



**Challenges Experienced by Primary and Secondary
Caregivers of Children on Antiretroviral Therapy at
Mutale Municipality in the Vhembe District of
Limpopo Province**

by

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Dissertation Submitted in Fulfillment of the Requirements for the Degree:

Master in Public Health (MPH)

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28 April 2015

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ABSTRACT

Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS), commonly referred to as HIV/AIDS, has a devastating impact on the lives of African men, women and children. HIV/AIDS decreases the life expectancy of affected South Africans and leave many families and children socially and economically vulnerable, and socially stigmatized. HIV/AIDS also results in increasing numbers of AIDS orphans and mortality among young adults. In 2007, 12.1 million South African (SA) children were estimated to have been orphaned due to HIV/AIDS. In addition, 300 000 SA children were estimated to be in need of antiretroviral (ARV) treatment (ART) in 2010, whilst the estimated ARV coverage was at 36%.

This study explored and described the challenges experienced by primary and secondary caregivers of children on antiretroviral therapy (ART) at Mutale Municipality, Vhembe District in the Limpopo Province. The study sought to achieve the following objectives: (i) identify the challenges experienced by primary and secondary caregivers of children on ART at Mutale Municipality, Vhembe District, (ii) to encourage government to use the identified challenges to develop more programmes to improve the quality of life of caregivers of children on ART and (iii) stakeholders may use the identified challenges to advocate for revision existing or development of newer policies to address the challenges experienced by caregivers.

The research design was qualitative, explorative, descriptive and contextual in nature. The study population consisted of all primary and secondary caregivers of children 0 to 15 years of age on ART at Mutale Municipality from April 2013 to March 2014. Non-probability, purposive sampling was used to select participants. The objectives of the study were met through data collection by means of unstructured interviews. One central question was asked and more questions emanated from the discussion. Data collection was done up to 16 female caregivers because no new information was forthcoming from the caregivers. Participants

were 10 primary caregivers and 6 secondary caregivers. The ages of caregivers ranged from 25 to 84 years. Tesch's open-coding method was used to analyze qualitative data in this study.

Data from participants were collated into themes and sub-themes. Three themes from primary and secondary caregivers emerged from analysis of the raw data, namely, (THEME 1) challenges faced by caregivers of children on ART, (THEME 2) psychological challenges experienced and (THEME 3) positive perceptions related to caring for children on ART. Sub-themes that emanated from THEME 1 were financial challenges, treatment management challenges, disclosure and non-disclosure complications, negative attitudes from family members and the community, stigma attached to HIV, ART and children, learning disabilities and inadequate support services from government and community structures. Sub-themes that stemmed from THEME 2 were feelings of hopelessness, sadness, depression, loneliness and isolation, whereas those that derived from THEME 3 related to benefits of disclosure to caregivers, children and the community. Sub-themes identified from THEMES 1 and 2 impacted negatively on caring for children on ART while THEME 1's sub-themes on disclosure of an HIV-positive status impacted positively on social support and psychological well-being of some caregivers.

The trustworthiness of the qualitative data was established following four criteria, namely, credibility, transferability, dependability and confirmability. Participant's rights were respected. Permission to conduct a study was sought from relevant authorities. In addition, freedom from harm was ensured, and the right to privacy and right to self-respect was maintained. It is recommended that all primary and secondary caregivers be motivated to participate in community projects to generate income and alleviate poverty. The study suggested that the government should develop organizations or community centres that will support and empower caregivers to cope with challenges of caring for children on ART. The conclusions were discussed in relation to the objectives of the study, specifically that primary and secondary caregivers of children on ART receive inadequate support services from government and community structures to secure financial and food security for affected children.