



HHS Public Access

Author manuscript

AIDS Care. Author manuscript; available in PMC 2024 March 01.

Published in final edited form as:

AIDS Care. 2023 March ; 35(3): 392–398. doi:10.1080/09540121.2022.2067315.

“They have given you the morale and confidence:” Adolescents and young adults want more community-based oral HIV self-testing options in Kenya

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Abstract

Community-based delivery of oral HIV self-testing (HIVST) may expand access to testing among adolescents and young adults (AYA). Eliciting youth perspectives can help to optimize these services. We conducted nine focus group discussions (FGDs) with HIV negative AYA aged 15-24 who had completed oral HIVST following community-based distribution through homes, pharmacies, and bars. FGDs were stratified by distribution point and age (15-17, 18-24). Participants valued HIVST because it promoted greater autonomy and convenience compared to traditional clinic-based testing. AYA noted how HIVST could encourage positive behavior change, including using condoms to remain HIV negative. Participants recommended that future testing strategies include individualized, ongoing support during and after testing. Support examples included access to trained peer educators, multiple community-based distribution points, and post-test support via phones and websites. Multiple distribution points and trained peer educators’ involvement in all steps of distribution, testing, and follow-up can enhance future community-based HIVST programs.

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Declaration of Interest Statement

Authors have no conflicts or competing interests, and no financial interest or benefit that has arisen from the direct applications of our research.

Keywords

Adolescent HIV; qualitative research; HIV self-testing

Introduction

In sub-Saharan Africa, 42% of new HIV infections were among adolescents and young adults (AYA) ages 15-24 (Global AIDS Update 2020). While HIV testing is a gateway to HIV treatment and prevention services, only 16% of adolescent boys and 27% of adolescent girls ages 15-19 in Eastern and Southern Africa had tested for HIV in the last year (UNICEF, Global and Regional Trends HIV). One reason for lower rates of HIV testing among AYA is that standard HIV Testing Services (HTS) strategies have been primarily designed for children or adults (WHO Consolidated Guidelines on HIV Testing Services). Barriers among AYA to provider-assisted HTS include fear of stigma and judgement, mistrust of providers, privacy concerns, wait times, inconvenience, and parental consent (Grispen et al, 2010; Macphail et al, 2008; Mokgatle, 2017; van Rooyen et al, 2015).

HIV self-testing (HIVST) is a promising strategy that may overcome testing barriers for hard-to-reach populations, including AYA. Studies among adults have shown that oral HIVST is acceptable, easy to use, and performs similarly to standard, supervised HTS (Kumwenda et al, 2019; Musheke et al, 2013). Additional benefits include speed, privacy, anonymity, fewer clinic visits, and reduced cost (Hector et al, 2018). While HIVST offers a potential solution, there have been concerns about offering HIVST to AYA including understanding how to test or interpret results, lack of access to post-test counseling and linkage to care, and potential social harms (Kumwenda et al, 2019; Mokgate, 2017).

While at least 77 countries have included HIVST in national testing guidelines (WHO Guidelines, 2018; WHO HIV Self-Testing, 2016), few programs offer community-based distribution of HIVST to AYA. Quantitative studies have shown high acceptability of HIVST peer-led social network distribution, as well as the feasibility of offering HIVST to youth who were absent for standard home-based testing to improve test completion (Amstutz et al, 2020; Matovu et al, 2020). One qualitative study among AYA ages 18-24 years in South Africa who had not used HIVST reported potential benefits of convenience and privacy and potential concerns about reliability of results and access to post-test support (Ritchwood et al, 2019). While Kenyan HTS guidelines recommend community-based distribution of HIVST as part of HTS, most HIVST services are only available through facilities. Understanding experiences of AYA offered HIVST through community-based distribution points would offer new insights into expanding HIVST access for this population (Mugo et al, 2017). This qualitative study explored AYA experiences using oral HIVST through a community-based distribution strategy and their recommendations for future HIVST programs in Kenya.

Methods

Study Design and Population

This qualitative study was part of a cohort study previously described (Youth Engaged Self-Testing, “YES Study”) that included 274 AYA ages 15-24 years living in an informal urban settlement in Nairobi, Kenya (~150,000 residents) (Wilson et al, 2022). The YES study evaluated community-based distribution of HIVST to AYA through homes, pharmacies, and bars (‘distribution points’). Recruitment, kit distribution, follow-up, and linkage to care or prevention services was conducted by local HIV Testing Service (HTS) counselors and peer educators according to national guidelines (NASCO, 2017). Only one participant was diagnosed with HIV. We used stratified purposive sampling by distribution point and age (15-17 and 18-24 years) to recruit and enroll 61 participants who had completed HIVST for the qualitative study (see Table One).

Ethical Considerations

This study was approved by the University of Washington Institutional Review Board and the Kenyatta National Hospital/University of Nairobi Ethical Review Committee. All participants provided written informed consent.

Data Collection

FGDs were conducted using a semi-structured discussion guide to elicit perspectives on 1) experiences using HIVST, 2) benefits and challenges of HIVST; 3) peer, partner, and parent influences on testing decisions; 4) influence of HIVST results on sexual behavior, and 5) suggestions for improving access and demand for HIVST. Focus groups were conducted by a Kenyan qualitative researcher using the group’s preferred language (Kiswahili, English, or Sheng, a local dialect used in Nairobi) and lasted about one hour. All participants were reimbursed 400 Kenyan Shillings (approximately 4 USD) for their time. FGDs were audio recorded, and transcribed verbatim, with translation into English as needed. A note-taker took detailed notes on group dynamics, discussion climate, and participants’ openness. The facilitator completed a debrief report of the main ideas discussed immediately following the FGD (Simoni et al, 2019).

Data Analysis

FGD transcripts were analyzed using thematic analysis (Braun & Clarke 2006). The initial codebook was developed collaboratively by the team using both inductive and deductive methods. Deductive codes were derived from literature reviews and discussions with study staff about their interactions with AYA in YES. Inductive codes were developed from detailed readings of FGD debrief reports and the full-length transcripts, and revised based on team discussions. Using an agreed final version of the codebook, two members of the team conducted consensus coding to ensure consistent application and interpretation of codes. All transcripts were coded in ATLAS.ti (v 8.4, 2019) independently by one member of the coding team. Code application was then reviewed by another member of the team. Disagreements in code application were resolved through group discussion between coders and additional team members. Queries of coded transcripts and memos written during the

coding process were used to develop an initial list of themes and supporting quotes. Themes were discussed and synthesized into larger thematic categories to characterize HIVST experiences and how they provide insight into decisions, perceptions, and recommendations related to HIVST and follow-up.

Results

Sixty-one AYA participated in nine FGDs, stratified by distribution point (home-based, pharmacy, and bars) and age (15-17 year-olds, and 18-24 year-olds) (Table One). All members had tested HIV sero-negative in the cohort study. The median age was 19 (IQR 17-23) and 66% were female. Two were married, 19 reported having a steady girlfriend/boyfriend, and 16 reported casual partners. Participants reported that their main reason for testing was to learn their HIV status. Most tested with a friend, caregiver, or other relative. Overall, AYA reported positive HIVST experiences, citing feeling supported when they tested and motivated to change behavior. We identified three major themes about AYA testing experiences: 1) HIVST is convenient and promotes autonomy and informed decision-making; 2) AYA want a variety of individualized, ongoing support options throughout the HIVST process; and 3) peers should play a key role in the HIVST process. Themes were consistent across age groups and distribution points.

HIVST is convenient and promotes autonomy and informed decision-making

AYA appreciated how HIVST promoted autonomy over testing decisions, allowing testing to happen when, where, and with whom they want. HIVST overcame barriers to traditional HTS offered through a facility because it could be completed at home, with friends, parents, or alone. Testing at home allowed adolescents to avoid long wait times and lack of privacy. AYA also appreciated that oral self-testing was less invasive and did not require blood draw, a barrier to traditional HIV testing methods used at facilities.

“My experience was good, the self-test really helps, because maybe, we have people that fear injections but for this we just use saliva and it is much [more] confidential. You don’t need to go to a doctor to test, you do it alone. You can lock yourself in a room and then after you finish, you wrap up.” 18-24 year-old female, home-based distribution point

HIVST also enabled AYA to avoid perceived judgement and stigmatization experienced through interactions with healthcare workers (HCWs), who may lack skills in working with young people.

“Trust me, with a healthcare [worker], you are never sure you will get a nice person to talk to.....Some attendants at health facilities will either discourage you or talk to you with mood swings. I have been to VCT [voluntary counseling and testing] before and the person attending to me told me, “don’t come here knowing you are negative, come if you know you are positive.” I left without doing the test.” 18-24 year old male, pharmacy distribution point

Participants described how improved ease of access to HIV status could directly inform sexual behavior decisions in real time. AYA described how a negative HIVST could motivate them to use condoms so to maintain their negative status.

“[L]et us say you have tested with the self-test kit and you find it is negative, when you go to have sex, you will protect yourself so that you don’t get it because you are sure you don’t have [HIV].” 18-24 year old female, home-based distribution point

Participants from the bars distribution point included sex workers who emphasized that self-testing could give youth like them the courage to negotiate condom use with clients. In addition, they reported feeling empowered to use HIVST on a routine basis and maintain agency over condom use decisions.

“It also gives you the confidence to use the condom so as to reduce the anxiety associated with having unprotected sex, like for us sex workers who have sex with many partners.” 18-24 year old female, bars distribution point

However, participants also noted obstacles with using HIVST to directly inform sexual behavior. While AYA felt that couples in established, romantic relationships were able to talk about HIV and test together, this was viewed as a challenge for newer couples. Some AYA noted that asking sexual partners to take a self-test could be seen as a lack of trust and described situations where trust within the relationship was used as a justification to avoid couples testing together.

“[Y]ou tell them it is okay, test first before we decide to do anything, so there they will challenge you and ask you ‘do you trust me’, and so you will just give in.” 15-17 year old female, home-based distribution point

Another obstacle to using HIVST results to inform sexual behavior in real time was young people’s impulsivity around sex.

“For we youth, we never plan for sex, and it is never on our diary, you see like how people wake up and they are like ‘I will brush my teeth, I will go to school and then come back.’ No, sex is never anywhere [planned].” 18-24 year old male, bars distribution point

AYA want a variety of individualized, ongoing support options throughout the HIVST process

While AYA liked the autonomy of HIVST, they also desired ongoing support from the moment they take the test to post-testing linkage to care and prevention services. AYA desired support from a variety of individuals when making decisions to test, including family members and friends, to help allay concerns about this new type of test.

“As for me, when I was given the kit and I had fear, I had tension and I was like I can’t test now maybe tomorrow, and because my mum was aware of this so she told me if you know you haven’t done anything, if you know you are okay... what do you fear, just try it and I was like, ‘it’s true,’ because I know myself, let me try. So,

I woke up in the morning and tried [it] out and it was okay.” 15-17 year old female, home-based distribution point

Most AYA reported that post-test support, including post-test counseling and linkage to care if they were to test positive, were critical to ensuring a comfortable and safe test experience. AYA used the term “mentor” several times in noting what attributes they hoped a post-test support person would have. To participants in the study, a mentor was described as person whom you could contact easily, at your convenience, by phone or via social media, and who would know and cater to your individual needs. AYA wanted post-test support to include multiple options for communication and venues to access this support.

“Because many people are scared of being seen going to hospitals for care and stigmatization, then it is easier to link the affected person to counsellors directly by the use of e-mails and phone numbers so that in case one needs the help, he can contact the counsellor directly.” 18-24 year-old female, pharmacy distribution point

Most appreciated the clarity of HIVST procedures and the helpfulness, friendliness, and positive communication of the study staff (trained HCWs and peer mobilizers) who distributed the HIVSTs. Being treated with respect and receiving positive guidance from these staff increased participants’ confidence to test and improved the overall HIVST experience.

Nearly all AYA voiced enthusiasm for a variety of options to link to post-test services, including toll free numbers on test-kits, confidential websites, and social media groups. They wanted personalized, ‘one-stop’ services so that when they chose to connect to support, they knew it would be immediately available, located within close proximity, and accessed on demand as they felt was convenient.

Peers should play a key role in the HIVST process

Participants reported that peers were vital to engaging AYA in HIVST. AYA suggested that peers be involved in a variety of distribution channels like schools, clubs, clothing markets and stores for teens, as well as malls and roadshows. AYA viewed peers as uniquely positioned to understand the specific issues facing AYA better than adults. Peers used the same local dialect and cultural terms, enabling youth to feel understood, less stigmatized, and more energized about HIVST.

“But I will be comfortable speaking about sex because he is my age mate because we will use the deepest “Sheng” possible, like... “kukatoa” [having sex], we would speak of that in front of my mom, because she doesn’t understand what we are talking about.” 18-24 year-old male, bars distribution point

Participants described how peers spread information faster and more effectively to other peers than adults and noted how peers who have already tested and are early adopters can motivate others.

“I would say just one thing, ‘send a thief to catch a thief’, like for us who are here, we have used it and we have the experience, they can just take us and send us to the field so that we can educate these guys, so that they can get the information about these things instead of idling around.” 18-24 year old male, bars distribution point

Discussion

This qualitative study among AYA who completed oral HIV self-testing found that community-based distribution of HIVST can overcome multiple barriers to HIV testing and may improve confidence in practicing safer sexual behavior. This builds on recent studies among AYA who are potential HIVST users, which have reported that self-testing is an acceptable and desired alternative to facility-based HTS (Hector et al, 2018; Mokgate, 2017; Spyrelis et al, 2017). Participants' reports of greater autonomy, empowered decision-making, and confidence using condoms through HIVST highlights their need for independence. At the same time, most participants expressed desire for support from friendly, patient, and caring providers. Our study is consistent with others highlighting the importance of support from adult provider-assisted HIV testing among AYA (Kassedde et al, 2013), as well as benefits of peer involvement in HIV prevention and care (Lietinger et al, 2018). Our study also provides new evidence that participants want peer mobilizers to engage them in all steps of HIVST, including education and linkage to post-test services, with the option of a trusted HCW available when needed.

Participants appreciated getting HIVST through the different community distribution points (homes, pharmacies, and bars) because they wanted a variety of options (Ritchwood et al, 2019). Our study contributes to the literature (Hatzold et al, 2019) by revealing preferences for future community-based venues and models of service delivery, including schools and clubs, that can inform future targeted HIVST programs in sub-Saharan Africa. Community-based distribution of HIVST to adults can be scalable and cost effective (Mangenah et al, 2019), and could be extended to AYA.

Our study revealed that HIVST offered through community-based distribution points may encourage young people to practice safer sex. Some AYA in hotspots, after HIVST, reported increased agency to negotiate condom use to maintain negative status, which led to an increased desire to know status through regular HIVST. This extends the knowledge of recent studies showing HIVST increased testing among sex workers (Ortblat et al, 2017). Other AYA reported that HIVST provided an opportunity to talk to partners about testing. This builds on a study which found that offering HIVST facilitated safer sexual decisions between adult sex workers and their partners (Thirumurthy et al, 2016). However, barriers remain in using HIVST to promote safer sexual behaviors among AYA, including impulsivity to have sex and relationship trust. This study adds qualitative information to support the previously identified important role of impulsivity among young people when making decisions about sex and sexual partners (Rosenburg et al, 2018). HIV testing programs should tailor self-testing messaging to help AYA balance desire for fun and relationships with strategies to support long-term risk reduction.

Strengths of this study include an AYA population of HIVST users from a real-world community setting in sub-Saharan Africa, perspectives from users reached through three different distribution points, and insights into influences of self-testing on partner communication. Limitations include potential loss of nuance in themes from FGDs conducted in Kiswahili and analyzed in English. We tried to reduce this limitation by including a Kenyan qualitative analyst on the coding team. This sample included AYA

who were HIV sero-negative and could not elicit perspectives from sero-positive AYA about HIVST and linkage to care. There was also the potential of FGD participants to report favorable testing experiences, which we tried to mitigate by having interviewers from outside the YES study conduct FGDs.

This study suggests that community distribution of HIVST is a promising strategy to reach diverse populations of AYA and potentially increase engagement in HIV prevention services. In addition, our study found that HIVST may influence positive intentions to communicate with sexual partners and use condoms. Future HIVST programs should consider providing optional assistance and supportive counseling by adolescent-friendly HCWs while still offering AYA the choice to test independently. Programs should also engage trained peer-educators to enhance education, testing engagement, distribution, and linkage to care. Finally, future programs should provide multiple community-based options and methods for AYA to connect with and to receive post testing support, including local facilities.

Acknowledgments

This study was funded by the National Institutes of Health, (Grant:A1027757 PI: Celum). Kate Wilson designed the study. Hellen Moraa, Vivianne Manyeki, and Carol Mung'ala, collected the data. Robert Lapsley, Hellen Moraa, Kristin Beima-Sofie, and Kate Wilson conducted the analysis. Robert Lapsley, Kristin Beima-Sofie, and Kate Wilson wrote the manuscript. All authors reviewed and approved the final manuscript. We gratefully acknowledge the time and contribution of YES study participants and the study team. We would like to thank Christine Kundu for assistance with translations, the CFAR Behavioral Science Core Qualitative Working Group (JIG-Q, P30 AI027757) for feedback and guidance on qualitative methods, and our collaborators (LVCT Health, National AIDS and STI Control Programme, Kenyatta National Hospital) for their support and guidance.

Funding Details:

This work was supported by the National Institutes of Health, Grant: A1027757 PI: Celum

Data Availability Statement:

De-identified data can be made available upon request

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Table 1

Participant Demographics – Characteristics of Focus Groups by number and percentage of community-based distribution channel (Home-based, Pharmacies, Bars), as well as percentage of all participants.

Focus Group Characteristic	Home-based n=23 (38% of all participants)	Pharmacies n=19 (31% of all participants)	Bars n=19 (31% of all participants)	Total n=61 (100% of all participants)
Age 18-24 (vs. 15-17)	6 out of 23 (26%)	19 out of 19 (100%)	19 out of 19 (100%)	44 out of 61 (73%)
Female (vs. Male)	15 out of 23 (65.2%)	14 out of 19 (73.6%)	11 out of 19 (57.8%)	40 out of 61 (65.6%)
Single/No Sexual Partner	16 out of 23 (69.6%)	8 out of 19 (42.1%)	1 out of 19 (5.3%)	25 out of 61 (40.9%)
Married	0 out of 23 (0%)	2 out of 19 (10.5%)	0 out of 19 (0%)	2 out of 61 (3.3%)
Steady Girlfriend/ Boyfriend	7 out of 23 (30.4%)	6 out of 19 (31.6%)	6 out of 19 (31.6%) ^a	19 out of 61 (31.1%)
Casual Partner	0 out of 23 (0%)	0 out of 19 (0%)	16 out of 19 (84.2%)	16 out of 61 (26.2%)

^aSeveral bars participants noted both steady girlfriend and casual partner.