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Context, culture and disability : a narrative inquiry into the lived experiences of adults with disabilities living in a rural area.

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ABSTRACT

This thesis documents the everyday experiences of adults with disabilities living in a rural area of South Africa. Given South Africa's tumultuous history, characterised by human rights violations incurred through cultural, political and racial disputes, and the country's current state of socio-economic and political turmoil, violence has come to represent a core feature in the lives of many South Africans. This, together with the impact of unemployment, food insecurity and unequal power distribution, has significantly affected the ways in which many people make sense of their life experiences. Despite the fact that exposure to unequal power dynamics, violence, marginalisation and exclusion are documented to dominate the life experiences of people with disabilities, little is understood about the ways in which these aspects manifest in the interpretation and reconstruction of experiences.

Previous research into the field of disability studies has depended primarily on quantitative measures, or on the reports of family members and caregivers as proxies, perpetuating the cycle of voicelessness and marginalization amongst adults with disabilities. Those studies which have adopted qualitative measures in order to explore the psychosocial experiences of disability have focussed largely on the limitations imposed by physical access, and have relied predominantly on the medical and social models of disability, or on the World Health Organisation's International Classification on Functioning, Disability and Health (WHO ICF, 2001). These models consider the psychosocial experience of disability to be universal, and do not adequately take into account the impact of cultural and contextual variables. This has negatively impacted on the establishment of a research repository upon which evidence-based practice has been developed.

This thesis aimed to explore and document the lived experiences of 30 adults with a variety of disabilities, living in 12 rural villages in the Mpumalanga Province of South Africa. A combination of narrative inquiry and participant observation was employed in order to examine the relationship between personal and social interpretations of experience. Data analysis was conducted using a combination of Clandinin and Connelly's (2000) Three Dimensional Narrative Inquiry Space, Harré's Positioning Theory (1990, 1993, & 2009), and Thematic Analysis (Braun & Clarke, 2006).

Results revealed that narratives were plurivocal in nature, giving rise to a complex relationship between personal and social interpretations of experience. The findings highlighted the impact of cultural norms, values and roles on making sense of experiences associated with disability. Four new types of narrative emerged, none of which conformed to the current interpretations of lived experience as reported in the literature. All of the narratives were pervaded by the embodied experience of violence, including evidence of structural, physical, psychological and sexual violence, as well as violence by means of deprivation. This gave rise to a sense of moral decay and highlighted the ways in which abuse of power has become woven into lived experience. In this way insight was gained into the complex interplay between impairment, exclusion, high mortality rates, violence, and poverty in rural areas.

Narrative inquiry proved to be a particularly useful tool for providing insight into disability as a socio-cultural construct, drawing attention to a variety of clinical, policy and theoretical implications. These gave rise to a number of broader philosophical questions pertaining to the role of memory, vulnerability and responsibility, and the ways in which all citizens have the potential to be complicit in denying the reality of lived experience amongst vulnerable members of society. These findings demand attention to the ways in which governments, communities and individuals conceive of what it means to be human, and consequently how the ethics of care is embraced within society.

Key Words: disability, context, culture, violence, narrative inquiry, responsibility