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Full Length Article

Accessing antiretroviral therapy for children: Caregivers' voices

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ABSTRACT

Despite efforts to scale up access to antiretroviral therapy (ART), particularly at primary health care (PHC) facilities, antiretroviral therapy (ART) continues to be out of reach for many human immunodeficiency virus (HIV)-positive children in sub-Saharan Africa. In resource limited settings decentralisation of ART is required to scale up access to essential medication. Traditionally, paediatric HIV care has been provided in tertiary care facilities which have better human and material resources, but limited accessibility in terms of distance for caregivers of HIV-positive children. The focus of this article is on the experiences of caregivers whilst accessing ART for HIV-positive children at PHC (decentralised care) facilities in Nelson Mandela Bay (NMB) in the Eastern Cape, South Africa. A qualitative, explorative, descriptive and contextual research design was used. The target population comprised caregivers of HIV-positive children. Data were collected by means of in-depth individual interviews, which were thematically analysed. Guba's model was used to ensure trustworthiness. Barriers to accessing ART at PHC clinics for HIV-positive children included personal issues, negative experiences, lack of support and finance, stigma and discrimination. The researchers recommend standardised programmes be developed and implemented in PHC clinics to assist in providing treatment, care and support for HIV-positive children.

1. Introduction

'No child should die due to lack of access to treatment' (UNAIDS, 2011). In order to achieve the vision of zero AIDS-related deaths proposed by the World Health Organisation (WHO), everyone living with human immunodeficiency virus (HIV) needs to have access to life-saving medication in the form of antiretroviral therapy (ART) (WHO, 2013). Approximately 260,000 (712 per day), children were newly infected

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with HIV during 2012, bringing the total number of children living with HIV to 3,3 million, 91% of whom live in sub-Saharan Africa (Elizabeth Glaser Pediatric Foundation, 2014 & UNICEF, 2013). Only 34% of the above mentioned children received ART in 2012 (UNICEF, 2013). The Joint United Nations Programme on HIV/AIDS (UNAIDS, 2011) highlights the need to adopt a holistic approach that builds on the country's existing maternal and new-born health platform in order to ensure the optimal impact of ART, care and support for HIV-positive children, particularly at the primary health care (PHC) level.

An impacting factor on morbidity and mortality rates in HIV-positive children in developing countries is under nutrition, caused mostly by lack of food in the household. In resource poor settings, such as where this study was done, food insecurity exacerbates lack of adherence to ART, which furthermore accelerates the progression of HIV infection to AIDS (Ivers et al., 2009). Early and intensive dietary interventions should be a fundamental part of the case management of HIV-infected individuals, especially children (Duggal, Chugh, & Duggal, 2012). The previous statements concur with reports of the levels of stunting, underweight and wasting in children in Africa (36% in 2011), which significantly increases under-five mortality rates in South Africa (UNICEF-WHO-World Bank, 2012).

The challenges to paediatric HIV care and treatment in South Africa are therefore multifaceted and further include lack of sufficiently trained healthcare professionals, inadequate facilities, drug regimens that are too complicated for caregivers to understand, particularly those who are illiterate; and lack of paediatric drug formulations (Meyers et al., 2007). Additional difficulties include the complexity of early infant diagnosis, lack of funds and personal/family challenges related to the caregivers (Fayorsey et al., 2013). Decentralisation of ART from tertiary sites – usually meaning a centrally placed hospital – to PHC clinics is essential for HIV-positive children in order to bring treatment closer to where children live (Rabie, 2009). Brichard and Van Der Linden (2009) advise that early HIV diagnosis, followed by immediate commencement of ART in infants who are HIV-positive, can reduce infant mortality by 76% and HIV progression by 75%. Once children begin treatment, the next obstacle is increasing retention on ART. Optimal adherence rates to ART are essential to suppress viral replication, which in the case of HIV-infected children has to be done by motivated caregivers (Vreeman et al., 2010).

1.1. *Statement of problem*

HIV-positive infants and children are being lost to follow-up after diagnosis, and before referral for ART, owing to the centralisation (at tertiary hospitals) of ART services (Morsheimer, Dramowski, Rabie, & Cotton, 2014). Hospitals are out of reach of most HIV-positive children due to the inability of their caregivers to travel the distance requisite to accessing treatment. Therefore decentralisation of ART services at PHC level is essential to improve the acquisition of ART for HIV-positive children (Rabie, 2009). The researchers noted that larger numbers of children in Nelson Mandela Bay (NMB) were being treated at public hospitals than at the clinics selected for this study, with raw data statistics indicating that 12, 592 children access ART at hospitals in NMB as opposed to the 479 children accessing ART at the six purposively sampled PHC clinics used in this study (District Health Information Systems, 2010).

The South African Department of Health (2004) emphasises the need to maintain optimal (95%) adherence to ART. Numerous challenges are experienced by caregivers regarding accessing ART for their HIV-positive children, such as the cost of travelling. Stigma remains a burden, is still widely encountered in many healthcare facilities, and leads to caregivers avoiding their local PHC clinics to access ART. Additional issues are the reported shortage of trained staff, long waiting times and lack of integrated services for HIV-positive children and their caregivers (International Treatment Preparedness Coalition, 2011). The dichotomy between the dire need for, and provision of, ART for children, particularly at decentralised levels such as primary healthcare clinics, initiated the research study. The aim of this study was to explore and describe the experiences of caregivers accessing ART for their HIV-positive children at PHC clinics in NMB, particularly related to the more vulnerable under-five age group.

1.2. *Contribution to the field*

The unique contribution of this article is the voices of the participants as they relate their experiences of accessing ART for their HIV-positive children, which will assist to improve access to ART at PHC clinics in NMB.

2. Research design and methods

Qualitative research was chosen because of its ability to provide the 'human' side, emphasising certain significant characteristics of how caregivers experience accessing ART for their children (Streubert & Carpenter, 2011). Descriptive was selected in order to describe the phenomena of interest as accurately as possible and portray how things naturally happen (Rebar, Gersch, MacNee, & McCabe, 2011). Exploration in qualitative research is considered to be inductive, and accomplished by flexible and reflexive methods of data collection and analysis. The researchers sought to understand perception and behaviour from the participants' own experiences, in their own words and in the context in which they live and work (Streubert & Carpenter, 2011). Context is important to augment description and exploration therefore PHC clinics that provide ART services in the NMB in the Eastern Cape were used. The population in NMB comprises 1.152.115 people, of which 25.5% are children under the age of 14 (Statistics South Africa, 2011). The areas in which the PHC clinics are situated are amongst those with extremely low socio-economic circumstances, 58.2% of the population receive at least one grant per household and 70.7% have to utilise public health facilities (Statistics South Africa, 2011).

2.1. *Population and sampling*

The research population comprised of caregivers of HIV-positive children who have to access ART at PHC clinics in