

“We Do Not Understand Each Other:” The Experience of Caregivers of Deaf Children in a Rural South African Setting

Abstract

The complexities of deafness, especially within a rural context characterised by poverty of resources and structural barriers to agency and self-efficacy, suggest that childhood deafness may impact significantly on the experience of caregivers of deaf children. Theoretical, practical, audiological, and contextual contributions to the understanding of deafness and Deafness revealed that these can impact on the caregivers' experience as do factors related to the specific support structures and requirements of caregivers of deaf children in a rural setting.

A qualitative approach was used in this study so as to interact respectfully within a human rights viewpoint. The experience of caregivers of deaf children in the Ehlanzeni District of Mpumalanga, South Africa, was explored by conducting 19 semi-structured ethnographic individual interviews and two group interviews with caregivers of deaf children. The participants were recruited through purposive, convenience sampling and snowball sampling strategies. Interviews were conducted in siSwati, South African Sign Language (SASL), and English. One principal and two assistant context mediators were recruited to conduct the interviews in siSwati and SASL. The siSwati and SASL interview transcriptions were translated into English and these, together with the transcriptions of the interviews conducted in English, underwent thematic analysis using the Framework method.

Five overarching domains appear to characterise the caregivers' experience: communication, finances, schooling, psycho-emotional support, and the caregiver role. Within these five domains, sub-themes were identified which delineated the specifics of each domain. This thesis confirms that the experience of deafness is mediated by its context.

Within the five interconnected domains, caregivers within this study, especially women, appear to have low self-efficacy and agency within their constrained structural setting and seem to experience a devolution of agency and also an embodied third-party disability.

These findings have implications for practice, policy, education, and further research with regard to the need for contextually attuned interactions and mutually co-constructed opportunities for structural developments and agency enhancement.

Keywords: deafness, Deafness, deaf children, caregivers, South Africa, Mpumalanga, siSwati, South African Sign Language (SASL), audiology, qualitative research, context, self-efficacy, agency, structure, disability, devolution, embodiment, third-party disability, community of practice (COP).