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## Adolescents' and caregivers' perceptions of caregiver-provided testing and HIV self-testing using oral mucosal transudate tests in Zimbabwe: a short report

Crissi Rainer<sup>a</sup>, Belinda Chihota<sup>b</sup>, Chido Dziva Chikwari<sup>c,d</sup>, Grace McHugh<sup>c</sup>, Ethel Dauya<sup>c</sup>, Hilda Mujuru<sup>e</sup>, Rashida A. Ferrand<sup>c,d</sup> and Kearsley A. Stewart<sup>f</sup> 

<sup>a</sup>Department of Psychiatry and Behavioral Sciences, Duke University School of Medicine, Durham, NC, USA; <sup>b</sup>Centre for Infectious Disease Research in Zambia, Lusaka, Zambia; <sup>c</sup>Biomedical Research and Training Institute, Harare, Zimbabwe; <sup>d</sup>Clinical Research Department, London School of Hygiene and Tropical Medicine, London, UK; <sup>e</sup>University of Zimbabwe College of Health Sciences, Harare, Zimbabwe; <sup>f</sup>Duke Global Health Institute, Duke University, Durham, NC, USA

### ABSTRACT

Uptake of HIV testing remains lower among children and adolescents compared to adults. This study explored adolescents' perceptions of HIV self-testing (HIVST) and caregivers' perceptions of testing their children using an oral mucosal transudate (OMT) rapid HIV test (caregiver-provided testing). We conducted 31 interviews with adolescents aged 16–18 years and caregivers of children aged 2–15 years who received an OMT test. Participants described barriers to HIV testing including lack of privacy and the potential for discrimination by community members towards children and adolescents who received an HIV test. Most participants felt caregiver-provided testing and HIVST could address these barriers through increased privacy. Some participants expressed worry about their ability to correctly perform the OMT and their anxious reactions to a positive result. Counseling and assistance from health care workers were viewed as ways to alleviate concerns. Concerns shaped participants' preferences for facility-based HIVST and caregiver-provided testing. Findings demonstrate HIVST performed by adolescents and caregiver-provided testing could increase the uptake of HIV testing. Concerns related to being able to test correctly and the availability of post-test counseling must be addressed in any future delivery mechanisms.

### ARTICLE HISTORY

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### KEYWORDS

HIV; oral mucosal transudate tests; HIV self-testing; children; adolescents; Africa

## Introduction

HIV testing is the critical entry point to accessing HIV care and prevention services. HIV testing coverage remains low among HIV exposed infants and adolescents compared to adults (UNAIDS, 2014, 2016). Recent population-based assessments in Africa demonstrated lower HIV testing coverage among adolescents compared to adults (Malawi Ministry of Health, 2017; Zambia Ministry of Health, 2017; Zimbabwe Ministry of Health and Child Care, 2017). Compared to adults, children and adolescents face additional barriers to HIV testing including fear of the perceived stigma associated with testing, fear of discrimination from health care workers (HCWs), fear of their caregiver's reaction to seeking testing, and need for guardian consent (Kranzer et al., 2014; WHO, 2013). Given these barriers, novel HIV testing and counseling (HTC) approaches are needed to increase uptake of HIV testing.

Previous studies among adults demonstrated acceptability and accuracy of HIV self-testing (HIVST) using oral mucosal transudate (OMT) rapid HIV tests (Kelvin

et al., 2016; Kurth et al., 2016; Mokgatle & Madiba, 2017; Pant Pai et al., 2013; Sarkar et al., 2016). Additionally, results from a study conducted in Malawi reported higher uptake of HIVST among adolescents aged 16–19 years compared to adults (Choko et al., 2015). Beyond HIVST, a further application of OMTs is caregivers testing their children (caregiver-provided testing), which may address some barriers to HIV testing.

We investigated caregivers' knowledge and attitudes towards caregiver-provided testing and adolescents' knowledge and attitudes towards HIVST using OMT. We specifically explored adolescents' perceptions of HIVST and caregivers' perceptions of caregiver-provided testing.

## Methods

This qualitative study was nested within a larger study that evaluated index-linked HIV testing for children aged 2–18 years in health facilities and communities in Zimbabwe (Dziva Chikwari et al., 2019; Dziva Chikwari

**CONTACT** Crissi Rainer  crissi.rainer@duke.edu

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et al., 2019). We purposively selected caregivers of children and adolescents aged 16–18 years from the larger study based on age and gender in order to reach thematic saturation. All participants gave informed consent. Research assistants (RAs) conducted semi-structured interviews with caregivers of children aged 2–15 years and adolescents aged 16–18 years. Interviews were conducted in Shona and audio recorded. RAs transcribed and translated recordings into English for analysis.

The interview guide explored test preference; perceived comfort performing OMT and HIVST; advantages and disadvantages of OMT and HIVST; and preferences for clinic-based testing or home-based testing. Semi-structured interviews gave RAs flexibility to follow the interview guide and also to explore themes that emerged during interviews (Bernard, 2011). Before interviews, caregivers observed RAs perform an OMT and finger-prick blood-based test (BBT) on their children. Adolescents observed RAs perform an OMT and a BBT on themselves.

Analysis followed a memo approach whereby we identified emergent themes and created a codebook (Guest et al., 2012). We jointly coded one transcript to confirm the reliability of our codebook. Afterwards, we individually coded the remaining transcripts using NVivo Version 11 software (QSR International, Melbourne, Australia).

Ethical approval was obtained from Medical Research Council of Zimbabwe, Biomedical Research and Training Institute Institutional Review Board, Duke University Campus IRB, and London School of Hygiene and Tropical Medicine Ethics Committee.

## Results

We conducted 31 interviews ranging from 30–45 min. Participant characteristics are summarized in Table 1. Due to the similar views expressed by caregivers and adolescents, we report the findings together; in cases where they differ, we describe them separately. Table 2 includes quotes representing key themes.

**Table 1.** Participant characteristics.

	<i>n</i> (%)
<b>Role</b>	
Caregiver	20/31 (64.5)
Adolescent	11/31 (35.5)
<b>Age (years)</b>	
16–18	11/31 (35.5)
19–30	6/31 (19.4)
31–40	5/31 (16.1)
41–45	9/31 (29.0)
<b>Gender</b>	
Male	6/31 (19.4)
Female	25/31 (80.6)

## Caregiver-provided testing and HIVST may reduce barriers to HIV testing

Most caregivers reported fear of themselves and their children being recognized at the health facility while seeking HIV testing. Caregivers and adolescents linked recognition at the health facility with discrimination. Caregivers expressed this fear of discrimination resulting from others talking about their child's and their own HIV status. Beyond the fear of discrimination from gossip, a few caregivers worried their child might be segregated from other children if their child's HIV status became public. One adolescent worried that a caregiver's reaction to their child's positive test could result in child abuse or abandonment.

Some participants felt caregiver-provided testing and HIVST could address these fears through added privacy. Caregivers also linked the privacy associated with caregiver-provided testing to control over other people's

**Table 2.** Themes and illustrative quotes.

### Theme 1: Caregiver testing and HIVST may reduce barriers to HIV testing

... People fear ... gossip ... that their child is positive, and that the neighbors may discriminate against the child and not allow their children to play with the positive child. (Female Caregiver, age 42)

... There are some caregivers ... who do not like the idea of other people knowing that their children are HIV positive as they feel that it also reflects on them and people will be suspecting that they are also HIV positive ... This method is a good method as the guardian will do it in privacy ... (Female Caregiver, age 32)

... I think the advantage would be I get to be the first to see my status, and then I can have time to think and understand what it would mean for me. I can always share the result when I feel like it's time to share with family and those who are close to me. (Adolescent Male, age 18)

### Theme 2: Concerns about caregiver testing and HIVST

You would have been told the instructions ... and you ... might have forgotten the instructions ... You may forget on the number of minutes as you do it from home yet at the hospital they always do the tests in the required timeframe. (Female Adolescent, age 16)

... I can get disturbed after testing my child and find out that my child is HIV positive. So, I can be stressed until my blood pressure is high and there is no one to give me counseling. (Female Caregiver, age 27)

... It could be your first time getting tested in life and you discover that you actually have HIV ... You are actually home. If this happens and you do not have anyone present to help with the counseling, you may get so stressed that you could even have ... high blood pressure ... or even commit suicide. (Female Adolescent, age 18)

... They do not want other people to know what has happened to their tests ... You may test your child and discover the results, then you keep the results to yourself yet the child should go to get medical assistance. (Female Caregiver, age 27)

### Theme 3: Concerns could be addressed with counseling

... We can incorrectly do the testing, but if there is a health worker helping you, he/she can tell you what to do and what not to do. Like where it is written "Do not touch", you might touch and the result will come out incorrect so I think it's good to have a health worker with you ... (Female Caregiver, age 43)

... If we get tested we may choose to be quiet and say whatever. So, if you get tested from a health center, you will familiarize with different solutions on approaching this situation ... You will get counseling so it's better to do the tests from a health facility. (Female Adolescent, age 16)

... At the hospital there is no way I would hide it [results] since it will be open. It would mean that my child would have to start getting the required medication so that he/she cannot be quickly affected. (Female Caregiver, age 41)

knowledge of their and their child's HIV status. Like caregivers, several adolescents reported HIVST could facilitate HIV testing through added privacy. A few adolescents described how HIVST done privately could increase their autonomy over disclosing their status to others and seeking treatment.

### **Caregiver-provided testing and HIVST concerns**

Even though most participants related HIVST and caregiver-provided testing to privacy and reduced barriers to HIV testing, many of these same participants expressed concerns. Concerns included properly completing the HIV test without assistance and dealing with reactions to a positive result. Participants worried they could make errors while performing the test without proper training or assistance from HCWs. Additionally, caregivers worried about the possibility of their unfavorable reactions to a positive home-based test. Caregivers' descriptions of unfavorable reactions varied but most often related to general shock after viewing a positive result. Adolescents expressed concerns about unfavorable reactions to positive home-based HIVST results such as fainting, high blood pressure, strokes, and suicide. Notably, over half of adolescents worried that other adolescents may commit suicide after receiving a positive home-based HIVST. However, no caregiver raised the possibility of suicide risk following a positive caregiver-provided test.

### **Concerns could be addressed with counseling**

Many participants noted how HCWs and counseling could address concerns. Most participants viewed HCWs as HTC experts and trusted their ability to perform HTC. Overall, participants related HCWs' assistance with accurate HIV test results. Some participants also felt that assistance and counseling during testing could counteract unfavorable reactions to positive HIV test results through home-based testing. These participants linked counseling to acceptance of a positive HIV test result.

Availability of counseling and assistance during caregiver-provided testing and HIVST influenced testing location preferences among participants. Many participants felt facility-based testing ensured accurate results because HCWs could be available to provide instruction during the testing process. While a slight majority of adolescents preferred facility-based HIVST, more adolescents compared to caregivers preferred home-based HIVST. These adolescents explained how home-based HIVST could decrease concerns related to HCW distrust

and provided additional time to accept their status before seeking care.

### **Discussion**

To our knowledge, this study is the first to ask caregivers about their attitudes towards performing OMTs on their children. Findings demonstrated caregivers' concerns about discrimination for their children resulting from HIV testing are similar to concerns they have for themselves during HIV testing. This study shows that caregiver-provided testing and HIVST could indirectly address the fear of discrimination by giving caregivers and adolescents greater privacy and control over others' knowledge of their status (Napierala Mavedzenge et al., 2013).

Our study confirmed previously reported concerns including the ability to correctly perform OMT and anxiety-provoking reactions to positive test results (Choko et al., 2015; Kelvin et al., 2016; Knight et al., 2017; Makusha et al., 2015; Martinez Perez et al., 2016; Zanolini et al., 2017). Some adolescents voiced concern about possible suicide attempts that could be triggered by a positive HIVST result. While there are no reports to date of suicides related to HIVST (Brown et al., 2014; Johnson et al., 2017), this concern does reflect a real fear of adolescents about their ability to cope with a positive result. It is crucial for HIV testing programs to ensure adequate support is accessible for adolescents undergoing HIVST, especially those undergoing HIV testing for the first time (Harichund et al., 2019; Kelvin et al., 2016; Knight et al., 2017; Makusha et al., 2015; Stevens et al., 2018).

The reported need for assistance and counseling during testing should be balanced against the autonomy and privacy HIVST or caregiver-provided testing provides. For example, HCWs or trained community lay workers could initially assist during testing (Sarkar et al., 2016; Stevens et al., 2018), boosting confidence in caregiver-provided testing or HIVST performance and ensuring accuracy. This initial assistance could facilitate future home-based testing through sensitization to these newer testing mechanisms. Caregivers could access facility-based caregiver testing with one of their children while also attending a primary care clinic, and then perform home-based caregiver-provided testing with their other children. Adolescents who initially need HCW support could first access facility-based HIVST and then perform home-based HIVST in the future.

A strength of the study includes two comparison groups giving their perspectives on OMTs either through caregiver-provided testing or HIVST. The study is



limited by caregivers' and adolescents' lack of first-hand experience performing OMTs on their children or HIVST on themselves. We conducted this study in two hospitals in Harare, Zimbabwe; therefore, results may not be generalizable to other settings.

Findings demonstrate caregivers and adolescents are interested in caregiver-provided testing and HIVST as an additional HIV testing option; however, they voiced concerns about the potential lack of counseling and feeling anxious when a positive result was discovered through home-based testing. Given these concerns and preferences for HCW assistance during testing, any caregiver-provided testing and HIVST implementation strategy should include delivery mechanisms to meet the individual needs of caregivers and adolescents.

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### Disclosure statement

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### ORCID

Kearsley A. Stewart  <http://orcid.org/0000-0002-9624-9956>

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