

ABSTRACT

While it is recognised that the burden on the caregiver of a person who has suffered a neurological event is great, research into the experience of caregiving and the effects of cognitive-communicative difficulties on intergenerational families is lacking. Studies examining these experiences within a multicultural and multilingual setting such as South Africa are few. The effects of neurogenic communication disorders in family systems also require further investigation. This study explores parent caregivers' experiences of caring for their once-independent adult child, who are now faced with the reality of parenting for the second time. A qualitative research design was employed. Eighteen parents of adult children who have suffered TBIs, strokes or brain tumours were interviewed. The data obtained were analysed by means of thematic analysis. Themes associated with caring for an adult child, specifically in the South African context, are identified and discussed. These themes related to the parent caregiver's experience of loss – loss of their child due to physical and cognitive-communicative difficulties as well as the loss of their own dreams and plans for the future. Multiple roles within intergenerational family systems, support and information are identified as significant factors in either minimising or exacerbating their experience of loss. These themes are explained within a Family Systems Theory framework and assist in identifying both positive and negative factors that impact on experiences of caring for an adult child. It stresses the importance of the implementation of sustainable programmes and support services specifically catering for parents of adult children with neurological communication disorders.

Keywords: caregivers, adult neurogenic communication disorders, quality of life, loss, South African context, thematic analysis, family systems theory.