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Primary care givers experience of taking care of children with intellectual disability in Mpumalanga Province, Bushbuckridge region

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ABSTRACT

In South African communities, especially rural societies, people have little or no knowledge about intellectual disabilities (ID), their causes and how they affect specific individuals. Societies which are governed by cultural and religious norms have different perspectives with regards to ID, which can result in different experiences because of fear and/or negative attitudes towards a particular phenomenon frequently caused by a lack of information. In most societies, the key focus is on the child who is intellectually impaired in terms of his/her psychological wellbeing and little consideration is given to the wellbeing of the caregiver. This study aimed to explore the lived experiences of caregivers of intellectually impaired children in Mpumalanga Province, Bushbuckridge region taking into consideration the multiple factors which are involved when caring for children with intellectual disabilities. The study therefore aimed at discovering primary caregivers' experiences, how they react to such experiences, as well as whether culture has an impact in the understanding of intellectual disabilities and attitudes towards individuals with intellectual disabilities.

This study was qualitative utilising a phenomenological research design and interpretive phenomenological analysis to analyse the data collected. A purposive sample of nine primary caregivers whose children attended a special school in Bushbuckridge was interviewed. The primary caregivers were all females between 31 and 77 years of age. Only one primary caregiver had higher education and the other eight participants either did not have any basic education or did not complete matric. Semi-structured interviews which consisted of 22 questions about the demographic information of both caregiver and child, background, knowledge/awareness of intellectual disability as well as the psychological well-being of primary caregivers were conducted.

Most caregivers indicated that they had experienced or are still experiencing psychological strain due to caring for a child with an intellectual disability. Despite this, some found the experiences fulfilling rather than a burden. The majority of primary caregivers had no knowledge of the appropriate professionals to consult who could help their children and themselves. The caregivers had very little knowledge about intellectual disabilities and their meaning in their different cultures. Most participants emphasised religion as some took their children to church for healing and some regarded their children as gifts from God. Participants reflected about the silence around ID in their communities. All participants mentioned their uncertainties with regard to their children's education and their lives

indicating that they would be open to help and guidance with this. Primary caregivers also expressed their financial strains. Overall, the study indicated that ID awareness in the rural areas must be conducted in terms of education and to support primary caregivers of children with ID.

Keywords: intellectual disability, primary caregiver, health, rural healthcare, disability and culture