

A Qualitative Study of Unmet Needs of Families of Children with Cerebral Palsy in Bangladesh

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Abstract : Objectives: Worldwide, it is well known that taking care of children with disabilities (CWD) can have a significant impact on the entire family unit. Over the last few decades, an increased number of studies have been conducted on families of CWD in higher income countries, and much of this research has identified family needs and strategies to meet those needs. However, family needs are incredibly under-studied in developing countries. Therefore, the aims of this study were to: (a) explore the needs of families of children with cerebral palsy (CP) in Bangladesh; (b) investigate how some of the family needs have been met and (c) identify the sources of supports that might help the families to meet their needs in the future. Methods: A face to face, semi-structured in-depth interview was conducted with 20 family members (12 mothers, 4 fathers, 1 sister, 2 grandmothers, and 1 aunt) who visited the Centre for the Rehabilitation of the Paralysed (CRP), Bangladesh between June and August 2016. Constant comparison method of grounded theory approach within the broader spectrum of qualitative study was used to analyze the data. Results: Participants identified five categories of needs: (a) financial needs, (b) access to disability-related services, (c) family and community cohesion, (d) informational needs, and (e) emotional needs. Participants overwhelmingly reported that financial need is their greatest family need. Participants noted that families encountered additional financial expenses for a child with CP, beyond what they would typically pay for their other children. Participants were seeing education as their non-primary need as they had no hope that their children would be physically able to go to school. Some participants also shared their needs for social inclusion and participation and receiving emotional support. Participants further expressed needs to receive information related to the child's health condition and availability/accessibility of governmental support programs. Besides unmet needs, participants also highlighted that some of their needs have been met through formal and informal support systems. Formal support systems were mainly institution-based and run by non-governmental organizations, whereas participants identified informal support coming from family, friends and community members. Participants overwhelmingly reported that they receive little to no support from the government. However, participants identified the government as the key stakeholder who can play vital role in meeting their unmet needs. Conclusions: In the next phase of this research, the plan is to understand how the Government of the People's Republic of Bangladesh is working to meet the needs of families of CWD. There is also need for further study on needs of families of children with conditions other than CP and those who live in the community and do not have access to the CRP Services. There is clear need to investigate ways to enable children with CP have better access to education in Bangladesh.

Keywords : Bangladesh, children with cerebral palsy, family needs, support

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