Barriers to and emerging strategies for HIV testing among adolescents in sub-Saharan Africa

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Abstract

Purpose of Review

HIV/AIDS is one of the leading causes of death among adolescents in sub-Saharan Africa and 40% of new HIV infections worldwide occur in this group. HIV testing and counselling (HTC) is the critical first step to accessing HIV treatment. The prevalence of undiagnosed HIV infection is substantially higher in adolescents compared to in adults. We review barriers to HTC for adolescents and emerging HTC strategies appropriate to adolescents in sub-Saharan Africa.

Recent Findings

There are substantial individual, health system and legal barriers to HTC among adolescents, and stigma by providers and communities remains an important obstacle. There has been progress made in recent years in developing strategies that address some of these barriers, increase uptake of HTC and yield of HIV. These include targeted approaches focused on provision of HTC among those higher risk of being infected e.g. index-linked HTC and use of screening tools to identify those at risk of HIV. Community-based HIV testing approaches including HIV self-testing and incentives have also been shown to increase uptake of HTC.

Summary

In implementing HTC strategies, consideration must be given to scalability and cost-effectiveness. HTC approaches must be coupled with linkage to appropriate care and prevention services.

Key Words: HIV, Adolescents, Testing, Strategies, Barriers

Introduction

HIV testing and counselling (HTC) is the critical first step to accessing HIV treatment and is an opportunity to promote healthy sexual behaviour through counselling and linkage to HIV prevention and sexual reproductive health services (1-3). The prevalence of undiagnosed HIV infection is substantially higher in adolescents compared to in adults (4). Population HIV Impact Assessments (PHIA) surveys conducted in Malawi, Zambia and Zimbabwe between 2015-2016 showed that less than 50% of young people aged between 15-24 years living with HIV were aware of their HIV status (5-7). Adolescents with HIV include those who have acquired HIV vertically as well as horizontally (2). In sub Saharan Africa (SSA), which bears 74% of the global burden of HIV infection, large numbers of adolescents, infected vertically before interventions to prevent mother-to-child transmission were scaled up have been presenting to health services with undiagnosed HIV in recent years (8). In addition, 40% of new HIV infections worldwide occur in adolescence and HIV infection rates in this age-group are projected to rise (5, 9). Delayed diagnosis is associated with an increased risk of mortality as well as onward HIV transmission (5). We review barriers to HIV testing for adolescents and emerging HTC strategies appropriate to adolescents in SSA.

Barriers to HIV testing and counselling among adolescents

Barriers to HTC among adolescents occur at individual, health service provider and policy levels (Table 1).

Table 1: Summary of Barriers to HIV Testing and Counselling in Adolescents

Individual and societal	
Individual	• Fear of positive HIV positive status and stigma (10-13) • Lack of comprehensive HIV knowledge (11) • Perception of low risk (14, 15)
Family/community	• Stigma and sanctioning of sexual activity in adolescents (10, 13, 16) • Caregiver non-involvement (10) • Parental fear of disclosure of own HIV status (15, 16) • Desire to protect children from stigma (16) • Competing priorities among caregivers (11) • Lack of HIV knowledge (11)
Health service provider	
Staff	• Healthcare worker judgemental attitudes (10, 12) • Lack of confidentiality (healthcare provider disclosure of HIV status to caregivers) (10, 12) • Lack of HIV knowledge (14) • Insufficient training of healthcare workers in discussing HIV, ethico-legal issues (14) • Concern about unavailability of support services for adolescents with HIV (14)
Health Facilities	• Lack of staff and testing kits (14) • Priority for HIV testing within facilities given to other services e.g. PMTCT (14) • Accessibility of facilities; location and unsuitable working hours (12)
Health policy and legal	
	• Legal age of consent (11, 14, 17) • Discrepancies in national HIV testing guidelines (14, 18)

Studies have reported a lack of comprehensive HIV knowledge and of inaccurate perception of personal risk, with some adolescents considering HTC to be neither necessary nor important (19). Other barriers to HTC reported by adolescents are fear of the consequences of having a positive test result, and stigma from peers and providers (10). Adolescents, particularly younger adolescents who are more likely to be vertically-infected, rely on their caregivers for accessing HTC. Many are orphaned and have changing caregivers. In addition, caregivers may have more urgent competing priorities which mean that they only consider having their child tested when the child gets sick and likely develops advanced disease

(13, 14). While many caregivers suspect their adolescent may have HIV either due to the parent having died or due to chronic ill-health, there is a misplaced desire to protect their child from the stigma s/he may face in the community (13). In the case of a vertically-infected adolescent, a positive HIV test deductively discloses the HIV status of the mother (and possibly the father) and the guilt and the fear of blame from their child has been shown to be a reason why caregivers may not have their children tested (13, 15, 16).

Since 2007, the World Health Organization (WHO) has recommended provider-initiated HIV testing and counselling (PITC) in high HIV prevalence settings, whereby HIV testing is offered proactively to all clients attending a healthcare facility regardless of the reason for attendance(20). This relies on clients attending the facility and a healthcare worker (HCW) then offering HTC. Distance from health facilities, transportation costs and inconvenient opening hours are barriers for accessing health services by adolescents. Common reasons adolescents report for not accessing HTC are the stigmatising and judgemental attitudes of healthcare providers, and lack of confidentiality (2, 10). In a 2013 study evaluating PITC among children aged 6-15 years attending primary healthcare clinics (PHCs) in Zimbabwe, only 54% underwent HTC, the primary reason for the low coverage being that HCWs did not offer HTC (14). Notably, being aged >11 years was associated with lower odds of being offered HIV testing. From a provider perspective, inadequate knowledge and training of healthcare providers in addressing the complexities of HIV in adolescents such as ethico-legal issues, disclosure and the "language" to discuss HIV serve as barriers to offering HTC (14). Other barriers include lack of adequate staff, and prioritisation driven by donor funding (e.g. prioritisation of prevention of mother-to-child transmission), concern about the availability of appropriate support services for those who test HIV-positive, and the perception of adolescents as a low risk group (particularly younger adolescents who would not be expected to be sexually active) (8, 14).

Most countries require consent from a guardian for minors to access HTC (17). Many adolescents in Africa do not live with their parents but within extended family structures, either because they are orphaned or because parents migrate for work (13). Caregiving arrangements are therefore unstable and guardianship is often not legally defined, leaving healthcare providers to make a difficult decision about whether the accompanying caregiver is "suitable" to give consent (17, 18). In five SSA countries, the legal age of consent for HTC is 18 years or above (17). There have been policy changes in some countries for example in South Africa, whereby a child above the age of 12 years can consent for an HIV test independently (21). However, the legislation also stipulates that it is an offence to have consensual sex below the age of 16 years, a legal barrier for sexually active adolescents at high risk of HIV infection to seek HTC (17, 18, 21). Policies do make provision for healthcare providers to give consent on behalf of the minor when a guardian is unavailable if HTC is "within the best interests of

the minor", or provision to consent independently by those deemed to be "mature minors" (17). However, these conditions are often subjective and rely on providers having to make decisions, which they are not always trained to do. The practical implications of legislature around consent has posed challenges for healthcare providers in terms of the conflict between maintaining confidentiality versus disclosing test results to caregivers to ensure that adolescents are supported (22).

HIV testing and counselling strategies for adolescents

HTC strategies have evolved over the last 10 years from client-initiated approaches such as voluntary counselling and testing (VCT) to provider-initiated testing and counselling approaches (PITC) offered routinely in health facilities, and more recently implementation of community-based strategies (7). These have largely focused on adults and not been tailored to the needs of adolescents (23). Recognising the need to prioritise adolescents as a key population for HIV prevention and care, the WHO developed specific HTC guidelines for adolescents in 2013 (24). Most of the WHO recommendations were based on low-quality evidence, and the guidelines highlighted the need to establish comparative effectiveness of interventions to improve access to HTC in this age-group (24). In this section, we discuss recent approaches to HTC tailored for adolescents in SSA. These strategies are summarised in Table 2 and relevant studies detailed in Table 3.

Table 2: Summary of HIV testing strategies for adolescents

Strategy Type	Delivery method
Self-testing	• Self-administered self-tests • Assisted self-testing
Use of Incentives (financial/non-financial)	• Incentives to caregivers • Incentives to adolescents • Incentives to facilities
Targeted testing	• Index-linked testing • Use of screening tools
Facility modifications	• Extended hours • Youth friendly services • Routine opt-out testing
Community based testing	• Door-to-door testing • Mobile testing • Campaign testing • Use of social events • Youth centres • School based
Technology and Edutainment	• Telephone based counselling • Simulated processes

Table 3: Studies describing HIV testing strategies in Adolescents in sub-Saharan Africa

	Lead Author, country, year	Age (years)	Testing Strategy	Setting	Type of HIV test	Number offered HTC	% accepted HIV testing	HIV prevalence	Yield	Comments
1.	Ahmed, 2017 Malawi (25)	1-24	Index linked	Home and Facility	Not specified	461 index cases 711 children and young persons	94% index cases	4%	Not reported	95.5% of tests conducted at home. 65% of adult index cases reported having at least 1 biological child with an unknown HIV status.
2.	Chaila,2017 Zambia (26)	10-14	Screening tool	Community	Not specified	17870	51%	1%	0.4%	Among participants tested HIV prevalence was higher in those termed as "at risk" (2.4%) compared to those not at risk (0.6%).
3.	Daniels, 2017 South Africa (27)	Unrestricted	Technology, Social marketing, telephone counselling	Community	Not specified	72 220 program participants	Not reported	Not reported	Not reported	
4.	Kranzer, 2017 Zimbabwe(28)	8-17	Financial Incentives	Facility	Blood based rapid	2050 households	20% (no incentive) 48% (fixed incentive) 40% (lottery)	Not reported	Not reported	HTC offered to all adolescents in households.
5.	Njuguna, 2017 Kenya (29)	0-12	Index linked HTC and Incentives	Facility	Blood based rapid test if >18 months HIV DNA PCR if <18 months	71 (index cases)	73% of randomised index cases	2%	Not specified	Uptake of HTC was higher in the group offered incentives compared to a cohort that did not receive incentives. Uptake of testing did not differ depending on incentive offered.
6.	Shanaube, 2017 Zambia (30)	15-19	Door to door	Home	Not specified	10809	81%	2%	1%	Intervention was coupled with HIV prevention services.
7.	Bandason, 2016 Zimbabwe (31)	6-15	Screening tool	Facility	Blood based rapid test	12057	80%	5%	4%	Tool sensitivity 88.4%; specificity 66.3% in identifying children living with HIV
8.	Fatti, 2016 South Africa (32)	10-19	Index linked Door to door HTC Campaign HTC	Home Home Outdoor events	Not specified	4800	99%	6%	6% 6% 9%	
9.	Ferrand, 2016 Zimbabwe (33)	6-15	ROOT	Facility	Blood based rapid test	7301	95%	5%	4%	Supplementation of test kits and personnel by study

PITC has been shown to have a high yield (proportion of individuals who test HIV positive of those eligible for testing), but as discussed above relies on providers offering HTC to clients (34). A study in Zimbabwe that compared routine opt-out testing (ROOT), whereby clients are tested unless they actively declined to test, to standard PITC among children aged 6-15 years attending in six PHCs in Zimbabwe, showed that implementation of ROOT increased the proportion of individuals who underwent HTC and the yield of undiagnosed HIV (33). An opt-out strategy transforms HIV testing into a routine, default clinical action, which removes some decision making from the providers and guardians. A potential concern of such an approach is that it may result in coercion of the client and reduce client autonomy, a concern that has been debated within prevention of mother to child transmission of HIV (PMTCT) programmes where such an approach is widely used (35). Such a concern needs to be weighed against the right to and also benefit of access to effective and life-saving treatment, and the reliance of adolescents on others to give consent on their behalf to access HTC. More recently, implementation and scale-up of HIV prevention programmes such as voluntary medical male circumcision (VMMC) and pre-exposure prophylaxis (PreP) include opt-out HIV testing and serve as an opportunity for adolescents to know their HIV status (36-38).

A potential concern about blanket HTC approaches such as PITC in adolescents is that it is an inefficient strategy given the relatively low HIV prevalence in this age-group compared to in adults (33). Thus, targeted approaches that identify those at higher risk of being HIV-infected have been proposed as potentially more cost-effective and sustainable (34). Two studies conducted in Malawi and Kenya between 2013 to 2015 showed that 45% and 42% of adults in care respectively had children and adolescents of unknown HIV status (25, 39). Notably, in the Kenya study, of adults who had children of unknown HIV status, 82% reported their child being >13 years, suggesting that adolescents are much more likely to be undiagnosed than younger children (39). Actively testing children of HIV-infected parents, an approach referred to as index-linked testing, showed a four-fold increase in HIV testing rates as well as a high yield of HIV (7-15%) compared to yield in studies that have offered "unselected" HTC (39). Similarly, in the Malawi study, index-linked testing of children (1-15 years) and young persons (aged 15-24 years), coupled with home-based testing and tracked follow-up was highly acceptable and resulted in high uptake (94%) and yield of HIV (4%) (25).

A screening tool consisting of five items (client-reported orphan hood, past hospitalization, skin problems, a sexually transmitted infection (STI) and poor functional ability) developed in 2011 to identify adolescents (10-18 years) at risk of being HIV-positive who could then be targeted for HIV testing, reduced the numbers needed to test to identify an HIV-infected adolescent by 60% in Zimbabwe (40). In a follow-up study in 2015 that field-tested a modified tool (4 items, STI removed) in older children and adolescents (6-15 years) attending PHCs, the sensitivity and specificity in detecting HIV

infection were 80.4% and 66.3% respectively (31). In a similar study in Zambia among 10-14 year olds, the odds of being HIV-infected was 4.3 higher among those classified at risk by the tool compared to those classified as not at risk (26). While both targeted approaches increase yield, they are more likely to identify vertically rather than horizontally-infected adolescents.

Community-based HTC strategies including door-to-door, mobile and campaign HTC may be able to diagnose individuals at an earlier stage of infection by being more accessible and not relying on providers' discretion or on a client visiting a health facility (41). The latter is particularly relevant as health facility usage rates among adolescents are low (42). A prevalence survey in Zimbabwe showed that while health facility based HTC resulted in high yield of HIV, it was insufficient to reduce community-level burden of undiagnosed HIV (43). Nearly 40% of adolescents (8-17 years) with HIV in the community-based survey were found to be undiagnosed despite implementation of optimised PITC over 2 years in the 7 study communities (43).

In Zambia, the PopART trial showed an 81% uptake of HTC among adolescents aged 15 to 19 years using a community based door-to-door approach. However, within households enumerated, contact was not made with 25% of adolescents and one of the major challenges cited in this study was difficulty in obtaining consent from parents for their adolescents to undergo HTC (30). The yield in this study was 3% among females and 1% among males. A study from Kenya and Uganda that used mobile community health campaigns where HTC was offered over 2 weeks, followed by door-to-door HTC reported 88% uptake of HTC among adolescents and young people aged 10 to 24 years (44). This was a significant increase in HTC uptake as only 28% of respondents reported prior HIV testing (44). Although there was high coverage of HTC, the number needed to test to identify one HIV positive adolescent was 88 in Uganda and 23 in Kenya. A cross-sectional study in South Africa conducted between 2014-2015, evaluating index linked HIV testing, campaign HTC and door to door testing among adolescents (10-19 years) reported uptake of 99% among adolescents who had received counselling. However, yield of HIV was highest through campaign testing (9%) followed by index linked testing (6%) and door to door testing had the lowest yield (5.9%) (32). The HPTN043 multi-country trial (Project ACCEPT) conducted in Zimbabwe, South Africa, Tanzania and Swaziland which combined community mobilisation and mobile HTC with post-test support services for adults (≥18 years), improved rates of HIV testing by 25% which were sustained over 36 months of continued evaluation, setting this intervention apart from traditional one-off community-based HIV testing campaigns(45). The increase in proportion of testers was especially pronounced in men (45% increase). However, overall incidence of HIV among young people (18-24) was the same in intervention and non-intervention communities (intervention effect 0.98 CI 0.80-1.22) p=0.86)(45).

While community-based HTC strategies appear to have high acceptance, reduced barriers to access, and may identify those who are otherwise hard-to-reach and are asymptomatic and would therefore not attend health facilities, they have a low yield of HIV, and require considerable resources (30). The cost effectiveness of these strategies must be assessed to inform the feasibility of scalability and long-term sustainability (46, 47). In addition, ensuring linkage to care may be more challenging with community-based HTC.

A study conducted among 16-24 years olds in South Africa to evaluate self-testing using a rapid blood test demonstrated that 96.4% completed the test correctly and were able to interpret the test results (48), and only 3% of participants failed to prick their finger (48). In recent years, HIV self-testing using oral mucosal transudate (OMT) HIV tests has been shown to be highly acceptable and accurately performed by adults in SSA (37, 49). Following a large-scale evaluation of HIV self-testing in SSA, there has been a rapid scale-up of this strategy with a consequent reduction in the cost of OMT tests(50). Self-testing provides individuals the flexibility to choose where and when to perform an HIV test without fear of judgement from a provider (51), and has the potential to bridge the gap that currently exists in access to HTC among adolescents (52). A community-based study in Malawi that evaluated self-testing found that the highest uptake was among 16-19 year olds. (49). This approach may however not be appropriate for younger adolescents (17, 21), and an alternative may be to train guardians to test their own children.

The use of incentives may be one approach to increase uptake of HTC (53). A recent randomised controlled trial conducted in Zimbabwe comparing a fixed incentive (US$2) or lottery participation (to win US$ 5 or US$10), both given to caregivers of 8-17 year olds, showed 3.67 and 2.66 higher odds respectively of adolescents accessing HTC compared to the control arm (no incentive) (28). A pilot randomised trial in Kenya also found higher uptake of HTC in children aged 0-12 years when an incentive of cash or mobile money transfer (KSH500, KSH1000, and KSH1500) was offered to their female caregiver when compared to a similar cohort that did not offer incentives (72% vs 14%) (29). In this study 25% of caregivers had children of unknown HIV status who were >12 years and therefore ineligible. Concerns have been raised about the potential for scalability, the cost-effectiveness and the potential for coercion from caregivers to adolescents to test (28, 29). However, the risk of coercion is unlikely to be significant given the small amounts of incentives given. In both studies incentives were given to caregivers suggesting that this strategy would likely be more sustainable for younger adolescents in the context of vertical HIV infection and repeated HTC would not be required until sexual debut. Further research is required to assess effectiveness of incentives offered to adolescents themselves on HTC uptake.

Organised social events (sports events and campaigns) that incorporate sexual and reproductive health services and HTC have been used to reach adolescents. "One-stop shop" services that incorporate HTC among a broader package of health services (e.g. nutritional counselling) could decrease the stigma associated with HIV testing and be more acceptable to adolescents. Such an approach has been used in South Africa delivered through mobile services and at youth centres (54). Grassroots Soccer, a non-governmental organisation, through their SKILLZ Street program for girls aged between 12 and 16 years in South Africa from 2011-2012 found that as part of their soccer based program 69% of girls had tested for HIV (55).

Use of mobile technology coupled with edutainment has been used to improve HTC uptake and intention to test among adolescents (27, 56). The Shout-It-Now program in South Africa used a step-wise process with a combination of technology, telephone counselling and social marketing with reports of testing uptake of 98.5% through their school program (27). More research is required to evaluate the yield and effectiveness of this approach.

Conclusions

HIV testing is the critical first step to accessing HIV treatment and prevention services. In recent years there has been progress made towards developing HTC strategies appropriate for adolescents. It is vital to consider not only the feasibility, acceptability and yield of strategies, but also their potential for scalability and cost-effectiveness. Finally, linkage to appropriate care and prevention services must be coupled with HTC approaches.

Key points

1) The prevalence of undiagnosed HIV infection is higher in adolescents compared to other age-groups.

2) Barriers to HTC among adolescents include need for guardian consent, negative attitudes and lack of training among healthcare workers, stigma, and distance from facilities, inconvenient opening hours of facilities and long waiting times.

3) Several strategies have improved uptake and yield of HTC in adolescents including HIV testing targeted at adolescents at high risk of being infected, community-based testing (campaigns, mobile testing, home-based testing), use of incentives and HIV self-testing

4) HTC strategies for adolescents must be evaluated for their potential for scalability and cost-effectiveness and should ensure linkage to appropriate treatment and prevention services after testing.

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Conflicts of interest

The authors have no conflict of interest.

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