
ORIGINAL RESEARCH

Understanding the Lives of Caregivers of Children with Cerebral Palsy in Rural Bangladesh: Use of Mixed Methods

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ABSTRACT

Cerebral palsy is the most prevalent health condition linked to childhood disability in Bangladesh, yet support and rehabilitation for this group is limited. Understanding the impact of cerebral palsy at family level is important for the development of appropriate interventions.

Purpose: *This study aims to explore the impact on the lives of caregivers of children with cerebral palsy.*

Methods: *The study used mixed methods. The PedsQL™ Family Impact Questionnaire Module was administered to the main caregivers in 135 families with a child with cerebral palsy and 150 families that did not have a child with a disability, from the same villages. In-depth interviews and observations were undertaken with 10 families, and 2 focus group discussions were conducted with representatives from 14 parent/caregiver groups. The project was conducted from April 2011- April 2013. Data collection was from September 2011- Dec 2012.*

Results: *The mean overall and sub-scale PedsQL™ scores were significantly poorer ($p < 0.001$) for caregivers of a child with cerebral palsy compared to scores from families that did not have a child with disability. Caregivers reported high levels of stress, anxiety, isolation, stigma, physical tiredness, and lack of time to complete everyday tasks. Knowledge and understanding about cerebral palsy was generally low.*

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Conclusion: *This study demonstrates the particular vulnerability of families of children with disabilities in resource-limited settings. It reveals the extent of the impact on the caregivers. Interventions therefore need to be holistic, addressing the well-being and empowerment of caregivers as well as children.*

Key words: *Disability, children with disabilities, quality of life, caregivers, Bangladesh*

INTRODUCTION

In 2005, the United Nations Children's Fund (UNICEF) estimated that 150 million children globally live with a disability. The majority live in low or middle-income countries (LMICS) where estimates of childhood disability prevalence range from 0.4% to 12.7% (UNICEF, 2005). It is well-documented that children with disabilities are often socially excluded, and frequently lack access to primary and rehabilitative healthcare and education (World Health Organisation 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. Both of these Conventions also recognise the important role of the family, and the role of the State in supporting the family (United Nations, 1989; United Nations, 2006).

The Community Based Rehabilitation (CBR) guidelines emphasise the importance of empowerment of both the persons with a disability and their families (WHO, 2010). An increasing body of research highlights the importance of services that not only focus on the individual child but also meet the wider needs of the family, based on a good understanding of the experience of families that have a child with disability (Beresford, 1994; Balasundaram, 1995; Mobarak et al, 2000; Hartley et al, 2005; Raina et al, 2005).

Developing a Community-based Training Programme for Caregivers of Children with Cerebral Palsy in Bangladesh

A large-scale survey of childhood disability in Bangladesh, using the key informant methodology, estimated a prevalence of 0.9% of moderate or severe targeted impairments among children less than 18 years of age (Murthy et al, 2014). All children were assessed by a paediatrician in a camp setting, and cerebral palsy made up the greatest number within the cohort of children with

disabilities, with a prevalence of 0.37%, which translates into almost a quarter of a million children in Bangladesh (Murthy et al, 2014). Despite cerebral palsy accounting for more than a third of moderate and severe childhood disability, rehabilitative services available for these children are extremely limited. As a result of this survey, there was a commitment to develop a training programme for caregivers of children with cerebral palsy; a training programme which would be relevant and acceptable to families in the rural Bangladesh setting.

In Bangladesh, a small number of studies have sought to understand the experience of carers with a child with cerebral palsy (Mobarak et al, 2000; McConachie et al, 2001), and how best services might be delivered to families of children with cerebral palsy (McConachie et al, 2000; Maloni et al, 2010). One study explored the outcomes of young children with cerebral palsy and highlighted the very high mortality rates which exist (Khan et al, 1998). The key factors which contributed to the children's increased vulnerability included: living in a rural area, low income of the families, non-literate mothers, and least contact with disability rehabilitation services. A key recommendation from their research was the need for empowerment of the mother and the family, and the need for additional social and community support.

In September 2011, fourteen parent/caregiver groups were established by the Child Sight Foundation of Bangladesh, and caregivers were invited to attend a monthly training course. The training programme was developed through a process of action research over a 12-month period, and involved the participation of parents, children, community workers, and a multi-disciplinary team of therapists. There were several research components to the project which informed the development of the training programme. The purpose of this article is to present one component of the larger research project, namely, the findings of a mixed methods study conducted on the lives of the caregivers of children with cerebral palsy.

Objectives of the study

The objectives included:

- (1) Understanding and assessing the family impact of caring for a child with cerebral palsy, and
- (2) Understanding local knowledge and beliefs about the child's disability.

METHODS

Study Setting

The study was undertaken in 2 sub-districts of the Sirajganj district in Bangladesh -Kamarkhand and Ulla Para - over an 18-month period in 2012-2013. Bangladesh is a low-income country. The mainstream Government health systems do not include rehabilitation. Some rehabilitation is provided on a limited scale by the non-government organisations. During the study period there was no disability rehabilitation programme in the study area.

Study Sample

Participants in the study were the families of children with cerebral palsy who were identified during a large-scale survey in Bangladesh (Mactaggart and Murthy, 2013). A paediatrician had clinically assessed all the children as having a moderate or severe form of cerebral palsy. The study sample consisted of 153 families who had children with cerebral palsy aged 14 years or younger, who were invited to participate in the development of a new training programme for parents. At the same time, 150 normative families who did not have a child with a disability, were selected as a comparison group for the quality of life measure. The normative families were randomly selected from the same villages, and children were matched by age and gender.

A purposeful sample of 10 families was selected for in-depth interviews. Selection criteria included having children of different ages and a gender mix; the children were between 1-14 years of age, and consisted of 6 girls and 5 boys. One family had 2 children with cerebral palsy. This sample also included 2 families who were not regular attendees of the training programme, in order to better understand reasons for poor attendance. On completion of the 12-month intervention, 2 focus group discussions were also conducted with representatives of each of the 14 parent/caregiver support groups established.

Quantitative Data Collection

The authors used the 36-item PedsQL™Family Impact Questionnaire Module (Varni et al, 2004), a health-related quality of life questionnaire, which is designed to measure the impact of paediatric conditions on parents and the family. It measures parents' self-reported physical, emotional, social, and cognitive functioning, communication, and worry, as well as daily activities of the family,

and family relationships. This questionnaire was translated into Bengali using the standard forward and back-translation procedures, and piloted in the local setting before use.

The questionnaire was administered to the main caregiver in: a) the families with a child with cerebral palsy, and b) the normative families. Interviews were conducted by trained community workers, in the respondents' homes, before the participants started on the training programme.

Qualitative Data Collection

Interviews with the main caregiver were conducted over 3 to 5 visits to the family home during a 6-month to 1-year period, to explore a) the knowledge and understanding of cerebral palsy, and b) the impact of caring for a child with cerebral palsy. A topic guide was used to allow participants to tell their stories, underpinned by an interpretive phenomenological approach to the collection and interpretation of qualitative data (Creswell, 2009; Green and Thorogood, 2009). A half-day observation of the child in the household setting was conducted by the same researcher, and detailed notes were taken of the child and parent activities, and interactions related to the care and support of the child. Finally, at the end of the year-long training programme, 2 focus group discussions with the caregivers were conducted to explore their views on participating in the training programme.

Ethics

The research was approved by the Ethics Committee of the London School of Hygiene and Tropical Medicine and by the Child Sight Foundation of Bangladesh. Written informed consent was obtained from the participants. Privacy and confidentiality of the information provided was maintained throughout the study and in any subsequent publications.

Data Analysis

Quantitative

The quantitative data was analysed using Stata V11. Demographic characteristics (age, gender and family size) of the children with cerebral palsy and their matched controls were compared using Chi-squared test. The PedsQL™ sub-scale scores were converted into scores out of 100, with '0' as the worst possible score and '100' as the best score. T-tests were used to compare the PedsQLTM

scores between families with and without children with cerebral palsy, for each domain, separately as well as the overall total score.

Qualitative

The in-depth interviews and observations of children in the family setting were conducted by a local researcher. Interviews were in the local language. Detailed notes were taken wherever possible during the observation, and were written up thereafter. These notes were translated into English. The data from the interviews and observation notes were thematically analysed by one researcher, and also checked by a second bilingual researcher. NVivo 10, a qualitative software package, was used to manage the data analysis.

RESULTS

Out of the 153 families who had children with cerebral palsy, 135 (88%) completed the questionnaire, while 18 families were not included because they had moved away, were not contactable, or their children had died. The demographic characteristics of the sample are presented in Table 1. The children with and without cerebral palsy were similar in terms of age, gender and family size. The main caregiver was the mother in the majority of the families (90% of families with a child with cerebral palsy and 94% of normative families).

Table 1: Demographic characteristics of Children with Cerebral Palsy and the Normative Controls

	Child with Cerebral Palsy N (%)	Child from Normative Families N (%)	P-value
Child age (years)			
0-4	42 (31%)	57 (38%)	0.17
5-9	59 (43%)	68 (45%)	
10-14	43 (25%)	25 (17%)	
Child gender			
Male	81 (60%)	75 (50%)	0.09
Female	54 (40%)	75 (50%)	
Number of children in family aged <16years			
1	34 (25%)	38 (25%)	0.83
2	52 (38%)	61 (41%)	
3	37 (27%)	42 (28%)	
4+	12 (10%)	9 (6%)	

PedsQL™ Family Impact Questionnaire

The overall mean PedsQL™ score for the main caregiver of a child with cerebral palsy was significantly lower (52.4) than the score for the main caregiver of the normative families (79.8, $P < 0.0001$). This difference remained significant across the different age categories and gender of the children (see Table 2). The scores were significantly lower ($p < 0.0001$) across all 8 domains for the caregiver of a child with a disability compared to normative families (Table 3).

Table 2: PedsQL™ Family Impact Module scores stratified by Age and Gender

	Families with Child with Cerebral Palsy		Normative Families		P-value
	n	Mean (SD)	N	Mean (SD)	
All children	134	52.4 (10.3)	150	79.8 (9.5)	<0.0001
Age					
<5 years	42	51.5 (9.3)	57	80.4 (9.6)	<0.0001
5-9 years	59	52.9 (10.6)	68	79.4 (10.3)	<0.0001
10-14 years	33	52.5 (11.2)	25	79.6 (7.3)	<0.0001
Gender					
Male	81	52.5 (10.0)	75	79.4 (9.5)	<0.0001
Female	53	52.2 (10.8)	75	80.2 (9.6)	<0.0001

*One case had approx. 50% of QoL information missing so was set to missing

Table 3: Individual PedsQL™ Family Impact scores across 8 Domains

Domains	Families with Child with Cerebral Palsy		Normative Families		P-value
	n	Mean (SD)	N	Mean (SD)	
Total Score	134	52.4 (10.3)	150	79.8 (9.5)	<0.0001
Physical Functioning	135	48.6 (14.7)	150	72.0 (12.5)	<0.0001
Emotional Functioning	135	25.1 (14.7)	150	78.1 (13.7)	<0.0001
Social Functioning	135	52.8 (22.4)	150	86.8 (12.6)	<0.0001
Cognitive Functioning	135	66.8 (18.2)	150	79.8 (13.2)	<0.0001
Communication	134	71.5 (15.8)	150	87.8 (11.0)	<0.0001
Worry	134	52.9 (13.2)	150	83.1 (11.9)	<0.0001
Daily Activities	134	38.9 (21.3)	150	72.1 (15.4)	<0.0001
Family Relationships	134	65.2 (20.0)	150	81.5 (13.8)	<0.0001

Qualitative Findings

In order to present the data coherently, aid interpretation of the mixed methods of data collection, and highlight areas of synergy with the quality of life data, the emerging themes were mapped, where relevant, under the PedsQL™ domains.

In-depth interviews were conducted with 8 mothers, 1 grandmother and 1 father. There were totally 11 children with cerebral palsy, ranging in age from 1-14 years, and consisting of 5 boys and 6 girls. In fact, one family had 2 children with cerebral palsy. Eight of these families completed the full parent/caregiver training course, while two stopped attending part way through. Key issues which arose from the in-depth interviews and observational data helped to corroborate the findings of the quality of life questionnaire. More importantly, the qualitative data provided explanatory information for the low quality of life scores and how the issues were interconnected, which was invaluable for the development of the training programme.

Impact of Caring for the Child

a) Emotional functioning and worry

Emotional functioning and worry were two of the lowest quality of life scores for families. Correspondingly, high levels of worry and anxiety felt by the caregiver were two of the most common themes of the qualitative interviews. These feelings were commonly explained by the lack of support in caring for the child, physical exhaustion, very low levels of knowledge about cerebral palsy, and high levels of stigma related to having a disability.

“I face terrible problem as my child does not sleep at night. If I can't sleep at night, I feel really bad and tired. I don't get assistance from anyone apart from the family members. A lot of my relatives and neighbours made remarks like 'This is the result of their sins'. [How do you feel when they make this kind of comments?] I feel very bad, I feel like committing suicide. A few days ago I put my sister-in-law's child on the chair of my disabled child and she said very bad things to me and my child. She said, 'You want my child to become disabled like yours, that's why you put him on that chair.' My husband cried for a while after hearing such disappointing comments from his own sister” (Mother of a 15-month-old son).

Anxiety and worry were commonly linked to concerns about the future of the child, including who would take care of the child later in life and whether the

child would be able to get married. The concern about marriage was expressed for both a male and a female child.

"I feel sad that my grandson is disabled. I am always worried about him. I don't worry about any of my children or other grandchildren. I take care of him now that I am alive, but what will happen to him after my death? Who will take as much care of him as me? I am always tense about these things" (Grandmother of 12-year-old boy).

"I feel really bad that I am a mother of a disabled child, I feel pain deep inside.I also am very tense about her future. If this problem persists in the future, then there will be problem in education, mobility, and even in marriage" (Mother of a 3-year-old girl).

b) Physical functioning and daily activities

Physical tiredness of the caregiver, combined with a lack of time to conduct everyday household chores, were key themes identified by the caregivers in the in-depth interviews. The mother was most often the sole carer, and also frequently combined this with livelihood activities. In some cases the child needed to be carried or supported by the caregiver throughout the day, which made it difficult to undertake even basic household activities.

"It becomes very difficult to take care of two disabled children. As the children are sick, it becomes problem for me to perform household work properly. Sometimes I have to skip cooking meal for once in the day.I usually take care of my children. But every member of my family takes care of them as well. But the children don't want to leave me for even a second. During cooking and other work I can't keep them close to me. And they cry during those times. That's why I can't work properly" (Mother of two children with cerebral palsy - a 7-year-old daughter and a 5-year-old son).

In the two cases where the parents stopped attending the training course, the main reasons they gave for non-attendance were the lack of time because of competing household and income-generating activities, and also not having time to care for the child. The observations of the family also highlighted the obvious neglect of their children with cerebral palsy; it was observed that the children were very poorly cared for, lying in their own urine for several hours, while their parents worked nearby. In both families, it was observed that the fathers had no interaction with their son or daughter with disability when they came home,

and that it was the mothers who took on the caregiving role, but often in a very limited way.

In one family with a 9-year-old daughter, the mother talked about feeling exhausted in her caregiving role which she combined with income-generating work.

“I do pottery at house all day long. I have to cook food for all at home three times a day. My father-in-law is ill; I have to take care of him. During sharecropping, when the crops arrive at our house, I have to work on that.I have to look after my disabled child all the time. My husband sometimes helps me a bit in household work, but he does not help me with the child. He has no interest in the child. I feel stressed working so much at home. I never get the chance to relax at home. That’s why I always feel weak. Now the child has grown up and she urinates and defecates lying down and sitting and it gets on her body. That’s why I feel bad to clear her stool and urine” (Mother of a 9-year-old daughter).

c) Social functioning, communication, and family support

Under the theme of family support, some caregivers described individual members of the family and neighbours who loved their child and were sympathetic and caring. However, the overall key themes were of isolation and lack of support; the difficulty in talking about their child’s condition within the family, which was often compounded by the high levels of stigma surrounding having a child with a disability.

“Many of the neighbours and relatives still say bad things about my child and me. On the other hand some say good things. One of my sisters-in-law told me that this was the punishment of my sins. She hates my child and don’t take her on lap. I feel very bad at these behaviours of others” (Mother of a 3-year-old daughter).

Caregivers also mentioned that they were not aware of other children with disabilities within their own village, and that coming together to form a parent support group provided an invaluable opportunity to talk about their experience with other parents.

“There are many physically challenged children in our village. I did not know them before now” (Focus Group Discussion-1).

d) Understanding and beliefs about cerebral palsy

Measuring levels of knowledge and understanding about cerebral palsy were not

a component of the quality of life measure, but the qualitative data highlights low levels of understanding about cerebral palsy, common myths held, and provides some explanation of the stigma felt by caregivers.

“I feel really sad as my child is a disabled person. What sin had I committed that Allah gave me a disabled child? I do most of her work although her father also helps me sometimes. I feel really bad about having to clean her up after toileting, as she is growing up and I can’t do this forever. I feel really sad inside when I see other children from my neighbourhood are playing and running around” (Mother of a 12-year-old daughter).

Parents commonly held several concurrent beliefs regarding the cause of their child’s condition. The most common beliefs were that it was caused by bad spirits and/or the result of something they did or that happened to them during pregnancy. Despite several reported visits to healthcare providers, most families had not received any diagnosis for their child. The exceptions were two families who had sought treatment in Dhaka, the capital of Bangladesh, and had a good level of understanding about the condition.

Family members and neighbours commonly influenced the decision-making regarding treatment and care for the child.

“The traditional healer after examining the baby told me that while I conceived him, he was caught by spiritual forces..... usually we don’t even believe in the treatment of the traditional healer, but took him [to a traditional spiritual healer].....after listening to the neighbours”(Mother of a 15-month-old son).

All the interviewed parents mentioned visits to traditional healers for treatment of their child’s condition. Caregivers commonly described having been to different types of traditional healers in their endless search for a cure for their child. This often involved various ceremonies to remove the bad spirits. One family mentioned having received a diagnosis of epilepsy (14% of the children with cerebral palsy in the original survey had been diagnosed with epilepsy) and that they had visited 20-30 traditional healers.

“The doctor gave her some medicines [for epilepsy], but I stopped giving the medicines to my child after two to three days. At that time I thought such a small child could not have epilepsy..... After I stopped giving her medicine, I took her to a traditional healer.....The healer told us that she was encountered by a bad spirit. The healer came to our house many times. He told us, if you sacrifice two pigeons, then your

child will be fine.After I gave the pigeons, the healer applied witchcraft and gave her a talisman, but she did not recover.....After that I took her to almost 20-30 healers” (Father of a 9-year-old girl).

DISCUSSION

Cerebral palsy is one of the most prevalent conditions among children with disabilities in low and middle income countries. It is a neurological health condition, and children also often have associated impairments such as hearing, visual, and cognitive impairments (Donald et al, 2015; Donald et al, 2014). However, despite these wide ranging needs, the rehabilitation on offer for these children and their families, is scarce or non-existent in many low or middle-income countries, including Bangladesh, and there is a call for more home-based care of community approaches well-suited to low-resource settings (Donald et al, 2015; Donald et al, 2014).

This study was conducted to inform the development of a community-based parent programme. It found that caregivers of children with cerebral palsy in rural Bangladesh had significantly poorer quality of life compared to caregivers of children without disability. This is one of the very few studies to have explored the quality of life of families caring for a child with disability in comparison with matched families that did not have a child with disability, in a resource-limited setting. The quality of life findings provide evidence to support the argument that families of children with disabilities are amongst the most vulnerable and disadvantaged in already resource-poor communities. Historically, disability rehabilitation programmes focus only on the adult or child with disability, with little or no attention to the impact of disability on the wider family. Studies on the rehabilitation of children with cerebral palsy in Bangladesh and other LMICs have generally focussed on barriers to the uptake of services (Nesbitt et al, 2011; Bedford et al, 2013), or on evaluating approaches for improving a particular aspect of care (Khan et al, 1998; McConkey et al, 2000; Mobarak et al, 2000; Maloni et al, 2010). However this study, using the perspectives of the caregivers and a measure of their quality of life, highlights the importance of taking a more holistic view of the family’s needs and priorities, particularly of mothers and other female caregivers such as grandmothers.

The current study supports the findings of a number of other studies in LMICs which have shown that the burden of care normally falls on a female member

of the family, and that high levels of stress and anxiety exist for the primary caregiver (Mobarak et al, 2000; Hartley et al, 2005). Other studies have also shown the role that the extended family plays in decision-making in relation to care of a child with disability (Hartley et al, 2005; Maloni et al, 2010; Bedford et al, 2013). Importantly, the present study provides additional details about the extent of the impact of caring on the primary caregivers, across a range of psychosocial domains; it also provides a richer picture of the complex lives of families who care for a child with disability. This understanding of the complexity of issues which influence the care of the child is crucial for planning relevant and acceptable family-centred community-based rehabilitation programmes in LMICS.

The isolation of the caregiver, and the seemingly limited support network and safety nets which exist to care for a child with disability in this rural Bangladesh setting, is a key finding with implications for development of an effective community-based intervention. In terms of the development of the parent training programme, the implication was the need to include home visits within the programme, which then facilitated an opportunity to engage with other members of the family and wider community. It was also imperative to ensure that the training included a focus on community-based rehabilitation. Consequently, an additional training module was developed on 'Disability in your community', to address wider issues around inclusion and stigma, access to disability funds, and access to education.

The study found low levels of knowledge about cerebral palsy, and traditional beliefs about aetiology associated with witchcraft were extremely strong in this rural area of Bangladesh. This often resulted in already very poor families spending considerable amounts of time and money seeking traditional cures. This supports findings from a number of other studies (Gona et al, 2006; World Health Organisation and World Bank, 2011; UNICEF, 2013). Engagement with traditional healers, as part of a wider community programme, may be beneficial and should be explored in future programmes.

Finally, the current study also highlights the value of using mixed methods. The qualitative research corroborated the findings of the quality of life scores, while also providing additional data on the underlying reasons and highlighting explanatory pathways in the dynamics of family and community life. Understanding these issues in greater depth is essential for informing the development of appropriate interventions at the community level.

Limitations

There were clear criteria for the purposeful sample of 10 families; however, the final choice was made by local project staff together with the local researcher, which may have resulted in the selection of families who were better known to project staff and more actively engaged in the training programme. The local Bangladeshi research assistant became familiar to the families over the course of the year, and this has benefits as well as possible limitations. Disadvantages include possible inhibition of the caregiver's responses (Morris, 1998). However, this was balanced against the level of trust between the researcher and the family, which meant that it was acceptable for him to enter the family home, and he was allowed to observe the child in the context of the family. For budgetary reasons, only a half-day observation of the families was planned. This was a short time period and may have given a biased representation of the daily activities and care of the child in the home setting.

CONCLUSION

The study findings show that any intervention for families of children with cerebral palsy needs to be holistic in its approach. There is a need to address the health and well-being of the caregiver, mainly the mother, as well as the child. Furthermore, it is imperative that interventions engage with the wider family and community. Poor communication in the family, high levels of stigma, and the need to build an effective support network for the families that have a child with disability, are all key issues which should be addressed in any community-based rehabilitation programme for children with cerebral palsy and their families.

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Khaled Hossain Joarder interviewed all the children.

Note:

PedsQL™, Copyright © 1998 JW Varni, Ph.D. All rights reserved. For any information on the Questionnaire, information and permission to use: Mapi Research Trust, Lyon, France. E-mail: PROinformation@mapi-trust.org

Internet: www.proqolid.org and www.pedsqol.org

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