



THE VOICE OF CHILDREN WITH CEREBRAL PALSY & THEIR MOTHERS IN SAUDI ARABIA

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Aims and Objectives

The purpose of this qualitative study was to explore the perception of the term CP with 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, and (3) Community Stigmatizations.

“ I believe what happened to my son was a strong evil eye that hit his health. I felt it one day when I had a large gathering in my house and one of the ladies without saying God protect you from envy, “she said you have a pretty child”. ” M6

A unique finding of the study was the influence of Islam in all of the

the mother’s 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 major source of support by their husbands, mothers and sisters. However , they believe that having a child with CP introduced great changes in their life style and stopped social events with their relatives and friends not only because of the child burden on the mother but also , because of not accepting the child in society.

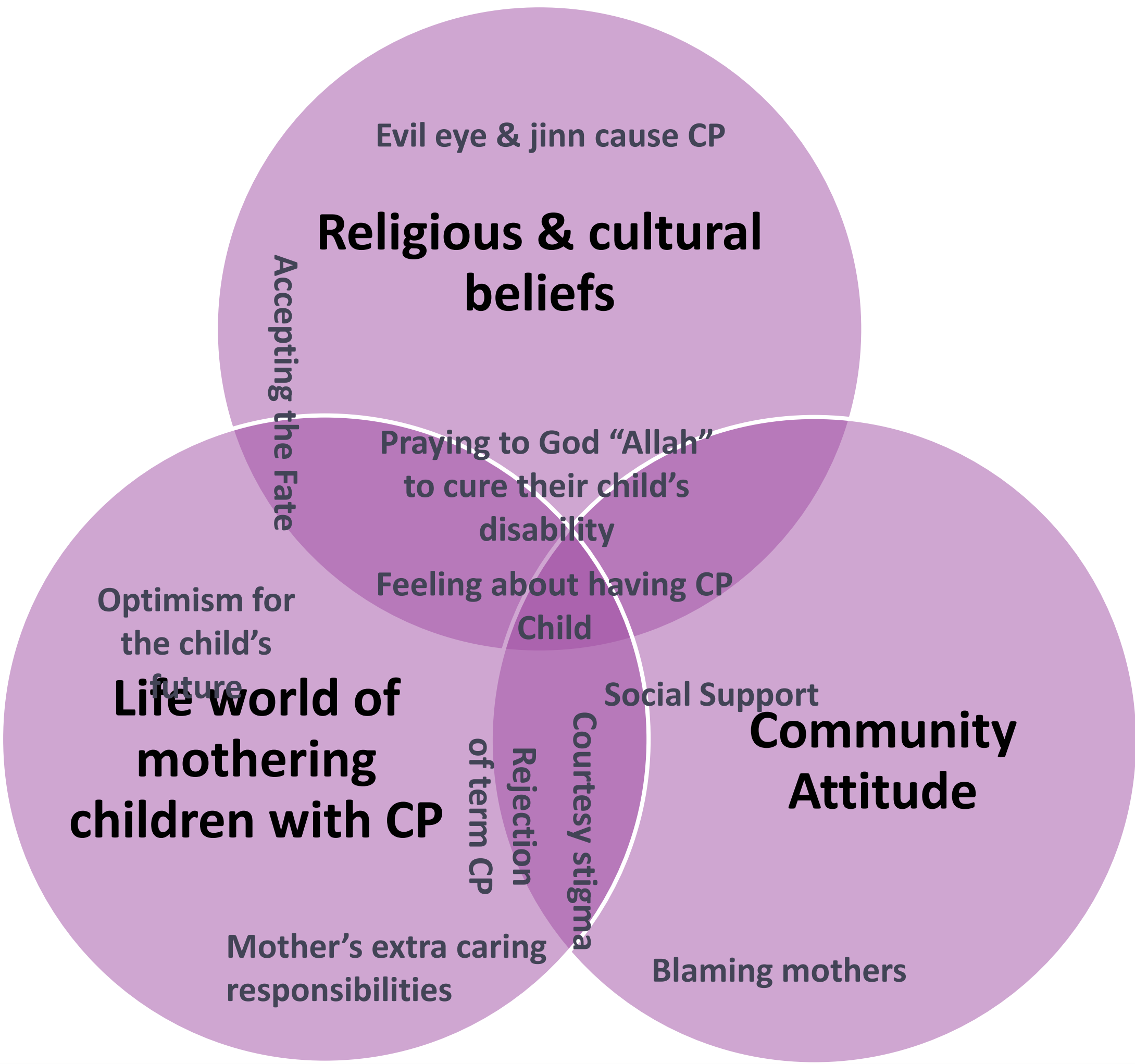
Discussion

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 about their perception, experiences, their own processes of adaptation and coping within the Saudi cultural context. The findings revealed that the dominant aspect 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 and culture beliefs suggesting that that concept of disability is framed from a spiritual perspective, not according to western disability models frameworks.

Moreover, the study explored the community and society attitude towards the child with disability and its consequences which include the stigmatization and exclusion from the society. It also explored the impact of these negative attitudes on the mother’s perception, experience and expectations, therefore in order to enhance better understanding, and integration into community, the study can help to recommend a process of mainstreaming Saudi children with CP and their families into the community, as the mothers noted that increased understanding of disability in the greater community would facilitate integration of their children.

These findings can also provide physiotherapist and health professionals with insight into the experiences those mothers in Saudi face. Outside Saudi, the experiences and cultural beliefs may be useful to health professionals who treat Saudi children who have seek medical advice abroad , as well as populations with strong similar religious beliefs.

Figure 1: The diagram considering the three main teams and the subthemes which emerged from the analysis.



Because CP is a visible disability, the mothers felt stigmatized by society at large, and particularly from 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-concept of the mother. The experience of being stigmatized also resulted in them experiencing feelings of powerlessness, social discrimination and exclusion from the society.

“They look at him and his wheelchair like a person [that] comes from another planet. They look at the disabled child differently. When people see him, they stare at him and his wheelchair. ” M1

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.

Summary

This research report the study conducted in Saudi Arabia, it has allowed mothers of children with 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 frank confusion between the two.