

Children with Cerebral Palsy in Bangladesh: Their Contribution to the Development of a Rehabilitation Training Programme

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ABSTRACT

Purpose: *Although cerebral palsy is the most prevalent health condition linked to childhood disability in Bangladesh, support and rehabilitation for this group is limited and intervention development is slow. An initiative to address these unmet needs was the development of a parent/caregiver training programme for the rehabilitation of children with cerebral palsy. The aim of this study was to explore what was important in the everyday lives of children with cerebral palsy in rural Bangladesh and take their views into account to inform the training programme.*

Methods: *Qualitative data was collected from 12 children with cerebral palsy, between 5 - 14 years of age. The children were purposively selected from among those who attended the training programme. A participatory method called the 'Feeling Dice' was used to elicit children's feelings about their everyday lives. The approach was easy to use, acceptable in the local context, the children enjoyed the activity, and it generated rich information.*

Results: *'Inclusion in play' and 'being able to attend school' made the children happy and were their two main priorities, yet were not key issues for parents. The children were frustrated by their dependence on others for day-to-day activities such as feeding, bathing, and transport to school. Children also played an important part in encouraging their parents to attend the training course.*

Conclusion: *This study showed that valuable information can be gathered from children with cerebral palsy by using a simple and adaptable participatory research tool. Children's views and priorities sometimes differed from those of their parents and carers, and is useful for developing more relevant and*

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valid interventions. Children need to be recognised as important ‘agents of change’ within their own rehabilitation. This methodology is in harmony with the UNCRPD recommendations, and supports inclusive and rights-based intervention development.

Key words: *Rehabilitation, cerebral palsy, children’s rights, disability, health, inclusion*

INTRODUCTION

Cerebral palsy is one of the most prevalent health conditions for children with disabilities in low- and middle-income countries (UNICEF, 2013). It is a motor disorder, but often children with cerebral palsy will have associated impairments such as hearing, visual, and cognitive impairments (Colver, 2014). Despite their wide-ranging needs, support and rehabilitation services for these children and their parents are scarce or non-existent in low- and middle-income countries (World Health Organisation and World Bank, 2011; UNICEF, 2013). It is well documented that these children are often socially excluded, and frequently lack access to primary and rehabilitative healthcare, and education (WHO and World Bank, 2011; UNICEF, 2013). The Convention on the Rights of the Child, and the Convention on the Rights of Persons with Disabilities direct governments to be responsible for ensuring that all children, irrespective of any disability, enjoy their rights without discrimination (United Nations, 1989; 2006).

A recent survey of childhood disability in Bangladesh, using a key informant methodology, estimated the prevalence of moderate or severe disability at 7.2 per thousand children (Mactaggart and Murthy, 2013). Cerebral palsy made up the greatest number with a prevalence of 3.7 per thousand children and accounted for more than half of the children with a moderate or severe physical impairment. Extrapolating these estimates to the whole country suggests that there are nearly a quarter of a million children with cerebral palsy in Bangladesh. However, this estimate is much lower than the global estimate (1 in 20) of children with moderate or severe disability of some kind (UNICEF, 2013).

Article 7 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) addresses the obligation States have to hear the views of children with disabilities in all matters which concern them. However, it is commonly argued that children and young people are often the least consulted

and most voiceless group at all levels within the family, community and wider political arena (Harper and Jones, 2008). Children with disabilities are often doubly disadvantaged, firstly because they are children, and then an additional layer of marginalisation because they are disabled (Beresford, 1997). Powell and Smith (2009) reported that those who have conducted research with children suggest that children's participation rights are particularly compromised when they are considered vulnerable and the research topic is considered to be sensitive. They argued that children should not be viewed as vulnerable passive victims but as social actors who are able to take decisions about participation in research; hence, they should have a more central role in decision-making about participation when research is about them. Although there is an increasing focus on promoting the active participation of children in research (Boyden and Ennew, 1997; Alderson, 2008) there is still limited children-centred participatory research among children with disabilities in LMIC settings.

Although Bangladesh was one of the first countries to sign and ratify the United Nations Convention on the Rights of the Child (UNCRC), a literature review for the current study was unable to identify any childhood disability rehabilitation programme in Bangladesh which had consulted children with disability in order to understand their priorities and opinions. With the ratification of the UNCRC there is now a clear legal framework for encouraging children and young people to participate in making decisions that affect their lives.

Despite cerebral palsy being a common form of childhood disability in Bangladesh, support and rehabilitative services available for these children and their families are very limited. To address this unmet need, a parent training programme was developed on rehabilitation and management of children with cerebral palsy in resource-poor settings, recognising the fact that parents and carers are at the frontline of caring for their children with cerebral palsy (London School of Hygiene and Tropical Medicine and Hambisela, 2013). The parent training programme sought to empower parents and caregivers to improve the quality of care for their children with cerebral palsy. The programme was developed and its relevance and acceptability were evaluated through action research with the families and children. Parents/caregivers participated in the training course along with their children with cerebral palsy.

The objective of this study was to explore what was important in the everyday lives of children with cerebral palsy in rural Bangladesh to inform the parent/

caregiver training programme on rehabilitation and management of these children. This paper reports on one component of this action research with children who participated in the training programme.

METHOD

Sample

A purposeful sample of children was selected from a larger group of 153 children with cerebral palsy in two sub-districts of Sirajganj district of Bangladesh. This larger group of children had been identified in a previous survey of childhood disability (Mactaggart and Murthy, 2013) and had participated in a parent training programme for improving the care and support of children with cerebral palsy in resource-poor settings. All the children had been clinically diagnosed two years previously by a paediatrician and were identified as having a moderate or severe level of cerebral palsy.

Inclusion criteria for study participants:

- Children from 5-14 years of age,
- A balance of both genders,
- Varying levels of severity of cerebral palsy as identified by community workers,
- A geographic spread across two sub-districts.

All the families were registered to participate in a research project to develop a training programme for parents and caregivers of children with cerebral palsy. Twelve children were interviewed: 7 females and 5 males. All the children, with one exception, were intermittent school-goers, often attending only 2-3 days per week. Further details of the children are presented in Table 1.

Study Design

A participatory approach was used for interviewing the children. Many issues were taken into consideration in the choice of a participatory tool for 'interviews' with the children. Participatory methods have a range of benefits: they are generally more visual, do not require high levels of literacy, they can be useful for sharing information, and promote learning and empowerment (Chambers, 1994).

Table 1: Characteristics of the Study Participants

Pseudo-nyms	Age	Gender	Family economic status*	School attendance	Functionality description- mobility, communication and self-care
Sumona	14	F	Poor	Grade 1 Irregular	Could not sit, stand or walk without support. Severe difficulties in speaking. Needed maximum assistance for all aspects of self-care.
Asma	12	F	Poor	Grade 1 Irregular	Some mobility difficulties. Left hand was very weak. Needed moderate assistance with toileting and other self-care activities.
Ayesha	8	F	Middle class	Grade 1 Regular school attendance	Could walk with some difficulties.
Jahid Hasan	12	M	Middle class	Grade 5	Difficulties in speaking, could not do anything with right hand, weak right leg, assistance required with self-care.
Tuba	5	F	Rich	Not school-going age	Could not walk or stand unaided. Assistance required with all aspects of self-care and play activities.
Shathi	11	M	Poor	Grade 1 Intermittent school attendance	Difficulties with mobility, limited use of hands, poor eyesight, difficulties with speaking. Needed assistance with self-care such as dressing and toileting.

Likhon	9	M	Poor Lives with adopted parents	Grade 1 Intermittent school attendance	Weak right leg and hand, difficulty with comprehension and speech. Required support with some aspects of self-care, e.g. dressing.
Raihan	7	M	Lower middle class	Grade 1 Regular school attendance	Some difficulties in using right hand and legs. Could perform self-care with some difficulties.
Samiul	11	M	Lower middle class	Grade 3 Regular school attendance	Could walk with some difficulties; little difficulties in speaking; poor eyesight. Some difficulties in self-care.
Lata	6	F	Poor	Grade 1 Regular	Could walk with some difficulties. Could perform self-care independently with some difficulties.
Halima	7	F	Poor	Grade 1 Intermittent school attendance	Could not stand or sit for a long period because of weakness in legs and hands. Frequently suffers from cold and fever. Support needed in self-care.
Bonna	11	F	Poor	Grade 1 Intermittent school attendance	Limited mobility- can walk with mobility aids. Needed minimum assistance in self-care.

* assessment made by the community health workers

It was important that the study activity should encourage active engagement of the children and should be appropriate to use in the rural context of Bangladesh. A central tenet of the parent and caregiver training programme was about encouraging children's development through play activities, therefore the research activity aimed to complement this. As the target group was children with a range of severity of cerebral palsy, another consideration was that the activity

chosen should be tactile, and that children with limited motor skills could engage with. It also had to be a tool which did not require children to be literate, taking into account the low level of schooling. A significant proportion of children with cerebral palsy may have cognitive, visual, and hearing impairments, and therefore the tool needed to be adaptable to differing needs.

The tool that was chosen was the 'Feeling Dice'. This tool was originally used in a study to explore children's feelings, in order to understand experiences of marginalisation in primary school (McNamara and Moreton, 1995). Accordingly, a giant colourful dice was used because it would be more tangible to touch, easy and lightweight to hold, and had large simple pictures of emotional expressions that were easy to understand. On each face of the dice was a picture with a different feeling, and according to whichever side of the dice was shown when it was thrown, the children were prompted to complete a sentence, "I am happy when..., I am sad when..., I am frustrated when..., I am angry when....". Prompt questions were then used to explore the issues further. Additionally, specific prompt questions about the training programme were included, to find what they liked/disliked about the training on offer. The children were encouraged to keep throwing the dice until the data was saturated and no further issues arose.

After some piloting it was decided to use a large colourful dice (12cm x 12 cm) with mini white boards on each face. The added advantage was that children could easily draw their own pictures depicting each emotion onto the dice, and therefore did not need to interpret someone else's drawings. In practice any type of giant dice, locally made, would suffice.

Figure 1: The 'Feeling Dice'



Data Collection

The activity was initially piloted during a group training session, but the chaotic environment of the meetings precluded the possibility of finding a quiet space to engage with the children. It was therefore decided to conduct activity in the home setting during follow-up home visits. This enabled the interviewer to build rapport with the child and family, and the quieter environment was important for children who needed additional support with communication.

In all cases the children were 'interviewed' on their own, except where they expressed a preference to have someone with them, and/or a caregiver was needed to help with communication. This was sometimes challenging because typically, in rural Bangladesh, households often consist of only one room with many family members living together. This mirrors similar methodological issues raised in qualitative research conducted in India (Singal, 2010). It was made more feasible in this research because the interviewer had built up a relationship of trust with the families during the training course, and therefore was known to family members, as well as the child. Familiarity with the researcher and the fun nature of the activity was important to minimise any feeling of distress felt by the child.

Some children required help with drawing the pictures, and some children needed to have the pictures drawn for them, while at the same time checking that they were happy with the illustrations and the feelings depicted. For children with more limited communication, additional pictures were used, and they were asked to point to illustrations of what they enjoyed doing, with closed questions asked, which required only a 'yes' or 'no' answer.

The researcher was also sensitive to any verbal and body language cues which indicated that the child wanted to discontinue the activity. In three cases the activity was not completed in one visit because the children were tired; they were then completed during a follow-up home visit.

Data Analysis

Detailed notes of all the interviews were written down by the interviewer in the local language and then translated into English. Notes were made on the experience of using the dice as well. Data was managed using NVivo10 data management software and a thematic content analysis of the children's interviews was undertaken. The analysis was underpinned by an interpretive phenomenological approach to the collection and interpretation of qualitative data (Green and Thorogood, 2009; Creswell, 2014).

Ethical Considerations

Ethical approval was obtained from the ethics committees of LSHTM and The Child Sight Foundation. The project took into account particular ethical issues of gathering information from children in international settings (Schenk and

Williamson, 2009), as well the guidance for research among children with disabilities (Alderson and Morrow, 2004; Beresford, 2012). Written consent was sought from the parents and verbal consent from the children.

RESULTS

This section reports on the research process of testing the 'Feeling Dice', as well as the reported experiences of the children.

Process

It was found that all the children, of different ages and abilities, responded positively to the activity and wanted to engage with the 'research' for longer periods of time, even up to an hour or more. The activity prompted discussion even among children who were generally very quiet. Most of the children in this setting were not used to having toys, but it was still an activity which was easy for them to understand and engage with, and they clearly enjoyed the opportunity of throwing the dice. After the 'interview' was completed, playing with the dice was sometimes turned into another game. Making the process more participatory and fun resulted in children being happy to stay engaged.

Over the course of the project the researcher had become a familiar figure to the children through the parent training sessions, and in many 'interviews' they referred to him affectionately as 'uncle'. The researcher felt this sustained contact and resultant level of trust as an important factor in building the children's confidence so that they could discuss their feelings openly.

Main Findings

What makes children happy?

In the rural Bangladesh context, there were four main sub-themes regarding what makes children happy: play, school attendance, being loved by their family, and enjoyment of their favourite everyday activities, such as eating their favourite food.

Consistent across every interview, the most important thing which made children happy was being able to play with other children. Play was also the main reason why children liked going to school and to the training sessions, as it afforded them the opportunity to meet with friends.

“When I go to school, I can play with my friends – that’s why I feel good” (Lata, 6-year-old female).

“I feel happy when I play. [What kind of games do you like?] I like to play with toy cars. I like to play with other children at home and at the school..... I like to go to school very much. [Why do you like to go to school?] I like to go to school because I can play with everyone at the school” (Samiul, 11-year-old male).

The second most common cause for happiness, identified by all children of school-going age, was attendance at school. As discussed, the main reason was because of opportunities at school to meet and play with friends. The second reason was because the teachers were helpful, respectful and caring. The least common reason given for attending school was because of the lessons.

“I like to go to the school. I never miss school even on rainy or stormy days. [Why do you like to go to the school?] I like it when my friends come and chat with me. The teachers are very nice and give lessons and never scold me. They love me and take care of me. They always call me by name and ask about my well-being...that’s why I like them” (Jahid, 12-year-old male).

All the children identified being loved and cared for by relatives as something which made them very happy. Children had individual favourite everyday activities which they enjoyed; these included events such as eating their favourite food or being bought sweets.

What makes children sad?

The terms ‘unhappy’, ‘sad’, ‘angry’ and ‘frustrated’ were used interchangeably in the children’s discourse and brought up similar issues; hence they are addressed together here.

The two main themes for the cause of unhappiness were: not being included in play and not being able to attend school. There was also mention of stigma and bullying, and frustration with being dependent upon others for some daily activities. Although children wanted to attend school, it was also a context in which they felt excluded and were sometimes bullied by other children.

Not being included in play was the most commonly reported issue for unhappiness, identified by two-thirds of the children.

“When all the children play around in the school and back at home, I feel sad because I can’t run. I also wish to be able to run and play” (Asma, 12-year-old female).

Another commonly cited reason for children being unhappy was their inability to attend school. The main barriers were transport to and from school, and dependence on a parent or some other person to carry them or accompany them to school. Parents usually lacked time to convey their children, or were sometimes not well enough to escort them. For example, one child could walk with the aid of a stick but needed someone present to provide extra support in case she fell.

“My mother now can’t take me to the school regularly anymore. When she is sick [pregnant] she can’t take me..... If I was healthy [no disability], then my mother would not have to take me to school. When I see the pain of my mother, I feel like leaving school. I walk on a stick and I rest every now and then. It’s very painful for me. Sometimes I cry when it’s too much painful for me. Sometimes when I really want to go to the school, but my mother can’t take me – I cry.One month ago, my mother gave birth to a baby, and since then my mother can’t take me to school” (Asma, 12-year-old female).

Being dependent on others for daily activities such as feeding, toileting and bathing were reasons for sadness, anger or frustration. In five of the participatory interviews, children described their frustration over waiting to be fed and difficulties with feeding. Having to find time to feed children was similarly highlighted by parents. For example, one 9-year-old boy described how he loved swimming and playing in the river with friends and going to school. However, he had a weak right arm and leg, and what made him angry was that he had to wait for his mother to feed him. He could feed himself with his left hand, but Bangladesh culture dictates that it is polite to eat only with the right hand.

“[When do you feel sad?] I can’t eat with my right hand. If mother doesn’t want to feed me, I cry. I cry when my mother delays in giving me food when I am hungry” (Likhon, 9-year-old male).

A pre-teen girl mentioned a similar issue related to feeding.

“When I am too hungry, my mum is away or busy, I cry. If I was healthy [no disability] today, I could have eaten rice on my own” (Asma, 12-year-old female).

Finally, in just under half of the interviews, being bullied or stigmatised by other children, family or community members, was identified as another cause of sadness. The community often views children with disabilities as worthless burdens on their family. They see no point in taking care of children with disabilities.

“Sometimes people make fun of me. This makes me very angry. They say ‘this child is not able to do anything; he only sits or lies down the whole day, so don’t give him food’. These make me very angry” (Shathi, 11-year-old male).

Feedback on the training course

All the children said that attending the training made them happy, as did the follow-up visits conducted by the community workers. The main reason was because of the opportunity to play, and the second most common reason was the caring and loving attitudes of the trainers. Refreshments and learning new things were other reasons for their enjoyment. They commonly used an affectionate term, ‘uncle’, to describe the community workers.

“The uncles [community workers] at the meeting care for me very much. They play with me too. I like that very much. The uncles and sir [trainer] teach us exercises, and after the meeting they give us biscuits and juice..... I can play with Anita [name changed] and others at the meeting. I didn’t know them before coming to the meeting, and now we are all friends. I love to be and play with them” (Ayesha, 8-year-old female).

Similarly, half of the children said that being unable to attend the training course made them sad. Interestingly, although the training course was targeted mainly at the parents, it was clear from the children’s ‘interviews’ that the children’s eagerness to attend was very often a key driving factor for a parent or caregiver’s attendance at the course.

“I feel angry when they [my grandparents] do not want to take me to the meeting. When they do that I start to walk there by myself and they follow me” (Jahid, 12-year-old male).

“Sometimes my parents don’t want to take me to training because they are busy. Then I feel sad. When they find that I am really sad, they take me to the training” (Asma, 12-year-old female).

“Sometimes my mother doesn’t want to take me to the meeting because of too much work.... I cry in anger then. My father or my brother takes me to the meeting if I cry” (Ayesha, 8-year-old female).

Other factors which made them sad, reported by two children, included that they did not enjoy being forced to do exercises after the training.

DISCUSSION

Cerebral palsy is one of the most prevalent health conditions among children with disabilities in low- and middle-income countries (LMICs). It is a neurological health condition, but often children will have associated impairments such as hearing, visual, and cognitive impairments. However, despite wide-ranging needs, the rehabilitation on offer for these children is scarce or non-existent. From a rights-based perspective it is essential that when planning services which affect children, including children with disabilities, their views should be consulted (United Nations, 1989; 2006). This research adapted and trialled a participatory research tool, the ‘Feeling Dice’, to elicit the views of children with cerebral palsy in rural Bangladesh, and ensured that their views also contributed to the planning of a participatory training course for caregivers.

The study showed that using this child-centred participatory research encouraged a focus on play, was fun, and was an acceptable activity in which children could easily engage in the rural Bangladesh context. The large and tactile dice with simple pictures is easily adaptable for children with disabilities who may require extra help with communication, who may have sensory impairments, or have additional physical needs.

Importantly, as a result of listening to children, there was recognition of the need to prioritise schooling issues as part of any parent and caregiver training programme, identify avenues for improving attendance, and find strategies to improve inclusion in play, both in and out of school. Other studies on the rehabilitation of children with cerebral palsy in Bangladesh and other LMICs have sometimes focussed more narrowly on approaches for improving the health and physical functioning of the child as assessed by parents or therapists, the impact of caring on the caregiver, and barriers around the uptake or services (McConkey et al, 2000; Mobarak et al, 2000; Hartley, 2005; Maloni et al, 2010; Nesbitt et al, 2012; Bedford et al, 2013). This study highlighted the importance of a broader understanding of health and well-being, and the importance of being

able to engage in social activities, from the perspective of the child.

This study highlighted that some children described feeling frustrated and hungry while waiting to be fed. This complements findings from other studies on the particular challenges around feeding for children with cerebral palsy: children can have difficulty chewing and swallowing, the food served may require special preparation, in some cultural contexts parents can find it difficult to allow children to feed themselves because of the mess that is involved, and caregivers can lack the additional time which is required for feeding the child (Gangil et al, 2001; Yousafzai et al, 2003a; Yousafzai et al, 2003b; Adams et al, 2012). The current study provided a unique children's perspective on the issue, highlighting that it is not only the caregiver who gets frustrated in the feeding process. Furthermore, any intervention to address feeding must address the cultural barriers to independent feeding and consider the family dynamics around feeding, in order to find strategies to better support feeding.

This study also showed that children were often key drivers in determining whether parents or caregivers attended training. Their enjoyment was a major factor which influenced attendance; therefore, it is essential to ensure that training remains attractive and relevant to children as well as to parents. When children do not want to do exercises or use assistive devices, then it is, unsurprisingly, harder for parents to impose these. Yet, this engagement with children is often overlooked in intervention studies targeted at parents. The results indicate that, when planning training programmes, it is important to recognise that children are also important 'agents of change' in their own rehabilitation, and should be actively engaged as part of any programme.

Limitations

There were a few limitations to this study. Having a local Bangladeshi research assistant who became well-known to the families over the course of the year has benefits, as well as possible limitations. The presence of a familiar person at the interview can sometimes have both advantages and disadvantages. Disadvantages include possible inhibition of the child's responses and/or that the adults can act as a filter and put their own interpretation on the data (Morris, 1998). It is possible that the children felt they had to say that they enjoyed the training course because the researcher was identified as part of the training programme. However, the level of trust between the researcher and the family went some way to mitigate this. In one case the interviewer observed that the child felt unhappy

talking freely in his own home, and hence continued the interview during a walk outside the house.

One of the main limitations of the study was that ten of the twelve children (83%) were attending school, albeit intermittently, which was not typical of children with disabilities in this rural area of Bangladesh. An earlier survey in the same study area showed that only 39% of children with targeted impairments attended school, compared to 84% of children without impairments (Mactaggart and Murthy, 2013).

Another limitation was that although the study aimed to include children with a range of severity of cerebral palsy, the researchers were reliant on the community workers to choose a range of children, and there may have been a bias whereby those known to be more able to communicate were more typically sampled. Children with severe cognitive impairment were not included, and in any future project more time would be needed to adapt the approach further for this group of children.

CONCLUSION

This study demonstrates the importance of research which is inclusive of children with disabilities and gives an example of a very simple participatory tool which can be easily adapted to a variety of cultural settings. This methodology is in harmony with the UNCRPD and supports inclusive and rights-based intervention development.

Implications

Clearly, engaging with children with cerebral palsy is a practical option, even in resource-poor settings. The data yielded is informative for developing and enhancing interventions. Children and caregivers can provide different perspectives on their lives, and these are needed to ensure that interventions are valid, relevant and acceptable to both children and their families.

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