

# The Children Left Behind

Barriers to Testing and Enrolling  
Children in HIV Care and Treatment in  
Njombe Region, Tanzania

May 2018



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Jackson Mbogela, MPH  
Alfred I. Kyando, MSc  
Riziki Mahenge, LLB

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### **MEASURE** Evaluation–Tanzania

TCRS Building,

1st Floor, Plot No. 436, Mwai Kibaki  
Road, Mikocheni B.

Dar es Salaam, TZ

+255 22 277 3023

[www.measureevaluation.org/tanzania](http://www.measureevaluation.org/tanzania)

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## ABBREVIATIONS

ART	antiretroviral therapy
ARV	antiretroviral
CTC	care and treatment clinic
CBO	community-based organization
DBS	dried blood spot
DC	district council
DNA-PCR	deoxyribonucleic acid-polymerase chain reaction
HCW	healthcare worker
HSHP	Health Sector HIV and AIDS Strategic Plan
HTC	HIV testing and counselling
MOHSW	Tanzania Ministry of Health and Social Welfare
NACP	National AIDS Control Program
NCTP	National Care and Treatment Plan
NGO	nongovernmental organization
OI	opportunistic infection
PIUMA	Pima Uishi Kwa Matumaini
PLHIV	people living with HIV
PMTCT	prevention of mother-to-child transmission
TC	town council

## EXECUTIVE SUMMARY

**Background:** The HIV prevalence rate in Njombe region is the highest in Tanzania (14.8 percent). Despite this high prevalence, nearly 60 percent of HIV-exposed infants in the region did not receive an HIV test in 2013–2014.<sup>1</sup> Subsequently, a much lower proportion of infants and children in the region have initiated antiretroviral therapy (ART), compared to adults. This is caused, in part, by barriers to testing HIV-exposed children. The purpose of this study was to explore the barriers to testing and enrolling infants and children with HIV in HIV/AIDS care and treatment programs and make recommendations for future research and interventions.

**Methods:** This was an exploratory, descriptive, and retrospective qualitative study. Data were collected through in-depth face-to-face interviews, using an interview guide with open-ended questions. The study population included 132 parents and guardians of HIV-exposed children who did not receive an HIV test, parents and guardians of infants and children that were confirmed HIV-positive but had not started ART, parents of HIV-positive children who had begun ART but stopped or were lost to follow-up, and 50 healthcare workers (HCWs, i.e., clinicians and nurses) at care and treatment clinics (CTCs) and facilities with prevention of mother-to-child transmission (PMTCT) services.

**Results:** Parents and guardians of HIV-exposed children and infants should be aware that their children are at risk; however, 61.4 percent of exposed children were not tested for HIV. Parents and guardians gave the following reasons for not seeking HIV testing service for the children: not living with them, failing to obtain permission from their spouse, conflicts between the parents, lack of awareness of the importance of testing children, fear of a positive test result, stigma, not feeling motivated because of lack of symptoms or signs of illness, the inconvenience of going to get tested, unavailability of services and staff, and the cost of travelling to a testing site. Parents and guardians acknowledged that it was important for the exposed children to be tested and for HIV-positive children to start treatment. The main barriers to enrolling children in HIV care and treatment programs were lack of understanding of how the HIV care and treatment system works and negligence. Other factors included self-denial, fear, embarrassment, feeling too shy to go to a treatment centre, and self-stigma. Healthcare workers said that parents and guardians declined to get their children tested, because of low levels of awareness among adults on the importance of testing, along with barriers related to transportation. A barrier for orphans is not having a parent or guardian to care for their health.

**Recommendations:** Health facilities, in cooperation with the community health service providers, should establish an escort system to the treatment facilities. The government should improve provision of medication for opportunistic infections (OIs) in pediatric HIV treatment units. Strategies should prioritize collaborations with nongovernmental organizations (NGOs) and community-based organizations (CBOs) in identifying and linking HIV-positive infants and children to care and treatment. The government should provide equipment, supplies, and training to regional hospitals on processing dried blood spot (DBS) tests to facilitate results and initiation of treatment.

**Conclusion:** There is no system for identifying HIV-positive infants and children outside health facilities. The policy that requires children under 15 years old to be tested with their parents/guardians' consent limits HIV-exposed children from accessing HIV testing and counselling (HTC) services. HCWs agreed that this requirement creates a significant barrier discouraging children from getting an HIV test. Parents and guardians suggested that a knowledge gap and inadequate awareness on the importance of testing their HIV-exposed children was a key barrier to testing children.

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<sup>1</sup> Population data are from the Ministry of Health and Social Welfare health information system, which operates on a DHIS 2 platform

## INTRODUCTION

Pediatric HIV infection is an ongoing problem in Tanzania. Only a small portion of HIV-exposed infants and children are tested for HIV, and among those who test positive, a relatively small portion are enrolled in care and treatment. According to the Tanzania Elimination of Mother to Child Transmission of HIV Plan (2012–2015), an estimated 160,000 children under the age of 15 were living with HIV by the end of 2010. Studies show that more than 90 percent of children living with HIV have acquired the disease through vertical transmission—i.e., from mother to child during pregnancy, delivery, or breastfeeding (Arunda, et al., 2016). An estimated 43,050 new pediatric HIV infections occur each year, with half of the newly diagnosed children dying before the age of two. Nearly one in five (18.6%) deaths of children under-five is attributed to AIDS. Most of these deaths could have been averted if these children were diagnosed, identified, and initiated on ART at the right time.

Tanzania’s Ministry of Health and Social Welfare (MOHSW), in collaboration with implementing and development partners, as part of its efforts to scale up HIV services, developed guidelines on early infant diagnosis, including new guidelines for early initiation of ART. Four referral hospitals (Muhimbili National Hospital, Mbeya Hospital, Kilimanjaro Christian Medical Centre, and Bugando Hospital) were equipped to perform early infant diagnosis using diagnostic Deoxyribonucleic Acid-Polymerase Chain Reaction (DNA-PCR). By the end of 2010, 1,520 sites were providing early infant diagnosis services through the collection of DBSs and were transporting them to reference laboratories for testing in Tanzania mainland (Tanzania Elimination of Mother to Child Transmission of HIV Plan, 2012–2015).

About 56 percent of the estimated number of HIV-exposed infants in the population receives antiretroviral (ARV) prophylaxis (Tanzania PMTCT Report, December 2011). By December 2012, 129,128 children were eligible for ART, yet only 86,929 children were enrolled in an HIV CTC, with 50,980 ever initiated on ARVs and 32,407 currently on ART (National Health Sector HIV and AIDS Strategic Plan [HSHSP] III, 2012–2017).

The National HIV/AIDS Care and Treatment Plan (NCTP) (2003–2008) set the target for HIV-positive children on ART based on a percentage of all people living with HIV (PLHIV) on ART. Based on limited information available, this target was set at 20 percent, however in the HSHSP II, the national target was reduced to 18 percent of all PLHIV in care (National HSHSP III, 2012–2017). This target has never been achieved in the period covered by NCTP and HSHSP II. The coverage of pediatric HIV care and services in Tanzania is extremely low. (HSHSP III, 2013–2017).

The early identification of HIV-positive children is important for disease treatment and management and USAID’s goal of controlling the HIV/AIDS epidemic. Improvements in this area respond to the PEPFAR mandate to do the right things in the right places at the right times, by addressing the first 90 in UNAIDS’ global targets.<sup>2</sup> However, very little information is known about the barriers contributing to the low number of HIV-positive infants and children identified and enrolled in care and treatment services. Pima Uishi Kwa Matumaini (PIUMA) conducted this study, with the support of the USAID- and PEPFAR-funded MEASURE Evaluation–Tanzania, to identify and document barriers to finding and enrolling infants and children with HIV in HIV/AIDS care and treatment programs and to make recommendations for future research and interventions.

### Identifying and Enrolling HIV-Positive Children

In the context of eliminating mother-to-child HIV transmission, the Ministry of Health and Social Welfare developed a costed national plan for the elimination of mother-to-child HIV transmission (2012–

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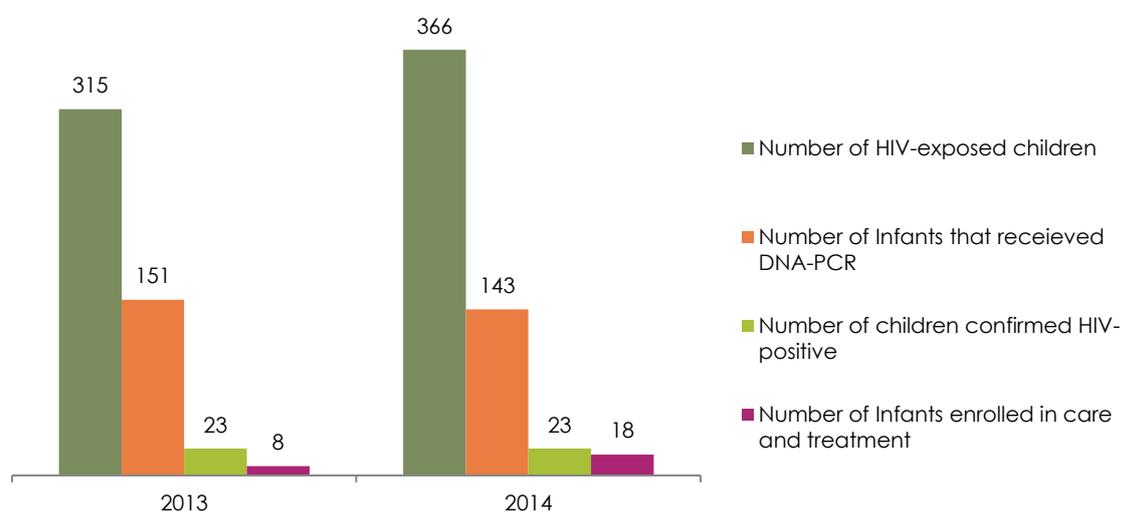
<sup>2</sup> By 2020, 90 percent of all those with HIV will have been diagnosed, 90 percent of those diagnosed will be on ART, and 90 percent of those on ART will be virally suppressed.

2015) to reduce new HIV infections in children from 26 percent to less than 5 percent. If this target is achieved, 90 percent of HIV-positive children will have been reached (National HSHSP III, 2012–2017). Currently, only about one-third (37%) of health centres that offer PMTCT services provide HIV early infant diagnosis, and only about 30 percent of the HIV-exposed infants have access to early infant diagnosis services (Tanzania PMTCT Report, 2011).

Unfortunately, only a small portion of HIV-exposed infants and children are tested for HIV, followed by enrolment in care and treatment (HSHSP III, 2013–2017). As shown in Figure 1, among the 681 HIV-exposed infants born in Njombe region in 2013 and 2014, fewer than half (43.2%) received a DNA-PCR test. Among those who were tested, 46 (15.6%) were confirmed HIV-positive. Only 26 (56.5%) of these infants were enrolled in a care and treatment program.

Thus, 56.8 percent (i.e., 387 out of 681) of HIV-exposed infants did not receive a DNA-PCR test in Njombe region from 2013 to 2014, thereby limiting the chance to identify 15.6 percent more infants who were likely HIV-positive and in need of care and treatment.

**Figure 1. HIV testing and enrolment in care for HIV-exposed infants in Njombe region**



The National AIDS Control Program (NACP) set a target for all health facilities providing HIV care and treatment services to ensure that at least 10 percent of all patients receiving ART are children under the age of 15 years (NACP Annual Report, 2015). For several reasons known and unknown, most districts have not yet achieved this target.

Njombe region, where this study was conducted, has a total HIV prevalence of 14.8 percent, the highest in Tanzania, yet, compared to adults, a very low number of infants and children initiated ART during the past three years. For example, in 2013, the total number of clients identified and enrolled in care and treatment was 22,483; 1,588 (7.1%) were children under the age of 15 years. In 2014 the total number of clients enrolled in care was 27,053; 1,880 (6.9%) were children under the age of 15 years. And in 2015, the total number of clients enrolled in care was 55,435; 4,662 (8.4%) were children under the age of 15 years (Ministry of Health and Social Welfare, 2013, 2014, 2015).

The literature shows that if there is good identification and enrolment of HIV-positive children in care and treatment programs, children will account for more than 25 percent of clients enrolled (PMTCT Partners Catalogue, 2013). A study conducted in South Africa by Meyers, et al. (2007) points out that early identification of HIV-positive infants and children is vital for their entry in comprehensive HIV care

and treatment. Early identification and entry in care is critical to reducing morbidity and mortality in children with HIV, as progression to AIDS is more rapid in children than adults.

Early diagnosis of HIV allows healthcare providers to offer optimal care and treatment for children living with HIV, assist in decision making on infant feeding, and avoid needless stress in mothers and families. Early diagnosis of HIV in infants assists families in life planning. Antiretroviral therapy is most effective if initiated before symptoms develop and will reduce the risk of developing OIs, HIV-related cancers, and AIDS (WHO, 2007).

According to the Tanzania PMTCT Partners Catalogue (2013), there are barriers to early identification and enrolment of HIV-positive children in care. Previous studies in resource-poor setting countries (Uganda, Zambia, South Africa, and Malawi) have identified several factors that hinder identification and enrolment of HIV-positive infants and children in HIV/AIDS care and treatment as follows:

1. Lack of health facilities in the nearby area and few financial resources for transportation to a health facility with HIV care and treatment services (Duff, et al., 2010)
2. Frequent stock outs of HIV testing kits (Ahmed, et al., 2013)
3. Lack of skilled human resources, including shortages of healthcare staff (Duff, et al., 2010; Ahmed, et al., 2013).
4. Complicated pediatric dosing in highly active ART regimes coupled with healthcare workers' lower treatment literacy (Meyers, et al., 2007; Duff, et al., 2010; Ahmed, et al., 2013).
5. Isolation of medical staff, frequently with only one physician appointed to each site, resulting in poor staff morale and logistical difficulties because training staff offsite leads to service interruptions (Ahmed, 2013)
6. Lack of a nationally standardized training program in pediatric ART (Ahmed, et al., 2013).
7. Little on-site mentorship of physicians and nurses (Meyers, et al., 2007).
8. Stigma, poor disclosure, parents lack of information about HIV transmission and treatment, lack of parents' willingness to adhere to HIV testing and treatment guidelines, and other parent-related barriers (Duff, et al., 2010; Ahmed, et al., 2013).
9. Policy-related barriers (Ahmed, et al., 2013).

The barriers mentioned above can be reorganized in thematic areas, as covered by this study: economic factors (e.g., lack of money for transportation); social or environmental factors (e.g., stigma towards HIV and AIDS); healthcare factors (e.g., long waiting times); and factors related to knowledge of HIV transmission, treatment, and disease progression (Duff, et al., 2010; Ahmed, et al., 2013).

## **Research Objective**

The purpose of this study was to examine barriers to testing and enrolling children in HIV care and treatment services in Njombe town council (TC) and Wanging'ombe district council (DC) in Njombe region, Tanzania.

## Research Questions

The general research question was what are the barriers to testing HIV-exposed children and infants and enrolling HIV-positive children in HIV care and treatment in Njombe TC and Wanging'ombe DC?

The following are specific research questions derived from thematic areas described in the literature:

1. What are the economic barriers to testing and enrolling infants and children with HIV in HIV/AIDS care and treatment services?
2. What are the social/environmental barriers to testing and enrolling infants and children with HIV in HIV/AIDS care and treatment services?
3. What are the healthcare-related barriers to testing and enrolling infants and children with HIV in HIV/AIDS care and treatment services?
4. What are the barriers related to knowledge of HIV treatment to enrolling infants and children with HIV in HIV/AIDS care and treatment services?

# METHODS

## Data Collection

This was an exploratory, descriptive, and retrospective qualitative study. This approach was chosen because qualitative methods can elicit extensive discussions that we hoped would reveal barriers to the testing and enrolment of infants and children in care and treatment programs, in a way that may not have been obtained from solely quantitative methods.

Data collection was conducted in Wanging'ombe DC and Njombe TC of Njombe region in the southern highlands of Tanzania. We conducted 182 in-depth face-to-face interviews using an interview guide with open-ended questions. In-depth interviews elicited information to achieve a holistic understanding of the interviewee's point of view or experience.

## Sampling

To obtain a representative sample, this study applied a multistage sampling technique. All seven (100%) CTC sites and 22 (25%) PMTCT sites in Wanging'ombe DC and Njombe TC were involved in the study. The inclusion criteria required PMTCT facilities to have more than 10 women clients with HIV-exposed children under the age of two. From the CTC2 files<sup>3</sup> and antenatal care registers, 148 HIV-exposed infants and children were identified and sampled, among whom 91 (61.4%) did not receive either an HIV rapid test or a DNA-PCR test. The remaining 57 (38.5%) children that tested HIV-positive had not started treatment. One parent or guardian of each of the sampled children was asked to participate in the study. Out of 148 adults that were approached, only 132 parents and guardians agreed or were available to participate in the study. With 16 parents and guardians refusing to participate in the study, the acceptance level for 148 parents and guardians that were sampled for study was 89.1 percent.

Additionally, we interviewed 50 HCWs (clinicians and nurses) from the 29 CTC and PMTCT study sites.

Parents were sampled to determine barriers to seeking HIV testing and enrolling in HIV/AIDS care and treatment programs. Healthcare workers were sampled to determine barriers for finding and enrolling HIV-positive infants and children in ART.

An interview was administered to both parents of children and infants who had not received an HIV test and those that were confirmed HIV-positive but had not initiated ART.

**Table 1. Study sites**

District	# of PMTCT Sites	# of PMTCT Sites Sampled (25%)	# of CTC Sites	# of CTC Sites Sampled (100%)
Njombe TC	45	11	4	4
Wanging'ombe DC	41	11	3	3
<b>Total</b>	<b>86</b>	<b>22</b>	<b>7</b>	<b>7</b>

<sup>3</sup> A CTC2 file contains information on the HIV-positive clients attending treatment at a care and treatment clinic.

## **Data Analysis**

Researchers read the transcripts multiple times to capture context and meaning, followed by coding and categorization of recurring concepts and ideas. A master list of all categories was established, assembled, and examined for common themes. Categories of codes were then organized into overarching themes, as follows:

- Economic
- Social/environmental
- Healthcare
- Knowledge

A second researcher conducted data verification and coded all transcripts. Codes were compared and added or removed based on the agreement between analysts. Following coding, a frequency distribution list was developed with the number of responses for each category of participants recorded and tallied. This allowed identification and magnitude of the most frequently mentioned barriers. Relative frequency of each thematic issue identified during analysis was calculated and expressed as percentages or in such statements as “most of the participants.”

## **Ethical Consideration**

The research protocol and data collection tools were submitted to the National Institute for Medical Research for ethical approval before data collection was conducted, and further a letter of intent was submitted to the Ministry of Community Development, Gender and Children through the NACP.

Researchers interviewed study participants individually and privately. The names and physical addresses of the respondents were obtained from the 29 health facilities that were involved in the study. The researchers visited the respondents' homes where they introduced themselves, then asked for consent to speak to the respondent in private. The respondents who agreed to be interviewed were informed about the study, the purpose of the research, their right to confidentiality, and the right to refuse to participate. Each participant provided written consent. Participants unable to read and write provided a verbal informed consent. Trained interviewers selected interviewing areas that provided privacy and confidentiality during the interviews and recorded data using unique patient identifiers.

## RESULTS

Among the parents and guardians interviewed, there were twice as many women as men. Most were poorly educated, with only four (3%) parents and guardians having more than a primary level education. Almost all (90%) were farmers, and more than half (64%) were married.

**Table 2. Characteristics of the parents and guardians of HIV-exposed children**

Variable	Njombe TC (n=46; 35%)	Wanging'ombe DC (n=86; 65%)	Total (N=132; 100%)
<b>Sex</b>			
Female	35	55	90; 68.2%
Male	11	31	42; 31.8%
<b>Highest educational level obtained</b>			
No formal education	3	20	23; 17.4%
Preprimary	0	1	1; 0.8%
Primary	39	65	104; 78.8%
Secondary	4	0	4; 3.0%
<b>Job type</b>			
Builder	2	0	2; 1.5%
Business man/woman	1	1	2; 1.5%
Entrepreneur	7	0	7; 5.3%
Farmer	36	83	119; 90.2%
Security guard	0	1	1; 0.8%
No job	0	1	1; 0.8%
<b>Marital status</b>			
Single	6	2	8; 6.1%
Married	29	55	84; 63.6%
Separated	1	7	8; 6.1%
Divorced	5	2	7; 5.3%
Widowed	5	20	25; 18.9%

### Barriers to Testing HIV-Exposed Children

Among the 91 (61.4%) parents and guardians interviewed who had not taken their children for HTC, the most common response given was because they were not living with them (32; 24%), while others (25; 19%) responded that it's because they did not have permission from their spouse. Some of the parents (20; 15%) did not feel motivated to bring their children for an HIV test because they did not notice any symptoms or signs of illness. However, some respondents (18; 14%), while admitting they were aware of the importance of testing an HIV-exposed child, had not yet tested their child because of fear of an HIV-positive test result and the stigma involved. This caused them to prioritize home activities over taking their child to health facility for HTC. Other reasons given for not having their child tested included not having the time or the inconvenience of getting tested (9; 7%), conflicts between parents (4; 3%), fear of negative public image (2; 2%), unavailability of health services and staff (2; 2%), and the cost of travelling to a testing site (2; 2%). Fifteen (11%) of the respondents did not have any justifiable reason for not testing their HIV-exposed children

Parents and guardians gave reasons they would take their children for HTC. Most of the parents (95; 72%) said it would be good to know their child's HIV status; 17 (13%) thought it would be beneficial for assisting with initiation to care and treatment; and nine (7%) thought it was important to help the parent or guardian know what kind of care to give the HIV-exposed child. One parent provided a financial incentive, saying that early testing allows for earlier initiation of treatment—which delays the disease progression, providing savings on the cost of care that would have resulted from the child developing AIDS. Other respondents (8; 6%) said that being exposed to HIV from the HIV-positive parents justifies testing the child. They added that, once the child is tested, it will help her or him avoid secondary infections.

Many parents and guardians (37%) said more awareness should encourage testing. A quarter (25%) of the respondents expressed that there are few testing centres and more should be established. Fourteen (11%) respondents said that HTC services should be more accessible to communities, while the same number suggested the government change its policy and make testing compulsory, rather than optional. Three people suggested offering HTC services at schools, to capture more children.

The criteria used to determine which children should be tested varied among the HCWs. The criteria included children that had signs and symptoms of the virus (22; 44%), children from parents living with HIV (18; 36%), those self-referred by their parents (5; 10%), those referred by doctors (3; 6%), and orphans (2; 4%).

National guidelines produced by the Ministry of Health advise health facilities to have special arrangements for pediatric HTC such as a designated time and place for conducting HIV testing for infants and children (National Comprehensive Guidelines for HIV Testing and Counselling, 2013). Among the HCWs interviewed, nearly half of the respondents (24; 48%) said there was no special arrangement for testing infants and children. Ten (20%) said some facilities had partial arrangements, such as a specific day for testing infants and children; nine (18%) said that specific HCWs were assigned to provide HTC; and six (12%) reported that specific space had been designated in a health facility for testing.

Healthcare workers reported different rates of testing between adults and children. Most respondents (47; 94%) said that testing is more common among adults than children. Only three respondents (6%) did not see any difference in testing rates between adults and children. The most popular response was that the higher testing rate for adults was attributed to adults being more aware, willing, and able to go for testing compared to children (26; 55%). Other reasons provided for the higher adult testing rates were that HIV testing services are offered where adults access other services such as antenatal care or tuberculosis treatment (10; 21%); adults have more access to HTC since they, unlike children, do not need permission to get tested (8; 17%); and more adults engage in risky behaviour that motivates them to get tested (3; 6%).

The HCW's reported actors contributing to low turn up of children and infants were children needing permission from parents and guardians (24; 48%) and low level of awareness among parents and guardians for the need to have HIV-exposed children tested (19; 38%). Other factors included transport costs, children busy with school, fear of receiving a positive test result, and lack of knowledge of the importance of HTC among children (4; 8%).

Eleven (22%) HCWs mentioned lack of trained HIV testing counsellors as a limiting factor for conducting HIV testing among infants and children; the other 39 (78%) said their facilities had enough HIV testing counsellors. HIV testing is conducted using SD-Bioline and Unigold, for children two and older, whereas DNA-PCR is used for children under two years of age, following a national algorithm, as stipulated in the national guidelines. Most HCWs (44; 88%) claimed there were no stock outs of testing kits during the most recent six-month period, but the remaining six HCWs (12%) admitted that stock outs of rapid kits had caused failure to test children and infants.

National HIV Guidelines dictates that children under the age of 15 must be accompanied by an adult to access testing services. Ninety-one percent (45) of the HCWs said children are brought in by their parents and guardians. The other five HCWs said children are also brought in by a community-based HIV service provider, present alone (commonly known as self-referral), or are accompanied by their teacher.

The main reason HCWs thought parents and guardians did not get their children and infants tested was because of a low level of awareness among the adults of the importance of testing (17; 34%). One-fifth of the HCWs (20%) said that not having a parent or guardian was a key factor, as orphans have no parent or guardian to care for their health. An equal number of HCWs (17%) said that parents and guardians avoided testing their children out of fear and because of barriers related to transportation. A few respondents (3; 6%) indicated parents not living with their children as a factor, while the same number of respondents said parental carelessness was the cause.

The researchers asked the HCWs what the health facility laboratories' contribution was in testing HIV-positive children. All the respondents admitted that laboratories play a great role in pediatric HIV testing, however, the responses differed in what specific role the laboratory played. Most (38; 76%) said the laboratory was responsible for testing and counselling and providing referrals for additional services to HIV-positive clients. Seven respondents (14%) said the labs' role was quality control, while the remaining five respondents (10%) gave various other responses, such as record keeping, ordering and distributing rapid test kits, and providing other important medical tests.

Most providers (70%) said their facilities have targets for testing and enrolling HIV-positive children and infants, while the remaining 30 percent of HCWs said their facilities have no targets.

## **Barriers to Enrolling HIV-Positive Children in Care and Treatment**

Forty-three parents and guardians of children who had tested positive for HIV confirmed that their children were not on treatment. The most popular reason given for this was lack of knowledge (28; 65%). Nine of the parents (21%) admitted that they did not take their children to the clinic because they do not really care about their children's health. Some parents (6; 14%) said they did not initiate their child in care and treatment because of self-denial. Fear, embarrassment, feeling too shy to go to a treatment centre, and self-stigma were also mentioned.

Transport was mentioned as a significant limiting factor. Many respondents (54; 41%) used a car to travel to the clinics. Almost a third (31%) used public transportation such as a *bajaji* (auto rickshaw) or *bodaboda* (motorcycle taxi), while nearly as many (29%) walk to and from the clinics.

When HCWs were asked about the barriers to enrolling HIV-positive children in care and treatment, over one-third (36%) believed low level of awareness among parents and guardians is a key reason. An equal percentage of services providers (18%) said that fear and self-stigma are factors, as well as transport, ARV stock outs, traditional beliefs, religious beliefs, marital conflicts, and change of parents' residence. Seven (14%) respondents said failure to enrol children was caused by carelessness, and five (10%) said parents were not ready to face the reality and responsibility of having an HIV-positive child.

After a child's HIV-positive status is confirmed, the parent or guardian is given a referral for enrolment in a CTC. Although the service providers said it was necessary for them to confirm that the referred child reached the CTC, only 33 (66%), said they confirmed the referrals by using referral feedbacks. The referral feedback system uses a slip from a referral form that has been filled out by the HCW to confirm that an HIV-positive client that was referred from the testing point has reached a CTC. These feedbacks were said to be followed up at the CTC by the nurse counsellors (9; 18%). Eight (16%) other services providers said they use an appointment book to confirm if a child has arrived at the CTC.

Most of the parents and guardians agreed that it was important to enroll HIV-positive children and infants in care and treatment, with the primary reason given that it would make the children live longer (53; 40%). Nearly as many (38%) said that treatment will improve the child's quality of life. Likewise, one-fifth (20%) of the respondents said that initiating treatment will prevent OIs and subsequently improve quality of life. One respondent said that enrolment at a CTC will lead to cost savings as other health problems (such as OIs) will be prevented and because most other services at CTCs are free of charge. Thus, the child enrolled in care and treatment benefits as well as the rest of the family members receiving other services.

Many of the parents (43%) had no information on NGOs that support the government in identifying HIV-positive children and enrolling them in HIV/AIDS care and treatment services, although 17 percent responded that they are aware of NGOs' role in providing HIV education. Fifteen respondents (11%) said there are NGOs that provide testing services, while more (13%) said NGOs have no contribution to HIV education and services.

Testing and enrolling children depends on how important parents and guardians perceive them to be. Many of the parents and guardians of HIV-positive children (22; 51%) said they did not enroll their children in care and treatment because they were not well informed of the treatment. These clients further said that they did not know it is necessary to enroll their children for HIV treatment, even when they are not showing any symptoms. They admitted not knowing the benefits of early initiation in HIV treatment, even for children who have a healthy appearance. Other respondents (14; 32%) failed to enroll their children in treatment because of shyness and fear of what others would think. Six (14%) of the respondents failed to enroll their children in treatment for reasons the researchers concluded as negligence. These excuses included forgetting the appointment date and failing to reschedule, claiming they could not take the child out of school to bring him or her to a CTC, and not believing the positive test results. Furthermore, two respondents claimed their marital status as single mothers prevented them from enrolling their HIV-positive child in treatment, because they did not discuss the topic with the child's father and obtain his consent to take the child to a CTC.

Yet when respondents were asked if they face any challenges in obtaining treatment, almost all (95%) said there were no obstacles or challenges. Those who said there were barriers to obtaining medication and treatment said it was because of medicine stock outs.

### **Alternatives to Enrolling at a Care and Treatment Clinic**

Some parents sought alternatives to healthcare outside of health facilities (i.e., hospitals, health centres, and dispensaries). More than half (59%) of the parents and guardians had used traditional doctors. The traditional service seekers divided into two groups: those who were seeking treatment (47%) and those who wanted to know the cause of the problem (53%). Some used Septrin (an antibiotic) as an alternative to ART, and others used prayer, saying they depended on their religious faith (21%). Four respondents associated sex with disease progression. Therefore, they believed that an alternative to HIV treatment is for PLHIV to stop having intercourse. Another four respondents said that consuming pork will work as an alternative to ART.

## DISCUSSION

This study explored barriers to testing and enrolling infants and children with HIV in Wanging'ombe DC and Njombe TC of Njombe region. Although infants and children born from HIV-positive mothers should be tested for HIV, this important intervention is frequently neglected. A survey by Ahmed, et al., (2013) conducted in Malawi reported greater than 80 percent of children of adult patients on ART had not been tested for HIV. Our study showed similar results; 61.4 percent of the sampled exposed children of index adult cases were not tested for HIV.

Testing rates are poor for older children, because of strict national guidelines stating that children younger than 15 years cannot be tested without parental consent. The country policy hinders efforts to reach many HIV-exposed adolescents (i.e., 13- and 14-year-olds). In the absence of parents or guardians intervening, the HIV-exposed adolescents fail to receive HTC services. Owing to various reasons, parents do not escort their children for testing, even though the children may be able to access HTC services themselves and subsequently link to essential HIV treatment, care, and prevention interventions.

An HIV knowledge gap contributed to the failure of guardians and parents to bring their children in for HIV testing, as did fear. A sentiment was expressed that parents cannot ask their children to get an HIV test for fear they will not be able to explain why the child is getting tested.

A myth persists that PLHIV are sick and appear symptomatic. Thus, if an HIV-exposed child were symptom-free, the respondents thought it unimportant for the child to be tested. This myth was not believed by just parents and guardians, it was also found that nearly half of HCWs believed that HIV testing should be done only when a child shows signs and symptoms of the virus. This is strictly against HIV testing guidelines, which encourages people to get tested as soon as possible, so they can initiate treatment early in the disease progression. The health providers were not knowledgeable about HIV nor the benefits of early testing.

In many villages, parents and guardians still believe in traditional doctors, who are very influential regarding people's health-seeking behaviour. The traditional doctors, who are often poorly informed about HIV, will not advise their clients to seek HIV testing services.

Likewise, some of the HIV-positive parents and guardians visited their religious leaders who convinced them prayer would make them healthy. Thus, some parents and guardians do not bring their children to HTC or enrol them in HIV care and treatment, because they are relying solely on prayer.

Many parents gave the reasons of engagement in work on the farm and daily inconveniences that take time as common reasons they did not take their HIV-exposed children to testing centres. Though income generation is important—because most parents surveyed were HIV-positive, causing their children's HIV exposure—and most are aware of the likelihood that their child has been exposed to the virus, the choice to avoid getting their children tested and treated (if necessary) can be attributed to ignorance or negligence.

None of the respondents in either of the two districts reported the presence of community-based testing. However, Community Concerns of Orphans and Development Association, an NGO based in Njombe, and Tanzania Wattle Company Ltd., a company that grows wattle trees and runs a tea plantation in the two DCs, conducted community-based HIV testing. Community-based models for HTC are feasible, reduce disparities in access to testing services, and are cost-effective for increasing HIV testing among infants and children. Home-based HIV testing, compared with facility-based voluntary counselling and testing and provider-initiated testing and counselling, can identify symptomatic and asymptomatic patients earlier in their disease progression.

Testing supplies were problematic at health facilities. The region had no capacity to manage DBS tests for infants. The process involved taking a blood sample from the infant, sending it to Mbeya region to be

processed at the referral hospital's laboratory, transmitting the results to the facility in Njombe by text message, and then inviting parents to come collect their results in person at the health facility. At that point, the baby would be enrolled in treatment. The clinical capacity needed to perform HIV DNA-PCR testing on infants, particularly at health facilities in Njombe region, was also found to be limited. Limited laboratory facilities for processing HIV tests create a critical delay in initiating treatment for infants in the region.

While this study was being conducted, there was a stock out of Cotrimoxazole, a prophylaxis used to prevent pneumonia and other commonly acquired bacterial infections among HIV-positive children. Parents and guardians mentioned they would have been much more motivated to bring their children to the CTC if there were other medicines available apart from ARVs, such as Cotrimoxazole and Septrin, to treat OIs.

## **LIMITATIONS**

One of the major limitations of this study is the generalizability of the findings to a wider population. The sampling procedure was purely non-probabilistic; therefore, the findings do not represent the diverse sociocultural differences present in Tanzania. Secondly, NGOs or CBOs working in HIV and AIDS were not included in this study. Therefore, the study does not include their perspective.

## RECOMMENDATIONS

Our findings yield several recommendations. This study found negligence as one of the key reasons parents and guardians failed to take their children for HIV testing (even when the parents knew their children were at risk for HIV) and for not enrolling HIV-positive children in treatment. Because one or both parents of the exposed child is HIV-positive, it is important for health facilities to educate the parents that are receiving HIV care and treatment about how HIV is transmitted, the importance of getting their children tested, and why, if they test HIV-positive, they should be enrolled in treatment as soon as possible. Lack of counselling on HCT for children is a missed opportunity for parents attending a CTC. Furthermore, HCWs should always ask female clients at CTCs if they have children that may be HIV-exposed. Family testing should be standard practice for all HIV-positive parents. Children diagnosed HIV seropositive should begin treatment immediately.

To capture all exposed children, HIV testing should be integrated into other child health services, such as reproductive health and child services clinics, so it is encouraged, accessible, and minimizes the stigma associated with stand-alone CTCs.

Likewise, HTC and care and treatment must be tailored to pediatric clients. Several problems arise when children receive services at the same service delivery point as adults: children are left behind; they are served very late, after the adults have been seen; or they do not receive child-friendly services. These problems discourage parents from seeking HIV services for their children and create a negative experience for pediatric clients. Therefore, we recommend a special day or specific hours to serve children and training for HCWs providing child-friendly HIV services.

If PMTCT services are available up to two-years postpartum, more effort should be made to test babies of HIV-positive mothers.

The referral system must be strengthened to effectively enrol HIV-positive children in care and treatment. Every child who tests HIV-positive should be immediately linked to HIV care and treatment services. Yet, after testing, parents are given an appointment to come back another day to be enrolled in care and treatment, which causes many parents to miss their follow-up appointment. Therefore, health facilities should establish an escort system, in cooperation with community service providers, for HIV-positive clients. This means that, when a child is tested at one unit of the health facility, a counsellor or a community-based health volunteer at the health facility will physically escort the parent and HIV-positive child to be enrolled in HIV care and treatment services.

Many HIV-exposed children under the age of 15 fail to be tested, because of the requirement that they be tested in the presence of a parent or guardian. We recommend reducing the age that requires a child to be tested under parent's or guardian's consent. The government should review global HTC guidelines and adjust the age for HIV-exposed children to receive HTC services without parental consent.

Nongovernmental organizations and CBOs play an important role in community-based health education, identifying PLHIV, and linking HIV-positive infants and children to care and treatment. More community education is needed to dispel myths around HIV and AIDS. Furthermore, NGOs and CBOs should be supported to counter the beliefs that traditional healers and spiritual leaders can heal HIV and AIDS.

The government should fund more home-based HCT, because NGOs and CBOs are able to reach more children in their homes. Home visits will help solve a geographical barrier to testing for those who reside very far from a health facility with HCT services. Also, community-based testing will allow children to be tested on weekends and evenings, thereby saving the amount of time children will spend seeking services and not disrupting children's school activities.

The government must provide the equipment, supplies, and training to increase the capacity of regional hospitals to process DBS tests, to facilitate easy initiation of treatment. The government should improve provision of medication for OIs in pediatric HIV treatment units.

Districts should establish a forum for district pediatric HIV that will address challenges with testing and enrolling children in HCT services. The forums should develop an action plan for identifying and addressing the challenges.

## CONCLUSION

Despite the availability of PMTCT services and CTCs in Wanging'ombe DC and Njombe TC, many HIV-exposed infants and children are not getting tested and enrolled in care and treatment, owing to several barriers.

Lack of money for transportation to a health facility and higher prioritization of income-generating activities acted as economic barriers.

Fear of stigma associated with being seen at a testing site, fear of discovering the child's HIV serostatus, embarrassment, and self-denial all created social barriers to receiving HTC services.

In the healthcare setting, there is currently no system for testing infants and children outside health facilities. The absence of Septrin to treat OIs in HIV treatment units creates a barrier for parents wanting to bring their children in for care and treatment services. Likewise, the absence of the means and capability to process DBS with the regional hospital hinders the ability of the districts' health departments to initiate treatment. There was very little contribution by NGOs and CBOs in testing and linking exposed infants and children to care and treatment in the study districts.

Lack of education on the importance of HCT, HIV disease progression, and the importance of early enrolment in care and treatment was a significant barrier to parents and guardians seeking HCT services for their HIV-exposed children. Yet nearly all parents agreed that it would be good to know their child's HIV status. Many HCWs lacked knowledge on the importance of early enrolment in care and treatment when a child appeared asymptomatic. In this part of Njombe Region, there is a lack of NGOs and CBOs providing HIV education.

More effort should be made to ensure early identification of HIV-positive children, because of the importance of initiating care and treatment services early.

## REFERENCES

- Ahmed, S., Kim, M. H., Sugandhi, N., Phelps, B. R., Sabellia, R., Diallo, M. O., Young, P., Duncan, D., & Kellerman, S. E., (2013). Beyond early infant diagnosis: Case finding strategies for identification of HIV-infected infants and children. *AIDS*, 27(0 2), 235–245. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4122794/>
- Arunda, M. O., Choudhry, V., Ekman, B., & Asamoah, B. O. (2016). Under-five mortality and maternal HIV status in Tanzania: Analysis of trends between 2003 and 2012 using AIDS indicator survey data. *Global Health Action*, 9(31676). Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/27329937>
- vanDijk, J. H., Sutcliffe, C. G., Munsanje, B., Hamangaba, F., Thuma, P. E., & Moss, W. J., (2009). Barriers to the care of HIV-infected children in rural Zambia: A cross-sectional analysis. *BioMed Central*, 9(169). Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/19835604>
- Duff, P., Kipp, W., Wild, T. C., Rubaale, T., & Okech-Ojony, J. (2010). Barriers to accessing highly active antiretroviral therapy by HIV-positive women attending an antenatal clinic in a regional hospital in western Uganda. *Journal of the International AIDS Society*, 13(37). Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2954932/>
- Meyers, T., Moultrie, H., Naidoo, K., Cotton, M., Eley, B., & Sherman, G. (2007). Challenges to pediatric HIV care and treatment in South Africa. *The Journal of Infectious Diseases*, 196(Suppl 3) 474–481. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/18181697>
- Ministry of Health and Social Welfare (MOHSW). Prevention of mother-to-child transmission programme: Tanzania's prevention of mother-to-child transmission (PMTCT) partner catalogue. Dar es Salaam, Tanzania: United Republic of Tanzania, MOHSW.
- Ministry of Health and Social Welfare. (2017). District health information system, Accessed December 2016 [Data set].
- Ministry of Health and Social Welfare (MOHSW). (2016). Tanzania elimination of mother to child transmission of HIV plan: 2012–2015. Dar es Salaam, Tanzania: United Republic of Tanzania, MOHSW. Retrieved from [http://www.healthpromotiontanzania.org/index.php/en/library122/doc\\_view/152-costed-emtct-plan-final-16-may-2.html](http://www.healthpromotiontanzania.org/index.php/en/library122/doc_view/152-costed-emtct-plan-final-16-may-2.html)
- Ministry of Health and Social Welfare (MOHSW). (2015). National AIDS control programme annual reports 2015. Dar es Salaam, Tanzania: United Republic of Tanzania, MOHSW.
- Ministry of Health and Social Welfare (MOHSW). (2014). National AIDS control programme annual reports 2014. Dar es Salaam, Tanzania: United Republic of Tanzania, MOHSW.
- Ministry of Health and Social Welfare (MOHSW). (2014). Third health sector HIV and AIDS strategic plan 2013–2017. Dar es Salaam, Tanzania: United Republic of Tanzania, MOHSW. Retrieved from <http://www.nacp.go.tz/site/news/hshsp3final2014.pdf>
- Ministry of Health and Social Welfare (MOHSW). (2013). National AIDS control programme annual reports 2013. Dar es Salaam, Tanzania: United Republic of Tanzania, MOHSW.
- Ministry of Health and Social Welfare (MOHSW). (2013). National Comprehensive guidelines for HIV testing and counselling. Dar es Salaam, Tanzania: United Republic of Tanzania, MOHSW. Retrieved from <https://aidsfree.usaid.gov/resources/national-comprehensive-guidelines-hiv-testing-and-counseling-tanzania>
- Ministry of Health and Social Welfare (MOHSW). (2011). Prevention of mother-to-child transmission report. Dar es Salaam, Tanzania: United Republic of Tanzania, MOHSW.

Ministry of Health and Social Welfare (MOHSW). (2003). The national HIV/AIDS care and treatment plan 2003–2008. Dar es Salaam, Tanzania: United Republic of Tanzania, MOHSW. Retrieved from <http://www.nacp.go.tz/site/download/careandtreatmentplan.pdf>

Swai, R. O., Somi, G. GR., Matee, M. I., Killewo, J., Lyamuya, E. F., Kwesigabo, G., . . . Ndayongeje, J. (2008). Surveillance of HIV and syphilis infections among antenatal clinic attendees in Tanzania: 2003–2004. *BMC Public Health*, *6*(91). Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1459129/>

World Health Organization (WHO). (2007). Early detection of HIV infection in infants and children. Geneva, Switzerland: WHO. Retrieved from [http://www.who.int/hiv/paediatric/EarlydiagnostictestingforHIVVer\\_Final\\_May07.pdf](http://www.who.int/hiv/paediatric/EarlydiagnostictestingforHIVVer_Final_May07.pdf)

## **APPENDIX 1. [Interviewing Guide for Healthcare Workers]**

### **Pima Uishi Kwa Matumaini (PIUMA)**

#### **Interviewing Guide – Health Care Worker**

Barriers to Testing and Enrolling Infants and Children with HIV into HIV/AIDS Care and Treatment in Njombe Town Council and Wanging’ombe District Council.

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District ..... Facility .....  
Date ..... Type (Gov/NGO/FBO/Private).....  
Department..... Title.....

#### **Interviewing Guide to Health Care Worker:**

##### **Questions:**

1. Is the Health Facility providing HIV testing Services?
2. Are you involved in Testing Children?
3. If Yes, How long have you been testing Children?
4. Is the health facility has a system for children testing? (Special Room? /Specific Day? /Specific Paediatric Counselors?)
5. Which group has many people being tested HIV (Children or Adults)?
6. Why do you think many people tested from the group you mentioned?
7. What would be the reason hindering volunteering to test HIV for a group that has least people volunteering to receive HTC services?
8. Who brings the children for a HIV test? (Parents/Neighbor/House maid/Relative/Teachers
9. For the children that were not brought by their parents or Guardian what would be the reasons for them not being brought by their parents?

10. How do you identify the children to be offered with HIV testing?
11. Is your Health facility having enough HIV testing counselors?
12. What do you use in Testing HIV (Reagents and algorithms)
13. Have you ever failed to test children in a period of last six months due to shortage of reagents? Lack of counselors? Space or room?
14. What is the roles of the laboratory in testing HIV to
15. Is there a policy or guideline for testing under 15 year's old children?
16. What do you think there would be the barriers hindering parents from brining their children for HIV Test?
17. Do you know any child that has been confirmed HIV-positive however have not started treatment?
18. What would be the reasons for confirmed HIV-positive child not being enrolled into treatment?
19. How do you confirm that the child tested HIV-positive and been referred to be enrolled into treatment that has started treatment?
20. Is the health facility having a target for a number of children to be tested or enrolled into treatment?
21. What is the contribution of CSO into identifying and enrolling children?

## **APPENDIX 2.** [Interviewing Guide for Parents and Guardians]

### **Pima Uishi kwa Matumaini (PIUMA)**

#### **Interviewing Guide – Community**

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Barriers to Identifying and Enrolling Infants and Children with HIV into HIV/AIDS Care and Treatment in Njombe Town Council and Wanging'ombe District council.

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Village name ..... Sex (Fe/M) .....  
Ward ..... Age .....  
Education level ..... Job .....  
Marital Status ..... Number of Children .....

1. Have you ever tested your children HIV? If Yes, How many?
  
2. Do you think it is important testing HIV to children?
  
3. Have you ever heard of HIV-positive mother with untested children?
  
4. Do you think it is important for children with HIV to be enrolled into treatment?
  
5. Have you ever heard a mother with a confirmed HIV-positive Child that is not enrolled into treatment?
  
6. What do you think would be the reasons for the children not being enrolled into treatment though they are confirmed HIV-positive?
  
7. Do you think why do people not see the importance for the children that have been tested HIV-positive to be enrolled into treatment?
  
8. Are there any difficulties in the availability of testing services of enrollment?
  
9. What would the children (That are not enrolled confirmed HIV-positive opt as an alternative to enrollment to ART?

10. What means do the people that reside very far from the health facility use to bring their children to collect medication?
11. What is the contribution of Civil Society into reaching the identifying and enrolling HIV-positive children?
12. What is the view of the society on the availability of HTC and treatments services to Children HIV-positive Children?
13. Do you think the services provided at health facilities encourage parents to bring their exposed children for HIV testing and treatment?
14. What would be the reasons for parents not to bring their exposed Children for a test or to be enrolled into treatment?
15. Do you think Economical Status of the parents contribute to the parents failing to take the children for HIV testing or enrolling into treatment?
16. What do you think the government should do to motivate Parents to take their children for HIV testing and enrollment into treatment?

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