

“It’s my secret:” Barriers to paediatric HIV treatment and related health care in rural South Africa

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Abstract

Without anti-retroviral therapy, half of all children infected with HIV will die before 2 years. Fewer than a quarter of children who need ART receive treatment in sub-Saharan Africa.. In this article, we describe barriers to paediatric treatment from a community perspective in rural South Africa. Data, drawn from interviews with caregivers of children identified as HIV positive in 2007 were supplemented by discussions with home-based care groups and a Community Advisory Group. Socio-demographic data were analysed using Stata. Qualitative data were coded in NVIVO 8 and analysed inductively to identify themes and their repetitions and variations. Paediatric HIV treatment and care is limited by poor access to health care, organisational and systems barriers, informational barriers, and social and attitudinal barriers to knowledge of a child's status and concern about discrimination. The results highlight the need for interventions to address these barriers, through focused awareness campaigns and interventions to improve livelihoods and access to ART and related care.

The majority of children aged less than 15 years, living with HIV, are from sub-Saharan Africa (Joint United Nations Programme on HIV/AIDS(UNAIDS), 2010). Although the prevention of mother-to-child-transmission is the most efficient and cost-effective way of preventing paediatric HIV, it is also critical that HIV is diagnosed and treated early in children because it progresses rapidly (European Collaborative Study, 1994). ART improves immunological outcomes, morbidity and survival (Fassinou, et al., 2004), and should be initiated early. However, in sub-Saharan Africa, less than one quarter of HIV infected children under 15 years who need ARVs are on treatment (WHO/UNAIDS/UNICEF, 2010).

South Africa has one of the most severe HIV epidemics in the world. Nationally, about a third of pregnant women visiting antenatal clinics are HIV-infected (Department of Health, 2008); about 5% of children aged 2-4 years are infected (Shisana, et al., 2005), and close to half (44%) of mortality of children < 15 years is HIV-related (Dorrington, Johnson, Bradshaw, & Daniel, 2006). Since 2003, the South African government has scaled-up HIV-related services including roll-out of free ART in public health facilities, but access to and utilisation of these services remains problematic (Department of Health, 2007; Doherty, et al., 2003; Dorrington, et al., 2006).

Between April and August 2007, we conducted community based voluntary HIV testing and caregiver counselling for children aged 1-5 years, randomly selected, in Agincourt, rural South Africa. We used two concurrent rapid HIV tests – Uni-Gold™ (Trinity Biotech, Ireland) and Determine™ (Abott, Germany). The testing was voluntary, as it was undertaken for research not therapeutic purposes. Results were disclosed to the child's caregiver only if he or she wished,

although the importance of knowing the child's status was explained to the caregivers during counselling. Children determined positive and those with indeterminate results were referred to community health facilities for further investigations and support. In total, 841 (96%) of participants consented to testing, and all but two received the test results: 35 (4.2%) children tested HIV positive and one had indeterminate results. A year later, we followed-up the caregivers of those children identified as HIV positive. In this article, we describe the barriers to ART and related care for these children, from the perspective of the caregivers and other community members.

Methods

The study was conducted in the Agincourt sub-district of Mpumalanga Province, rural northeast South Africa, bordering with Mozambique. The study was nested within the Agincourt health and socio-demographic surveillance system (HDSS) framework, which from 1992 until 2007 (when the site was extended) followed some 70,000 people living in 21 contiguous villages (Kahn, et al., 2007; Kimani-Murage, Kahn, et al., 2010). The population comprises Tsonga-speaking people, around 30% of whom had entered South Africa from Mozambique following the civil war. The poverty level in the area is high (Gelb, 2003), with most people working as wage labourers, particularly on commercial farms and mines, nearby and elsewhere in the country (Collinson, Tollman, & Kahn, 2007; Collinson, Tollman, Wolff, & Kahn, 2006). Despite government development initiatives, infrastructure is limited. A network of five primary care clinics refer patients to a larger public health centre, and this is 25 kilometers from the nearest district hospital. About a third of pregnant women visiting public health clinics are HIV positive (Department of Health, 2008).

The study on which we draw in this article was conducted between May and June 2008, and involved 35 children aged 2-6 years (12 boys and 23 girls), identified as HIV positive the previous year from a random sample. A semi-structured questionnaire was administered to all caregivers who were available and consented to participation (n=31), and in-depth interviews were conducted with those caregivers aware of the child's positive HIV status (n=22). The questionnaire included sociodemographic details of the caregiver and open-ended questions on child's health status, health seeking, and feeding. In in-depth interviews, we explored 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.

Field work was conducted by three local fieldworkers, one female, two males, whose first language was Tsonga. They were well trained in collecting qualitative data and the specific study before beginning field work. Both the questionnaire and in-depth interview guide were translated by first language Tsonga speakers from English to Tsonga, then retranslated back to English to enable the principal researcher, who was not Tsonga speaking, to ensure that meaning to questions was not lost in the translation. The questionnaire was administered first, and an appointment was made for an in-depth interview on a different day. Interviews were conducted in Tsonga and were tape-recorded. Two respondents refused tape-recording, but neither was aware of the child's HIV status and so only responded to the questionnaire. The questionnaire took about 20-30 minutes to complete; in-depth interviews took between 45 and 90 minutes. Transcription and translation of interviews were undertaken by a local first-language Tsonga speaker. Data from the caregivers were supplemented with data from focus group

discussions (FGDs) with participants from five home-based care groups (HBCGs) operating in villages in the study area, and the Community Advisory Group (CAG).

Ethical approval for the study was granted by the University of the Witwatersrand Committee for Research on Human Subjects (Medical). Written informed consent was obtained from each caregiver separately for the questionnaire and the in-depth interview. Group verbal consent was obtained from the HBCGs and the CAG.

Qualitative data analysis was inductive: themes were developed from literature and from respondents' narratives. Preliminary analysis occurred concurrently with the continued administration of interviews to identify emergent themes to pursue in subsequent interviews (Guest, Bunce, & Johnson, 2006). Transcribed word files were imported into NVIVO 8 software (QSR International Pty Ltd). Primary coding of the transcripts was undertaken by the first author; following this, meta-codes and primary themes were identified. Authors then discussed these findings to ensure consistency of understandings and interpretation. Analysis across all transcripts was conducted using a constant comparative method to identify themes and their repetitions and variations (Ryan & Bernard, 2003; Strauss & Corbin, 1990). Questionnaire data were analysed using Stata version 10.0 (StataCorp LP, USA).

Results

As indicated, 31 of the 35 caregivers of children determined HIV positive in 2007 participated in the 2008 follow-up study; two children had died, one was away with the mother, and one caregiver refused to participate. Most caregivers who participated were the biological mothers (n=24); four were grandmothers and three were other relatives. Over half the caregivers had no

formal education or some primary education only (see (Kimani-Murage, Manderson, Norris, & Kahn, 2010).

Twenty four caregivers knew the child's HIV status, three before the 2007 screening. Results were not disclosed to two mothers, one because she did not await the test results and the other because she did not want to know, and non-maternal caregivers who took on caregiving after the 2007 screening also did not know the child's status. In-depth interviews were only conducted with caregivers who knew the child's HIV status, and were willing to be interviewed. Twenty two caregivers participated in in-depth interviews; two refused after responding to the questionnaire. One interview was erroneously not recorded, and consequently the data below derive from 21 in-depth interviews (19 with mothers, one with a grandmother, and one with a sibling), from open-ended questions in the questionnaires, and from focus group discussions.

Seeking anti-retroviral treatment and HIV-related care

Although caregivers generally accepted the test results and were optimistic about their child's future (Kimani-Murage, Manderson, et al., 2010), only three children had been initiated on ART in 2008. Eight other women had sought ART, but their children were not yet on medication. Barriers to paediatric ART provided by caregivers and other members of the community are described below.

Social barriers

Although children had been tested and results disclosed to all but two caregivers in 2007, not all caregivers knew the child's HIV status – two biological mothers who did not seek to know the

results, and five non-mother caregivers who had taken on caregiving after the 2007 screening. In four cases, the results of the child's HIV test had not been disclosed to the non-mother caregiver before the death of the mother. Disclosure of the test results was expressed as a difficult task, as respondents expressed: "I never told anyone," "I don't want to talk about it," "it is my secret." Most people only felt comfortable disclosing to their close relatives, primarily the child's father, and where the child's father was not part of the family, to other relatives including grandparents or child's siblings, who were often the next-line caregivers.

Failure to disclose related to lack of trust that others would maintain confidentiality, and fear of stigma and discrimination of the child and the mother:

I don't like telling other people because if you tell a person he/she will tell their friends. ... Some can say, 'this child is ill; do not play with her, she has a certain illness'. You know children will keep on telling each other that this child is ill, it will go all over the place. ... Someone may kill your child, because you said she has a particular illness. The time when I grew up it was said that our father had TB, because the neighbours knew about it, they finally killed him and they said he was killed by TB. If they didn't tell one or two people that he has TB, he would be alive (Mother, 42 years).

Failure to disclose test results prevented some caregivers from acquiring HIV-related support for their children, and few caregivers accessed special support and services for people living with AIDS, such as food supplements or being in support groups.

There were considerable gaps in knowledge about paediatric HIV testing, HIV status and treatment. Only three caregivers knew the child's HIV status before the 2007 screening, and

there were several misconceptions regarding paediatric infection and treatment, including that children were too young to be tested for HIV, that HIV did not exist or that it was caused by witchcraft. However, in one group discussion it was emphasised that witchcraft related to adults but not to children:

People do not want to admit their children are HIV positive. They want to hide behind other names like TB; for example people from Mozambique do not understand HIV, they say it is *inzaka* (witchcraft) (Community Group B).

Our people have a problem, some of them when they are sick they say that they are bewitched, some of them say they have a disease which is caused by not practicing traditional rituals after the funeral perfectly. People need to be educated about these issues, that if a person is HIV positive, he is not bewitched (Community Group A).

A few caregivers believed that being HIV positive meant that the child's blood was dirty, but since the child was young, the blood would be cleaned over time through good feeding, traditional medicine, or by ceasing breastfeeding. Conventional ART was not seen as appropriate as it would not cure. Some caregivers preferred to have their children on traditional medicine:

As they say, if the person is sick with shingles or 'reeds', they say it is AIDS. I understand that because she was born the time I was having shingles, it means that her blood is dirty. ... I know that if I can give her this food with energy, at the end this blood will be clean; she is still young she will be cured. The blood will be clean and get back where it was in the past. It is easy for a young child to be cured, it is the same as a child who injured an arm or leg; she gets cured if she is still young, it is not the same with an

old person. ...I see that they say AIDS tablets are not curing HIV, they make it quieten, if she abandoned them, it (the virus) will wake up, I think it is better to leave them. I give her traditional medicine, it is killing (the virus) ... we were syringing her (with the traditional medicine) so that the dirt that is inside comes out.... Pills (ARVs) are better for me because I am old. ... When I syringe (her with traditional medicine), the virus comes out and goes (Mother, 42 years).

Traditional medicine was sometimes a first step before the conventional ART:

I knew the HIV status of my child in December 2004 while for my status I knew it in June 2004. The child was very ill he could have passed away with his father. So I took him to the Hospital where they tested the child with me and the results were the same (HIV positive). They said that that's why the child was very ill. I also went to the traditional healers, they said that the child was bewitched. The 'doctor' (traditional) gave me many medicines and it is like I was having a chemist. So at the hospital they have told me not to give the child that medicine again but I must go to Mpilo clinic and take ARV treatment for the child; then the child was better. (Mother, 34 years)

The instability of care for HIV positive children also affected treatment. Several HIV positive children were orphans cared for by relatives, and they often move from house to house, complicating adherence. Non-mother caregivers, particularly grandmothers, were also reported as misusing the child support grant (offered by the government to needy children), and were often drunk and unable to care for HIV positive orphans, and home-based carers argued for an orphanage to be established in the community to ensure care for HIV positive orphans:

You will find that the child is not staying in one place but stay in different places, may be the child is staying with grandparents and they don't know how to give the child treatment. Some other grandparents are always drunk and forget to give the child treatment. (Community Group C)

Physical and financial barriers

ARVs are provided by only one service provider in Agincourt, a public-private health centre distant from many of the villages. Although ARVs are free, participants argued that the enrolment fee and cost of drugs for opportunistic infections discouraged treatment, and access was limited due to distance to the facility, cost of transport, and long queues and waiting lists at the facility. ARVs are also provided by the district hospitals, but these are even further away (minimum 25km). Another barrier to taking ARVs was lack of food:

People are running short of food yet they need food to be able to take ARVs. You cannot take ARVs on an empty stomach; you need to eat first and you find that the food supplements given at the clinic are not enough; they are not food; to take ARVs, you need real food (Community Group B)

Organizational barriers

Delays in acquiring treatment/support, poor confidentiality and the negative attitudes of health care workers discouraged access to treatment. Several caregivers reported delays in acquiring test results to determine eligibility for ART, and this also discouraged them from pursuing ART.

Caregivers lacked confidence in the health care workers in the local clinics in maintaining confidentiality concerning HIV status, and considered some providers to be disrespectful and unkind. Other caregivers reported that local clinics lacked drugs for opportunistic illnesses:

When we go to the hospital they help us, but at the clinic they have a bad attitude; I went there and I found that they were treating me in a bad manner, I didn't go back there. The way they talk, it doesn't make me feel free. Most times when I want to visit the clinic I go to the mobile clinic. If you take them (children) to the clinic with flu, they say 'these people have one illness; we have a shortage of medicine here at our clinic and they'll use up the drugs for other people.' Most of the time there is no medicine at the clinic and at the end of the month, I buy medicines and headache pills (from a private outlet) and keep them safely (mother, 42 years).

Other organizational barriers included health professional advice that the child was too young for ART or that the child's immune system was still good. Reassessment of immune status was rarely mentioned. Health facilities were often unable to undertake definitive HIV testing for children less than 18 months, for whom virological tests such as HIV DNA/RNA polymerase chain reaction (PCR) tests rather than antibody tests are recommended (World Health Organization, 2006). There was also little confidence in home-based carers linked to local health facilities, who are expected to visit households with HIV positive patients and to assist in caring for them. Home based carers confirmed that they were often rejected from households with people living with HIV.

Discussion

From a community perspective, there are multiple barriers to paediatric HIV treatment and related care. Seeking HIV treatment and support begins with knowledge of HIV status, but few were familiar with paediatric HIV testing and only three caregivers knew the child's HIV status before our screening. Various misconceptions about paediatric HIV and failure of disclosure related to fear of stigma and discrimination (Biadgilign, Deribew, Amberbir, & Deribe, 2009; Yeap, et al., 2010) may prevent effective implementation of the policy recommending early testing of exposed or at risk children (within 6 weeks of birth), and immediate initiation of ART for infected infants (National Department of Health South Africa, 2010; World Health Organization, 2010), which has changed from the earlier South African guidelines (2005) (Meyers, Harriet Shezi Children's Clinic; Chris Hani Baragwanath Hospital, Eley, & Red Cross Children's Hospital, 2005). There is need for continued re-assessment of children to determine their eligibility for treatment; but in the current study, there was little mention of re-assessment once the child was said to have 'strong immunity'. As suggested by community groups, there is need for focused campaigns to enhance awareness of HIV in the community particularly regarding paediatric HIV and treatment. Additionally, there is need for interventions to educate and motivate, hence improve the attitudes and practice of health care professionals particularly in the local clinics, who may have low morale due to heavy workload.

The study identified compromised care for HIV positive orphans, in line with studies elsewhere in sub-Saharan Africa (Ntanda, et al., 2009; Nyandiko, et al., 2006), which is important in a country with HIV prevalence. A credible caregiver, capable of ensuring proper adherence to ART is a requisite for initiation to ART (National Department of Health South Africa, 2010).

The suggestion by community members that HIV positive orphans be put in an orphanage to enhance adherence may be an option for children without a credible caregiver. Some evidence indicates that such institutions facilitate adherence to ART for children (Yeap, et al., 2010). However, evidence also indicates that residential facilities may not be the most appropriate option for orphans for various reasons including high staff turn-over making continuity of care difficult, inadequate care due to high child-staff ratio, and inability to provide adequate psychosocial support to this high risk population (UNICEF, 2006). Extended family is considered the most viable option for providing optimal care for orphans (Ansell & Young, 2004). However, these families face financial, social and psychological challenges associated with care for orphans and may need assistance (Freeman & Nkomo, 2006). Expert opinion suggests collaborative community-based care for orphans with the extended families, community groups, health professionals, the government, aid agencies and other organizations as key players (Murray, 2010).

Financial limitations including food insecurity may relate to high levels of poverty (Gelb, 2003), high unemployment levels (Collinson, 2009), and continuing socio-economic impacts from HIV/AIDS on affected households in the area (Hunter, Twine, & Patterson, 2007). The child support grant, instituted to address the problem of food insecurity, was regarded as inadequate in caring for the children (Kimani-Murage, Manderson, et al., 2010). There is need for creative and effective income generating strategies for caregivers of HIV positive children, often themselves infected, hence have limited opportunities for formal employment (Kompaore, 2004). There is also need for revision of criteria for accessing social assistance grants (Hardy C. & Richter M., 2006; Kimani-Murage, Manderson, et al., 2010). Supplementary nutritional support

is currently targeted at malnourished children. Given the importance of food in adherence to ART, there is need to reconsider this criteria with regards to HIV positive children in food insecure communities. To bridge the access gap to ART, hence reduce cost of transport , the government may need to consider increasing the number of service providers in this and similar communities, as suggested by community groups.

Although sample size and the qualitative methodology may limit generalizability, because of the in-depth nature of the study, we have identified issues to be addressed in policy and practice to improve the health, survival and general wellbeing of HIV positive children. In line with the spirit of universal access to HIV treatment for infected children, several interventions need to be put in place to address rural poverty, enhance awareness of paediatric HIV and treatment, and improve access to treatment and care.

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