

## “It’s my secret”: Barriers to paediatric HIV treatment in a poor rural South African setting

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In South Africa, a third of children born are exposed to HIV, while fewer undergo an HIV confirmatory test. Anti-retroviral therapy (ART) coverage among children remains low-despite roll-out of the national ART programme in South Africa in 2004. This study sought to understand critical barriers to seeking HIV-related care for children in rural South Africa. Data presented in this article derive from community-based qualitative research in poor rural villages in north-east South Africa; this includes 21 in-depth interviews in 2008 among caregivers of children identified as HIV-positive in 2007 from a randomly selected community-based sample. Using NVIVO 8, data were coded and analysed, using a constant comparative method to identify themes and their repetitions and variations. Structural barriers leading to poor access to health care, and social and systems barriers, all influenced paediatric HIV treatment seeking. Of concern was the expressed need to maintain secrecy regarding a child’s HIV status to avoid stigma and discrimination, and misconceptions regarding the course of HIV disease in children; this led to a delay in seeking appropriate care. These barriers need to be addressed, including through focused awareness campaigns, improved access to health care and interventions to address rural poverty and development at both household and community levels. In addition, training of health care professionals to improve their attitudes and practice may be necessary. However, this study only provides the perspective of the caregivers; further studies with health care providers are needed to gain a fuller picture for appropriate policy and practice guidance.

**Keywords:** ART; barriers to health care; children; HIV; rural South Africa

### Introduction

There has been a steady decline in the prevalence of paediatric HIV in South Africa in the past decade (Shisana et al., 2005, 2009). However, nearly half (44%) of the mortality of children <15 years is HIV-related (Dorrington, Johnson, Bradshaw, & Daniel, 2006). While some third of infants are HIV-exposed, fewer undergo the confirmatory viral detection test [HIV DNA PCR test (Meyers et al., 2007)]. Anti-retroviral therapy (ART) coverage for children remains low (Johnson, 2012), due to lack of awareness, misclassification of HIV stage and socio-economic barriers (Feucht, Kinzer, & Kruger, 2007; Meyers et al., 2007; Yeap et al., 2010). This study aimed to better understand barriers to HIV-related care for rural South African children.

### Methods

The study, conducted in a poor rural community of Tsonga-speaking people in Mpumalanga Province,

South Africa, was nested within the Agincourt health and socio-demographic surveillance system (HDSS; Kahn et al., 2007). There is high migrant labour, unemployment and poverty, with limited access to public health care and transport (Collinson, 2010; Kahn et al., 2007). A third of pregnant women visiting public clinics are diagnosed as HIV-positive (National Department of Health, 2011).

In 2007, we conducted community-based voluntary HIV testing and caregiver counselling with disclosure for 880 children aged 1–5 years, randomly selected, in the rural Agincourt sub-district. We used two concurrent rapid HIV tests – Uni-Gold™ (Trinity Biotech, Ireland) and Determine™ (Abott, Germany). Children with HIV-positive or indeterminate results were referred to community health facilities for further investigations, support and treatment. One year later (in 2008), we followed up the HIV-positive children ( $n=35$ ). Caregivers who consented ( $n=31$ ) responded to a semi-structured

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questionnaire on socio-demographics, child's health status, health seeking and feeding. Caregivers aware of the child's positive HIV status ( $n = 22$ ) participated in in-depth interviews on attitudes and reactions to knowing the child's HIV status, experiences in caring for an HIV-positive child and access to ART- and HIV-related support. Interviews were conducted by local Tsonga-speaking fieldworkers and were tape-recorded (Kimani-Murage, Manderson, Norris, & Kahn, 2010).

Transcribed files were imported into NVIVO 8 software (QSR International Pty, Ltd.) for coding. Analysis was inductive and drew on respondents' narratives, with constant comparison across interviews to identify themes and variations (Ryan & Bernard, 2003). Meta-codes and primary themes were identified and discussed with all authors to ensure consistency of understandings and interpretation.

Ethics approval was granted by the University of the Witwatersrand Committee for Research on Human Subjects (Medical). Signed informed consent was obtained from each caregiver.

## Results

Of 841 consenting caregivers (96%) in 2007, all but two elected to receive the test results; only three knew their child's HIV status beforehand. Thirty-five (4.2%) children tested HIV-positive and 1 had indeterminate results. Thirty-one of 35 caregivers participated in the follow-up study; two children had died, one was away with the mother, and one caregiver declined to participate. Most caregivers were the biological mothers ( $n = 24$ ); four were grandmothers, three other female relatives. The mean age of the caregivers was 33 years (range 18–61), and over half had no formal education or incomplete primary education.

### Seeking ART

Three children were initiated on ART by 2008. Eight other caregivers had sought ART, but this had not commenced as the child's immune system was said to be strong enough, or they were awaiting eligibility tests. However, primary reasons for not initiating ART were social, structural, financial and health system barriers, as described below.

### *Risks of disclosure and the importance of privacy*

While many caregivers disclosed the child's HIV status to close relatives, particularly the child's father, about half wished to keep it secret. Caregivers

believed that confidentiality would be broken by local health workers or home-based carers who follow up those on treatment, and were thus reluctant to present their child for care. For both child and mother, disclosing a child's positive status was associated with high perceived social costs, including stigma and discrimination/isolation, with perceived detrimental effects on the child's development. Caregivers reported negative treatment from health workers: "They were treating me in a bad manner, so I didn't go back. The way they talk, it didn't make me feel comfortable" (Mother, 42 years).

### *Misconceptions about paediatric HIV and treatment*

Health care providers at times advised caregivers that the child was too young for ART. Caregivers believed that children could be cured with good feeding, traditional medicine or stopping breastfeeding, or that the child's blood was "dirty" and could be cleaned. Adults in contrast lacked the time to heal and so took ART, however, ART was not believed to cure the disease and so people chose traditional medicine for children. Traditional healers viewed children as bewitched, so requiring their treatment: "I have also gone to the traditional healers, they said that the child was bewitched. They gave me so many medicines it's like I was having a pharmacy" (Mother, 34 years). The narrative below elaborates on such perceptions:

(HIV) means that her blood is dirty... I know that if I give her this food with energy, in the end, this blood will be clean; she is still young enough to be cured... It is easy for a young child to be cured, it is the same as a child who injured an arm or leg... it is not the same with an old person... AIDS tablets do not cure HIV, they quieten it. If you abandon them (ARVs), it (the virus) will wake up. I think it is better to leave them. I give her (the child) traditional medicine, it is killing (the virus)... we syringe her (with traditional medicine) so that the dirt inside comes out... Pills (ARVs) are better for me because I am old. (Mother, 42 years)

### *High cost of treatment*

Caregivers explained that both direct and indirect costs prevented their seeking treatment. At the time of the study, ART was available from one public-private health centre in the study site, distant from many villages and at district hospitals, even further away. Antiretrovirals (ARVs) were free, but people had to pay an enrolment fee and pay for drugs for opportunistic infections; they, therefore, considered the costs of ART prohibitive. Transport costs, long

queues and waiting time all discouraged access. Access to treatment was also affected by delays in acquiring test results, including CD4 tests to determine eligibility. Respondents described having to return repeatedly to the health facility until they gave up. Psychological costs related to concerns about confidentiality and health workers' negative attitudes.

## Discussion

Community-based HIV counselling and testing for children is uncommon in sub-Saharan Africa including South Africa, and existing studies are largely among children already enrolled in HIV programmes or visiting health facilities (van Dijk et al., 2009; Yeap et al., 2010). We address this gap by identifying barriers to paediatric HIV treatment uptake at community level. Two barriers were especially concerning: caregivers lacked confidence that their child's status would be kept confidential and held misconceptions about HIV disease in children. There is need to consider how to overcome these barriers to enhance timely uptake of paediatric ART.

At the time of the study, the South African National Guidelines recommended that infants be tested at 6 weeks and accepted for treatment subject to certain clinical and social criteria (National Department of Health, 2005). However, only 3 of 35 caregivers knew that their child was HIV-positive, and there were reports of health workers declaring the child "too young" for ART. Caregivers consequently sought traditional treatment. As is widespread, caregivers believed that traditional healers and medicine can cure HIV, and consulted healers for many childhood illnesses including to clean "dirty blood" (Friend-du Preez, Cameron, & Griffiths, 2009; Peltzer, 2009; Peltzer, Mngqundaniso, & Petros, 2006). Several caregivers also feared stigma and discrimination, and, therefore, chose to keep the child's HIV status a secret. As noted by others, early disclosure is critical for prompt health care seeking but may lead to detrimental effects to child and mother (Medley, Garcia-Moreno, McGill, & Maman, 2004).

Structural barriers affecting health care access include physical, financial and organisational constraints, high levels of poverty (Gelb, 2003), high unemployment (Collinson, 2010), and the ongoing socio-economic impacts of HIV/AIDS (Hunter, Twine, & Patterson, 2007). The South African child support grant, instituted to alleviate poverty, was insufficient to adequately support children (Kimani-Murage et al., 2010); however, caregivers relied on

this because of limited employment opportunities. Other barriers included distance to health facility, delays, high costs of seeking care and irregular public transport (Kahn et al., 2007).

There was a striking lack of awareness and misperceptions of paediatric HIV disease and treatment, and fear of stigma and discrimination, despite multiple communication campaigns. Immediate actions are needed to enhance awareness of paediatric HIV and treatment, address misconceptions, increase access to treatment and care and improve attitudes and practices of health professionals. Further research can help determine effective ways of communicating health messages. This study focused on the demand side, and studies of health providers' views would help complete the picture.

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