Original Article

Overview and Impact of Attending Training Program on "Functional Ways of Working with Cerebral Palsy Child in Low-resource Setting"

Fatema Newaz[1], Nuzhat Nuery[2], Shohag Chakrabarty[3], Ashik Ul Islam[4], Taslim Uddin[5]

Abstract

Background: *There is a lack of available services including rehabilitation intervention for children with physical disability living in rural Bangladesh. Rehabilitation in Bangladesh is not a health priority and rehabilitation teamwork has been reported to have multiple challenges including few trained rehabilitation workforce, poor inter-specialty relationships, and scarcity of assisted devices for rehabilitation.*

Objective: *To provide a comprehensive overview of the training program and assess the knowledge and skills acquired by trainees in developing countries. Additionally, to investigate potential strategies for moving forward and planning the effective implementation.*

Materials and Methods: *Six days training was designed by Enablement Nepal with ice-breaking session, experience sharing, group working and presentation by participant, game of life played by participant, CBR establishment and ICF implementation, group work regarding CP child examination, goal set up, home visit, environmental barriers detection of that child in school and family and proposed solution. About twelve participants of different professional like physiatrist, physiotherapist, occupational therapist, rehabilitation facilitator, social worker, CBR worker attended six days interactive classes, group-works, home visit, field visit under supervision of instructor. Pre-training evaluation sheet and after-work questionnaire reveals thought differences of participant.*

Result: *The outcomes of the training reflected a dynamic and continuous learning process. Participants, driven by their interests and diverse perspectives, actively took part in the training sessions. After the program, participants expressed a range of opinions and reactions concerning the training methods and their potential implementation. The mixed expressions highlighted the varied experiences and perspectives brought by the trainees.*

Conclusion: *The participants acknowledged that similar training initiatives would further enhance their understanding and broaden their perspectives regarding functional rehabilitation. This underscores the importance of continuous training and collaborative efforts to address the challenges associated with caring for children with CP in low-resource settings.*

Key words: *Cerebral Palsy, CBR (Community based Rehabilitation), ICF (International Classification of Functioning)*

Date of received: *16.09.2024*

Date of acceptance: *29.11.2024*

DOI: https://doi.org/10.3329/kyamcj.v15i04.83365

KYAMC Journal. 2025; 15(04): 173-177.

Introduction

There are an estimated 233,514 children with cerebral palsy (CP) in Bangladesh with a prevalence of 3.4 per 1000 children and they are mostly living in rural areas. Earlier studies reported that the diagnosis of CP is typically delayed, about 80% of them suffer from motor delay with spasticity. Observed prevalence was 3.4 per 1000 children (95% confidence interval [CI]: 3.2–3.7), resulting in an estimated 233 514 children (95% CI: 219 778–254 118) with CP in Bangladesh. The majority (79.6%) had spastic CP. Altogether, 79.6% of the children with CP had at least one associated impairment (speech 67.6%, intellectual 39.0%, epilepsy 23.7%, visual 10.2%, and hearing 10.2%). In total, 78.2% never received rehabilitation.[1] There is a lack of available services including rehabilitation intervention for

1. Assistant Professor, Department of Physical Medicine and Rehabilitation, Kumudini Women's Medical College, Mirzapur, Tangail, Bangladesh.
2. Medical Officer, Department of Physical Medicine and Rehabilitation, Shaheed Suhrawardy Medical College, Dhaka, Bangladesh.
3. Junior Consultant, Department of Physical Medicine and Rehabilitation, Cumilla Sadar Hospital, Cumilla, Bangladesh.
4. Junior Consultant, Department of Physical Medicine and Rehabilitation, Manikgonj Medical College and Hospital, Manikgonj, Bangladesh.
5. Professor, Physical Medicine and Rehabilitation, Bangladesh Medical University, Dhaka and President, Bangladesh Society of Physical Medicine and Rehabilitation, Dhaka, Bangladesh.

Corresponding author: Dr. Fatema Newaz, Assistant Professor, Department of Physical Medicine and Rehabilitation, Kumudini Women's Medical College, Mirzapur, Tangail, Bangladesh. **Cell**: +8801636110089, **E-mail:** newazfatema18@gmail.com

children with CP living in rural Bangladesh. Rehabilitation in Bangladesh is not a health priority and rehabilitation teamwork has been reported to have multiple challenges including few trained rehabilitation workforce, poor inter-speciality relationships and scarcity of assisted devices for rehabilitation. Population-based data show that the proportion of severe cases of CP is very high in Low- and Middle-Income Countries (LMICs). Children with CP in LMICs lack access to rehabilitation and educational services and a large proportion of children have potentially preventable risk factors, for example, birth asphyxia and neonatal infections. Delayed diagnosis, severe motor impairments, and lack of rehabilitation in most children call for urgent action to identify preventive opportunities and promote early diagnosis and intervention for children with CP in LMICs. Between January 2015 and May 2019, 2664 children were recruited from Bangladesh, Nepal, Indonesia, and Ghana (mean age [SD] at assessment: 7 years 8 months [4 years 8 months], 95% confidence interval 7 years 6 months −7 years 11 months; male [n=1615] 60.6%, female [n=1049] 39.4%). Overall, 86.6% children acquired CP prenatally and perinatally (e.g. preterm birth, birth asphyxia, neonatal encephalopathy). Median age at CP diagnosis was 3 years. Moreover, 79.2% children had spastic CP and 73.3% were classified in Gross Motor Function Classification System levels III to V. Notably, 47.3% of children never received rehabilitation services (median age at receiving rehabilitation services was 3y; 12.7% received assistive devices) and 75.6% of school-age children had no access to education. 56 children with CP were recruited (77 in Group A and 79 in Group B). The total score of GMFM-66, CFCS level, and VSS level significantly improved statistically in Group A ($p < 0.05$ for all) and deteriorated in Group B ($p < 0.001$, $p = 0.095$, $p = 0.232$). The intervention showed promising outcomes particularly for children with CP under five years of age.[2] Once age and level of severity were controlled for, children in the outreach-based treatment group improved their motor function 6% more than children receiving institution-based services.[3]

There were no differences detected between the groups with regard to caregiver well-being and 51% of the caregivers reported signs consistent with clinical distress/depression. Most caregivers (83%) expressed that they were overwhelmed by the caregiving role and this increased with the chronicity of care. The financial burden of caregiver was predictive of caregiver strain. this study indicates that, majority telehealth receivers are interested to take practical session but need assurance of service betterment in future.[4] A qualitative study showed Practical therapy session was more benefited rather than tele rehabilitation services.[5] Though satisfaction of parents are influenced by tele rehabilitation service are less benefited for autism children rather than engaging in home base therapeutic activity to follow tele rehab services.

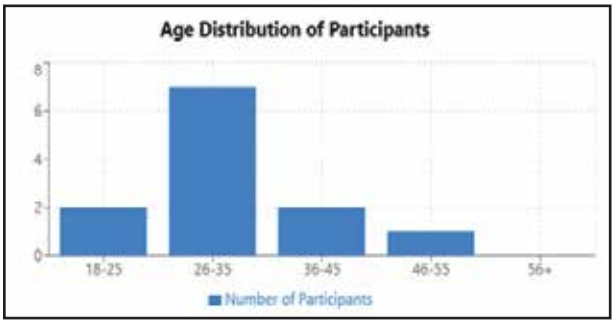
At last November an international training program was arranged by Enablement Nepal with the help of enablement Netherland. About 12 participants were joined 6 days long international training program. Among them four were physician (Physiatrist), one Occupational therapist, three physiotherapist, one rehabilitation facilitator, one CBR worker, one principle of day care center (special school), one social worker. At the very first day, after a warm welcome speech, resource person gave an introduction about current scenario of cerebral palsy and situation of community-based rehabilitation program in low to middle socio-economic countries/developing countries. In his speech he mentioned that, in developing countries person with cerebral palsy are commonly neglected, mostly in rural area. At first refuse to accept the disease then after acceptance and knowing about prognosis refusal of continuing treatment. Not only the person with CP, but also their families live an isolated life because of social taboo and superstition he also explained about divine model commonly followed by these people. So only focusing on physical disability of Person with CP is not enough, to ensure the participation of person with CP in society identification of the strength and weakness is very important, as well as pointing out social and environmental barrier and proper approach is also significant. In developing countries health care facilities are still struggling to meet the demand. Health care staff are alarmingly less against the huge patient load. So, Community based rehabilitation can play a vital role in rehabilitation of Person with CP in remote parts of countries in a less equipped and low resourceful setup. Even though having some basic skills of rehabilitation like physio-skill they can provide home-base rehabilitation measures and way-out solution by contact with doctor or physiotherapist. Even tele-rehabilitation can play an important role in case of follow up of CP child.

Materials and Methods

At first enlist number and criteria of participant attending training program. Their setup at their workplace. Different role of each participant on management at their place. A questionnaire was submitted to all participant and after training another paper were submitted and filled by all the participant. Efficiency that we should gather from these training program. How often these programs should carry on to improve skill at our workplace. What was the hindrance we faced to establish CBR according to ICF. This was an observational (descriptive qualitative) study.

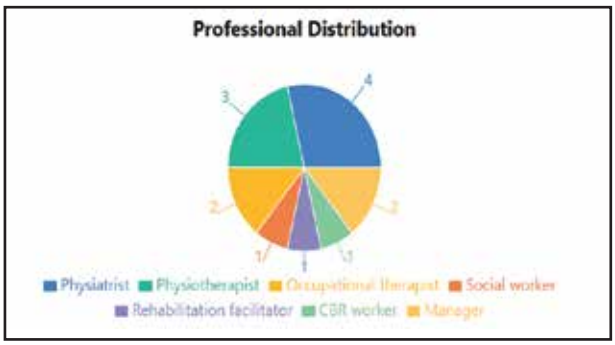
Results

Figure 1: Age distribution among participants



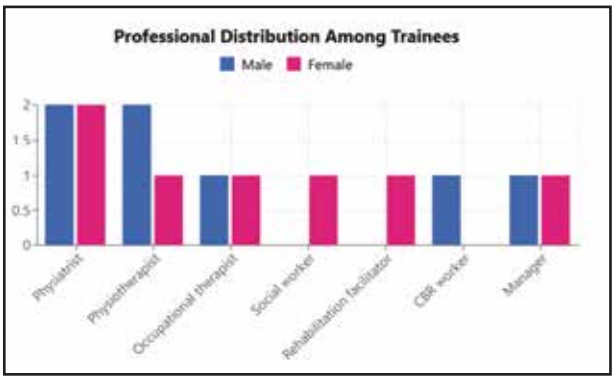
Above table shows that 1st time attended at training program: 4 more in 26-35 years age group which is 7, then 2 in 18-25yr and 36-45yr, lowest in 46–55 year group.

Figure 2: Type of professions among trainee



According to participant instructor did his job wonderfully. They gave 88.33% about engagement of instructor. Training was relevant as participant were acknowledge about their interest on that topic. But apparently, they express training content was not that useful. That showed their expectation didn't meet. They have some suggestion regarding quality of venue and course materials.

Figure 3: Professional Distribution among trainees



n=14, Male female ratio: 1:1

Discussion

A well discussed topic was Community mapping- resources and identification of stakeholder, to emphasize community-based rehabilitation. Local facilities location is important for proper utilization of locally available resources. In rural area local government, Professional rehabilitation staff- physiatrist, PTs, OTs, SLTs, rehabilitation front line workers, parents and other family members can play a vital role of stake holder. Community mapping based on available facility over local area it can be also a small center even other health professional, social worker to act as a primary receiver. Roles and Responsibilities of Professionals/parents/caregivers were discussed in detail later. Professionals set goal in functional way keeping in mind "Quality of life" and train the parents to participate in rehab plan. Parents are taught to prioritize goal and integrate interventions in daily life. Rehabilitation front line workers set goals together with parents, coach parents to handle child, act/ link/ liaise within CBR. Next session was about Cerebral palsy and its classification on Gross motor abilities GMFCS (Gross Motor Functional Classification System). After confirming diagnosis staging done according to scale and rehabilitation. The day ended with the discussion on power and privilege- Ableism, Inter sectionalism and disability. Ableism is a belief that non-disabled people are inherently superior to disabled people. It is stereotyping, negative attitudes, and discrimination towards people with based on their physical or mental disability resulting into discrimination and or prejudice. Disability is not a single identity but rather a complex and multidimensional one that is influenced by many factors like race, ethnicity, sexuality, social economic status, gender and age. Second day was another fruitful day with lots of discussion on evidence practice traffic lights, barriers, group discussion on barriers and its solution, correlation of ICF and CBR. All the things on goal setting and goal should not be more than two. After completion of one goal then another goals setting. Evidence traffic light is a concept of evidence-based intervention practice in rehabilitation of cerebral palsy patients, what should be done and what should not be done. How much the developing countries are doing evidence traffic light practice was also a point of discussion. Under the topic of barrier to inclusion of person with CP, social barrier, environmental barrier, lack of awareness, poor leadership, geographic barrier, lack of knowledge about the right of disability were elaborately discussed. ICF (International classification of Functioning, Disability and Health) of Cerebral Palsy and CBR are inter-related. ICF for cerebral palsy focus not only in physical disability also personal & environmental factors. So ICF helps the CBR worker identify multi-sectoral barriers and set goal according to priorities of patient/caregiver. Grief process/ counseling, early identification and intervention impact, feeding, eating, drinking, ADLs and communication lastly group work-case study were the topic of third day. Understanding the stages of Grief process of parents are very important for proper counseling and motivation for starting rehabilitation for CP child. Rehabilitation process and prognosis depends upon parent's adaptation and well-being. That's why it should be encounter as an important issue and find out the solution like CP parents meeting once a month, day care center for CP can be in great help parents get time for household work. Next day was about visiting Spinal Cord Injury Rehabilitation Center, Nepal. The leadership of physiatrist and group work with other medical personnel were well visualized. More intellectually designed institute thought about patient caregiver's accommodation and their training about transfer, exercises for home-based rehab program, 3D printing splint, tele-rehabilitation, Rehab meeting with physio, social worker and nutrition specialist, wheel-chair training and wheel-chair drive testing before discharge, gardening, vocational rehabilitation. That made us think about rehabilitation center for child not only school or day-care center even after that employment at that institute. Early identification and proper intervention can ensure inclusion in the society, make a child independent, more physically active, proper vocational training can make them financially more stable, improve quality of life, make life much more meaningful. Some evidence-based motor interventions are action observation training, bimanual training, CIMT (Constraint Induced Movement Therapy), functional chewing training, goal-directed training, home programs using goal-directed training, mobility training, treadmill training, occupational therapy. During case study trainees were divided into 3 groups. Each group get a

cerebral palsy patient with different GMFCS level and intellectual disabilities. All three were from the same Day care center for children with Multiple/ Severe disabilities of CBRO, Nepal. Each group took detail history from day care center caregivers and after examination and finding strength, weakness, cognition, sitting balance, standing capability, swallowing, other physical & mental ability to perform ADL of the patient they found some of the barriers. Each group set goals for the child they are tagged with. After goal set up all three groups sat together to discussed about their journey with the particular child. Preliminary goal set up and solution regarding goal was discussed briefly. The conversation of day four was, importance of nutrition, positioning, toileting of cerebral palsy patient with low facilities. Monitoring and evaluation of CBR was also brought on the table to proper understanding of successful CBR program. Day five was the reality check for the participants like implementation of rehab program on their home set-up. On that day, there was a field visit in the house of the same children to access the 'already set goal' in the institute-based rehabilitation set up can be applicable at their home environment or not. To the participant surprise, the goal of the parents was not always the same as institute-based goal. Also due to environmental and social barriers preset goal can be applicable only to some extent. Importance of field visit was understood properly cause Institute based rehabilitation has its own limit. Last day of training, the one of the founders from SERC school (Special Education and Rehabilitation Center), Lalitpur Nepal, she gave a description about how she established the center and what are the facilities available at their school, the special able children getting FIT CARE (Functional Intensive Training), which focus on function than rectifying physical deformity. She also mentions about different class according to age and mental ability; they also have vocational training and job opportunity there. When they offer job to the especially able children, they always give then equal salary as others. They also help the students to start up to any small business in their own locality. They share their difficulties during their journey despite of successful establishment of a very exceptional school for special child even after completion of rehab program.

Community rehabilitation workers have a vital responsibility in imparting the services to disabled population. To provide better services, there is a need to be competent to organize outreach activities in society and provide awareness to the community about the prevention of diseases. They need to help PWDs to get benefited from medical services and need to provide referral services and assistance to get social support. They need to have the competency to deliver training to PWDs about self-management to acquire their health-related target.[6] CBR for TBI patient which was designed with 24.6 weeks duration found effective with a RCT.[7] Thirty-three of 35 learners completed the program, 31 (94%) of whom had no prior knowledge of CBR. Learners implemented nine community engagement CBR projects, in which 1,293 community members participated.[8] In one study Evaluators consistently recommended that CBR projects should be more connected and collaborative at governmental, organizational, political and community levels.[9] The synthesis also noted that evaluators questioned the emphasis in CBR on project expansion and income generation. CBR programme in Palestine has had a pronounced impact on individuals with disabilities and their families. The programme has also had a positive impact on awareness, attitudes and practice towards individuals with disabilities in their local communities.[10]

There is a disproportion of health care professionals and patient in many developing countries. So, rehabilitation focusing particular disease by efficient health care professionals are so difficult to manage. In CBR concept, local community member with minimal education level can be trained to execute preset goal planned by health care professionals. These community field workers can also teach rehabilitation to the parents of CP child. They are easily available and approachable for the parents. CBR can make a huge positive difference to the current scenario of CP children in developing countries if it is applied properly.

Participants thought and skills

The participants are doing different jobs, as PTs, Social worker, CBR worker, Rehab facilitator. So, they were focused on particular goals. Though CBR concept were not new for them and they are identifying physical disability and other barriers by using ICF but directly they are not working with Community Based rehabilitation program. Physiotherapist, social worker sometimes had to go to home visit, they are highly focused in their particular jobs, like one of the physiotherapists is practicing institutional based physiotherapy, other PT is doing home visit but confined to physiotherapy only, social worker much more focused on solving social or environmental barrier or helping the parents with financial issue. Their aim was to do hands on training to facilitate independence in children with cerebral palsy patients. Some participant also express that it was a revision for her as she was already done this at her institute. After knowing the detail of CBR concept they start to look into the matter very positively. 'Focusing in particular problem of a CP child will not solve the actual problem' is now well understood by all. Institute-based rehabilitation is necessary but sustainability need community based and at the point of right of disable child a long way to go. After getting a child ready to switch at normal school, they should be ready to accept them and as well at job sector. Our work is not only rehabilitation but also community integration. Many more training at participant's own place to others to spread out the concept can be done. Together a team can contribute much rather than one. During training one of social worker also got a thought about have some training regarding occupational therapy. Occupational therapist shares some swallowing techniques of Cerebral palsy child with swallowing problem. About newer treatment like regenerative medicine were well discussed topics and having so many controversies. Every training has its own effect but special about this training it was a group work with lively experience. Attending one child at institute and other day same questionnaire at home with parents and surroundings just made us thinking how important is community integration, field visit, community-based-rehabilitation. Community worker chosen from local area with the help of that community leader that's why they are well accepted by patient parent's then other. Social taboo, divine model can overcome by counselling of community worker. About impact on trainee, everyone attended with lots of interest and learn new techniques on cp-management. As

many professionals were in the same umbrella mixture of expression at the end of training program. Like among two physio one has already worked at special school as departmental head and already practiced the things we shared at training program and about another physiotherapist newly met with those word and management plan. Everybody has their portion of work like social worker do better when we were in field-visit, she could communicate in a second that other needs time to build rapport with especially able child. It was more eye-opening session and made us thinking out of box. Instructor always allow us to share our thought and our way of management at work. That helps us a lot.

Conclusion

Community Based Rehabilitation empowers the person with disability including cerebral palsy and support them to overcome physical and social barriers. As CBR can reach a lot of Person/Children with CP involving their parents/ caregiver in rehabilitation process, its success rate is higher. CBR uses local resources avoiding expensive one, so it can be easily incorporate in developing countries. Moreover Inclusion of person with Cerebral palsy, as well as person with other disabilities in society can make them main workforce, who can contribute to the society as a responsible member leads the society towards prosperity.

Acknowledgment

We are thankful to Enablement Netherland, Enablement Nepal.

References

1. Velema JP, Ebenso B, Fuzikawa PL. Evidence for the effectiveness of rehabilitation-in-the-community programmes. Leprosy Review. 2008;79(1):65–82.

2. Karim T, Muhit M, Jahan I, Galea C, Morgan C, Smithers-Sheedy H, Badawi N, Khandaker G. Outcome of community-based early intervention and rehabilitation for children with cerebral palsy in rural Bangladesh: a quasi-experimental study. Brain sciences. 2021;11(9):1189.

3. Dambi JM, Jelsma J. The impact of hospital-based and community based models of cerebral palsy rehabilitation: a quasi-experimental study. BMC pediatrics. 2014;14:1-0.

4. Khandaker G, Muhit M, Karim T, Smithers-Sheedy H, Novak I, Jones C, Badawi N. Epidemiology of cerebral palsy in Bangladesh: a population-based surveillance study. Developmental Medicine & Child Neurology. 2019;61(5):601-609.

5. Al Imam MH, Jahan I, Das MC, Muhit M, Akbar D, Badawi N, Khandaker G. Situation analysis of rehabilitation services for persons with disabilities in Bangladesh: identifying service gaps and scopes for improvement. Disability and Rehabilitation. 2022;44(19):5571-5584.

6. Channaveer RM. Effectiveness of Competency-based Training of Village Rehabilitation Workers in Strengthening Their Community-based Rehabilitation Domains: A Policy Implication. Journal of Social Policy, Social Change and Development. 2024;2(1):57-70.

7. Powell J, Heslin J, Greenwood R. Community based rehabilitation after severe traumatic brain injury: a randomised controlled trial. Journal of Neurology, Neurosurgery & Psychiatry. 2002;72(2):193-202.

8. Omar Z, Otaka Y, Saitoh E. Design and implementation of a community-based rehabilitation curriculum for training multidisciplinary rehabilitation teams to serve people aging with disabilities. Fujita Medical Journal. 2025;11(1):1-0.

9. Kuipers P, Wirz S, Hartley S. Systematic synthesis of community-based rehabilitation (CBR) project evaluation reports for evidence-based policy: a proof-of-concept study. BMC International Health and Human Rights. 2008;8:1-5.

10. Eide AH. Impact of community-based rehabilitation programmes: the case of Palestine. Scandinavian Journal of Disability Research. 2006;8(4):199-210.