ABSTRACT

Introduction: The experience of undergoing a tracheotomy is an emotional journey for both a caregiver and their child. Life change is instantaneous for family members of a child with a tracheostomy as they become responsible for the child both at the hospital and at home. South Africa appears to be a unique context for the current study, with challenges such as limited resources, poverty, diversity of the population, multilingualism, and access to services such as speech therapy. Little is known specifically about the lived experiences of caregivers of children with a tracheostomy in the South African context.

Methodology: To explore the lived experiences of caregivers of the 0-5-year-old paediatric population with a tracheostomy, post hospital discharge, in the Gauteng and the Western Cape provinces of South Africa. The following sub-aims were explored: 1) the experiences of caregivers of children with tracheostomies between the ages of 0-5-years post-hospital discharge, during their transition back into family, home and society. 2) The support systems available to the caregivers. 3) To gain insight into the role of caregivers. A qualitative and interpretative phenomenological approach was employed. Semi-structured, face-to-face interviews were conducted in English & IsiXhosa, using open-ended questions. The study consisted of ten caregivers of children with tracheostomies, who were recruited from two government hospitals in the Gauteng and Western Cape Provinces. The study included caregivers of children of any gender, between the ages of 0-5 years, who had a tracheostomy for at least one month, and had been discharged from the hospital for at least one month. Data was collected over a three month period. Data was transcribed and analysed using thematic analysis.

Results: The experiences of the caregivers appeared to be complex and individually-based. The results confirmed that not only do these experiences include coping with the physical properties of the tracheostomy, but also the medical and emotional experiences. Caregiver roles, the grief process, faith and family support were significant themes that emerged as contributing to the experience of home-based care for the caregivers.

Conclusions: Feelings and attitudes are inseparable from the health condition itself, and thus the insertion of a tracheostomy is not just a medical experience, but rather a combination of concomitant emotional feelings and experiences. The results of this study correlated with the biopsychosocial model of a health condition, illustrating the close connection between one's health, activities and participation within one's context, whereby the diagnosis and insertion of a tracheostomy, contributed to multiple experiences and changes in the lives of the caregivers, specifically in their home, social and family environments. The financial, social, emotional and physical implications expressed by the caregivers suggested that perhaps home-based care is not ideal for caregivers in the South African context.

Implications: Results obtained increase awareness and provide valuable information to nurses, medical practitioners, speech therapists, speech therapy students, as well as amongst caregivers themselves of children with medical conditions, specifically, those with a tracheostomy. Speech therapists have a very important role in advocating success of reintegration back into their family, home, and society, post discharge from the hospital. Faith, religious practice and the grief process can be used as tools to strengthen relationships between patients, families and medical practitioners. The potential benefit of caregiver support groups was emphasized.

Keywords: caregiver, experiences, children, tracheostomies