ABSTRACT

Background: Many people who have suffered from a neurological condition, including stroke, have an employed caregiver who cares for them within their home environment. Previous studies have investigated caregiving within the family unit, when a family member takes the role of the primary caregiver. These family caregivers often experience many physical, emotional, and psychological burdens such as anxiety, depression, and stress. However, there seems to be a lack of investigation into the experiences and needs of employed caregivers, working as the primary caregiver within a patient's private home in South Africa.

Aims: This research aimed to explore the experiences and perceived needs of employed caregivers working for patients who have suffered from a stroke within home settings in South Africa. It further aimed to explore the unique challenges to caregiving that may be present within the South African context.

Methods: A sample of fifteen participants with experience in working as an employed caregiver for patients who have suffered from a stroke, within a home setting in South Africa, were included in the study. The qualitative research design took place in two phases. Phase one consisted of semi-structured interviews between each participant and the researcher. The open-ended questions focused on the caregivers' backgrounds, training, experiences, and possible needs while working within South African homes. Phase two involved two focus groups consisting of five participants per group. Within each focus group, open-ended questions and discussions allowed for exploration into the caregivers' experiences and needs while working in South African homes. Thematic analysis of the collected data from both phases was triangulated and analysed.

Results: The findings of the study revealed that the relationships that employed caregivers develop with patients, patients' families, and with other workers within the home setting, influence levels of happiness and burden in the caregiving role. Employed caregivers feel unheard and voiceless within South African society, as evident by their perceived lack of support, resources, and rights. The caregiver burden experienced by these caregivers seems to be influenced by contextual factors within South Africa. These factors include gender stereotypes and being task shifted between household roles, not receiving reciprocal care from employers, experiencing financial stressors, and receiving limited benefits and support both within the home and within South African society.

***Conclusion*:** The findings of this study provide insight into the experiences and needs of employed caregivers in South Africa, allowing for a recognized voice to be established for this caregiving population. The findings of this study contribute to current caregiving literature specifically with reference to employed caregivers, caring for patients who have suffered from a stroke, and caring within the South African context. The experiences and needs of employed caregivers explored in this study may lead to the development of various support structures for employed caregivers in South Africa.

Key words: Caregiver, Employed, Stroke, South Africa, Private home, Experiences, Needs, Voice, Care, Support, Training, Task shifting, Role delineation, Burden.