

Linkage to care amongst adolescent girls and young women self-testing HIV positive in Lusaka, Zambia



Background

The number of new HIV infections among adolescent girls and young women (AGYW) in sub-Saharan Africa remains exceptionally high. In 2015, 450,000 [380,000–530,000] new infections occurred among AGYW aged 15 to 24 years, which translates into approximately 8,600 new infections per week. Zambia has made important strides towards HIV epidemic control, with more than 960,000 people on antiretroviral therapy (ART) as of end-2018. However, adolescents and young people remain at disproportionate risk of HIV in the country, with AGYW carrying almost three times the burden of HIV compared to their male counterparts. In response, Zambia's Ministry of Health (MoH) has provided guidance on strategies to reduce new annual HIV infections through early testing and linkage to care in this young population.

In order to support linkage to confirmatory testing amongst AGYW in urban settings, the Centre for Infectious Disease Research in Zambia (CIDRZ) and ICAP at Columbia University (ICAP) partnered with the Zambia MoH, the U.S. Health Services and Resources Administration (HRSA) and the U.S. Centers for Disease Prevention and Control (CDC) in Zambia to conduct a qualitative study. The study explored the experiences of AGYW following a positive HIVST and barriers and facilitators to linkage to clinical services among AGYW who reported self-testing HIV positive.

Methods

The evaluation was designed to explore facilitators and barriers to linkage to HIV treatment after self-testing HIV positive in Lusaka, Zambia, with a focus on AGYW's journey from accepting a HIVST kit to linking to ART services (or not). Data collection took place from three high-density compounds, three universities, and their environs in Lusaka. and included:

- 12 in-depth interviews (IDIs) with AGYW reporting self-testing HIV+;
- A survey with 536 AGYW who received HIVST kits exploring their socio-demographic and socio-economic status, sexual practice and HIV testing history;
- Screening of 1437 AGYW who attended social events (e.g. nail painting) hosted by the study, to establish eligibility, i.e. 16-24 years old, sexually active with inconsistent condom use, and self-reported as unknown or HIV-negative.

Structured data for routine monitoring of the project was collected on open-source software Open Data Kit (ODK) via electronic template and analyzed on STATA to describe our enrollees. We conducted an in-depth analysis of each individual interview, then made cross-group comparisons to create a final set of themes based on saliency.

Participant Flow and Characteristics

A total of 1,630 AGYW attended 106 events: 80 community-based social events and 26 university-based health fairs. Amongst these, 1437 (86%) were interested in HIVST, of whom 536 (37%) met the eligibility criteria of being 16-24 years old and sexually active with inconsistent condom use and unknown or negative HIV status. All eligible AGYW gave informed consent and enrolled into the program. We interviewed 12 AGYW who reported self-testing HIV positive; all eventually linked to clinic for confirmatory testing, 11 were confirmed to be HIV positive and 1 was found to be HIV negative.

Compared to all those enrolled, interviewees were less educated, had never married, and worked with low or inconsistent pay. Almost all AGYW had mobile phones and were dependent on public transport. Overall, 77% (414) AGYW had tested for HIV at least once before, half (266) in the last 6 months, usually at a health care facility's counseling and testing services. Most enrollees (84%) and interviewees (75%) reported having 1 sexual partner in the last month. A higher proportion of interviewees reported never using condoms (60% vs 30%), not knowing their HIV status (66% vs 44%) and testing at most once previously (75% vs 40%).

Key Findings

- HIVST was highly acceptable:** Though the program areas had been saturated by HIV testing, almost 90% of all attendees expressed interest in trying HIVST. Interviewees said curiosity and perceived risk motivated them to self-test. They preferred the privacy, control, and stigma-free environment of HIVST over clinic-based testing.
- Testing yield was highest in AGYW recruited from communities:** Of the 177 AGYW recruited by Neighborhood Health Committees, 10 (6%) reported self-testing HIV positive, compared to 1/359 (0.2%) recruited by other methods. In total, 12 (2%) AGYW reported self-testing HIVST+.
- Some AGYW needed help reading HIVST results:** Of 16 AGYW who reported being HIVST+, three wrongly read their results as positive and one as negative. We interviewed 12 AGYW who reported being HIVST+. All interviewees expressed significant distress and varying ability to cope with self-testing HIV positive. This suggests that AGYW may need both technical support to interpret their results as well as emotional support to process the results. Contact information or resource materials may be appropriate to meet this need.
- AGYW who went to clinic after a positive HIVST articulated a wider range of feelings and coping mechanisms than those who did not go to clinic:** At the time of the IDIs, 9/12 interviewees reported going for a confirmatory test. They described experiencing depression, fear, hopelessness, self-stigma, sadness, disappointment, and anger. Seven AGYW coped by either seeking emotional support from their mother, sister, and/or friend who normalized their situation and two through non-disclosure to avoid saddening parents, gossip among friends, and being treated differently.

The three who had not yet sought confirmatory testing at the time of the IDI lacked social support, did not trust the health system due to experience, and did not feel ready to begin ART. They did not want to go to the clinic close to home because of the crowded environment that increase wait time and visibility, which compromised privacy and confidentiality during HIV testing and ART collection. By the end of the study all three had linked to care and two were confirmed sero-positive and one sero-negative.



At the clinic when they find you [HIV+], they immediately start giving you treatment, but that's not what you want, that's not the time you would want to start ... They put you on treatment, now you would find those whom you know at the clinic ... So better at least I go alone. I take [a HIVST kit] myself and I test myself ... Then go to that clinic that I want.

- Many factors influenced linkage to ART:** Six interviewees reported linking to ART on the day of their confirmatory test. They displayed trust in the health system and test results, emotional maturity, and the ability to 1) seek support from female relatives and friends on ART, 2) weigh risks and benefits of being on ART, and 3) access their clinic of choice. They reported receiving swift service and good counsel at the clinic.

The three who reported not linking to ART the same day as their confirmatory test said that they wanted a re-test because they could not believe their HIV+ result. They expressed shame and had existential questions arising from foundational concerns related to their identity, self-image, daily life, marriage and having children. They also perceived clinics as uninviting, staff as hostile, and pharmacy pick-up as too exposed to public scrutiny.



But the [confirmatory test results] were not as painful considering that I had already seen the first ones [HIVST results]. So I just accepted the second ones to be mine.

Conclusions

This study confirms the acceptability of HIVST among AGYW. HIVST increases reach to first time testers, increases privacy and reduces exposure to perceived stigma during testing. Social supports and positive perceptions of the health system facilitated linkage to confirmatory testing and ART initiation for those with positive HIVST results. Young people need clear information on what to do if unable to perform a HIV self-test or if the result is invalid. Early social support may be critical to confirmatory HIV testing and ART initiation. Counseling needs to be adolescent-specific, addressing shame and concerns about the future.