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The Voices of Mothers of Children with Disability in Cardenas Cuba

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This research study explores how mothers of children with disability in Cardenas, Cuba make sense of their child's disability. The primary objective of this investigation is to understand how mothers in this distinctive socio-cultural context view their child's disability and how their interpretations influence the roles and actions they take in the care and management of their child. Research methodology includes administration of questionnaire surveys, interactive interviews with mothers and participant observation of the rehabilitation environment. The research questionnaire is used to elicit demographic data, maternal attitudes toward disability, appraisal of mother's knowledge of disability, maternal caregiving roles, routines and supports. The interviews seek to uncover how mothers understand their child's condition and their experiences within the rehabilitation context. Mother-therapist interactions are the focus of the participant observation. Results from this study suggest that there is an association between Cuba's particular socio-cultural context and the roles and actions mothers in Cardenas take on when caring for their child. Cuba's community based, humanistic approach to health care provides families with dedicated, caring health professionals and fosters emotional support. Lack of material resources and cultural attitudes toward motherhood appear to constrain some mothers' agency in meeting their child's needs. Most mothers understand their child's disability from a practical, medical perspective. Findings also indicate that the roles mothers adopt in the care of their child may be classified into three categories; the resourceful mother, the good mother and the mother that is a combination of these two typologies. Quantitative information obtained through surveys support an association between demographic data and maternal attitudes toward disability. Observation of the mother-therapist dyad during rehabilitation procedures reveals friendly though passive interactions. In conclusion this study serves to elucidate the relationships between structural, institutional and individual factors that contribute to mothers understandings of their child's disability and the actions they take in supporting their child's needs. This study informs and contributes to occupational therapy practice by drawing attention the socio-cultural aspects of client centered treatment, education and advocacy.