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Factors Shaping Initial Decision-Making to Self-test Amongst Cohabiting Couples in Urban Blantyre, Malawi

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Abstract In sub-Saharan Africa, most new HIV infections occur in stable relationships, making couples testing an important intervention for HIV prevention. We explored factors shaping the decision-making of cohabiting couples who opted to self-test in Blantyre, Malawi. Thirty-four self-tested participants (17 couples) were interviewed. Motivators for HIV self-testing (HIVST) emerged at three main levels. Individual motivations included perceived benefits of access to treatment, and self-checking of serostatus in the hope of having been cured by prolonged treatment or faith-healing. HIVST was considered convenient, confidential, reassuring and an enabling new way to test with one’s partner. Partnership motivations included both positive (mutual encouragement) and negative (suspected infidelity) aspects. For women, long-term health and togetherness were important goals that reinforced motivations for couples testing, whereas men often needed persuasion despite finding HIVST more flexible and less onerous than facility-based testing. Internal conflict prompted some partners to use HIVST as a way of disclosing their previously concealed HIV positive serostatus. Thus, the implementation of community-based HIVST should acknowledge and appropriately respond to decision-making processes within couples, which are shaped by gender roles and relationship dynamics.

Keywords HIV self-testing · Couples · Decision-making · Gender · Malawi

Introduction

In 2011, 1.7 million lives were lost to HIV/AIDS and 2.5 million people were newly infected, including 1.8 million sub-Saharan Africans [1]. In the region, stable heterosexual relationships are an important source of ongoing HIV transmission [2, 3] resulting from pre-existing discordancy or as a result of extra-marital sex [4]. HIV-testing followed by timely uptake of services is vital to both prevention and treatment of HIV [5, 6]. Although existing approaches such as facility-based HIV-testing and counseling (HTC) and provider initiated testing and counseling (PITC) have demonstrated increased uptake of HIV-testing, particularly amongst women, gaps include low coverage in rural areas, low uptake by men and couples and infrequent retesting [7–10]. Despite limited resources, a forward thinking public health approach to HIV prevention and treatment has provided highly innovative and successful scale-up of HIV services including HTC in Malawi: 51.2 % of men and 71.6 % of women had tested for HIV at least once by 2010 [11]. In 2012, 76 % of those in need were receiving ART in Malawi [1].
Community and home-based HTC services show promise as a way to complement facility-based HTC services, increasing coverage and also providing early HIV diagnosis, but requiring considerable commitment of resources [8, 12–15]. HIV self-testing (HIVST) is a novel community-based option that could be scaled-up at low cost, and may also be empowering to users [16–18]. HIVST is a test that is “collected, performed and interpreted in private by an individual who wants to know their HIV status” [19, 20]. Pre-test information is provided through the package insert and/or via online or telephone hotlines providing post-test counseling and supporting linkage to care.

HIVST strategies range from supervised models to unsupervised models [21]. Public health concerns about HIVST include increased risk of unmanaged anxiety; potentially negative impacts from bypassing counseling; potential for coercive testing, lower test accuracy and lower linkage to care following a positive HIV-test-result [22, 23]. Counter arguments based on autonomy, feasibility and coverage, particularly the relevance and acceptability for groups poorly served by current testing strategies (such as men) [20, 24, 25], support HIVST. Limited evidence to date suggests that HIVST may be the preferred option for many first-time, and most repeat, HIV-testers [17, 20].

There is need to further explore concerns relating to coercive testing and how gender roles and relations impact on the experiences of HIVST for both women and men within couples. Here we explore the long-term consequences of semi-supervised HIVST within couples on partnership dynamics and on linkage to care through a longitudinal qualitative cohort study. This paper focuses on the factors shaping decision-making amongst cohabiting couples deciding to self-test for HIV in urban Blantyre, Malawi.

**Methods**

The findings reported here are based on the analysis of baseline data within a 12 month qualitative longitudinal cohort study nested into a cluster randomized trial (CRT) investigating the impact of intensified HIV/TB prevention on the incidence of bacteriologically confirmed TB. Adult residents in the intervention arm (approximately 16,600 adults in three high density suburbs in urban Blantyre) had free access to professional-use OraQuick® ADVANCE II (Orasure Inc.—assembled in Thailand for OraSure Technologies, Bethlehem, PA) with a range of supervision options (from supervised to semi-supervised) provided by community counselors (CC). These CCs were recruited using participatory methods and trained in HTC by the Ministry of Health. Following a brief test of understanding, clients took HIVST kits home to use in private after pre-test counseling with provision of self-testing instructions (developed through the study). They were encouraged to disclose results to sexual partners and to return to the resident CC for post-test counseling.

Thirty-four participants (17 heterosexual couples) provided consent to participate in the longitudinal sub-study reported here. Recruitment took place over a 5 month period from September 2012 with follow-up at 3 and 12 months. Purposive sampling was used to provide maximum variation of participants [26] in terms of HIV serostatus, gender and concordancy (Table 1).

Data were collected using in-depth interviews (IDI), conducted within 21 days of self-testing to reduce recall bias. Partners were interviewed separately to enhance openness to discuss confidential issues. A pre-tested topic guide was used by two male interviewers (DM and MP) and included motivation for HIVST, decision-making processes and household power dynamics. Reliance on male interviewers reflected human resource constraints: however both interviewers had several years of experience in interviewing women on sexual behavior, and training included a focus on rapport building and using open ended non-judgemental questions. Data were captured through digital audio recorders in Chichewa, the dominant local language, then transcribed verbatim, cleaned and reviewed for accuracy. Data were validated and triangulated across couples. Using a constant comparison approach [27], we compared within couples the reports from both male and female partners with respect to motivation for HIVST. Narratives from women and men largely confirmed each other despite being interviewed separately.

Transcripts were imported into NVIVO 9 QSR software (QSR, Melbourne, Australia) for organizing, management and analysis. Units of meaning for analysis were text in Chichewa to optimise trustworthiness of interpretation and credibility [28, 29]. Each transcript was read, re-read, coded and classified according to emerging themes using content analysis by MK, DM and MP. The codebook was generated using deductive and inductive coding frameworks [30]. Free nodes were then collapsed into tree nodes.
to generate themes. Translation of relevant text for key quotations followed detailed content analysis. Couples were linked using unique identifiers and a participant register that contained basic demographic information.

Ethical clearance was obtained from the College of Medicine Research Ethics Committee (COMREC), affiliated to the University of Malawi. Participation in the study was voluntary and all participants provided written informed consent.

Results

The results are presented against three key themes that emerged in the analysis of factors shaping decisions around HIVST namely: 1) individual-level motivations; 2) couple power dynamics; and 3) serostatus disclosure.

Individual-Level Motivations for HIVST Within the Context of Being in a Couple

Perception of the benefits of HIV-testing amongst couples was a strong motivation to self-test with a partner since access to HIV-related health information was an important element for informing decision-making within a relationship. Testing separately was felt to limit the extent to which partners would adjust their lifestyles based on test-results.

Self-checking a previous HIV positive diagnosis was common with semi-supervised HIVST, where opportunities for repeat-testing played into beliefs around the possibilities of healing HIV. Cure through prayer emerged as a common theme. There was a growing market in faith-healing as illustrated by a woman (whose husband was also open to faith-healing), hoping to reverse their status, having been on ART for more than five years:

_We have been going to prayers. …they tell us that we should ’now believe that HIV has left your body.’ But I cannot just believe… we felt that it is important to check using these new home test-kits…_ (Female, HIV positive, Concordant).

HIV was believed to be curable with prolonged ART, with participants citing the extent to which health recovers following ART initiation. Coupled with a need to return to a ‘normal’ life in all respects, notions of the ‘curability’ of HIV prompted mutual self-checking of HIV serostatus amongst partners in the hope of being able to stop treatment, resume unprotected sex and have more children:

_… I heard that ‘if you have taken drugs for a long time, the virus disappears in your body. This is why I insisted on testing again…_ (Female, HIV positive, Concordant).

Reactions to semi-supervised HIVST amongst both women and men were highly favorable, thus reflecting gender similarities. HIVST was valued as non-invasive and easy to use, with locally accessible kits that could be taken home. It was also considered convenient, confidential, and capable of accurately identifying the true status of partners and, therefore, often by implication, the relationship. Advantages over facility-based HTC included savings in time and money, avoiding embarrassing and stigmatizing experiences of queuing, and reducing fears around breaches of confidentiality or swapped results.

For women, the ease with which men could be encouraged to self-test was seen as a major benefit—with some participants contrasting this experience with previously unsuccessful attempts to get their husband to test and arguments triggered by trying to persuade male partners to attend facility-based HTC. Similar sentiments were shared amongst men who saw facility-based HTC as intimidating and less responsive to their testing needs:

_These things [HIV testing] are frightening… that you should go there [facility], and stand in the queue. If my wife had told me to go to a hospital to test, I would have refused… ‘I cannot go to the hospital and follow the line while I don’t have money in my pocket…. What will I eat after I have returned home since I have not worked?’_ (Male, HIV positive, Discordant).

Some HIV positive participants re-tested using HIVST were linked back into HIV care if previously unsuccessful or if they had dropped out. One woman self-tested with her partner hoping to re-enter care without being recognised as “a defaulter”, which had previously lead to humiliation by healthcare providers.

_I was on ARVs… but… I stopped…. I wanted to start again but was shouted at the hospital because I did not remember my number. This [HIVST] was a better way of re-starting taking ARVs._ (Female, HIV positive, Discordant).

Promotional activities (leafleting and door-to-door visits) by CCs influenced some couples’ decision to self-test since counselors were appreciated for being courteous and informative.

_It is what the counselors said that made us happy. They said ‘we will not force you — if you don’t want to, it is your decision. If you want, then you will get tested’._ (Male, HIV negative, Concordant).

Couple Dynamics and Decision-Making Trajectories

Despite individual motivations, complex couple dynamics underpin and inform decisions by both partners to test
together. In some cases, partners negotiated self-testing in advance. In others, knowing that one of the partners had self-tested, or seeing his/her results on a used test-kit encouraged the other to self-test. At times this was through mutual agreement using persuasion. For example, a married woman whose husband’s job would not allow him to access facility-based HTC described how HIVST presented her a rare opportunity of testing with her partner:

*They [CCs] did not come by surprise. They came nicely and told me what to do if I tested positive. What I also liked is that it [self-testing] allowed me to test with my husband.* (Female, HIV negative, Concordant).

Suspected or known infidelity, with the risk of bringing HIV into the partnership, was a strong motivation to negotiate HIVST by both partners. Although most commonly voiced by women, this could be a major motivator for men too:

*…last year I caught my wife committing adultery… It was important that I should find out about my life from that time.* (Male, HIV negative, Concordant).

However, there were also occasions where pressure was brought to bear. Pressure to test often arose when one partner brought test-kits into the home with the suggestion of testing together. Participants who had tested under these circumstances described feeling reluctant to “opt-out”, and instead feeling obliged to self-test in order to demonstrate commitment to the relationship, or to remove existing mistrust. For example, one sero-negative woman in a discordant relationship reported very heavy pressure to test from her husband who was already on ART:

*My husband just gave me the test-kit and told me to test. I feel that this is a problem. …I did not have a choice to say no… my husband initially went to test alone. According to his test-results, he also wanted me to get tested…. So I was in a dilemma….* (Female, HIV negative, Discordant).

As this example and the next two quotes demonstrate, men tended to feel more openly entitled to pressuring their partner into HIVST, with women instead using less overt means.

*Because we are one body, both parts of the body should be tested. So I forced her to have a test to find out if she has it [HIV].* (Male, HIV negative, Concordant).

*It was my wife who brought these toothbrushes1 [test-kits] because she wanted to know my status. At first, I refused to test…then I felt that if I continue refusing, she may think that I am afraid of testing because I sleep with other women when I go out for beer.* (Male, HIV negative, Discordant).

Despite these instances, HIVST was mostly considered empowering by both men and women. Both sexes appeared to put forward the concept that sexual partners have a special interest in knowing about each other’s HIV status and are, therefore, allowed to use a degree of persuasive pressure. For women, the extent of entitlement was often directly related to their pre-existing level of social or economic empowerment within the household. In urban Malawi, economic empowerment related to exposure to modern lifestyles and particularly employment status was important. For example, a woman who earned a regular monthly income in formal employment equivalent to that of her partner said about having persuaded her husband to test:

*I was very suspicious that he was hiding his status from me. This is why I told him to do this [self-test]. He accepted without hesitation.* (Female, HIV positive, Concordant).

Women were often initiators of self-testing due to greater familiarity with health facilities, greater likelihood of being found at home to meet CCs and interactions with peers in the community who often influenced their decision to self-test.

*When I went to a house of my friend, I found these [test-kits] on her table….she told me they are used for testing HIV. She said ‘I have found a man whom I want to marry and we would like to know our status.’ I told her to show me where she got them so that I should also test with my husband.* (Female, HIV positive, Discordant).

Serostatus Disclosure Enhanced Through HIVST

For both women and men knowledge of a partner’s HIV status cultivated openness and psychosocial support, including support to adhere to ART. Prolonged illness of one partner could trigger the other to request HIVST for both, anticipating the cause of the illness as HIV-related and, therefore, with one or both partners in need of diagnosis in order to access treatment. The experience of having witnessed recovery on ART of seriously ill relatives or friends added to the motivation to encourage symptomatic partners to self-test.

*…if I test…alone and am positive, I cannot be free to take my medication at home when my husband is present. I would be hiding my drugs from him but if*

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1 Toothbrushes were links to oral HIVST test-kit which show some resemblance in appearance and how it is used. This depicts how people situate HIVST technology within social norm and reflect how this new technology is normalised and accepted.
we test together, he would support me to take my medication. (Female, HIV negative, Discordant).

Whilst HIVST often encouraged communication between partners, there were examples where couples were unable to initiate a discussion about HIVST. A range of strategies to trigger discussion about HIVST emerged from the analysis. For example one woman individually approached the CC to visit them at home and offer HIVST at a time when her husband was available:

...he was already on treatment and was hiding it from me. One day I found his ARV drugs where he had hidden them but he denied that they belonged to him. This is why I told these people to come without him knowing that it was me who had invited them.

(Female, HIV positive, Concordant).

Similarly, in relationships where partners were unable to discuss sensitive subjects such as HTC, test-kits were deliberately displayed where a spouse could easily spot them (see quote on ‘toothbrushes’ above). In this way, enhanced availability through HIVST became an “ice-breaker” facilitating discussions about health, fidelity and HIV status–topics that were otherwise extremely difficult to raise. In some cases, HIVST provided a convenient route to confirm or disprove suspicions about a partner’s HIV status. It also increased access to a partner’s results: enhancing credibility, often restoring trust and understanding to relationships, particularly if a suspected partner tested negative.

Twelve couples in our cohort were unaware of their partner’s HIV serostatus prior to HIVST. Of these, seven were discordant, two were HIV positive concordant and three HIV negative concordant. Six participants who had failed to share past positive results used the HIVST as an opportunity to disclose to their partner. Previous failure to disclose was ascribed to fear of negative consequences, such as divorce and loss of economic support, or fear of jeopardising a promising new relationship. Disclosure using HIVST was motivated by guilt and a desire to foster openness about HIV, and also to ensure diagnosis and access to care on the incorrect assumption that they would almost certainly have already infected their partner. Although initiating HIVST as a couple, in most cases the known-positive partner tried to maintain the pretence by claiming to be testing for the first-time or having had previous negative test results as explained by a man already taking ARTs for several years:

...I realized that it is good to tell each other the truth… this is why I invited the person [CC] to test us after realizing that it was not good that I should continue hiding that I am HIV positive from her…. I was afraid that I had infected her. Since I was found to have HIV some years back, I expected that she would also be positive. I did not believe it when her result was negative after all these years that I have lived with her.

(Male, HIV positive, Discordant).

Discussion

In this study, the main motivations for initiating couples-HIVST, including disclosure and fear of infidelity, are similar to those described for other modalities of couples-HTC [31–33]. However the unique attributes of HIVST bring a new layer to the ways in which these are experienced. As with other home-based models, testing together as a couple is logistically easier with HIVST than facility-based services [9, 13, 34]. Our findings show that placing the control for initiating and conducting the test in the hands of the user(s), bring new dynamics, fluidity and complexity to the HIV testing process. This requires framing the idea of couple testing as a uniform joint event involving both partners testing together and at the same time. Although women were most often the initiators of couples-HIVST, there was a multitude of different patterns of decision-making and relative timing. For instance, some couples went for counseling and collecting kits together while in others one partner tested alone first or brought kits into the house. HIVST does not provide the full package that comes with a counselor-delivered service, but may have other unforeseen advantages. As HIVST is scaled-up, it will be critical to understand and capitalise on the advantages of couples-HIVST and to mitigate the disadvantages from loss of the joint counseling process (rather than the testing per se).

We have discussed how couples define routes to HIVST and how this depends heavily on pre-existing levels of trust within the relationship, previous experience of HTC, and the extent of gendered power-imbalances. We demonstrated how the initiative to undergo HIVST could be taken by either partner, reflecting the interplay between a range of motivations at the individual level but shaped by the realities and experiences at the couple level. At each of these levels, gender and power imbalances within relationships influenced the decision-making process [35]. Women often used more subtle and less direct ways than men in introducing self-testing. In two of the 17 couples we found some evidence of pressure from a partner to test. In both cases it was a husband pressuring his wife to test with the justification that it was the husband’s right to know this information about his wife. Further work needs to be conducted to understand the extent and dynamic of coercive testing experiences within HIVST. However, the more direct introduction of HIVST and the overt coercion by men demonstrates that men had more power in the
decision making process for HIVST. This reflects the broader gendered social norms in Malawi which often give men more power than women in a wide range of areas [36, 37].

We observed the interplay of individual and couple levels, with the need to self-test mainly originating from the individual interests of one partner before germinating into a testing decision within the partnership dynamic. Mistrust and risk behavior generated a great deal of interest amongst partners to test for HIV, contrary to what was reported in eastern Uganda and rural South Africa where mistrust and risk behavior deterred people from testing, possibly because HIV testing occurred within a facility-based framework [38, 39]. HIVST made it considerably easier for women to negotiate and for men to accept testing.

The fluid nature of testing within a couples-HIVST demonstrated by our findings raises the need for more flexible definitions of what constitutes “couples testing”. In Table 2 we list definitions of couples-testing defined by the World Health Organisation (WHO), whilst Fig. 1 summarizes different trajectories through which decisions were made. Painter emphasized the importance of ‘social interaction’ between both partners and a counselor within couple HIV testing and counseling [40]. Couples-HIVST, is, instead, highly heterogeneous and dictated by the nature of specific relationships, especially by the attitude of the man, emphasising the importance of gendered household relations to couples-HIVST.

The uptake of HIVST by both partners often combines one risk-based motivation (with the extreme example of this being previous non-disclosure of the initiator’s known HIV infection) with the other partner then drawn in by convenience and persuasion [17, 20]. In facility-based HTC models, numerous financial, logistical and psychological challenges tend to inhibit spontaneity and enthusiasm for couples HIV-testing, making it hard to harness the impetus to test together [41, 42]. For men, whose lives are defined by daily pressure to generate income, facility-based services, attended primarily by women and children, were considered to be insensitive, unaccommodating, intimating and time consuming demonstrating how prevailing hegemonic conceptions of masculinity deter men from utilizing HIV-related health services [43]. As recounted by our couples, partners found the modality of the semi-supervised HIVST model accessible and easy to use, which in turn reinforced the momentum to test together. In addition, in scenarios where couples did not undergo the whole self-testing process together, they were more likely to disclose test-results than in previous testing situations.

The one clear example of male-initiated self-testing other than for disclosure was in the context of suspected female-infidelity, which stands out within a broader cultural setting where male infidelity is more common and less open to direct challenge [44]. Women too reported their suspicions concerning their husbands’ suspected extramarital affairs as motivating them to initiate couples-HIVST: wanting to “test out” their man’s fidelity as well as to know the results in order to act upon them. However, these underlying gender norms, coupled with limited economic autonomy, meant that women were less able to directly confront their men and discuss this rationale explicitly with their partners.

Siu et al. [45] observed that masculinity and economic concerns threaten up-take of HIV-testing amongst men when family income has been used to treat HIV-related symptoms prior to HIV diagnosis and also when disclosure of HIV positive status undermines men’s position at work and reduces future work opportunities. Our male participants felt “put on the spot” by self-testing but saved face through exerting their authority and maintaining a measure of control over the HIVST process, even when fearing that they may indeed have acquired HIV as a consequence of extramarital sex. This highlights how biomedical technologies can interplay with gender roles and relations and the importance of a context embedded and nuanced approach.

This analysis was conducted within the context of a CRT implementing HIVST in a manner that is unlikely to
be adhered to outside of the research context and that included door-to-door promotion of HIVST as well as self-presentation of clients. Discussion around HIVST was often confused in participant perceptions as identical to discussion around door-to-door access (which has high uptake and tends to be favoured over facility-based testing even when providing conventional HTC and not HIVST). Our analysis should therefore be understood with these limitations.

**Conclusion**

HIV self-testing is a novel strategy that is attractive to both women and men and may prove better suited for reaching male partners than many other current models. By its very nature, HIVST is more flexible and autonomous than other forms of HTC, and so may resist narrow definitions of couples-HTC, as we report here. Gender and power relations will continue to shape the different stages of decision-making, but the ability to tailor-make the exact circumstances and timing was in some cases empowering and enabling for women, allowing them to influence domestic decision-making without provoking negative reactions from their male partner. Other important functions of HIVST include facilitating disclosure and re-entry into HIV care for people who already know that they are HIV positive. Self-checking of positive HIV status is common, and needs to be included in informational materials. The door-to-door option proved most successful in ensuring that couples underwent the entire HIVST process together, emphasizing the linkage between full couples’ testing and the presence of a counselor.

Through examining gendered power dynamics at global level, policy makers can define overarching guidelines for implementation of HIVST. However, at national and sub-national levels, these guidelines should be sufficiently flexible to allow implementation that takes into consideration decision-making processes within couples and gendered power dynamics shaped by the local context; and to ensure that services optimize experiences and meet the diverse and multiple needs of different couples.

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