POSTER P4

The Voice of Children with Cerebral Palsy and their Mothers in Saudi Arabia

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Summary

This research reports the study conducted in Saudi Arabia. It has allowed mothers of children with cerebral palsy (CP) to express their beliefs about the term CP. The data yielded information regarding mothers' beliefs surrounding the meaning of the CP term. These ranged from traditional and cultural beliefs to medical explanations, and to confusion between the two.

Aims and Objectives

The purpose of this qualitative study was to explore the perception of the term CP in Saudi mothers of children with CP, and to explore the implication of the meaning for mothers of children with CP within Saudi culture.

Background

CP is one of the most common childhood disabilities and makes heavy demands on health, educational, and social services as well as on families and children. In Saudi Arabia there is limited research related to disability: the term Cerebral Palsy is recognized by most health and social service professionals as a physically disabling condition; however this is not the case for the general public nor, more importantly, for mothers of children with CP. Misinterpretation of the term CP in the Arabic language clearly exists. In addition there is a lack of research describing people's perception of the CP term in Saudi Arabia.

Methods

Critical ethnography was adopted as the methodological approach; data were collected through focus groups, follow-up individual interviews, field notes and participant observation. Carspecken's five-stage method of critical ethnography provided a theoretical framework for data analysis.

Findings

Three themes emerged from the data:
(1) Religious and cultural beliefs
(2) Aspiration and optimizing the child's future
(3) Community stigmatizations.

A unique finding of the study was the influence of Islam in all of the mothers' focus group themes. Although most of mothers use the medical terminology and explanation for the cause of CP, they also constantly highlighted various religious and socio-cultural causal agents. The mothers also expressed a deep trust in God (God's will), and relied on God for their child's cure and better health outcome using these beliefs to cope with their children's circumstances. Another important issue related to this theme is that mothers' religious and socio-cultural beliefs hinder the process of treatment, and tend to encourage them to seek assistance outside of rehabilitation services, such as taking advice from traditional healers.

The findings of this study clearly indicate that mothers were perceived as a major source of support by their husbands, mothers and sisters. However , they believe that having a child with CP introduced great changes in their lifestyle, curtailing social events with their relatives and friends, not only because of the burden of the child on the mother, but also because of the society not accepting the child.

Because CP is a visible disability, the mothers felt stigmatized by society at large, and particularly by mothers-in-law who blamed them for their child's condition. This has a great impact in determining the acceptance of the child into the family and the self-perception of the mother. The experience of being stigmatized also resulted in them experiencing feelings of powerlessness, social discrimination and exclusion from the society.

There was a strong stigma attached to the label of CP which was interpreted as having brain dysfunction; it was preferred instead to believe that the children were experiencing developmental delay which is a more acceptable term. This led mothers to reject the term CP and to believe that their child was capable of many activities, and that their disability was not a limitation on their future potential.

Discussion

This study has provided preliminary data on the perception of Saudi mothers who have a child with CP. It presented the voice of mothers of children with CP regarding their perception, experiences, their own processes of adaptation and coping within the Saudi cultural context. The findings revealed that the dominant aspects shared across the data and the themes were the issues of culture, religion, and traditions related to disability. This study found a strong link between perception of disability and religious/cultural beliefs, suggesting that the concept of disability is framed from a spiritual perspective, not according to western disability model frameworks. Moreover, the study explored community and social attitudes towards the child with a disability and their consequences which include stigmatization and exclusion from society. It also explored the impact of these negative attitudes on the mother's perception, experience and expectations.

By enhancing understanding, and recommending integration into the community, the study can encourage a process of mainstreaming Saudi children with CP and their families into society, as the mothers noted that increased understanding of disability in the greater community would facilitate integration of their children.

These findings can also provide physiotherapists and other health professionals with insights into the experiences those mothers in Saudi face. Outside Saudi, the experiences and cultural beliefs may be useful to health professionals treating Saudi children who have sought medical advice abroad, as well as those populations with similar religious beliefs.

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