Fear of an HIV positive test result: an exploration of the low uptake of couples HIV counselling and testing (CHCT) in a rural setting in Mukono district, Uganda

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Abstract: Background: Couples HIV counselling and testing (CHCT) is a key preventive strategy used to reduce the spread of HIV. In Uganda, HIV prevalence among married or cohabiting couples is 5.6%, compared to 2.2% among those never married. CHCT can help ease disclosure of HIV positive status, which in turn may help increase opportunities to obtain social supports and reduce new infections. The purpose of this study was aimed at exploring the possible reasons for the low uptake of CHCT in Mukono district, a rural in setting in Uganda.
Methods: The study was conducted in two sub-counties in a rural district (Mukono district) using a descriptive qualitative research design. Specifically, we conducted four focus group discussions and 10 key informant interviews. We also interviewed 53 individuals in couple relationships. Data were collected mainly in the local language Luganda and English, all data were transcribed into English and coded for emergent themes. Ethical clearance for this study was obtained from the Mengo Hospital Research Review Board and from the Uganda National Council of Science and Technology.
Results: Fear of a positive HIV test result emerged strongly as the most significant barrier to CHCT. To a lesser extent, perceptions and knowledge of CHCT, mistrust in marriages and culture were also noted by participants as important barriers to the uptake of CHCT among couples. Participants offered suggestions on ways to overcome these barriers, including peer couple counselling, offering incentives to couples that test together and door-to-door CHCT testing.
Conclusion: In an effort to improve the uptake of CHCT, it is crucial to involve both females and males in the planning and implementation of CHCT, as well as to address the misconceptions about CHCT and to prioritise CHCT within health care systems management.

Keywords: couple HIV counselling and testing, fear, disclosure

Background

Globally, in 2012, 35.3 million people were living with human immunodeficiency virus (HIV), including 2.3 million new HIV infections (1). Sub-Saharan Africa is the region most severely hit by the HIV/AIDS pandemic (1). It accounted for 22.1 million (63%) of the HIV infected people and 70% of all new HIV infections in 2012 (1), yet it is only 12% of the entire world's population. In Uganda, the prevalence of HIV among individuals aged 15–49 years increased from 6.4% in 2005/06 to 7.3 % in 2011 (2). Non-disclosure of HIV status among

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couples (3), coupled with not knowing one's HIV status, illiteracy, polygamy and resistance to sexual behaviour change, are believed to be some of the factors contributing to increase in HIV spread (4).

A study in Zambia demonstrated that HIV transmission between couples occurred in 87% of HIV discordant couples (5). In southern and eastern Africa, 49% of the HIV affected couples are discordant (6). In Uganda, approximately 3% of couples are discordant, and this is more common where the man is older by 10 years or more (2). Previous research has indicated that male partners are more likely to bring HIV infection into a couple relationship, while females become infected at a higher rate than males (7).

A study in Ethiopia revealed that previously being tested for HIV, not having a sexual partner and unwillingness of a partner to test are some of the barriers to couple HIV counselling and testing (CHCT) (8). In Rakai, Uganda, fear of the negative consequences of testing such as mistrust in marriages and the resultant challenges in negotiating the process for testing are some the barriers to utilising CHCT (9). Although many males know the importance of CHCT, they believe their marriages are unstable and distrustful, making the idea of couple testing unappealing as this may lead to marital conflicts (6). In general, males are known to have low uptake of voluntary counselling and testing services (10). Most HIV-positive women do not disclose their HIV status to sexual partners for fear of abandonment, violence and accusation of bringing HIV infection into the family (3).

Other CHCT studies report that behavioural CHCT is known to reduce HIV incidence among HIV-negative sex partners and viral load among HIV-positive partners (11). In Uganda, CHCT was included in the HIV Counselling and Testing policy in 2011 as one of the key strategies identified to prevent HIV transmission among couples; however, uptake has remained low (12). A study in rural Uganda revealed the uptake of CHCT remains at 27% (13). This study was therefore aimed at exploring the reasons for the low uptake of CHCT in a rural setting in the Mukono district of Uganda.

Methods

Study setting

This study was conducted in the Mukono district in Uganda and employed a descriptive, exploratory qualitative research design. This qualitative approach allowed for an in-depth understanding of the perceived benefits and barriers to CHCT uptake in this district. The Mukono district is located in Central Region Uganda, 28 km east of the capital Kampala. According to the population projection from the 2002 national census, it is estimated that there is a total population of 536,400 people in this region. The HIV prevalence rate in this region is 12.5% among females and 8.4% among males aged 15 to 49, with approximately 11% of the couples being HIV sero-discordant. In addition, this district has two counties and 15 sub-counties and within these there is one private hospital, two health centres (H/C) IVs (at the county level), 13 H/C IIIs (at the sub-county level), 26 H/C IIs (at the parish level) and 845 village health team (VHT) members (these are composed of community volunteers who offer mainly education and management of common child illnesses such as malaria, pneumonia and diarrhoea). CHCT is offered at all hospitals, H/C IV and H/C III. The study was conducted in two sub-counties in Mukono, the Central division (urban) which has the highest CHCT uptake, and Kyampisi sub-county (rural) which has the lowest CHCT uptake. The approaches that are used for CHCT in Uganda are through provider initiated counselling and testing, voluntary, outreach HCT services and home-based services, including door-to-door services (12).

All study participants were required to be individuals in a couple relationship in order to meet the eligibility requirements. For the purpose of this study, a couple relationship was defined as two adult individuals in an ongoing sexual relationship (14). Data were triangulated through three different data sources (see Table 1): interviews, focus group discussions (FGDs) and key informant interviews. The key informants included key personnel in the community identified by the Assistant District Health Officer and were to include two religious leaders, district local leaders, the district HIV focal person and five VHT leaders. The interviews and FGDs took approximately 40 and 60 min each, respectively. Participants in the FGDs were homogeneous with regard to place of residence, such as rural or urban, and age (20–49 years). FGDs were held at a time and place convenient to the study participants, such as in the village where other meetings are usually held. The study team attempted

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Table 1. Characteristics of interviewed individuals in couple relationships attending rural lower health centres in Mukono, 2013.

		Individual HCT (%)	*Couple HCT (%)*
Gender (*n* = 53)	Female	23 (21)	13 (46)
	Male	6 (79)	11 (54)
Age group (*n* = 53)	18–29 years	14 (48)	13 (54)
	≥30 years	15 (52)	11 (46)
Education (*n* = 52)	Primary	14 (50)	10 (42)
	Post-primary	14 (50)	14 (58)
Occupation (*n* = 53)	Peasant	8 (32)	5 (18)
	Salaried	1 (4)	4 (14)
	Self-employed	11 (44)	15 (54)
	Unemployed	5 (20)	4 (14)
Marriage type (*n* = 53)	Monogamous	19 (66)	23 (96)
	Polygamous	8 (28)	1 (4)
	Regular partner not co-habiting	2 (7)	0 (0)

HCT: HIV Counselling and Testing

to maintain confidentiality of study participants by ensuring no names or other identifying information were collected. Ethical clearance was obtained from the Mengo Hospital Research Review Board and from the Uganda National Council of Science and Technology.

Data collection and analysis

The purpose of the study was explained to all participants and they were invited to voluntarily participate in the study after providing informed consent. Data were collected using semi-structured interview guides and the research team ensured an open and collegial atmosphere for the discussions. All data were collected in the local language Luganda or English, transcribed verbatim and translated into English. The principal investigator moderated the FGDs, while a research assistant wrote notes on the overall discussions. Audio recording of all the interviews was done with permission of participants. All transcribed data were coded and analysed according to emergent themes and managed using NVivo 8 software.

Results

For this study we interviewed 53 individuals in couple relationships, 10 key informants and four FGDs in two sub-counties in Mukono district, Uganda. Forty-five per cent (45%) of the individuals in couple relationships had tested as couples. The other socio-demographic characteristics of the interviewed individuals are shown in Table 1. Of the nine key informants, three (two VHTs and one district HCT focal person) had tested as couples.

Most respondents reported that CHCT was a helpful intervention because it can enable early initiation into care and treatment and prevent the further spread of HIV. However, most respondents also expressed various barriers to the uptake of CHCT. Among the males, 65% had CHCT versus 36% among the females. The key emergent themes that influenced CHCT uptake were fear of a positive test result, perceptions and knowledge of CHCT, CHCT service delivery, mistrust in marriages, and culture.

Fear of a positive test result

Fear of an HIV positive test result was seen as the most significant barrier to the uptake of CHCT among all participants. This fear was brought about by the perceived consequences of an HIV positive test result. The fear of death, stigma, separation, disharmony in the home, fear of denial of conjugal rights, fear of failure to get treatment, and the accusation of having brought HIV into the home were all linked to the key issue of fear of a positive test result. Many women were believed to fear being tested due to likely loss of support from their partner.

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This fear was also facilitated by the lack of understanding of HIV discordance and mistrust of Western medicine. This fear was, in part, fuelled by the memory of people who died in the early 1980s of AIDS when there was no treatment or support.

Fear when people think about how AIDS used to treat people of long ago, people lost weight, had a pale skin they fail to test. (male FGD participant)

…do not know their status and imagine if they are told are HIV positive they may die of pressure and would rather die without knowing. (female FGD participant)

…Fear brings shame, you imagine your situation, I am an old man who has a family and now I am HIV positive. The man may end up committing suicide. (male FGD participant)

…in case we test and my wife is positive and I am negative. I don't think I can go back to her. This is a hindrance to CHCT because the man may love his wife so much and cannot imagine her HIV positive. (male FGD participant)

…the more one gets medicine the more they will die faster. (male FGD participant)

Participants believed that the delivery of CHCT at the health unit level is an appropriate approach. Despite the fact that couples are given priority at the health unit and the health care workers are, for the most part, friendly, it was also reported that the quality of delivery of CHCT has been reduced. For example, some health units lack testing equipment and were believed to use coercive methods to encourage women to test for HIV during antenatal care visits. These perceptions only served to increase men's resistance to attend these health centres and to avoid testing. Participants also suggested that some health care workers have negative attitudes towards testing and that there is lack of confidentiality and privacy at health units. Another barrier identified was related to the belief that those who test HIV positive are no longer given handouts such as food, which has been a significant motivator to getting tested. It was also reported that the testing services are limited to hospitals and sub-county health centres.

…one time I was in the health unit and at the bleeding point a patient was found to be HIV positive. The health workers mistreated this client; they shouted at him and were treating him like rubbish…..by the time we left everyone knew the status of this person because there was no privacy. (female FGD participant)

The health workers disclose client's status to other people especially those who live in the communities we live in. (male local council) leader

Government used to give those who test HIV positive aid in form of milk, flour which it's no longer doing. They used to give proper counselling too, which is not the case anymore. (male FGD participant)

Perceptions and knowledge

While participants had varied perceptions about CHCT, there was a general belief that CHCT is beneficial in that it can help facilitate knowing one's HIV status and improve the uptake of care and treatment among those who test positive. However, participants were quick to point out that many males do not want to test with their partners as they may have more than one sexual partner which is linked with an increased risk of HIV infection. It was reported that most males believe that their partner's results are a proxy of their results and as such, they do not see the importance of CHCT. Of great concern in this regard was that disclosure of a positive test result may lead to disharmony in the home. Although many participants recognised that the failure to test as a couple affects treatment in that many clients may be forced to take their HIV treatment in hiding. In addition, most participants suggested that there is limited knowledge on the issue of HIV discordance and as such, HIV is given limited attention within couples. This was believed to have been brought about by the advancement in HIV treatment in that an individual with HIV can now live longer than when HIV was seen as a terminal disease, and thereby rendering HIV testing as less important. Based on this perception, it was reported by the Community Development Officer (CDO) that there was a need for more sensitisation in the community about CHCT.

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Our findings suggest that most women prefer individual HIV counselling and testing. This is likely due to the fear of having an HIV positive result. Literature shows that most women fear abandonment and violence from their male partners (3). From the FDGs, it also appears that women may test alone because they have no power over men and they therefore often work to prevent acquiring HIV as stated in the following quotes:

Good to test as a couple; one gets to know their status such one cannot go looking for HIV. In most cases the women test alone, we get to know our status and lay strategies for prevention but we don't know whether the men have tested. In most cases some start the treatment and hide while taking the drugs… (female FGD participant)

…the women have to be tested because they are the ones who conceive so when the wife suggests to the husband to come and test they tell the women that go and test if negative the husband is also negative. (male FGD participant)

The people do not care about HIV anymore. This has been brought by the fact that we now have treatment and one can live long with HIV. (male FGD participant)

Mistrust

Mistrust in couple relationships was found to be a significant barrier to the uptake of CHCT according to our participants. Specifically, our participants believed that in most cases couples have other sexual partners and as such, they may refuse to test because they do not know the status of their partners. This often results in couples testing individually and if positive, initiating HIV treatment secretly. However, this was also reported by some participants as a potential motivator for CHCT uptake, in that couples may want to prove to each other that they are faithful.

…the wives are not trustworthy, the only time *that you know that this is my wife is when you are with her in bed but other times have other partners. The husband may be faithful but the woman is not. She has a partner responsible for her hair…and she only knows you as the father of her children. This makes it hard to go with this partner for testing because you're not sure whether the wife is yours or not. (male FGD participant)*

One of the partners may be cheating on the other. The man or the woman may want to test but if the partner is cheating he or she may suspect that they are HIV positive and do not want the partner to know. (female FGD participant)

Culture

Although some participants expressed that culture has no influence on the decision to access CHCT, the majority felt that some cultural factors impede couple testing. In the case of polygamy, the man will to choose which wife to go with to the hospital. It is also not the cultural norms to find husbands accompanying their wives to hospital for treatment, including antenatal visits, making it challenging to increase uptake of CHCT. Witchcraft is also another cultural factor that creates potential barriers to CHCT in that some families attribute any calamity to witchcraft, making it hard for couples to believe in the CHCT messages that are delivered.

…in case one has more than one wife; he may find it hard to go with all the four… (male FGD participant)

…and also the men being the bread winners of the home, they cannot find time during the day to accompany their wives to health units. (female FGD participant)

…most of the time men are fending for the home; those that are employed their bosses do not give them time to go for HCT. (male FGD participant)

How to improve CHCT

When asked how CHCT could be improved to maximise the uptake of testing, participants offered several key suggestions. Among these were suggestions to utilise couples that have already tested as CHCT peer counsellors, to offer incentives to couples that wish to be tested, to educate the broader community about the benefits and dangers

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of not testing as a couple, and door-to-door testing.

Peer couple counselling was emphasised by many respondents as an important health promotion and prevention intervention strategy. Most participants believed that couples that have already tested will be more empathetic. The couples that have previously tested for HIV together may be better to understand the complexities of the circumstances through which couples go through before agreeing to test for HIV together. As stated by the following participant, peers can serve as a strong voice for encouraging the uptake of testing:

> *Sensitisation involving the utilisation of those who have tested as couples to educate others and also to counsel them. (female interview participant)*

The use of incentives following testing was suggested as a means of increasing CHCT uptake. For example, participants reported that among the barriers to CHCT, the removal of incentives given to persons that tested HIV positive was problematic. Participants also reported that some individuals prefer going to particular health units for services due to the incentives that are given there.

> *Give gifts to couples that test for HIV together like sugar, T shirts, transport, etc. (female interview participant)*

In addition, large-scale HIV community health promotion education was suggested as a key means to help address the CHCT knowledge gaps. Participants suggested the use of various avenues to educate others about CHCT, including through religious institutions, community gatherings, and burials grounds. As stated by the following participant, many churches have encouraged, and in some cases required, CHCT prior to a couple getting married.

> *Utilise the religious leaders; church and mosques, VHTs to reach out to couples. (male community development officer)*

Door-to-door counselling would also allow CHCT to be brought to people's homes. One of the health system barriers to CHCT noted by participants was that CHCT services are often limited to the health units. In this regard, participants suggested a community approach to CHCT, including greater outreach, would necessitate door-to-door CHCT services. Although this strategy had never been employed in this community, it would help ensure that more couples are aware of and offered these services.

Discussion

This study was aimed at exploring the reasons for the low uptake of CHCT and to identify strategies to increase uptake in Mukono district, a rural setting in Uganda. From our findings the key barriers to CHCT include fear of an HIV positive result, knowledge and perceptions, mistrust, and culture. The proposed health promotion strategies offered by our participants for improving CHCT uptake included emphasising peer counselling, provision of incentives, mass HIV community-based health education campaigns and door-to-door counselling.

Although a number of issues related to the lack of CHCT uptake are important to consider in the development of subsequent HIV prevention interventions, fear of a positive test result emerged as the most pressing issue to address. The issue of fear, as documented in other studies, is regarded as one of the most significant barriers to HIV testing interventions such as CHCT (15). This fear is brought about by the perceived or likely consequences of receiving an HIV positive test result. As indicated in a study by Baiden *et al.* (16), most HIV-positive women do not disclose their HIV status to sexual partners for fear of abandonment, violence and accusation of bringing HIV infection into the family. Stigma permeated the experiences of HIV-positive people on highly active antiretroviral therapy (HAART) who participated in this study. The intensity of HIV/AIDS-related stigma can threaten to compromise the value of HAART, thus impacting on the daily lives of people living with HIV/AIDS (PLWHA) (17,18). As such, there is an urgent need to employ public health interventions, including health education campaigns, aimed at reducing both fear and stigma associated with being tested for HIV.

In addition to the fear associated with an HIV positive result, there is a widespread misconception about CHCT, as reported by the participants in this study. As indicated in other studies, it was reported that many males still believe that their partners' HIV

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test results are a proxy for their own results (19). The limited knowledge on issues pertaining to HIV discordant couples is a significant public health challenge, particularly in light of the fact that in sub-Saharan Africa approximately 75% of couples affected by HIV are discordant (20). This is further aggravated by the fact that most married individuals have more than one sexual partner (21). This suggests key knowledge gaps in CHCT which need to be addressed, including better knowledge on HIV to help encourage a greater level of willingness to be tested for HIV (22).

In addition, it was also revealed by our participants that the perception of Western medicine being unable to treat or cure various ailments can also create barriers to CHCT. This perception is widespread where, in one study in western Uganda, individuals believed traditional medicine is more effective and has minimal side effects compared to Western medicine (23), while in Bulamogi, Uganda, Western and traditional medicine are perceived as different but complimentary (24). As recommended by participants in this study, there is need for greater education to address these perceptions and knowledge gaps.

In relation to health care system related barriers to CHCT, it was felt that when health care workers are unfriendly to clients, or where there is limited counselling of clients, or an overall perceived lack of privacy and confidentiality at the health unit, couples refuse testing. Unfriendly interactions could be brought about by the fact that routine counselling may challenge physicians' personal beliefs, assumptions of patients' sexual risk, perceived incoherence with reasons for the consultation, or by the time pressure associated with busy health units (25). Regardless, the need for privacy is essential in an effort to increase uptake of CHCT (26). In addition, the fact that health care centres often run out of needed medications and drugs and that they lack incentives for people to test may serve to further reduce the perceived benefits of testing. As indicated in a study in Rwanda, when the health care workers were paid to increase the number of married couples tested, the number of couples tested was substantially increased (27). In addition, it was also reported that many women are forced to test for HIV during antenatal visits. A study on uptake of HCT among pregnant women revealed that lack of information, erroneous perceptions of privacy and confidentiality, poor relationship with health staff, and fear of being positive all served to negatively impact on uptake rates for HCT (28). Given this, CHCT should be made a priority in the management of health systems, particularly in relation to ensuring privacy and confidentiality and in creating avenues for motivating both the staff and peers to help achieve this shift in increasing testing uptake rates.

Mistrust among couples emerged from our study data as a significant barrier to accessing CHCT. In instances where males report their marriages as unstable and distrustful, couple testing is difficult to achieve (6). This leads to situations where couples test individually and if found to be HIV positive, they may start treatment without their partner's knowledge. Interestingly, the issue of mistrust was also reported by some participants as a motivator to CHCT, in that couples may want to prove to each other that they are faithful by accessing testing.

In our study, as in other studies, males tend to be less supportive of CHCT than females (6,10,29). Reasons for male lack of support for CHCT include the erroneous assumption that their partners' results can serve as a proxy for their HIV status, limited time to accompany their wives to health units, and the fact that they are not feeling ill. This suggests that gender roles and expectations can hamper CHCT uptake, and is illustrative of the overall lack of influence females have on male testing behaviour, the gender-based social expectation of men's extra-marital relationships, and how CHCT could threaten masculine self-esteem and male peer norms (30). In this regard, it is important to note that males can have an important influence on the success of CHCT (31). For example, if males continuously refuse CHCT, the progress towards eliminating the onward transmission of new infections will be challenged, particularly given that the majority of the discordant couples do not know their partners' HIV status (32,33). Although our study revealed that there are some males willing to undergo CHCT, this needs to be further explored to determine how men can further influence their male peers to utilise CHCT.

As indicated earlier, participants in this study highlighted a number of possible approaches to improve CHCT. These suggestions included peer couple counselling, provision of incentives, mass HIV health education campaigns, and door-to-door testing. In other studies, peer counselling has been

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shown to improve the quality of life of persons living with HIV through better coping mechanisms and social supports (34,35). In addition, peer counselling should be joined with couple peer education as this has been shown to improve both knowledge levels and attitudes towards HIV (36). Health education messaging is known to increase uptake of HIV testing (37). It has been suggested that through mass health education messaging efforts, communities respond positively to new knowledge that is believed to reduce risk in their lives (38,39). Further, participants in our study suggested the use of incentives based in part on the fact that in the past many organisations gave incentives to clients that have tested HIV positive in order to ensure continuation of HIV treatment. It is believed that if this approach is applied to CHCT, more couples may be willing to be tested. These incentives can be given to staff or to the clients themselves, and this approach has been highly successful based on the findings of other studies (27,40,41). In addition, door-to-door CHCT, sometimes referred to as home-based HIV counselling and testing (HBHCT), has the potential to reach couples who would not otherwise access health services. This approach has proven successful in increasing the proportion of previously untested husbands and wives accepting CHCT (42,43). Although this strategy has been reported to reach fewer clients than other CHCT approaches (12), our participants suggested this model should be considered in subsequent CHCT campaigns.

Limitations

There are several limitations to our study findings which should be noted in moving CHCT research forward. Given that there were more females in the study population than males, our study population may not reflect the general community's perspectives. This is particularly important given that we purposively recruited from individuals that had accessed health care at the selected health units which may suggest these individuals possess higher levels of health seeking behaviours than those who avoid health services. In addition, our study design did not specifically focus on gender-based differences in testing behaviours. Additional research in the area of gender inequity and testing is warranted.

Conclusion

In this study, we explored the reasons for the low uptake of CHCT as well as possible strategies to improve the current situation. It is important to note that this study was conducted in an urban and rural setting near a major city where proximity to health services can be challenging. Although not the focus of this study, the availability of HIV testing in smaller locations is complicated by issues of privacy and confidentiality. Given this, it is not entirely surprising that that fear of a positive result emerged as the key barrier to CHCT. In addition, fear was coupled with perceptions of CHCT and knowledge on the utility of CHCT, how CHCT service delivery occurs, mistrust in marriages, and the cultural context within which HIV testing must be negotiated. In response to these challenges, our participants suggested peer couple counselling, the offering of incentives to couples who test together and door-to-door CHCT testing may assist with increasing CHCT uptake rates. These CHCT programming improvement strategies, such as door-to-door testing, have been implemented elsewhere and have produced promising results. We believe these results present an opportunity to pilot strategies to improve CHCT in Uganda. In addition, the effort to advance uptake of CHCT offers additional opportunities for intervention research in this area, including among males, in an effort to better understand how to scale-up testing opportunities for couples.

In moving forward, it is crucial to recognise that fear of a positive HIV test result is related to many interconnected negative health and social outcomes (e.g. stigma, depression, early death from taking medication, separation). Fear remains a major barrier to HIV screening in general, whether through CHCT or as an individual. Additional research and health promotion advocacy work should be done to not only decrease the fear associated with HIV, but also to increase the awareness of the benefits of an early diagnosis, including the effectiveness of the treatment on one's health and the reduction of transmission to one's sexual partner. Further research in specifically exploring and addressing gender-based inequities in HIV testing behaviours is also warranted.

Conflict of interest

The authors declare that there are no conflicts of interest.

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