African Journal of AIDS Research 2017, 16(4): 321–328

AJAR
ISSN 1608-5906 EISSN 1727-9445
https://doi.org/10.2989/16085906.2017.1380677

A qualitative analysis of the barriers to antiretroviral therapy initiation among children 2 to 18 months of age in Swaziland

Charisse V Ahmed[1], Pauline Jolly[1]*, Luz Padilla[1], Musa Malinga[2], Chantal Harris[1], Nobuhle Mthethwa[3], Inessa Ba[4], Amy Styles[4], Sarah Perry[5], Raina Brooks[1], Florence Naluyinda-Kitabire[6], Makhosini Mamba[6] and Peter Preko[7]

[1]Department of Epidemiology, University of Alabama at Birmingham, Birmingham, Alabama, USA
[2]Lusweti Institute for Health Development Communication, Mbabane, Kingdom of Swaziland
[3]Swaziland National AIDS Program, Mbabane, Kingdom of Swaziland
[4]Clinton Health Access Initiative, Mbabane, Kingdom of Swaziland
[5]Baylor International Pediatric AIDS Initiative, Mbabane, Kingdom of Swaziland
[6]United Nations Children's Fund (UNICEF), Mbabane, Kingdom of Swaziland
[7]President Emergency Plan for AIDS Relief, Mbabane, Kingdom of Swaziland
**Corresponding author, email: jollyp@uab.edu*

HIV/AIDS remains one of the leading causes of death among children under 5 years old in Swaziland. Although studies have shown that early initiation of infants and children diagnosed with HIV on antiretroviral therapy (ART) significantly reduces mortality, many children do not initiate ART until the later stages of disease. This study was designed to collect qualitative data from mothers and caregivers of HIV-positive children to identify the barriers to ART initiation. Focus group discussion (FGD) sessions were conducted in siSwati between July and September 2014 among caregivers of aged children 2–18 months in Swaziland who did or did not initiate ART between January 2011 and December 2012 after HIV DNA PCR-positive diagnosis of the infants. Denial, guilt, lack of knowledge, tuberculosis (TB)/HIV co-infection, HIV-related stigma, lack of money, and distance to clinics were reported by the participants as barriers to ART initiation. The findings further revealed that non-initiation on ART was not linked to a negative perception of the treatment. Findings suggest a need to improve sensitivity among healthcare workers as well as education and counselling services that will facilitate the ART initiation process.

Keywords: children, infants, HIV, ART initiation

Introduction

Like other countries in Southern Africa, children living with HIV in Swaziland tend to initiate treatment at advanced stages of HIV disease (Boender et al., 2012; Davies et al., 2009; Davies et al., 2013; Kabue et al., 2012; KIDS-ART-LINC Collaboration, 2008; Lahuerta et al., 2013; Sauvageot, Schaefer, Olson, Pujades-Rodriguez, & O'Brien, 2010; Ubesie, 2012). However, early initiation of antiretroviral therapy (ART) has been shown to significantly reduce early infant mortality by 76% and HIV disease progression by 75% (Violari et al., 2008). A study conducted among South African children demonstrated that infants with early, but limited ART had better clinical and immunological outcomes than infants with deferred ART (Cotton et al., 2013). Without ART, half the infants living with HIV infection in Africa are expected to die before the age of 2 years and a third of them are expected to die before the age of 1 year (Newell et al., 2004).

Swaziland has the highest HIV prevalence (26%) in the world and a HIV prevalence of 31% among women aged 18–49 years (UNAIDS, 2014). According to the most recent Swaziland Demographic and Health Survey, the HIV prevalence among pregnant women aged 15 years or older is nearly 40% (CSO & Macro International Inc., 2008). Hence, there is a high potential for maternal to infant HIV transmission in Swaziland. In 2013, an estimated 10 000 women living with HIV gave birth in Swaziland and the country's mother-to-child transmission rate was 10% (UNAIDS, 2014). HIV/AIDS is also one of the leading causes of death among children under five years in the country (WHO, 2015). Therefore early ART access among pregnant and post-partum women is critical for prevention of mother-to-child transmission (PMTCT) of HIV and for early ART initiation of infants diagnosed HIV-positive to prevent HIV-related child morbidity and mortality (Sutcliffe, van Dijk, Bolton, Persaud, & Moss, 2008; UNAIDS, 2014).

According to Swaziland's Paediatric HIV Guidelines, all children under the age of 2 years should initiate ART irrespective of their clinical stage (Ministry of Health and Social Welfare, 2010). The Ministry of Health also integrated early HIV testing and diagnosis of HIV-exposed infants into routine post-natal and under-five healthcare, contributing to a nearly twofold increase in the number of children receiving ART between 2009 and 2012 (UNAIDS, 2013). Despite these efforts, including the free and wide availability of antiretroviral (ARV) drugs, infants and children living with HIV still lag behind adults with regard to ART initiation (Ministry of Health, 2011; UNAIDS, 2013, 2014).

Research focused on barriers to ART initiation among HIV-positive infants in resource-limited settings has identified several barriers, the most common being financial constraints, fear of disclosing the child's status to family members and friends, lack of spousal involvement and fear of stigma (Aluisio, Richardson, Bosire, Mbori-Ngacha, & Farquhar, 2011; Boender et al. 2012; Byamugisha, Strom, Ndeezi, & Karamagi, 2011; Coetzee, Kagee, & Bland, 2014; Donahue, Dube, & Dow, 2012; Feucht, Kinzer, & Kruger, 2007; Hodgson et al., 2014; Yeap et al., 2010). Some of the mothers in these studies mentioned that if the husband or father knew of the child's HIV status he would try to keep the child from taking the medications. Many mothers therefore keep clinic visits and medication a secret, but this can prove challenging when the mother needs to administer the medicine to the child. Mothers who reported financial constraints mainly faced problems with affording transportation to and from clinic visits, and finding money for food. Some caregivers have to decide whether to buy food for the family or pay for the child's treatment and transportation to the clinic. For caregivers who also live with HIV, many do not want the child to experience the discrimination or stigma that they have experienced. Problems associated with health facilities and provision of healthcare services to women and children living with HIV such as patient blaming, rudeness and breach of confidentiality have also been identified as barriers to ART initiation (Hodgson et al., 2014; Yeap et al., 2010).

Considering efforts being made in Swaziland to prevent mother-to-child transmission of HIV (Katirayi et al., 2016; Parker et al., 2015), to improve paediatric ART initiation it is imperative to understand the multi-level influences on ART initiation among children. The socio-ecological model (SEM) derived from Bronfenbrenner's (1979) Ecological Systems Theory (EST) has been found useful for understanding multifaceted structural barriers (e.g., poverty-related, institutional, cultural, and political) tied to ART adherence in Southern Africa (Kagee et al., 2011). However, multi-level influences on HIV care and treatment are usually considered in a broader context, with little country-specific insights on the barriers to paediatric HIV treatment uptake. Therefore this study was conducted to understand the barriers to ART initiation for children living with HIV in Swaziland from a socio-ecological perspective using the socio-ecological elements of Bronfenbrenner's (1979) EST as a basis for understanding ART initiation barriers. These elements include consideration of individual-level barriers as well as barriers within the child's interpersonal and organisational framework (Figure 1). Since then, a study has been published by Coetzee et al. (2015) using the SEM as a framework for understanding barriers to paediatric HIV treatment uptake in rural South Africa. Our study is the first to examine the barriers to ART uptake by children diagnosed with HIV in Swaziland, a country that has one of the highest rates of maternal to infant transmission of HIV in the world.

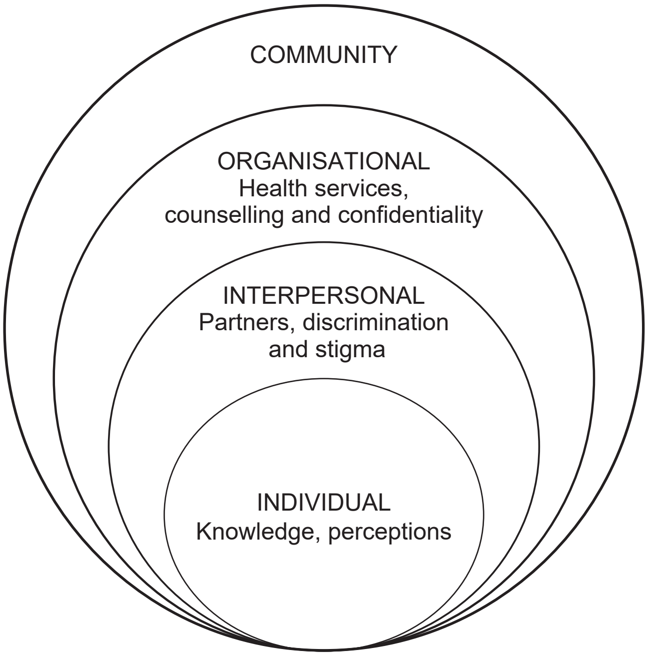

Figure 1: Elements of the socio-ecological framework used to examine the barriers to ART uptake by children diagnosed HIV-positive in Swaziland

Methods

Study design and population

The data for this qualitative study were collected from focus group discussion (FGD) sessions conducted with caregivers of children aged 2 to 18 months who received an HIV DNA PCR-positive test result and either enrolled or did not enrol on ART between January 2011 and December 2012. Four FGDs were conducted in siSwati, two among caregivers of ART-enrolled children and two among caregivers of non-enrolled children. The topics for the FGDs focused on caregivers' feelings about HIV and their children having the disease, perceptions of the safety and benefits of ART, the quality of HIV services available for children living with HIV, ease of access to ART, factors that prevent mothers from initiating their children diagnosed with HIV on ART, whether they took ART during pregnancy, and, suggestions on how to improve access to ART among infants younger than 2 years. The focus group guide was developed in English, translated to the local language (siSwati), and pilot tested. The questions asked were developed to identify individual, interpersonal, organisational and community level barriers to ART initiation of infants based on the SEM.

Data collection process

Patient registers from purposively selected health facilities were used to identify the children who tested positive for HIV and who were either enrolled or not-enrolled on ART, and the caregivers listed. Caregivers were called by the clinic staff, told about the study and asked if they would like to participate. Caregivers who agreed to participate were invited to an FGD session. If the person called declined, stated that the contact number was incorrect, or if the contact number was no longer in service, no further attempts were made to contact the caregiver of that particular child. Four focus group sessions were held, 2 with 20 caregivers of ART-enrolled children (10 in each FGD session) and 2 with a total of 14 caregivers of non-enrolled children (1 with 6 and the other with 8 caregivers). FGDs lasted 90 to 120 minutes. FGDs among caregivers of enrolled infants took place in July 2014 and in September 2014 among caregivers of non-enrolled children. All FGDs were conducted in siSwati and later translated to English for data analysis. Moderators of the FGDs were data collectors or qualitative researchers who had been trained in focus group techniques. Each FGD session was facilitated by a moderator who was assisted by one note-taker. All of the discussion sessions were audio-recorded with the permission of the participants. No names were used on the audio tapes. All participants were given lunch and transport reimbursement after the FGDs.

Data management and analysis

The audio records from the FGDs were transcribed verbatim, and translated into English by the data collectors. *A priori* themes were constructed to analyse the transcripts which were based on factors in the SEM that serve as barriers to ART initiation among children. ATLAS.ti 7.5 (Scientific Software Development GmbH, Berlin) was used to code and analyse the data using a quantified measures of consistency approach. During the construction of all themes, differences and similarities between the responses among caregivers of enrolled and non-enrolled children were considered.

Ethical considerations

The Institutional Review Board of the University of Alabama at Birmingham and the Swaziland Scientific Ethics Committee reviewed and approved the protocol before study implementation. A consent form was given to each of the caregivers to read and sign to confirm their permission to participate in the study. Caregivers were also encouraged to ask the researchers questions regarding the process of the study. All data collected from the participants were kept strictly confidential. The audio tapes were destroyed after they were transcribed and the transcripts verified.

Results

Individual factors

All 34 FGDs participants were female caregivers. Among the caregivers of non-enrolled children 8 were ≥18 years of age. Caregivers of both ART enrolled and non-enrolled children identified denial, guilt, problems with getting the child to take ART, distance to the clinic for ART, lack of knowledge, co-infection of HIV and tuberculosis (TB), and lack of money for food as individual-level barriers to ART initiation of infants.

Denial

With regard to denial, caregivers from both groups reported that denial of one's own HIV status or that of one's child acts as a challenge to ART initiation of infants. One caregiver of a non-enrolled child stated the following:

> *A lot of people are afraid of AIDS. My sister had a positive baby. She refused to believe, gave the baby to my mother and didn't breastfeed. After 9 months, the baby was still not crawling, walking, he was sick.*

Also, a caregiver of an ART-enrolled child stated,

> *I think most parents are in denial. They do not want to accept their status and their children's even when they try counselling them at clinics.*

Guilt

With regard to guilt both groups of caregivers suggested that guilt for failing to protect their children from HIV acts as a barrier to ART initiation. A caregiver of a non-enrolled child stated,

> *My other child who is 12 years hasn't tested for HIV. I am scared that it can be discovered that he is positive. How can I explain that to him? He can ask, "mom how am I positive because I haven't started sex". A lot of people outside also have that same fear, some of them are pregnant also."*

The caregiver of an ART-enrolled child stated, *"Also the problem is that it is hard to accept as a parent that your child is already taking ARVs while you haven't started yet."*

Perception of and problems with taking ART

With regard to perception of ART, both groups of caregivers agreed that ART resulted in better health for themselves and their children and knew that taking ART during pregnancy prevented HIV transmission from mother to child. Caregivers of ART-enrolled children stated that they were encouraged to start their infant on ART by seeing the improving health conditions of other infants on ART. They also mentioned that the access to free and good quality antiretroviral drugs helped the initiation of their infants on treatment. A caregiver of an ART-enrolled child stated,

> *I am grateful to government for making sure that everyone gets the pills by making them free of charge. If ARVs were sold, then more and more people would die so that's why I am grateful to the government of Swaziland.*

However, caregivers of non-ART enrolled children emphasised the challenges with ART treatment for children, including children refusing to take their medication due to the bitter taste of the syrup or to treatment fatigue.

Distance to clinic

It emerged from the FGDs that another barrier to ART was the distance to health facilities coupled with lack of transport. When paediatric ART services were not available at the local clinic, mothers/caregivers had to travel to a clinic further away from their homes. Some participants decided to go to a clinic further away due to fear of discrimination and stigma. The caregiver of an ART-enrolled child explained:

> *The clinic is very far and there is no transport so you have to walk long distances" and a caregiver of a non-enrolled child stated "If I can run short of money to come here, I would stay at home until I find money to come back here.*

ART initiation barriers that were particularly mentioned by caregivers of non-enrolled children included lack of knowledge, co-infection of child with HIV and TB and lack of money for food.

Lack of knowledge

Lack of knowledge on HIV and on PMTCT was also highlighted as a reason for not initiating a child on ART. One caregiver of a non-enrolled child stated:

> *At the clinic I was attending, I was never counselled on how to take care of myself and my baby when you are HIV-positive, when to start attending antenatal care, and the need to deliver in a hospital setting was never emphasised, breastfeeding duration or anything relating to treatment received to try and prevent the child from getting HIV vertically. Furthermore, I delayed testing my baby for HIV; I tested him for HIV when he was already very sick.*

Co-infection of HIV and TB

The FGDs revealed that many of the non-enrolled children were suffering from both TB and HIV. As a result, the child was started on TB treatment, which delayed ART initiation. One mother stated, *"[My child] was found to be positive and the illness was at an advanced stage. They started him on TB treatment first but he died while still on TB treatment."*

Lack of money for food:

Some mothers were unable to take their children to the clinic for follow-up visits since they did not have enough food to give the baby to support the medication. One mother of a non-enrolled child stated,

> *I think it's because of lack of money, because I can fetch the medication but if we do not have enough food to go with the medication, it becomes a problem. Because once I initiate him on treatment, he must not stop taking it, so it's better [to not initiate the child on treatment].*

Interpersonal factors

Caregivers of non-enrolled children in particular mentioned interpersonal barriers associated with infant ART initiation such as failure to disclose HIV status to partner or family, and discrimination and fear of stigma.

Failure to disclose HIV status to partner or family

Some participants mentioned that partners would blame the mothers or refuse to discuss this topic with their wives. Many reasons for not disclosing were stressed by the participants, including the child was from a previous relationship, or the mother was scared of losing her partner. Notably, both partners would pretend they were HIV-negative and secretly take medication. Hence, the parents were unable to discuss the HIV status of their child, hindering the initiation of the child on ART. One caregiver of a non-enrolled child stated, *"When [my husband] learned our baby was positive, he accused me of killing our baby and he left."*

Discrimination and fear of stigma

Caregivers of non-enrolled children reported that discrimination was still a major challenge in accessing ART or enrolling children on ART. Many participants, caregivers both of ART-enrolled and non-enrolled children, reported being discriminated against due to their HIV status. A caregiver of a non-enrolled child stated,

> *When you have [HIV], you are regarded as promiscuous. Then they gossip about you. When I take my pills, I do so in private. My pills are under the bed. I am scared my friend might visit me and find my pills in the open and gossip about me in the community.*

However, some respondents revealed that having the support of their partners helped them initiate their child on treatment. A caregiver of a non-enrolled child stated,

> *I think the big issue is men; when your husband supports you, you tend to feel good about yourself." Another said, "I was fortunate to be able to talk to him until he understood. Now, he helps me with everything relating to treatment, even my child is now old, he has never been sick. He advised me to stop working so I could take care of my child, so I did, he supports me.*

Organisational factors

Caregivers of non-enrolled children also highlighted delays in the ART initiation process, unavailability of counselling and education, poor treatment at facilities and lack of privacy and confidentiality as organisational barriers to ART initiation for their children.

Delays in the ART initiation process

Caregivers of non-enrolled children reported that they experienced many delays in the process of ART initiation. In some cases, the delays resulted in the death of the child before the date of initiation on ART. One such caregiver stated,

> *Then I came here and received a warm welcome. It was found that I came late. The baby was already sick. They gave us a day to come back for sessions before initiation. That same day, he died. I then came back alone for the sessions.*

Unavailability of counselling and education

Participants also revealed that healthcare workers did not spend enough time explaining health conditions and treatments to the clients. Comments from FGDs with caregivers of non-enrolled children indicated that many participants did not understand the process of ART initiation for their children. They did not understand the need to bring treatment supporters, of the reasons why their children could not be initiated on treatment on the same day (due to TB co-infection, for instance). It also seemed to caregivers that the healthcare workers did not have time to educate and counsel the clients, thus the clients did not feel free to talk and ask questions. One caregiver of a non-enrolled child stated,

> *So I went a bit later to hospital. I don't know whether they gave me the prophylaxis, because they just gave me a lot of pills and I assumed it was just the routine pills you take when pregnant."*

Another said,

> *We are not treated well, you sometimes wish to change facility and go somewhere where you will be welcomed and free to talk about whatever is troubling you. It's like they are in a hurry when attending patients. They don't have time to sit down and talk to you.*

Poor treatment at health facilities

There were similarities found in comments made by caregivers of both ART-enrolled and non-enrolled children regarding poor treatment at health facilities. Both groups recalled receiving unfair treatment from healthcare workers. Examples of poor treatment by healthcare workers included shouting at patients, gossiping about clients, delayed service provision, and unnecessarily long wait times. Long queues and high patient volume resulted in poor treatment, including healthcare workers being short-tempered and unwelcoming to clients. A caregiver of a non-enrolled child stated:

> *Sometimes you get there at 7 or 6 and the lines are too long. Then at 10 they leave you waiting and go for lunch. You had said you will be back at work at 10. Even at 1 they also leave and go to lunch. When you start to talk they tell you, you should have come earlier in the morning.*

A caregiver of an ART-enrolled child stated,

> *…sometimes you wait for more than 2 hours and the nurses would not help you until it suits them and there's nothing to do or say because they might end up not helping you at all.*

One participant indicated that a barrier to ART access was the unprofessionalism of healthcare workers. It was reported by clinic staff that patients had ART booklets to record progress, but if they missed/skipped the next appointment, they were afraid to go back because they might be reprimanded by the healthcare workers. A caregiver of a non-enrolled child added:

> *I think finding people of the right attitude, who are approachable, is very important to us when we come to the health facilities. When you get ill-treated by a person at the health centre, you get demotivated even to come back for refills just because the image of that person who treated you badly comes to mind. You start thinking twice.*

Lack of privacy and confidentiality

Respondents stressed that people opted not to take their infants to the clinic for ART because the services were not private or confidential, but were provided in highly visible open spaces or designated areas. This meant people were queued such that anyone could see them and know they were accessing ART. This was reported to be difficult because people from the community might stigmatise someone who had been spotted queuing for ART. The participants discussed that local healthcare workes lacked confidentiality as they often disclosed the HIV status of their patients to other community members. As a result, mothers would leave one clinic for another in an attempt to gain privacy and confidentiality, compromising the treatment routine and causing them to miss appointments. A mother of a non-enrolled child stated that: "*…there was a nurse who used to tell other visiting patients about my status. When I left her room, she would tell the next client that I had come to refill my ARV"* and another stated

> *I think people have the information about HIV, but the problem is discrimination. When we see someone queuing to take ARVs we start asking people if they have seen so and so queuing for ARVs or have you heard X's bag making the sound of ARVs ricocheting in their containers. Or have you seen so and so, he is wasted due to the virus, "have you seen the rashes?" the problem is that people start discriminating based on status so people get afraid to enrol on treatment.*

Recommendations by focus group participants

Focus group participants shared some recommendations for reducing the barriers to ART initiation among infants in Swaziland. These include education and counselling, male involvement, disclosure counselling, and enforcement of confidentiality and privacy and patient follow-up. The caregivers stressed the need to invest in counselling for primary caregivers of the children who are eligible for or on ART. With regard to male involvement caregivers said it was important to include partners in the provision of healthcare services. For example, they recommended that the clinics invite the partners of pregnant women so that both could be educated on the importance of ART, and HIV in general. Asking the community health workers (i.e., rural health motivators) to visit homes to educate men on the issues of ART was also presented as a way to improve access to ART for the parents and the child. Participants recommended that the nurses ensure that all pregnant women disclose their HIV status to their partners by facilitating the process and further educating both partners. Participants regarded privacy and confidentiality as paramount in HIV service provision at health facilities. In the discussions, they also emphasised that nurses needed to be trained on issues of confidentiality and treatment of clients. One participant recommended that ART should be provided in consultation rooms to ensure privacy and confidentiality of treatment. Some participants highlighted that receiving follow-up calls and patient reminders from healthcare workers would be really helpful.

Discussion

The barriers to child ART initiation mentioned throughout this study align with those from other qualitative research studies which have analysed the barriers to paediatric HIV treatment engagement. Similar to the Yeap at al. (2010) study of paediatric ART initiation barriers in South Africa, our study also revealed that lack of money for food, maternal guilt, long waiting times, and negative attitudes among clinic staff were barriers to child ART initiation. Like Boender et al.'s (2012) study on the barriers to paediatric treatment initiation in Uganda, long distances to the clinic sites were also cited as barriers to ART initiation in this study. Another barrier that was found to child ART enrolment was co-infection with TB, which was also found in a similar retrospective study conducted in South Africa (Feucht, Kinzer, & Kruger, 2007). Hence, there is a need to improve the integration and coordination of HIV and TB services offered to children in Swaziland to ensure timely treatment for both conditions. Additionally, fear of disclosure and HIV-related stigmatisation and discrimination is an ongoing barrier for accessing HIV services (Biadgilign, Deribew, Amberbir, & Deribe, 2009; Boender et al., 2012; Donahue, Dube, Dow, Umar, & Van Rie, 2012; Hodgson et al., 2014; Yeap et al., 2010). As recommended by other studies, public dissemination of HIV education may discourage misinformation and contribute to reducing misconceptions and stigma related to HIV/AIDS (Boender et al., 2012; Yeap et al., 2010).

The results from this study also highlight that female caregivers in particular need additional support in managing HIV infection among children. As highlighted in similar studies, this study reveals the lack of male spousal involvement and negative views regarding HIV among male spouses, which can discourage the uptake of HIV services (Aluisio et al., 2011; Byamugisha et al., 2011). Male involvement in antenatal care was recommended by caregivers in this study and by healthcare providers in Boender et al.'s (2012) study. The respondents also recommended the involvement of nurses in the disclosure process among partners as a way to facilitate HIV education and further involvement of males in paediatric HIV care. Yeap et al.'s (2010) study also revealed the need for a coordinated effort among multiple caregivers to strengthen the quality of care among children living with HIV, as non-disclosure among secondary caregivers is potentially a missed opportunity for additional support towards a child's HIV care. HIV disclosure among a spouse or involvement of a spouse in the process can improve ART initiation and even adherence and retention (Hodgson et al., 2014). Caregivers also mentioned that lack of familial support in HIV child care. Other studies have shown that psychosocial and family support is crucial for improving HIV treatment engagement (Biadgilign et al., 2009; Donahue et al., 2012; Lahuerta et al., 2013). Hence, encouraging an environment for families and other social networks to engage in care of children living with HIV may improve paediatric ART initiation in Swaziland and in other resource-limited settings.

This study also aligns with research that suggests that there are inadequate counselling services available to assist caregivers with managing HIV among their children. The lack of knowledge regarding PMTCT expressed by participants, especially the cases in this study was also echoed in similar studies (Biadgilign et al., 2009; Donahue et al., 2012; Dube et al., 2012; Gourlay, Birdthistle, Mburu, Iorpenda, & Wringe, 2013; Hodgson et al., 2014; Yeap et al., 2010). Increasing knowledge about HIV transmission from mother to child can help to reduce the risk of transmission (CSO & Macro International Inc., 2008). Caregiver responses demonstrated the lack of knowledge that prophylactic antiretroviral drugs, when adhered to, are highly efficacious in preventing mother-to-child transmission. This suggests the need to improve PMTCT counselling among pregnant and post-partum women living with HIV. Some caregivers in this study also lacked sufficient knowledge on the ART initiation process or were unsure of how to navigate maternal and child HIV services. Hence, there is need to improve knowledge of HIV services offered for pregnant and post-partum women living with HIV in the community.

Some caregivers mentioned that there were delays in the ART initiation process, which may discourage enrolment. The Ministry of Health (2010) noted that lack of timely CD4 assessments and limited clinic staff were challenges faced in antenatal healthcare facilities . Unpredictable episodes of ART supply shortages can possibly delay the availability of laboratory results and initiation of ART for infants (Bancheno, Mwanyumba, & Mareverwa, 2010). Poor treatment by healthcare workers, including patient-blaming, stigmatisation, and rudeness in health facilities was a commonly stated barrier to child ART initiation, which was also found in other studies (Hodgson et al., 2014; Yeap et al., 2010). Hence, there is need to improve service delivery practices and for healthcare providers to provide a confidential, non-judgmental, and comfortable environment for caregivers to engage their children in care. Healthcare workers also need a better understanding of the challenges of strict, lifelong ART adherence. A study in Swaziland revealed the need to increase sensitivity among healthcare providers in understanding ART adherence challenges (Phelps, Hathcock, Werdenberg, & Schutze, 2010). Additionally, a qualitative study of pregnant and lactating women enrolled in a PMTCT programme in Swaziland also revealed that women feel overwhelmed with the challenge of coping with lifelong commitment of ART (Katirayi et al., 2016).

Since a child's engagement in HIV care depends on a parent and/or caregiver, it is important to encourage parents and caregivers to be adequately involved in their children's care and in their own care. Some caregivers in this study mentioned that they were discouraged from initiating their children on ART due to their own lack of ART initiation. Determining the reasons for the lack of initiation of ART among caregivers living with HIV and providing counselling services that reinforce the benefit of ART enrolment may further encourage caregivers to initiate ART among their children. Available evidence indicates that positive beliefs about ART encourage HIV treatment initiation (Parkes-Ratanshi et al., 2010).

Research shows that it is still possible to scale up ART coverage among infants and children in Swaziland and in other resource-limited countries (Kabue et al., 2012). However, it is important to also address socio-economic barriers such as poverty, and lack of money for food or to pay for transportation that may have an impact on ART initiation among children (Boender et al., 2012; Feucht et al., 2007; Hodgson et al., 2014; Marais, Esser, Godwin, Rabie, & Cotton, 2008; Yeap et al., 2010). As many studies have confirmed, there is need to address the multifactorial challenges to early initiation of ART among children to increase early ART enrolment and reduce infant mortality in Southern Africa (Fenner et al., 2010; Schomaker et al., 2013).

Limitations of the study

The purposive sampling method used to conduct the FGDs limits the generalisability of this study. Furthermore, it was difficult to reach caregivers of children diagnosed with HIV, especially those who did not initiate their children on ART. There are complex ethical considerations in conducting research among caregivers of children diagnosed with HIV such as ensuring sensitive wording and preventing accidental disclosure of HIV status. In addition, as with all qualitative research, the role of the moderator is a source of potential bias. Focus group moderators trained in focus group methods were selected for the study in an attempt to mitigate undue influence by moderators on participant responses. Additionally, while focus groups are useful for understanding community attitudes, a certain inevitable amount of bias occurs through group dynamics.

Participants may be reluctant to voice opposing views, or the more assertive participants may disproportionately influence the results. Despite such limitations, this study provides practical suggestions to improve access to ART for caregivers of infants diagnosed with HIV in Swaziland. Although generalisability is limited to this study, this work includes representation of caregivers of children who were not initiated on ART, which is an improvement on Yeap et al.'s (2010) study. Furthermore, the recommendations provided in this study offer insights for healthcare workers in improving care and ART initiation from the caregiver perspective.

Conclusion

Overall, the individual-level barriers to ART initiation were denial, maternal guilt, lack of knowledge, TB/HIV co-infection, lack of money, and distance to clinics. Failure to disclose HIV status to a partner or the family and discrimination and fear of social stigma were the main interpersonal factors that prevented ART initiation among caregivers of infants. Organisational barriers emphasised by the participants were delays in the ART initiation process, rude and inappropriate treatment at the facilities, lack of privacy and confidentiality, and inadequate counselling from healthcare workers. Interestingly, the results indicated that non-initiation of ART was not linked to negative perceptions of ARVs.

In conclusion, the themes represented in the FGD sessions highlight numerous barriers to ART initiation and provide good insight into the challenges faced by caregivers of infants and children diagnosed with HIV in Swaziland. Findings suggest a need to improve service delivery practices to make the process of ART initiation more efficient and comprehensible among caregivers of children diagnosed with HIV. There is also a need to improve health worker sensitivity, including ensuring patient confidentiality to caregivers living with HIV to encourage clinic attendance, and treatment engagement and retention. Additionally, the integration and linkage of maternal, child, TB, and HIV services may ensure timely initiation of ART. Increasing access to education and counselling services that will facilitate the ART initiation process may also be beneficial for caregivers with children diagnosed with HIV.

Acknowledgements — We thank the mothers/caregivers of the infants for participating in this study and the data clerks and interviewers for their invaluable assistance in collecting the data. We thank Sarah Franklin for editing and formatting the paper. This study was supported by the Minority Health International Research Training (MHIRT), grant no. T37-MD001448, from the National Institute on Minority Health and Health Disparities, National Institutes of Health (NIH), Bethesda, MD, USA, the United Nations Children's Fund (UNICEF), Swaziland, the Ministry of Health, Swaziland, The Baylor Hospital, Swaziland, The Clinton Health Access Initiative, Swaziland, and the President's Emergency Plan for AIDS Relief, Swaziland.

References

Aluisio, A., Richardson, B. A., Bosire, R., John-Stewart, G., Mbori-Ngacha, D., & Farquhar, C. (2011). Male antenatal attendance and HIV testing are associated with decreased infant HIV infection and increased HIV-free survival. *Journal of Acquired Immune Deficiency Syndromes, 56*(1), 76–82. https://doi.org/10.1097/QAI.0b013e3181fdb4c4

Bancheno, W. M., Mwanyumba, F., & Mareverwa, J. (2010). Outcomes and challenges of scaling up comprehensive PMTCT services in rural Swaziland, Southern Africa. *AIDS Care, 22*(9), 1130–1135. https://doi.org/10.1080/09540121003615079

Biadgilign, S., Deribew, A., Amberbir, A., & Deribe, K. (2009). Barriers and facilitators to antiretroviral medication adherence among HIV-infected paediatric patients in Ethiopia: A qualitative study. *Journal of Social Aspects of HIV/AIDS Research Alliance, 6*(4), 148–154. https://doi.org/10.1080/17290376.2009.9724943

Boender, T. S., Sigaloff, K. C., Kayiwa, J., Musiime, V., Calis, J. C., Hamers, R. L., … Kityo, C. (2012). Barriers to initiation of pediatric HIV treatment in Uganda: A mixed-method study. *AIDS Research and Treatment, 2012*, 1–10. https://doi.org/10.1155/2012/817506

Bronfenbrenner, U. (1979). *The Ecology of Human Development: Experiments by Nature and Design*. Cambridge, MA: Harvard University Press.

Byamugisha, R., Åstrøm, A. N., Ndeezi, G., Karamagi, C. A. S., Tylleskär, T., & Tumwine, J. K. (2011). Male partner antenatal attendance and HIV testing in eastern Uganda: A randomized facility-based intervention trial. *Journal of the International AIDS Society, 14*(1), 43. https://doi.org/10.1186/1758-2652-14-43

CSO and Macro International Inc. (2008). *Swaziland Demographic and Health Survey 2006-07*. Mbabane, Swaziland: Central Statistical Office and Macro International Inc.

Coetzee, B., Kagee, A., & Bland, R. (2015). Barriers and facilitators to paediatric adherence to antiretroviral therapy in rural South Africa: A multi-stakeholder perspective. *AIDS Care, 27*(3), 315–321. https://doi.org/10.1080/09540121.2014.967658

Cotton, M. F., Violari, A., Otwombe, K., Panchia, R., Dobbels, E., Rabie, H., … Team, C. S. (2013). Early limited antiretroviral therapy is superior to deferred therapy in HIV-infected South African infants: Results from the CHER (Children with HIV Early antiRetroviral) randomized trial. *Lancet, 382*(9904), 1555–1563.

Davies, M.-A., Keiser, O., Technau, K., Eley, B., Rabie, H., van Cutsem, G., … Moultrie, H. (2009). Outcomes of the South African National Antiretroviral Treatment Programme for children: The IeDEA Southern Africa collaboration. *South African Medical Journal/Suid-Afrikaanse Tydskrif Vir Geneeskunde, 99*(10), 730–737.

Davies, M.-A., Phiri, S., Wood, R., Wellington, M., Cox, V., Bolton-Moore, C., … Eley, B. (2013). Temporal trends in the characteristics of children at antiretroviral therapy initiation in southern Africa: The IeDEA-SA collaboration. *PLoS ONE, 8*(12), e81037. http://doi.org/10.1371/journal.pone.0081037

Donahue, M., Dube, Q., Dow, A., Umar, E., & Van Rie, A. (2012). They have already thrown away their chicken: Barriers affecting participation by HIV-infected women in care and treat-ment programs for their infants in Blantyre, Malawi. *AIDS Care, 24*(10), 1233–1239. https://doi.org/10.1080/09540121.2012.656570

Dube, Q., Dow, A., Chirambo, C., Lebov, J., Tenthani, L., Moore, M., … Van Rie, A. (2012). Implementing early infant diagnosis of HIV infection at the primary care level: Experiences and challenges in Malawi. *Bulletin of the World Health Organization, 90*(9), 699–704. https://doi.org/10.2471/BLT.11.100776

Fenner, L., Brinkhof, M. W. G., Keiser, O., Weigel, R., Cornell, M., Moultrie, H., … Davies, M.-A. (2010). Early Mortality and Loss to Follow-up in HIV-Infected Children starting Antiretroviral Therapy in Southern Africa. *Journal of Acquired Immune Deficiency Syndromes (1999), 54*(5), 524–532. http://doi.org/10.1097/QAI.0b013e3181e0c4cf

Feucht, U. D., Kinzer, M., & Kruger, M. (2007). Reasons for delay in initiation of antiretroviral therapy in a population of HIV-infected South African children. *Journal of Tropical Pediatrics, 53*(6), 398–402. https://doi.org/10.1093/tropej/fmm060

Gourlay, A., Birdthistle, I., Mburu, G., Iorpenda, K., & Wringe, A. (2013). Barriers and facilitating factors to the uptake of antiretroviral drugs for prevention of mother-to-child transmission of HIV in sub-Saharan Africa: A systematic review. *Journal of the International AIDS Society, 16*(1), 18588. https://doi.org/10.7448/IAS.16.1.18588

Hodgson, I., Plummer, M. L., Konopka, S. N., Colvin, C. J., Jonas, E., Albertini, J., … Fogg, K. P. (2014). A systematic review of individual and contextual factors affecting ART initiation, adherence, and retention for HIV-infected pregnant and postpartum women. *PLoS One, 9*(11), e111421. https://doi.org/10.1371/journal.pone.0111421

Kabue, M. M., Buck, W. C., Wanless, S. R., Cox, C. M., McCollum, E. D., Caviness, C., … Kline, M. W. (2012). Mortality and clinical outcomes in HIV-infected children on antiretroviral therapy in Malawi, Lesotho, and Swaziland. *Pediatrics, 130*(3), e591–e599. https://doi.org/10.1542/peds.2011-1187

Kagee, A., Remien, R. H., Berkman, A., Hoffman, S., Campos, L., & Swartz, L. (2011). Structural barriers to ART adherence in Southern Africa: Challenges and potential ways forward. *Global Public Health: An International Journal for Research, Policy and Practice, 6*(1), 83–97. https://doi.org/10.1080/17441691003796387

Katirayi, L., Chouraya, C., Kudiabor, K., Mahdi, M. A., Kieffer, M. P., Moland, K. M., & Tylleskar, T. (2016). Lessons learned from the PMTCT program in Swaziland: Challenges with accepting lifelong ART for pregnant and lactating women – a qualitative study. *BMC Public Health, 16*(1), 1119. https://doi.org/10.1186/s12889-016-3767-5

KIDS-ART-LINC Collaboration. (2008). Low risk of death, but substantial program attrition, in pediatric HIV treatment cohorts in sub-Saharan Africa. *Journal of Acquired Immune Deficiency Syndromes, 49*(5), 523–531. https://doi.org/10.1097/QAI.0b013e31818aadce

Lahuerta, M., Ue, F., Hoffman, S., Elul, B., Kulkarni, S. G., Wu, Y., … Nash, D. (2013). The problem of late ART initiation in Sub-Saharan Africa: A transient aspect of scale-up or a long-term phenomenon? *Journal of Health Care for the Poor and Underserved, 24*(1), 359–383. https://doi.org/10.1353/hpu.2013.0014

Marais, B. J., Esser, M., Godwin, S., Rabie, H., & Cotton, M. F. (2008). Poverty and human immunodeficiency virus in children: A view from the Western Cape, South Africa. *Annals of the New York Academy of Sciences, 1136*(1), 21–27. https://doi.org/10.1196/annals.1425.012

Ministry of Health. (2011). *2011 ART programme annual report.* Kingdom of Swaziland, Ministry of Health, Strategic Information Department. Available at http://www.gov.sz/images/art_annualreport%202011.pdf

Ministry of Health. (2010). *Elimination of new HIV infections among children by 2015 and keeping their mothers alive: national strategic framework for accelerated action 2011–2015.* Mbabane, Kingdom of Swaziland. Available at http://www.nationalplanningcycles.org/sites/default/files/planning_cycle_repository/swaziland/national_framework_to_stop_new_hiv_infections2015.pdf

Ministry of Health and Social Welfare. (2010). *Swaziland paediatric HIV guidelines.* Available at https://www.medbox.org/swaziland-paediatric-hiv-guidelines/download.pdf

Newell, M. L., Coovadia, H., Cortina-Borja, M., Rollins, N., Gaillard, P., Dabis, F., & Children, G. I. (2004). Mortality of infected and uninfected infants born to HIV-infected mothers in Africa: a pooled analysis. *Lancet, 364*(9441), 1236–1243. https://doi.org/10.1016/S0140-6736(04)17140-7

Parker, L.A., Jobanputra, K., Okello, V., Nhlangamandla, M., Mazibuko, S., Kourline, T., Kerschberger, B., … Teck, R. (2015). Implementation and operational research: Barriers and facilitators to combined ART initiation in pregnant women with HIV: Lessons learnt from a PMTCT B+ Pilot Program in Swaziland. *Journal of Acquired Immune Deficiency Syndromes, 69*(1): e24–e30. https://doi.org/10.1097/QAI.0000000000000537

Parkes-Ratanshi, R., Bufumbo, L., Nyanzi-Wakholi, B., Levin, J., Grosskurth, H., Lalloo, D. G., & Kamali, A. (2010). Barriers to starting ART and how they can be overcome: Individual and operational factors associated with early and late start of treatment. *Tropical Medicine & International Health, 15*(11), 1347–1356. https://doi.org/10.1111/j.1365-3156.2010.02620.x

Phelps, B. R., Hathcock, S. J., Werdenberg, J., & Schutze, G. E. (2010). Experiencing antiretroviral adherence: Helping healthcare staff better understand adherence to paediatric antiretrovirals. *Journal of the International AIDS Society, 13*(48).

Sauvageot, D., Schaefer, M., Olson, D., Pujades-Rodriguez, M., & O’Brien, D. P. (2010). Antiretroviral therapy outcomes in resource-limited settings for HIV-infected children <5 years of age. *Pediatrics, 125*(5), e1039–e1047. https://doi.org/10.1542/peds.2009-1062

Schomaker, M., Egger, M., Ndirangu, J., Phiri, S., Moultrie, H., Technau, K., … for the International Epidemiologic Databases to Evaluate AIDS–Southern Africa (IeDEA-SA) Collaboration. (2013). When to Start Antiretroviral Therapy in Children Aged 2–5 Years: A Collaborative Causal Modelling Analysis of Cohort Studies from Southern Africa. *PLoS Medicine, 10*(11), e1001555. http://doi.org/10.1371/journal.pmed.1001555

Sutcliffe, C. G., van Dijk, J. H., Bolton, C., Persaud, D., & Moss, W. J. (2008). Effectiveness of antiretroviral therapy among HIV-infected children in sub-Saharan Africa. *The Lancet Infectious Diseases, 8*(8), 477–489. https://doi.org/10.1016/S1473-3099(08)70180-4

Ubesie, A. (2012). Pediatric HIV/AIDS in sub-Saharan Africa: Emerging issues and way forward. *African Health Sciences, 12*(3), 297–304.

UNAIDS. (2013). *2013 progress report on the global plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive.* Geneva, Switzerland: Joint United Nations Programme on HIV/AIDS (UNAIDS).

UNAIDS. (2014). *2014 progress report on the global plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive*. Geneva, Switzerland: Joint United Nations Programme on HIV/AIDS (UNAIDS).

Violari, A., Cotton, M. F., Gibb, D. M., Babiker, A. G., Steyn, J., Madhi, S. A., … McIntyre, J. A. (2008). Early antiretroviral therapy and mortality among HIV-infected infants. *The New England Journal of Medicine, 359*(21), 2233–2244. https://doi.org/10.1056/NEJMoa0800971

WHO. (2015, January). *Swaziland:WHOstatisticalprofile.* Retrieved from http://www.who.int/gho/countries/swz.pdf?ua=1

Yeap, A., Hamilton, R., Charalambous, S., Dwadwa, T., Churchyard, G., Geissler, P., & Grant, A. (2010). Factors influencing uptake of HIV care and treatment among children in South Africa — a qualitative study of caregivers and clinic staff. *AIDS Care, 22*(9), 1101–1107. https://doi.org/10.1080/09540121003602218