

Index case finding facilitates identification and linkage to care of children and young persons living with HIV/AIDS in Malawi

Saeed Ahmed^{1,2,*}, Rachael A. Sabelli^{1,*}, Katie Simon^{1,2}, Nora E. Rosenberg³, Elijah Kavuta¹, Mwelura Harawa¹, Spencer Dick¹, Frank Linzie⁴, Peter N. Kazembe^{1,2} and Maria H. Kim^{1,2}

1 *Abbott Fund Children's Clinical Center of Excellence, Baylor College of Medicine, Lilongwe, Malawi*

2 *Baylor International Pediatric AIDS Initiative at Texas Children's Hospital, Baylor College of Medicine, Houston, TX, USA*

3 *University of North Carolina, Chapel Hill, NC, USA*

4 *Malawi Ministry of Health, Lilongwe, Malawi*

Abstract

OBJECTIVES Evaluation of a novel index case finding and linkage-to-care programme to identify and link HIV-infected children (1–15 years) and young persons (>15–24 years) to care.

METHODS HIV-infected patients enrolled in HIV services were screened and those who reported untested household members (index cases) were offered home- or facility-based HIV testing and counselling (HTC) of their household by a community health worker (CHW). HIV-infected household members identified were enrolled in a follow-up programme offering home and facility-based follow-up by CHWs.

RESULTS Of the 1567 patients enrolled in HIV services, 1030 (65.7%) were screened and 461 (44.8%) identified as index cases; 93.5% consented to HIV testing of their households and of those, 279 (64.7%) reported an untested child or young person. CHWs tested 711 children and young persons, newly diagnosed 28 HIV-infected persons (yield 4.0%; 95% CI: 2.7–5.6), and identified an additional two HIV-infected persons not enrolled in care. Of the 30 HIV-infected persons identified, 23 (76.6%) were linked to HIV services; 18 of the 20 eligible for ART (90.0%) were initiated. Median time (IQR) from identification to enrolment into HIV services was 4 days (1–8) and from identification to ART start was 6 days (1–8).

CONCLUSIONS Almost half of HIV-infected patients enrolled in treatment services had untested household members, many of whom were children and young persons. Index case finding, coupled with home-based testing and tracked follow-up, is acceptable, feasible and facilitates the identification and timely linkage to care of HIV-infected children and young persons.

keywords case finding, paediatric HIV, linkage to care, adolescents, HIV testing

Introduction

Significant progress has been made in paediatric and adolescent HIV treatment with an estimated 740 000 children in low- and middle-income countries accessing life-saving antiretroviral treatment (ART) as of 2014 [1]. Simplified guidelines and policies [2] in combination with an impressive global effort to increase accessibility of paediatric ART regimens have helped increase the number of children on ART and improve patient outcomes [3, 4]. Despite these advances, less than a quarter of eligible children are receiving ART in low- and middle-income countries as compared to nearly 40% of adults [1]. A significant challenge to

improving ART coverage amongst children is timely identification and linkage [5], without which children are at a high risk of mortality and morbidity [6–9]. Unfortunately, there are few studies or guidelines providing high-quality evidence to inform child-focused case finding interventions [10].

Index case finding interventions or strategies that use a known HIV-infected person receiving HIV care as an index reference case to actively and systematically target partners or spouses for HIV testing have been shown to be acceptable, feasible and high yield for identifying HIV-infected adults [11–16]. Several studies suggest that the majority of children of HIV-infected adults in care remain untested [17–19]. Nevertheless, there is a paucity of evidence describing the use of this type of index case finding for the identification and linkage to care of HIV-infected children and young persons [17, 19–22].

*These authors contributed equally to the development of this manuscript.

This study describes the implementation of an index case finding and linkage intervention and evaluates its impact on identification and linkage to care of HIV-infected children and young persons.

Method

Setting and patient population

This study was conducted between July 2014 and April 2015 at Mponela health centre, a semi-urban, government-funded health facility in central Malawi, with an estimated adult (age 15–49 years) HIV prevalence of 5.2% and a catchment area of 65 300 patients [23]. At the start of the intervention 1567 people were enrolled in the HIV treatment programme and 1243 of them were on ART.

Details of the intervention

The household HIV testing and counselling (HH-HTC) programme was aimed at identifying and linking HIV-infected children and young persons to care. The HH-HTC programme was part of Tingathe Outreach Program activities. The Tingathe programme and details of how CHWs were selected, trained, supervised and remunerated are described elsewhere [5, 24, 25]. In brief, in partnership with the Malawi Ministry of Health, Tingathe uses community health workers (CHWs) to support HIV care services. CHWs' key roles include providing HIV testing and counselling (HTC) services, linking HIV-infected patients to care and conducting adherence monitoring of HIV-infected pregnant and breastfeeding mothers and their children. Further, in a focused effort to enrol and retain HIV-infected and exposed children into HIV care, a dedicated CHW is assigned to each child to provide routine home and facility-based follow-up.

All patients enrolled in HIV care between July 2014 and February 2015 were eligible for HH-HTC services. One CHW was assigned per day to screen patients to determine the HIV status of their household members. As per community and health centre recommendation, paediatric patients (defined as those 16 years and younger) were only screened if a parent or guardian was present. After screening, any patient reporting a household member with an unknown HIV status was offered the option of either home- or facility-based HH-HTC for their untested household members. An index case was defined as any patient already enrolled in HIV services who reported having an untested household member. A household member was defined as any person living within the

same compound of the index case at the time of screening.

For index cases that chose home-based testing, a CHW visited their home at a time/date most convenient for the index case. If untested household members were not at home during the initial visit, the CHW made one additional visit in an attempt to capture all members. Index cases that chose facility-based testing were instructed to bring their untested household members to the facility and upon arrival go directly to the CHW office to receive HTC services. CHWs offered at least two phone-based reminders to come for HIV testing for index cases that did not bring their household members to the facility for HTC.

During home- and facility-based testing sessions, HTC services were offered to all household members in addition to any other person present at the testing session. HIV testing history and the individual's relationship to the index case were recorded for all persons present. Relationship status included spouse, biological child, biological sibling or other. CHWs then offered an HIV test to those with an unknown HIV status. As per national guidelines, consent was obtained prior to testing from each individual, or in the case of minors under the age of 13, from their guardian [26]. All those who consented were given group pre-test counselling followed by individual testing in accordance with Ministry of Health (MOH) HIV Testing and Counselling guidelines [26]. Infants under one were referred to the health facility for DNA-PCR testing. Family members and spouses were encouraged to receive post-test counselling together to facilitate disclosure.

All persons newly diagnosed with HIV infection and those who were identified with a known HIV infection but not enrolled in HIV care were followed for up to three months by CHWs. The last person eligible for follow-up was identified in January 2015 and follow-ups were concluded in April 2015. During this time, CHWs offered in-depth counselling, provided guidance in accessing HIV services and assisted those eligible for ART to start. Those who missed a scheduled enrolment appointment or were hesitant to enrol in HIV care services were visited at home and phoned by CHWs to follow-up and provide additional support including adherence counselling, assistance with disclosure, and in-depth counselling on the importance of ART to prevent transmission and promote healthy living. Outcomes were recorded for persons identified as HIV-infected either when they enrolled into HIV care, or if not yet enrolled, at the end of the 3-month follow-up period. Outcomes included started ART, enrolled into HIV care (enrolled in care, but not eligible to start ART), died, moved, lost to follow-up and refused. ART eligibility was assessed by MOH clinicians. As per Malawi Ministry of Health ART guidelines in place at the time, pregnant and

breastfeeding women, children less than 5 years of age, persons with WHO Stage 3 or 4 and persons with CD4 less than or equal to 500 cells/mm³ were eligible for ART [27, 28].

Data collection and analysis

Programme data from paper medical records of consenting index cases and those tested aged 1–24 years were extracted and included in the analysis. Infants under one were excluded from the analysis because early infant diagnosis (EID) required a DNA-PCR test at the health facility. Due to the nature of existing EID interventions at the health facility, it was impossible to determine whether the testing was a result of the HH-HTC intervention. Testing and HH-HTC outcome data were stratified by age group into children (age 1–15 years old) and young persons (>15–24 years old). The 15-year cut-off is in line with Malawi Ministry of Health and UNICEF definitions, facilitating comparison with other studies [29, 30].

Data were anonymised before analysis. Aggregate data were reported as mean with standard deviation (SD) if normally distributed and median with interquartile range (IQR) otherwise.

Analyses were performed using Stata Version 13 (Stata-Corp LP, College Station, Texas). The Malawi National Health Sciences Research Committee and the Baylor College of Medicine institutional review board granted ethics approval.

Results

Index cases and uptake of HH-HTC

During the intervention, of the 1567 patients enrolled in HIV services, 1030 (65.7%) were screened for eligibility for HH-HTC services (Figure 1). Of those screened, 461 (44.8%) were eligible for HH-HTC (index cases). Uptake of HH-HTC was high amongst index cases with 431 (93.5%) consenting, of whom 380 (88.2%) preferred home-based over facility-based testing.

Of the 416 consenting adult index cases, 259 (66.6%) were on ART for more than one year, 258 (62.0%) were non-pregnant females and 299 (71.9%) had only primary-level education. The median (IQR) age of the adults was 37 [31–45] years. The remaining 15 consenting were paediatric index cases. Of these, the majority (57.1%) were on ART for less than one year and were females (66.7%) with a mean (SD) age of 7 years (0.89). Of the adult index cases, 272 (65.4%) reported an untested biological child and 7 (46.7%) of the paediatric index cases reported an untested biological sibling.

Testing, identification and characteristics of HIV-infected children and young persons tested

CHWs conducted testing sessions at 358 households in total. Of those, 270 (75.4%) had at least one child or young person tested. In 26 (9.6%) of those households where a child or young person was tested, at least one child or young person was newly diagnosed with HIV. In total, 711 children and young persons were tested, and 28 were newly diagnosed with HIV, resulting in a 4.0% yield [95% CI: 2.7–5.6] (Table 1). The average number of individuals who needed to be tested to yield one new case was 25.4 (28/711).

Characteristics and outcomes of HIV-infected children and young persons identified during HH-HTC

During home-based testing sessions, CHWs also identified two additional children that had a known HIV infection but were not enrolled in care, resulting in a total of 30 HIV-infected children and young persons in need of linkage to care. The mean (SD) age of those identified was 10 years (7.6), and the majority were a biological child to the index case (56.7%), had never been tested for HIV (66.7%) and were eligible for ART (66.7%) (Table 2).

Of the 30 HIV-infected children and young persons identified, 23 (76.7%) were enrolled in HIV services, two (6.7%) died, two (6.7%) moved, one (3.3%) was lost and two (6.7%) refused HIV care. Of the 23 that were enrolled in HIV services, 18 were eligible for ART and started (Table 3). Median time (IQR) from identification to enrolment into HIV services was 4 days (1–8) and from identification to ART start was 6 days (1–8).

Testing yield and outcomes of children and young persons by HIV testing location

Of the 711 HIV tests conducted on children and young persons, 679 (95.5%) were conducted at the index case's home. Home-based testing yielded 19 (2.8% of those tested) new HIV infections and facility-based testing yielded 9 (28.1% of those tested) (Table 4). Of the 19 children and young persons newly diagnosed through home-based testing, 15 (78.9%) were linked to care, whereas six (66.7%) of the nine diagnosed in the facility were linked.

Discussion

To improve ART coverage in children and young persons, novel approaches to identifying and linking them to care, such as index case finding interventions, are needed. Despite country and international guidelines that

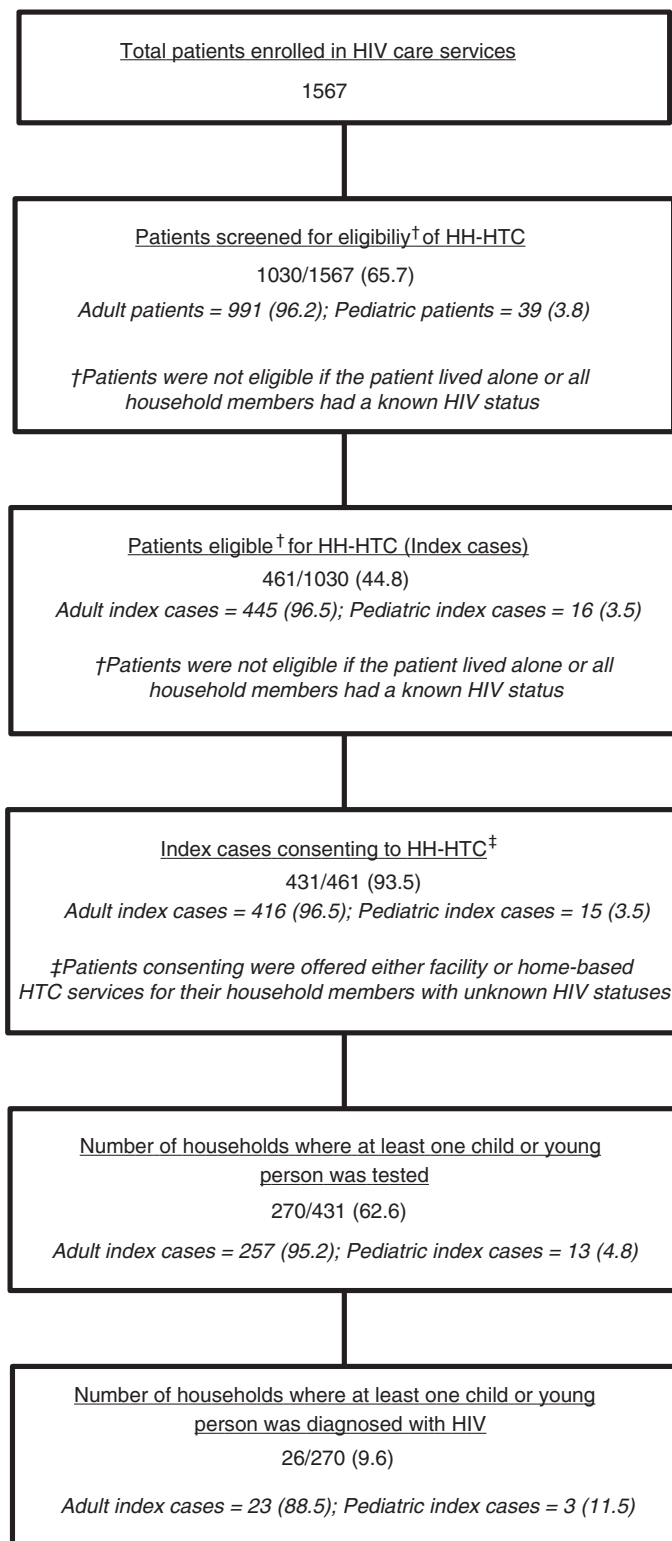
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Figure 1 Summary of screening, enrolment and testing of Household-HTC (HH-HTC) programme.

S. Ahmed *et al.* Index case finding for linkage to HIV care**Table 1** Characteristics of children and young persons who received a HIV test

Characteristic	Children	Young Persons	Total
	Tested 1–15 years <i>n</i> = 546 (%)	Tested >15–24 years <i>n</i> = 165 (%)	Tested 1–24 years <i>n</i> = 711 (%)
Index case type			
Paediatric	16 (2.9)	4 (2.4)	20 (2.8)
Adult	530 (97.1)	161 (97.6)	691 (97.2)
Sex			
Male	280 (51.3)	67 (40.6)	347 (48.8)
Female,	266 (48.7)	93 (56.4)	358 (50.5)
Non-pregnant			
Female, Pregnant	0 (0.0)	5 (3.0)	5 (0.7)
Median Age, years (IQR)	8 (5–11)	21 (18–23)	10 (6–15)
Relation to Index			
Biological Child	355 (65.0)	35 (21.2)	390 (54.8)
Sibling	20 (3.7)	10 (6.0)	30 (4.2)
Spouse	0 (0.0)	9 (5.5)	9 (1.3)
Other	171 (31.3)	111 (67.3)	282 (39.7)
Rapid test result			
Positive	21 (3.8)	7 (4.2)	28 (4.0)
Negative	523 (95.8)	157 (95.2)	680 (95.6)
Inconclusive*	2 (0.4)	1 (0.6)	3 (0.4)

*Inconclusive: both sets (first pass and immediate repeat) of tests were discordant.

encourage testing of family members of persons living with HIV [27, 28], our study suggests that household HIV testing of people enrolled in HIV care is not routinely performed. More than half of the index cases screened reported having an untested household member and nearly two-thirds of those consenting to HH-HTC reported the untested household member as being a biological child. Further, unlike similar studies that only used HIV-infected adults as index cases [14–16, 19, 31, 32], we included paediatric patients and found that 18% of those screened reported an untested sibling. With a 93% acceptance rate of household testing, reinforcing the importance of family testing and offering it either at home or the health facility to patients at every clinic visit represents a crucial opportunity for reaching this high-risk population.

A recent systematic review of HIV testing strategies of children and adolescents including 21 studies conducted in sub-Saharan Africa found the average yield of home-based and family-centred testing efforts to be 2.3% [95% CI: 0.7–4.0] and 3.3% [95% CI: 1.7–4.9], respectively [10]. In a similar index case study by Wagner *et al.*, yield was 7.4% ([95% CI: 3.3–14.1%] [19]. Our 4.0% [95% CI: 2.7–5.6] yield is within the upper level of those described in the systematic review, though on the lower

Table 2 Characteristics of HIV-infected children and young persons identified

Characteristic	Children	Young	Total
	1–15 years <i>n</i> = 23 (%)	Persons >15–24 years <i>n</i> = 7 (%)	1–24 years <i>n</i> = 30 (%)
Index case type			
Paediatric	2 (8.7)	2 (28.6)	4 (13.3)
Adult	21 (91.3)	5 (71.4)	26 (86.7)
HIV status at identification			
New Rapid	21 (91.3)	7 (100)	28 (93.3)
Positive			
Known Infected, not in care	2 (8.7)	0 (0.0)	2 (6.7)
Relationship to index case			
Biological Child	17 (73.9)	0 (0.0)	17 (56.7)
Biological Sibling	1 (4.4)	1 (14.3)	2 (6.7)
Spouse	0 (0.0)	4 (57.1)	4 (13.3)
Other	5 (21.7)	2 (28.6)	7 (23.3)
HIV testing history			
Never Tested	18 (78.3)	2 (28.6)	20 (66.6)
Last Negative	3 (13.0)	3 (42.8)	6 (20.0)
Last Positive	2 (8.7)	0 (0.0)	2 (6.7)
Missing/Unknown	0 (0.0)	2 (28.6)	2 (6.7)
Sex, Male	10 (43.5)	2 (28.6)	12 (40.0)
Mean Age, years (SD)	6.1 (4.6)	21 (1.9)	10 (7.6)
Eligible for ART reason			
Not Eligible	4 (17.4)	1 (14.3)	5 (16.7)
Yes, under five	12 (52.2)	0 (0.0)	12 (40.0)
Yes, breastfeeding	0 (0.0)	1 (14.3)	1 (3.3)
Yes, CD4 < 500	3 (13.0)	2 (28.6)	5 (16.7)
Yes, WHO Stage 3 or 4	2 (8.7)	0 (0.0)	2 (6.6)
Unknown Eligibility	2 (8.7)	3 (42.8)	5 (16.7)
WHO stage			
Stage 1	11 (47.8)	3 (42.9)	14 (46.7)
Stage 2	2 (8.7)	0 (0.0)	2 (6.7)
Stage 3	4 (17.4)	0 (0.0)	4 (13.3)
Not done*	6 (26.1)	4 (57.1)	10 (33.3)

*Was not done because did not return to see a clinician after identification or normally do not stage if patient is universally eligible or staging was not recorded.

range of the Wagner study. However, our 3.8% [CI: 2.5–5.8] yield in children is higher than the national estimated prevalence of 1.6% [95% CI: 1.2–2.0] according to a recent national survey [33]. Further, this yield is comparable to programmatic data from Tingathe's provider-initiated testing and counselling (PITC) paediatric inpatient yields in Malawi of 3.3–4.1% [34] in areas where HIV prevalence is approximately 16% [33]. Thus, the yield from this study is likely higher than what could be achieved with universal testing and is comparable to

Table 3 Outcomes of HIV-infected children and young persons identified

	Children 1–15 years <i>n</i> = 23 (%)	Young Persons >15–24 years <i>n</i> = 7 (%)	Total 1–24 years <i>n</i> = 30 (%)
Outcome*			
Started ART	15 (65.2)	3 (42.8)	18 (60.0)
Enrolled in HIV care programme (not eligible for ART)	4 (17.4)	1 (14.3)	5 (16.6)
Died	2 (8.7)	0 (0.0)	2 (6.7)
Moved	2 (8.7)	0 (0.0)	2 (6.7)
Lost	0 (0.0)	1 (14.3)	1 (3.3)
Refused	0 (0.0)	2 (28.6)	2 (6.7)
Median number of days from identification to enrolment into HIV services‡ (IQR)	4 (1–8)	4 (0.5–37)	4 (1–8)
Median number of days from identification to start of ART† (IQR)	6 (1–8)	6 (0–37)	6 (1–8)

*Outcome was recorded once the patient was enrolled in HIV services and if eligible started ART, or if not enrolled at the end of the 3-month follow-up period.

†Using data from only those that started ART.

‡Using data only from those that started ART and those enrolled in HIV care programme.

Table 4 Testing yield and outcomes of children and young persons by HIV testing location

	Home-Based <i>n</i> = 679 (%)	Facility-Based <i>n</i> = 32 (%)
HIV tests done		
Children (1–15 years)	523 (77.0)	23 (71.9)
Young Persons (>15–24 years)	156 (23.0)	9 (28.1)
Total (1–24 years)	679 (100.0)	32 (100.0)
New HIV infections diagnosed		
Children (1–15 years)	17 (2.5)	4 (12.5)
Young Persons (>15–24 years)	2 (0.3)	5 (15.6)
Total (1–24 years)	19 (2.8)	9 (28.1)
Linked to HIV Care*‡	<i>n</i> = 19	<i>n</i> = 9
Children (1–15 years)	14 (73.7)	3 (33.3)
Young Persons (>15–24 years)	1 (5.3)	3 (33.3)
Total (1–24 years)	15 (78.9)	6 (66.7)

**n* is the number of patients identified as eligible to be linked to HIV care (equal to number of new HIV infections diagnosed).

‡Linked to HIV care includes ART initiation for those eligible, or if not eligible, enrolment into HIV care programme.

the yield from targeted interventions in high prevalence areas. This suggests an approach similar to the one used in this present study which actively screens, then tracks both paediatric and adult HIV-infected patients with untested household members is a more effective strategy for identifying HIV-infected children and young persons than universal testing alone.

The vast majority (88%) of index cases in our study preferred home-based testing. Similar to another study in Kenya [35], we found that both men and women preferred home-based testing to facility-based testing.

However, in some cases, CHWs were unable to provide home-based testing because no one was present at home, or the homes could not be found due to poor directions. Despite this, home-based testing remains a viable option for many patients because of its convenience and privacy. In higher prevalence, more densely populated areas or in areas where home visits could be more accurately planned, this strategy could have greater yield. Further, with 75% of index case households tested providing testing of a child or young person, home-based testing provides an opportunity to reach this population of young adults that may not be found in a facility-based setting [36].

Facility-based testing found 28% of persons tested to be HIV positive, which was eightfold greater than home-based testing and threefold greater than similar facility-based outpatient testing efforts in children and adolescents [10]. We believe our higher yield may be due to index cases being prompted to test their household members while already suspecting their positive status. However, routine facility-based testing efforts, including provider-initiated testing and counselling (PITC) and interventions that systematically track untested children of HIV-infected patients and provide referrals for testing, can increase paediatric HIV testing. These strategies remain an important method of identifying children and young persons living with HIV in areas where human resources are inadequate for home-based testing [10, 19, 32, 37–40].

A systematic review of linkage-to-care programmes in sub-Saharan Africa estimates that less than one-third of people identified with HIV are retained in care between the time they are tested and the time they commence

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ART treatment [41]. The multifaceted linkage approach used in this intervention which combined in-depth counselling, phone call reminders and home- and facility-based follow-ups resulted in over 75% of those identified with HIV being enrolled into HIV care services. In studies specifically looking at linkage from home-based testing initiatives [42–45], linkage rates range from 42% to 96%. Our study's linkage rate was on the higher end of the spectrum at 78.9%, a result we believe to be due in part to the family-based approach to pre- and post-test counselling. Several studies have suggested that family-based approaches such as this improve intrafamily disclosure and communication surrounding HIV care, thus improving linkage and response to treatment [31, 46]. Another reason for our high linkage rate could be the continued support and follow-up of CHWs. Qualitative data from a study by Ware *et al.* suggests that home-based testing combined with follow-up reduces linkage barriers by building supportive, 'social-bridges' between the CHW and the patient [47, 48].

To improve paediatric outcomes, those identified as HIV-infected need timely entry into care. Our results show a median time to ART initiation of 6 days (IQR: 1–8), a marked improvement to the standard of care demonstrated in a similar clinic in Malawi with median time to ART initiation of 59 days (IQR: 10–330) [49]. Long waiting times, poor staff–patient relationships and inadequate counselling [50, 51] have all been cited as barriers to ART initiation. In our study, CHWs helped with the initiation process at the facility, provided targeted counselling, prioritised children and guided patients through ART initiation procedures. However, linkage to care is only one step in the continuum. Recent systematic studies have shown younger age to be a predictor for non-adherence [52] and paediatric retention in care to be suboptimal [53]. To achieve viral suppression in children and adolescents, further research on improving adherence and retention post-linkage need to be explored.

The strengths of our study included that we were able to evaluate both identification and linkage outcomes of the intervention with our multifaceted strategy. We also included young persons, addressing a gap in adolescent-focused testing strategies. However, some limitations must be taken into consideration when interpreting the results. First, we cannot be sure that patients honestly reported their household members' HIV status or those members in need of testing, leading to potential response bias. Some patients may have underreported household members in need of testing for reasons such as fear of disclosure or stigma by family or community members and/or fear of knowing the HIV status of their household members. Overreporting may have been caused by

participants thinking that falsely reporting untested members and participation in the activity would bring them additional incentives. To avoid this, it was clearly communicated during screening that no incentives or special treatment would be given to participating patients. Further, the HH-HTC intervention took place within the Tingathe Programme's routine intervention. This may have influenced the uptake of household testing as patients were already accustomed to CHWs and their involvement within the community. Therefore, they may have been more likely to consent and choose home-based *vs.* facility-based testing. This study was conducted at one health facility and may not be generalisable.

Conclusions

Early identification and timely linkage to care are essential to improve outcomes of children and young persons living with HIV. In our study, almost half of HIV-infected patients enrolled in treatment services had untested household members. A family-centred, index case finding approach, coupled with home-based testing and tracked follow-up is acceptable and feasible, and facilitates the identification and timely linkage to care of HIV-infected children and young persons.

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Corresponding Author Saeed Ahmed, Abbott Fund Children's Clinical Center of Excellence, Baylor College of Medicine, Lilongwe, Malawi. E-mails: saeeda@bcm.edu; sahed@tingathe.org