

Caring for Children with Intellectual Disabilities in Malawi: Parental Psychological Experiences and Needs

Authors : Charles Masulani Mwale

Abstract : Background: It is argued that 85% of children with the disability live in resource-poor countries where there are few available disability services. A majority of these children, including their parents, suffer a lot as a result of the disability and its associated stigmatization, leading to a marginalized life. These parents also experience more stress and mental health problems such as depression, compared with families of normal developing children. There is little research from Africa addressing these issues especially among parents of intellectually disabled children. WHO encourages research on the impact that child with a disability have on their family and appropriate training and support to the families so that they can promote the child's development and well-being. This study investigated the parenting experiences, mechanisms of coping with these challenges and psychosocial needs while caring for children with intellectual disabilities in both rural and urban settings of Lilongwe and Mzuzu. Methods: This is part of a larger Mixed-methods study aimed at developing a contextualized psychosocial intervention for parents of intellectually disabled children. 16 focus group discussions and four in-depth interviews were conducted with parents in catchments areas for St John of God and Children of Blessings in Mzuzu and Lilongwe cities respectively. Ethical clearance was obtained from COMREC. Data were stored in NVivo software for easy retrieval and management. All interviews were tape-recorded, transcribed and translated into English. Note-taking was performed during all the observations. Data triangulation from the interviews, note taking and the observations were done for validation and reliability. Results: Caring for intellectually disabled children comes with a number of challenges. Parents experience stigma and discrimination; fear for the child's future; have self-blame and guilt; get coerced by neighbors to kill the disabled child; and fear violence by and to the child. Their needs include respite relief, improved access to disability services, education on disability management and financial support. For their emotional stability, parents cope by sharing with others and turning to God while other use poor coping mechanisms like alcohol use. Discussion and Recommendation: Apart from neighbors' coercion to eliminate the child life, the findings of this study are similar to those done in other countries like Kenya and Pakistan. It is recommended that parents get educated on disability, its causes, and management to array fears of unknown. Community education is also crucial to promote community inclusiveness and correct prevailing myths associated with disability. Disability institutions ought to intensify individual as well as group counseling services to these parents. Further studies need to be done to design culturally appropriate and specific psychosocial interventions for the parents to promote their psychological resilience.

Keywords : psychological distress, intellectual disability, psychosocial interventions, mental health, psychological resilience, children

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