ABSTRACT

Background: Most children with Cerebral Palsy (CP) are dependent on their caregivers for their activities of daily living. This places a huge responsibility on caregivers. Studies on the experiences and needs of primary caregivers of children with CP in Africa and specifically in South Africa are limited. The structures and tools needed to take care of the primary caregiver need to be explored and documented. It is important to understand the perceptions of caregivers of children living with CP on the resources and structures available to them to provide relevant, comprehensive interventions.

Methods: An explorative qualitative study design was used. Semi-structured interviews were conducted with primary caregivers of children with CP. All interviews were audio-recorded. Data analysis was guided by Colaizzi's seven-step methodology.

Results: Ten caregivers were interviewed. The study revealed financial, psychological, social and physical challenges faced by the caregivers. Caregivers also reported positive experiences from providing care such as strengthened relationships, building resilience, a sense of fulfilment and an increase in CP knowledge. Inner strength was identified as a strong support structure. There are various unmet needs that become barriers to self-care and to the role of caregiving that need to be addressed to lessen the burden of providing care.

Conclusion: The needs of caregivers should receive more attention as they carry out their caregiving role. Areas of concern such as self-care, poverty, discrimination, access to health care, and lack of health promotion knowledge need to tackling the challenges that caregivers face in their role. Healthcare interventions should cater not only for the children with CP but for their caregivers as well.

Key words: cerebral palsy, primary caregivers, experiences, support structures