many of the answers received were along these lines:

*"I am a mother and it's my responsibility to take care of my child like other able children."*

There were also answers that stated the necessity of caring for a child with Cerebral Palsy and the effort required to do this due to presence of complications affecting almost all the major systems of the body. These complications make a child either partially or completely dependent on others for activities of daily living.

*"I am taking care of my child because he is completely dependent and can't perform any activity of his own. And I am the only one to look after him."*

Parents are sincere well-wishers of their child. The parents in the study wanted their child to be happy and healthy, and to have a good future. Most of them also said that they wanted their child to be educated and become a good citizen of the country; hence, almost all the children were being sent to inclusive schools. No matter how hard it was, the parents were ready to do all that they possibly could.

*"I am taking care of the child because he should improve physically and lead a happy life. I am also taking care of his education so that he can learn basic things and can spend quality time in school as well as with his friends."*

*"We accept him as he is but we are worried about his future. We are trying to make him able up to possible extent so that in future he becomes less dependent on others."*



## Theme 2: Challenges faced by Parents

The study uncovered various challenges experienced by parents in taking care of a child with special needs. The answers differed according to their locality and needs. In rural as well as urban areas the most challenging task was to find the right person for consultation. Parents said that it was really difficult for them to visit several doctors at different hospitals. Another problem was that they did not get the right rehabilitation guidelines to follow.

*“Carrying her to different hospitals in public transport was difficult and the distance was very far from one hospital to another. After visiting various hospitals, we could not find the answers that we were looking for. Finally, one doctor suggested visiting APD; we came here and took appointment for rehabilitation. Now she has grown up and admitted to inclusive school within APD campus, here she gets rehabilitation as well as education. She uses wheelchair for mobility. I am here with her in school for whole day. I hardly get time for other things. Though the school is taking care of all the children, still being a mother, I cannot leave her alone.”*

*Apart from these challenges, some parents found it difficult to perform activities of daily living as the child was growing up.*

*“Carrying the child outside for social gatherings and doing her exercise at home is very difficult as her hands and legs are so tight, and she feels pain and cries. No doubt we are getting parents’ training but still it’s really challenging to perform those exercises. I am giving my best to cope up with all the difficulties.”*

In semi-urban and rural areas, the most common challenges were the use of assistive devices, access to education, and services available for these children; all caused by lack of accessibility. The durability of wheelchairs, orthotics, and other assistive devices was very inadequate due to uneven or rough roads. Most of the children are homebound because of poor accessibility both outside and inside the home.

*“My child’s name is registered in the school. Few days we took him to school but now we stop because we cannot carry him all the time as he is a grown-up child, and the wheelchair cannot move in this road. His class is in second floor and there is no ramp inside the school. Though we are getting facilities, yet we cannot utilise it due to various problems. Inside home this wheelchair is helping us a lot as he is sitting in proper position and plays with his brother and sisters and it also helps me in feeding his meals.”*

### Theme 3: Adjustments

The authors attempted to find out whether any “reasonable adjustments” were needed to help mothers, from their own point of view. Surprisingly, 98% said nothing was needed and claimed that they were happy with the on-going process of Community-Based Rehabilitation. Only 2% said that more frequent visits by the community worker would be a great help for them.

*“We are happy with the service of APD in our community. It helps our children a lot; also, it helps me to perform his activities in an appropriate way. The parental training that we are getting at APD helps us to learn a lot about our own children and also, we can see the differences in our children’s activity. The training I got helped me a lot to do exercise for my child and I am also aware of the benefits of doing exercises and using assistive devices. Before the training I was completely unaware about cerebral palsy, its complications and the uses of assistive devices. Thanks to APD for providing us such training and helping us to take care of our children.”*

### Theme 4: Training

Finally, respondents were asked whether training was needed specifically for mothers. The stated requirements were not very different from what was available in the ongoing training programmes. The mothers had benefited from these programmes and in future they expected training specific to their child’s needs. They wanted to learn new skills and techniques so that they could do their best towards taking care of the child.

*“I need training on specific exercise for my child because he is growing now and to cope with his physical growth, I need to learn new exercises based on his condition so that I can do for him at home.”*

All the mothers were very active and willing to explore new treatment protocols which could help their child improve. They were very hopeful that training would help them in future with their growing child. Overall, there was good response from parents and their involvement in training showed their dedication towards their child’s well-being.

## DISCUSSION

Lang (2011) stated that organisations providing CBR services need to focus on awareness programmes related to disability and rehabilitation as well

as vocational training for person with disability in order to achieve positive effectiveness of CBR services. The objective of this study was to identify the effects of the CBR programme on the lives of parents of children with Cerebral Palsy. CBR programmes are found to be effective not only for children with Cerebral Palsy but also for their parents, in various ways (Zuurmond et al, 2018). This study shows significant changes in parents' health, knowledge and social life, and also in community attitudes towards disability. The overall findings point to a good (positive) effect of CBR training programmes on parents' health, knowledge, social lives and their empowerment.

Family and society attitude towards mothers of children with Cerebral Palsy improved. As a result of continuous awareness raising as part of the CBR programme mothers indicate that they have sufficient time to participate in social activities and do not feel neglected. Training of mothers or parents not only helps in children's interventions but also reduces the physical and mental burden on parents. Use of assistive devices is helpful for both children with Cerebral Palsy and their parents as it helps in the positioning and mobility of the child and reduces the burden of carrying the child outside. Though CBR programmes are providing rehabilitation along with the assistive devices, it is often difficult to use the available assistive devices due to poor accessibility of the environment outside their home such as in various schools.

Significant associations were found between the various areas of CBR. The odds among them were more than 3, therefore it can be said that training parents is highly effective in terms of inclusion, rehabilitation and achieving the intended goal of rehabilitation.

Apart from the positive effect on the child, CBR programmes have a positive impact on parents' overall activity. The radar graph shows that priority should be given to the provision of assistive devices as it was the least benefited area among all the variables. The reasons could be lack of accessibility within and outside the home, lack of service, and lack of awareness among the groups. It could be assumed that if accessibility of the internal and external environment improves, the uses and service of assistive devices will increase, and this would have a positive effect on both children with Cerebral Palsy and their parents (Copley & Ziviani; 2004; Mihaylov et al, 2004). Based on the qualitative findings, more hands-on training should be provided to parents so that they would be better equipped to care for their children as they grow older. It is really difficult to find professionals in the rural community to provide rehabilitation to Cerebral

Palsy children on a day-to-day basis (Bunning et al, 2014); therefore, training of parents is required. Training parents along with teachers could be of added benefit. Counselling of school staff is also needed in order to achieve inclusion in schools. To further this, grassroots workers and community facilitators need to work together, and training and continuous support to the group is a must (Barth, 2009).

## **CONCLUSION**

The study results demonstrate that CBR programmes have a positive effect on parents' health, knowledge, social lives and empowerment. The odds ratios between them are greater than 1 and show that CBR programmes are very effective for parents and children with Cerebral Palsy. To make them even more effective, different service provisions under the CBR programme are needed at community level as well.

It is recommended that further studies should be done to gauge the effectiveness of each parents' training programme in the community centres. This could help the CBR training provider to know how much parents have learnt, to what extent they are putting it into practice and whether any improved method or new training item should be included in the training programme.

To get a clearer picture about the effectiveness of the programmes, further studies must include those organisations and NGOs that are working along CBR lines.

A study that focuses on the challenges experienced by grassroots workers in implementing or providing service in rural communities is also recommended.

The study results can help CBR programmes to identify groups of persons (parents) who benefit less from specific activities, and thereafter develop and adopt strategies to improve their participation. It could be useful in the further development of CBR programmes to place more emphasis on the training of parents of children with disabilities.

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