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Authors

Armstrong-Hough, Mari

Ggita, Joseph

Ayakaka, Irene

et al.

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“Give Me Some Time”: Facilitators of and Barriers to Uptake of Home-based HIV Testing During Household Contact Investigation for Tuberculosis in Kampala, Uganda

Mari Armstrong-Hough, MPH, PhD^{1,2}, Joseph Ggita, BS¹, Irene Ayakaka, MBChB, MIPH¹, David Dowdy, MD, PhD³, Adithya Cattamanchi, MD⁴, Jessica E. Haberer, MD⁵, Achilles Katamba, MBChB, PhD^{1,6}, and J. Lucian Davis, MD^{1,2,7}

¹Uganda Tuberculosis Implementation Research Consortium, Makerere University, Kampala, Uganda ²Department of Epidemiology of Microbial Diseases, Yale School of Public Health, New Haven, Connecticut, USA ³Department of Epidemiology, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland, USA ⁴Division of Pulmonary and Critical Care Medicine, University of California San Francisco, San Francisco, California, USA ⁵Massachusetts General Hospital Global Health and Harvard Medical School, Boston, Massachusetts, USA ⁶Clinical Epidemiology Unit, Makerere University, Kampala, Uganda ⁷Pulmonary, Critical Care, and Sleep Medicine Section, Yale School of Medicine, New Haven, Connecticut, USA

Abstract

Background—Integrating home-based HIV counseling and testing (HCT) with tuberculosis (TB) evaluation could improve uptake of HIV testing among household contacts of patients with active TB. We sought to identify the facilitators of and barriers to HCT during household contact investigation for TB in Kampala, Uganda.

Methods—We nested semi-structured interviews with 28 household contacts who were offered home-based HCT in a household-randomized trial of home-based strategies for TB contact investigation. Respondents reflected on their experiences of the home visit, the social context of the household, and their decision to accept or decline HIV testing. We used content analysis to identify and evaluate facilitators and barriers to testing, then categorized the emergent themes using the Capability, Opportunity, Motivation, and Behavior (COM-B) model.

Results—Facilitators included a pre-existing desire to confirm HIV status or to show support for the index TB patient; a perception that home-based services are convenient; and positive perceptions of lay health workers. Key barriers included fear of results and feeling psychologically unprepared to receive results. The social influence of other household members operated as both a facilitator and a barrier.

Conclusions—Pre-existing motivation, psychological readiness to test, and the social context of the household are major contributors to the decision to test for HIV at home. Uptake might be improved by providing normalizing information about HCT prior to the visit, by offering a second

Corresponding author: J. Lucian Davis, MD, Lucian.Davis@yale.edu, Department of Epidemiology of Microbial Diseases, Yale School of Public Health, New Haven, Connecticut, USA.

HCT opportunity, by offering self-tests with follow-up counseling, or by introducing HCT using “opt-out” language.

Keywords

Home-based HIV counseling and testing; tuberculosis; household contact investigation; lay health workers; integrated HIV/TB evaluation; implementation science

Introduction

In settings with high HIV prevalence, guidelines recommend that household contacts of persons with active tuberculosis (TB) undergo HIV counseling and testing (HCT).¹ HCT facilitates early HIV diagnosis and provides an opportunity to increase status awareness among vulnerable populations.^{2–6} Expanded access to HCT is critical to reaching the goal of 90% of people living with HIV (PLHIV) knowing their status.^{7,8}

Offering home-based HCT during household contact investigation for TB eliminates some barriers to HIV testing, including need to travel to clinics. The home may also afford more privacy and social support than a clinic, addressing some stigma-related barriers.⁹ However, there is limited understanding of how integrating HIV and TB evaluation may influence acceptance of HCT, especially in the context of a household visit. At a time of heightened stress following a household member’s diagnosis with TB, there is risk that offering these services together could be antagonistic rather than synergistic. We carried out a mixed-methods study to examine facilitators and barriers to home-based HCT during household contact investigation for TB, and to identify interventions to overcome these barriers.

Methods

Setting

This study took place in Kampala, Uganda. Uganda is a high HIV-TB-burden country; HIV prevalence is estimated at 7.1% among 15-to-49-year-olds and TB prevalence at 202 per 100,000.¹⁰ In previous studies, 69–95% of Ugandans accepted HCT.^{11–13}

Design

We nested in-depth interviews in a household-randomized trial of enhanced TB contact investigation.

Sampling

Trained lay health workers (LHWs) enrolled TB patients at seven public-sector TB units, then visited patients’ homes to perform TB contact investigation. HIV education was delivered to the entire household. Individuals 15 years without known HIV were offered HCT, with individual pre-test counseling and testing apart from others.

Each week, we randomly sampled contacts who had been offered HCT during the previous week. We stratified by gender, prior HIV testing, and HCT decision, oversampling participants who reported no other recent HIV test. During the final two rounds, we targeted

populations by age/gender not captured during random selection. We contacted participants by telephone two weeks after their home visit and invited a 30-minute face-to-face interview in their preferred language, English or Luganda, at a location of their choice. We concluded sampling upon reaching thematic saturation.¹⁴

Analysis

Using semi-structured content analysis, we coded interview transcripts, adapting the initial code tree from an earlier study¹⁵ and generating additional codes through open coding. We applied codes independently, allowing co-occurrence, and resolved differences by consensus. After interpretation, we categorized emergent themes using the Capability, Opportunity, Motivation, and Behavior (COM-B) model and used the Behavior Change Wheel (BCW) framework to identify intervention strategies.^{16,17} See Supplemental Digital Content S1–S2 for additional details.

Human subjects

Each participant or parent/guardian provided written informed consent. Participants <18 years old also provided written assent. The Makerere University School of Medicine Research Ethics Committee, Uganda National Council for Science and Technology, and Yale University Human Investigation Committee approved the study.

Results

Twenty-eight contacts (72%) from 28 households participated; two declined and nine were unreachable (Table S1). Twenty (69%) accepted HCT and six (21%) shared households with an index patient living with HIV. Median age was 27 years (IQR 21–34.5) and 20 (69%) were women, similar to the overall contact population (Tables S2–3).

Facilitators

Pre-existing desire to confirm HIV status—Reflecting on the home visit, most respondents who accepted testing described a pre-existing desire to confirm their status (Table 1A). For these respondents, home-based HCT provided an opportunity to act on a motivation developed prior to the visit. Some were regular testers for whom HCT was fully normalized. Others had specific reasons to seek testing.

Desire to support the index patient—Though LHWs described the visit as a service for contacts when they approached the home, many respondents associated the visit with care for the sick index patient. Respondents perceived cooperation as a way of supporting the index patient (Table 1B). While respondents did not directly link testing to supporting the index patient, they were inclined to cooperate with visit activities.

Convenience—Respondents who accepted HCT emphasized how home-based services eliminated need for transport, reduced waiting time, and enabled them to ask questions (Table 1C). Most respondents had negative perceptions of clinics.

Rapport—In contrast to clinics, respondents—including those who declined testing—praised the character and interpersonal skills of LHWs (Table 1D). While positive perceptions facilitated testing for those *who were already motivated to test*, they did not override motivational barriers.

Barriers

Fear—Fear of receiving an HIV diagnosis was the most commonly repeated barrier. Respondents tended to revisit this theme throughout the interview (Table 2A). However, many respondents who expressed fear nonetheless decided to test, describing it as a barrier they ultimately overcame.

In the COM-B model, fear falls in the *motivation* domain because it refers to an internal influence that drives action, and is “automatic” because it derives from emotion (SDC S2). Interventions that use persuasion, incentivization, modeling, or enablement target automatic motivational barriers.¹⁸ For example, providing normalizing language about HIV and HCT could reduce the impact of fear through persuasion.

Feeling unprepared—Respondents who declined home testing due to fear also described themselves as psychologically incapable of acting during the visit. Several—all women—later reconsidered. For example, a woman who rejected HCT described her state of mind that day: “I was not prepared. I still had a shock.” Troubled by the revelation that her husband was infected with TB, she felt overwhelmed (Table 2B). Although too preoccupied to test during the home visit, she later traveled to a clinic for testing. Another woman who was unprepared to test during the visit said she later tested during a pre-natal check-up. Her sister also reconsidered, telling the respondent that if the LHW returned, she would test.

Feeling unprepared to act falls in the psychological *capability* domain, because it refers to the capacity to perform a behavior, and in the “reflective” *motivation* domain, because it involves beliefs about capability (SDC S2). Education, training, modeling, enablement, or persuasion can target barriers in one or both of these domains. For example, providing information earlier to facilitate planning could reduce the impact of this barrier.

Not offered—Four participants reported not being invited to test. In most cases, respondents said that the LHW did not have the necessary supplies (Table 2C). Some said that the LHW nonetheless motivated them to go to the clinic for testing.

Bi-directional contributors

Respondents described the influence of other household members as both facilitator and barrier. Observing others accept testing emboldened some respondents to follow suit. Some referenced the affirmative decision of a partner when recounting their own choice:

I had actually refused to be tested. I had feared to be tested... My husband was around and he immediately accepted and [then] I felt there was no need for me to refuse. (Female, 30)

Here, the husband’s decision to test increased the wife’s confidence and facilitated testing. In other cases, distrust motivated direct requests:

It was my wife who went first. I think it is because she was not trusting me because most of the times I am away on duty... She first showed me the [consent form] she had been given and then she told me to also have the test done before health workers leave the home. I was also tested...(Male, 24)

Anticipated distrust also influenced decisions: one man worried that declining after his wife consented would suggest that he was unsure of his status, and so chose to test.

Social influence could also impede testing. A respondent from a household where all members declined observed,

You cannot accept to test when the rest have refused to do so.(Female, 20)

While results were confidential and tests were offered privately, respondents alluded to difficulty concealing the decision to test. In this environment, some participants rejected privacy altogether. One respondent described how a lone son in his large household accepted, but only if the test was carried out in the presence of the family.

Discussion

These findings complement a growing literature that finds high levels of acceptance and satisfaction regarding home-based HCT.^{11–13,19–24} Most respondents say their home is a more private setting for testing than a health facility.¹² However, a substantial minority of clients consistently decline home-based HCT. Our study contextualizes the test decision within the interaction with the LHW, household, and wider community. We have characterized the facilitators and barriers that drive home-based HCT acceptance and linked them to strategies for intervention using a behavioral framework.

Surveys suggest that home-based HCT may be an effective way to increase status awareness.¹² In our study, however, we found that some household contacts of TB patients felt emotionally unprepared and declined testing. Moreover, the contacts who felt unprepared were the very individuals who believed that a positive result was possible. This suggests that participants who are unready when initially offered HCT may be a critical, unreached group.

We identified two strategies to improve uptake: giving contacts time to form an intention to test, and reframing home-based testing with normalizing language. These strategies can be enacted through minor changes to home-based HCT service provision, protocols, and communication efforts.

Several participants indicated that they or a family member changed their mind after declining. To “give time” to hesitant contacts without losing them from the testing cascade, we suggest three interventions. First, pre-educating index patients and their supporters that HCT will be provided during home visits could better prepare contacts to test. Second, offering a follow-up opportunity to test could improve uptake for contacts who have not formed an intention to test at the initial visit. Finally, selective distribution of self-test kits may improve uptake, provided there are mechanisms to ensure linkage to care.^{25,26}

We also recommend reframing home-based testing as a default procedure in order to reduce the psychological burden associated with choosing to test. In clinical settings, uptake is higher when testing is framed as the default course of action, rather than as an opt-in choice.^{27–29} LHWs could use normalizing “opt-out” language to introduce home-based testing as standard, similar to that used in some clinical settings.^{30–35} As there is evidence that clients may perceive opt-out testing as compulsory^{36,37}, this adaptation must be approached with care.

We further found that the decisions of other household members influenced individual testing decisions. Others have found that distrust can contribute to couples’ decisions to decline joint HCT.^{38,39} Our analysis showed little evidence that distrust negatively influenced acceptance. Rather, respondents described how distrust between marriage partners drove the decision to *accept* rather than decline the test opportunity. More generally, social influences within households can normalize testing when influential family members participate, or inhibit testing when one member’s refusal discourages others.

Finally, sometimes HCT was not offered. This is a reminder that barriers faced by clients are intertwined with the barriers faced by those delivering services. The LHWs conducting visits provided a bundle of services. Failure to offer HCT may reflect a paradox of complex interventions: as more services are provided, they become more appealing to clients, but also more challenging to deliver consistently.

Our study has some strengths. We integrated demographic data and information about prior testing with participants’ own reflections on their testing decision. Our study also leverages a strength of qualitative inquiry: the ability to explore unanticipated participant responses. Our sampling process allowed us to explore emerging themes until we reached saturation.

This study also has certain limitations. First, there was at least a two-week lag between the HCT opportunity and interview. This may increase the risk of recall error. Second, we were unable to reach several selected household contacts, although only two declined. Those not reached were more likely to have declined HCT or to reside with a PLHIV.

Conclusion

Home-based HCT can reach populations who are unmotivated or unable to visit clinics. Pre-existing motivation, psychological readiness to test, and the influence of other household members are important contributors to the decision to test for HIV at home. Uptake might be improved by providing information about HCT prior to the visit, by building multiple HCT offers into contact investigation activities, by offering self-tests with follow-up counseling, and by introducing HCT with “opt-out” language.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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Table 1

Major facilitators of accepting HIV counseling and testing, categorized by their underlying behavioral determinants

	Sample excerpts
MOTIVATION	
A. Desire to confirm status	<p><u>Female, 61, accepted</u>: I felt so happy; I never had any problem with it. I always test myself for HIV...I always want to know my status together with my grandchildren.</p> <p><u>Male, 21, accepted</u>: I had almost prepared to ask about the same; to test for HIV and TB...the patient had already told us that she would be coming to test for HIV and TB. Actually when she came, I asked her "Will it be possible to test me for HIV?" but she was also in the process of requesting if I needed that service... I actually wanted to have [the test]... There is a girl I had sex with but before doing that I had never heard anyone say something bad about her. But after having sex people started talking about her and her behavior.</p> <p><u>Female, 25, accepted</u>: I don't know...I just waited for the LHW to come and I was ready for her. I actually longed for an HIV test...</p>
B. Desire to support patient	<p><u>Female, 26, accepted</u>: Wow...I felt so good, I eagerly waited to listen to her, I wanted her to guide me and make me confident that my husband will heal...I really felt so good and I was happy at it.</p> <p><u>Female, 36, declined</u>: Of course my child said "Mummy, my dad is so loved; health workers have come to see his condition!" and I told him "Yes...that is what they promised; to come visit us."</p>
OPPORTUNITY	
C. Convenience	<p><u>Female, 50, accepted</u>: [The home test] helped me a lot and I was so happy... I truly wanted to go to the clinic but I would also think that I will find a long line... "Line up here... get a piece of paper from there..." When she met me from home, it really helped me...</p> <p><u>Male, 24, accepted</u>: I felt good because I never used transport to go to the clinic; I felt happy as an individual because having to get transport for all those people at home is not easy.</p>
D. Rapport	<p><u>Female, 16, accepted</u>: They said "The LHW has not asked for anything...she is so good... what can we do for her!"</p> <p><u>Female, 20, declined</u>: I think [the LHWs] are good people because they come to rescue our lives. She actually checks on us a lot; she calls me so many times asking about some updates which I usually tell her as it is.</p> <p><u>Male, 24, accepted</u>: I do not have any other question...but the ladies who worked on us are very good people, they talk to you as someone they know, they do not have any problem...</p>

Table 2

Major barriers to accepting HIV counseling and testing, categorized by their underlying behavioral determinants

Sample excerpts	
MOTIVATION	
A. Fear of HIV diagnosis	<p><u>Male, 32, declined:</u> [Testing for HIV] makes them get so worried because when they get to know that they are infected they will keep in constant fear... That makes people refuse to test for HIV.</p> <p><u>Female, 20, declined:</u> She asked whether we would like to be tested and all those people refused...I also refused because I had fear. We all refused but later I went to [the clinic] and I was tested.</p> <p><u>Male, 16, accepted:</u> I first got terrified a bit because I had spent a long time without testing and asked myself "In case I am infected, what will I do?" I had two hearts; one was saying that I have HIV and the other was saying that I am safe.</p>
CAPABILITY	
B. Feeling unprepared	<p><u>Female, 28, declined:</u> There were too many questions and that is why for some of the questions I kept on telling her "Let's leave that..." You know...when she asked "When do you plan to test for HIV?" I told her "Give me some time..."</p> <p><i>I: Did she talk about HIV?</i></p> <p><u>Female, 28, declined:</u> She talked about it but I wasn't prepared by then and I asked her to give me some time.</p> <p><i>I: What made it so hard for you to have it done?</i></p> <p><u>Female, 28, declined:</u> I was not prepared; I still had a shock.</p> <p><u>Female, 20, declined:</u> I didn't want to stay worried about it even though the CHW comforted us. I felt like I didn't want to keep worried about being HIV-positive.</p>
OPPORTUNITY	
C. Not offered	<p><u>Male, 51, declined:</u> I wouldn't have had any problem if she had come with the testing kits.</p> <p><u>Female, 36, declined:</u> [HIV testing] is not bad...if they had come with all the testing kits they would have been able to do it but they never had the testing kits and that is why they requested me to go to the clinic.</p>

Abbreviations: HCT, HIV Counseling and Testing

Legend: The COM-B model organizes determinants of behavior into three major domains. *Capability*, which refers to the capacity to perform a behavior, consists of physical and psychological sub-domains. *Opportunity*, which refers to the environmental context of a behavior, consists of physical and social sub-domains. *Motivation*, which refers to the internal influences that drive individuals to act on opportunities and capabilities, consists of automatic and reflective sub-domains. Motivation is automatic if it derives from emotion, desire, impulses, habits, or reflexes. For more details, see Supplemental Digital Content S2 ("COM-B model and BCW framework.")

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