

BRIEF REPORTS

Perceptions of Primary Caregivers of Children with Disabilities in two Communities from Sindh and Balochistan, Pakistan

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ABSTRACT

Purpose: *This study explored the perceptions, attitudes and practices of primary caregivers towards children with disabilities in two communities from Sindh and Balochistan, in Pakistan.*

Method: *6 focus group discussions and 7 in-depth interviews were conducted with 37 women in the two communities – one urban and the other rural.*

Results: *Primary caregivers perceived disability as physical, functional limitations and the absence of any functional body parts. Complications during pregnancy and delivery were regarded as the major cause of disabilities. Lack of financial resources and limited access to medical and rehabilitation services were identified as the main reasons for frustration among caregivers, resulting in their giving reduced attention to the child with disability. Caregivers felt that behavioural problems of children with disabilities were a major challenge, and also limited their participation in social activities.*

Conclusion and Implication: *There is a need to raise awareness among the families of children with disabilities and in the community at large. Home-based community-level interventions are needed to reduce the social stigma attached to children with disabilities.*

Key words: *primary caregivers, urban and rural communities, childhood disabilities, knowledge and practices, home management, inclusive community.*

INTRODUCTION

National data reveals that a possibly underestimated figure of approximately 2.5 % (3.28 million) people with disabilities live in Pakistan (Population Census Organisation, 1998). One of the causes of childhood disabilities is the high

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incidence of morbidity and mortality which is evident in developing countries, especially in rural areas – which amount to 66% in Pakistan – possibly due to lack of facilities such as safe water, sanitation and health services. Besides heredity, diseases are another significant cause for sensory impairments and for disabilities (Mitra et al, 2011).

Research shows a strong association between the type of disability and caregivers' behaviour and practices with children with special needs, at home and in the community at large. Nurturing a child with disabilities is a major challenge for caregivers, especially those living in resource- poor communities of developing countries. This includes bearing the additional financial burden for treatment of the child's condition, and also dealing with the stigma associated with disabilities (Tareen et al, 1982).

Several factors are associated with caring for children with disabilities. These include the support system from immediate family members at home, cultural values and beliefs, financial resources and stability for seeking treatment and rehabilitation services for the children with disabilities (Monk and Wee, 2009). However, the social and emotional demands caused by the child's disability vary across the different racial and ethnic groups, given the diverse cultural norms, resources and support available to caregivers. Family values and lifestyles in some cultural groups serve as a source of strength when coping with a child with special needs (Miles, 1983; Ceylan and Aral, 2007).

Socialisation of children with special needs is a vital determinant for assessing their overall quality of life. Almost all exceptional children, regardless of their disabilities, have significant social handicaps (Monk and Wee, 2009). This creates misunderstanding about the disability and about the capabilities of the person with disability. It also prevents the family members from seeking information about treatment/rehabilitation and educational opportunities for the children with special needs (Thomas and Thomas, 2002). Physical and attitudinal barriers, coupled with stereotypes play a large role in shaping public perceptions of persons with special needs (Shahzadi, 1992; Thorburn, 2006; Chiang, 2007).

With significant regional disparities, the position is much worse in disadvantaged regions where there is wide-spread poverty, illiteracy, cultural barriers, and gender discrimination. It is widely acknowledged that personal attitudes and circumstances, combined with environmental factors, can either precipitate or help to prevent disability. Beliefs about causality, valued attributes and perceptions

of adult roles in the community will determine how a particular cultural group views disability (Groce, 1999). It has been found that the children's gender contributes towards people's positive or negative attitudes towards them (Stein, 1981; WHO, 1981). Asian parents tend to attribute the cause of a child's disability to supernatural influences or sins committed by the child's ancestors or parents. Most of these notions are based on preconceived ideas, which include shame and feelings of obligation toward the child with special needs. It has been noted that positive interactions when raising a child with special needs had a significant moderating effect on the relationship between the child and parental well-being (Jackson and Mupedziswa, 1988; Thorburn, 1993; Chan, 1997; Shahzadi, 1992).

There has not been much research in Pakistan which specifically explores the behaviour of primary caregivers towards children with special needs. Pakistan is a country with minimal resources for information dissemination regarding different health-related areas including social issues of disability, poverty and gender. Studies on caregivers can help to identify the potential areas for an educational intervention for children with special needs and their caregivers.

The present study was part of a larger project conducted during March 2009 - July 2011 to establish the prevalence of childhood disabilities and to assess the feasibility of the World Health Organisation's training manual for people with different disabilities in resource-poor communities of Pakistan.

OBJECTIVE

The objective of the present study to explore the caregivers' perceptions regarding children with special needs, and to assess the extent to which differences in culture and ethnic backgrounds influence their understanding of disability and its causes, management and the inclusion of children with disabilities in their respective communities.

METHOD

In order to meet the research objectives, exploratory descriptive qualitative approach was adopted. The project was implemented in an urban and a rural area in two provinces of Pakistan, namely Sindh and Balochistan. Both field sites have diverse socio-demographic characteristics and are geographically apart. For the purpose of this study, perceptions of caregivers were explored through focus group discussions (FGD) and in-depth interviews (IDI), developed based on

literature reviews and past experiences. Separate guidelines were developed for focus group discussions and in-depth interviews; the content and probes were checked in terms of being understood by some respondents, before the actual data collection with the groups in the field. Along with the note-taking, the sessions were tape-recorded to get accurate verbatim accounts for data validity and transcription. The discussion guide contained open-ended questions. Probes were introduced where required during the discussions. Study coordinators who were qualified psychologists, trained in qualitative methods and fluent in local languages, were the moderators of the group discussions and the IDIs.

Caregivers of children with special needs were invited to take part in the study. They were identified by early child development workers (ECDWs) in two communities. Purposive sampling techniques were used as per the inclusion criteria of the study. The selected women had children in the age group of 2-8 years, who were identified with some disabilities during the baseline survey of the larger project. Some of the women selected were those who took care of the children as secondary caregivers, e.g. grandmother and maternal aunt. The selection was based on informants' vocal and voluntary participation, and deeper understanding of the topic. No incentives were offered.

The study was approved by the Ethical Review Committee of Aga Khan University. Each study participant gave her consent before the FGDs and IDIs were held. Totally, 6 focus group discussions were conducted with 37 women at two field sites (17 women from a urban field site in Tandojam, Sindh, and 20 women from a rural field site in Mastung, Balochistan). An average of 6 women participated in each focus group discussion. A total of 7 in-depth interviews were conducted with the most vocal women identified during focus group discussions, who had children with disability and understood disability issues well. The average duration of each focus group discussion was about 60-90 minutes.

Data quality and credibility of the analysis were maintained as two neutral researchers were involved. Similar themes were identified and over-arching themes were merged for clarity. Transparency of the data was maintained by analysis on NVIVO 2.0, which is single-user software. During the coding of the data, emerging themes were re-analysed. The use of software for the analysis also made re-analysis of the data easier. To maintain the rigour of the research, constant comparative analysis was also performed (Glaser and Strauss, 1967).

Data analysis was performed based on Grounded theory (Glaser and Strauss, 1967) and an inductive approach was applied. Initially 19 cross-cutting themes were identified, which were later merged and shortened, so that seven major themes emerged from the data.

1. Understanding about the concept of “disability”: Myths or facts about the causes of disability
2. Attitudinal barriers
3. Maternal behaviour towards children with disability
4. Difficulties in handling a child with disability
5. Availability of infrastructure for health and education
6. Perception of inclusion and barriers
7. Knowledge about rights

RESULTS

Seven major themes were identified while exploring perceptions of caregivers of children with disabilities.

Theme 1: Understanding about the concept of “disability”: myths or facts about the causes of disability

Most of the respondents viewed physical functional limitations and absence of any functional body parts as disability.

“Disability means when the child is not able to do what the other normal children can do.”

“The child who cannot walk due to weakness in the back”

“When a person cannot walk, is mentally retarded and cannot think like other persons. It also means not having legs, hands, and when you cannot hear or speak”

Most of the responses were related to deformities that were visibly noticed and recognised, including deformity of any of the functional body parts or anywhere in the body. Participants said that disability was of many types and of different levels of severity. The data reflected that caregivers also considered it a disability when a child did not comprehend things easily.

The major causes which emerged from the findings, according to most of the respondents were:

1. **Due to accident/diseases** (unintentional injury, falling) - *“High fever also caused disability in children”.*

“Physical disability is by birth but mental disability is due to some illnesses” **Due to the vaccination after birth** (specifically after polio vaccination) - *“Everyone says that children become disabled especially when they are vaccinated for polio”.*

Due to maternal health (non-availability of healthy and sufficient diet during antenatal period) - *“When a woman is pregnant and she does not take care of herself and does not eat properly, this causes calcium deficiency, due to the reason she gives birth to a child with disability.”*

2. **Due to intermarriages between families, social construct and cultural values** (most of the respondents perceived marriage between cousins as a major cause for disabilities among their children) - *“Doctors always said to avoid cousin marriages, but it is against our traditional values, marriages within the families are highly appreciated than outside the family.”*
3. **“God’s will”** - *“It is by birth and natural, God made them like this, they are beautiful but with missing functional body parts or sensory impairments.”*

Many disabilities were attributed to unusual complications or to health and nutritional issues of the mother during the antenatal period; also, if the child suffered from any disease, fever or infection, the unavailability of healthcare facilities and doctors led to the child’s disability. Most of the respondents were able to clearly define “disability” and seemed knowledgeable about the causes of the disabilities. Geographical location and literacy levels did not seem to have much relation to the awareness levels. Caregivers at the two sites had different levels of education but showed similar understanding about the concept and causes of disability.

Theme 2: Attitudinal Barriers

Most of the respondents in this study indicated that management of a child with disability is largely dependent upon the support system from immediate family members, siblings and relatives.

“Taking care of a child with disability required exclusive attention and time, and this is not possible due to other household chores and burden of taking care of other children at home”.

“The family attitude is not good to the child, and always turns their face away when they see the disabled child. They always try to smack and beat him whenever they get chance for this”

"The attitude of the siblings with the disabled child is not good. They beat them and avoid eating with them which results in social withdrawal and isolation"

"Siblings call her (pagal) and she had started giving response to that as if that is her name"

"Relatives don't like to eat from his hand. Both the family and the surrounding people have bad behaviour with them"

"Everyone makes fun of them but it is in the hand of God"

"The other family members do not help the mother to take care of the child"

It was indicated that disability and children with any kind of disability are not accepted in the community, which has neither tried to understand them nor provided support to families, specifically caregivers, with help in caring for these children at home. The community's attitude towards children with disability and towards disabilities is a major factor that determines the change in behaviour of people. Mothers are expected to manage most things including their children's hygiene, regular medical check-up and feeding. The data showed no difference in opinions between the groups of women from the two communities. It also revealed that caregivers in both communities faced similar kinds of stress factors while taking care of their children with disabilities.

Theme 3: Maternal behaviour towards children with disability

"Sometimes I need support and help from others to hold him and fulfil his toilet needs, doing his cleanliness and feeding, as he is too big for me to hold him alone and do his tasks"

"Taking care of a child with physical disabilities or with mental disabilities, is a very difficult task to do as it causes extra workload along with physical and mental stress to the caregivers".

"Sometimes parents over-sympathise with a child who has some disability and ignore the needs of other children at home; this also caused stress among caregivers."

"When my child tries to go outside to play with other children, other children make fun of him, due to that he does not want to go outside, the behaviour of other children restricted his social involvement"

"Primary caregiver has to pay more attention to the children with disabilities as compared to other children, and all the time caregivers are preoccupied with the needs of the children with disabilities, resulted in fatigue and irritable mood."

“Every mother wanted to have a healthy child, and her affection remains the same irrespective of the health of the child; disabled or nondisabled”

Caregivers' behaviour is also associated with, and modified according to, the socioeconomic status and family structure. Caregivers who receive positive support in terms of sufficient financial resources for the treatment, management and rehabilitation of the child with disability at home, are more actively involved with the child.

Theme 4: Difficulties in handling a child with disability

The majority of the respondents expressed that the greatest challenge in caregiving was in managing behaviour problems and in teaching social self-care skills to a child with disabilities at home.

“The child is helpless and parents are always stressed, and under pressure. They have to feed the child, take care of his toilet needs which are always a problem for parents, especially for mothers”.

Theme 5: Availability of infrastructure for health and education

Healthcare facilities and services are also recognised as key issues. Lack of professionals, healthcare centres and hospitals, and lack of rehabilitation professionals were problems caregivers faced when seeking treatment and rehabilitation services for their children with disabilities. Information and awareness about the available health facilities within their communities was also found to be lacking among both groups. Even if some of the facilities such as Rural Health Centres, Basic Health Units, and some private clinics were available nearby, most of the caregivers did not utilise them as they were perceived to be non-functional most of the time.

“Government is doing nothing for these children and there are no facilities available for disabled children. No one has done anything for them”.

“I always try to help my son, but cannot help him due to lack of financial resources and non-availability of health facilities for his treatment”.

Lack of information from the professionals regarding management and treatment of the child with disability at home, was perceived as a problem for parents, especially for the mothers.

“I am always expecting the doctors to give full attention and information regarding the child's problem and about his treatment procedure but it never happens. The doctor just does the routine checkup and prescribes tonics.”

“When parents take their disabled child to the doctor, they are expecting support and guidance from them and want to know how to handle the child with disability; and how to take care for their diet and cleanliness, food and health and other needs.”

Theme 6: Perception of inclusion and barriers

It was felt that children with disabilities should go to regular schools with other children. Primary caregivers believed that it would enhance the learning abilities of the children with disabilities and also build up their confidence. They believed that inclusive education would promote acceptance, which is crucial to their children’s social and emotional development. While the concept was understood by the caregivers, they were unfamiliar with the term “Inclusive Education”.

“Our children should go to normal schools where other children go, they can learn better if they join children without any disabilities, but in our area schools for normal children are not functioning properly, and found no possibility for sending our children with disabilities to these schools.”

All the respondents did not share the same views regarding inclusive education for children with disabilities. Some of them were found to be in favour of the special education system, as they believed that their children would get proper attention and education according to the nature and severity of their disability. However, a few of them also perceived that these children would learn more if they were with other children in regular schools. Other issues which were highlighted were the presence of untrained teachers, lack of necessary attention towards the children with disabilities, scarce financial resources (to send their children to local schools for education), inadequate transportation facilities and lack of initiatives from the Government regarding provision of infrastructure and coordination with the community. Mothers’ concerns regarding inclusion were identified, such as the shortage of qualified personnel and the lack of expertise in implementing inclusion. The data also brought out potential concerns, such as frustration with schools which failed to provide inclusive placements, and the effects of inclusion on their children’s academic, social and behavioural development.

“There is no opportunity of schooling for these children with disabilities in our area. They should go to proper school and teachers should give them proper time.”

“There is no opportunity of education for these children in the area”

Theme 7: Knowledge about rights

“Proper education and proper treatment is their right and they should study with normal kids.”

Most respondents were aware of the rights of a child with disability, but they indicated that these rights were hardly supported in the community. They felt that society did not display positive attitudes towards families that had children with disability.

“These children should be given love and care and training as well” .

“My son understands others’ behaviour and when somebody says anything wrong or scolds him he reacts and shows his aggression. We should treat them with love and care”

Mothers identified formal education as an important right of children with disabilities. They perceived it as a way of socialisation for their children, and a stepping stone towards an inclusive community.

“Every child has their rights but it is the duty of the parents to give proper rights to these children. The mother is supposed to take good care of their health and cleanliness”.

“People in our area are not good with disabled children. They make fun of them and for the reason I do not let my children go outside the home”

The negative attitude of the community could be due to cultural and religious beliefs connected with disability. Consequently, the families could not expect support or help from others, and were isolated from society. The burdens of caregiving, with or without formal or informal support, often clearly overstretched the families’ resources and affected each member in the household but particularly the primary caregivers. Therefore, the care of a child with disabilities not only depends upon information from healthcare professionals about the management of the disability, but also relies on the social network to provide the required education, training and support services.

DISCUSSION

Based on the findings of this study, it appears that perceptions, practices and attitudes of caregivers and people in the community are shaped by the prevailing cultural beliefs. These beliefs and practices are also found to be strongly associated with the religious, socioeconomic status and educational backgrounds of the families of children with special needs.

Irrespective of the difference in geographical regions, and cultural and ethical values, there was similarity in the perceptions of primary caregivers regarding children with disabilities and their management.

The most common causes for the disabilities were accidents, possibly due to the geographical terrain where the family lived; genetic/hereditary and congenital causes; maternal sickness, and infections during the antenatal period. Findings were consistent with those reported in a previous study (Chiang, 2007).

Literature shows that mothers are mainly blamed for giving birth to children with disability; in addition, they are responsible for the management of children with disabilities at home and are not provided support by extended family members (Seltzer et al, 2001).

From the information gathered from the two sites, it was observed that lack of financial resources and limited access to medical and rehabilitation services caused frustration among mothers, which resulted in reduced attention to the child with disability, as reported by Stein (1981).

In addition to this, caregivers were distressed that the child's behaviour problems were a source of social embarrassment when the child was taken outside the home. Such difficulties are perceived to be consistent with previously reported findings (Kermanshahi et al, 2008).

It was also observed that parents and society should both be educated about children with disability and their needs. It would reduce the feelings of self-blame, helplessness and loneliness among the mothers, and give hope for the future regarding the prognosis of the child with disability. In addition to this, awareness and understanding about the management of a child with disability reduces extra workload and decreases the emotional disturbances among caregivers (Thorburn, 2006).

Findings showed that socioeconomic status of the families is the major factor which contributes either positively or negatively to the way the caregivers raise a child with special needs. Poverty and lack of sufficient resources, along with weak social security net, are perceived as major hurdles in the care of the child with disabilities (Marder, 2008).

Caregivers found it difficult to attend social gatherings and felt ashamed when relatives asked about the child's disability. Pakistan is a poor country with limited resources and as the majority of the families have limited incomes, expenditure

on the child with disability creates great problems for the caregivers. Findings also demonstrated that having a child with disabilities significantly impacts the primary caregiver's life – generally the mother – and her relationship with relatives and other community members.

CONCLUSION

This preliminary study provides information regarding the experiences of mothers of children with and without special needs, in two urban and rural communities of Pakistan. The findings indicated a significant impact on the social and emotional well-being of the primary caregivers. The primary caregivers emphasised that the attitudes of other people in the community towards their children played a vital role when taking care of children with special needs. The data also reflected that the sharing of knowledge and provision of professional support could improve the life of children with special needs and would change mothers' attitudes and practices towards these children in the resource-poor communities of Pakistan.

The recruitment of groups of mostly mothers may be a limitation. The perspectives of other stakeholders, fathers, could have enriched the data.

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