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PAPER

Stress and Coping Experiences of Parents of Children with Neurodevelopmental Disorders in Sri Lanka: A Qualitative Study

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Objectives: To describe how parents of children with autism, cerebral palsy or Down syndrome understand and explain the child's disability, and identify stressors affecting these parents and their coping strategies.

Method: A qualitative, phenomenological study was carried out. Thirty parents (15 mothers and 15 fathers) of children with autism, cerebral palsy and Down syndrome aged between 3 and 11 years of age participated. Individual, semi-structured interviews were conducted with participants and tape-recorded. Transcripts of interviews were analysed for emerging themes and concepts.

Results: Most parents used medical explanations to explain their children's conditions. Some parents of children with autism used brief separation from an attachment figure as a possible reason for their child's condition. The physical burden of care, financial cost, travelling for various treatments and worries about the future were identified as being key stressors for parents. Developing a routine, facing one day at a time, avoidance and spending time with family were some of the coping mechanisms described by parents. Parents used the image of a 'special parent' to describe themselves which likely helped them to cope. Family members, friends, parents of children with similar disorders, institutions and professionals were identified as main sources of social support that helped parents cope.

Conclusions: The results of this study can help raise awareness among health care workers about the stressors experienced by parents of children with neurodevelopmental disorders in Sri Lanka and aid them to address these issues, as well as strengthen parents' adaptive coping mechanisms.