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Title: Uptake of Home-Initiated Tuberculosis Evaluation During Household Contact Investigation in Kampala, Uganda: A Mixed Methods Study

Authors: Mari Armstrong-Hough[1,3], Joseph Ggita[1], Patricia Turimumahoro[1], Amanda J. Meyer[1,3], Emmanuel Ochom[1], Achilles Katamba[1,2], J. Lucian Davis[1,3,4].

Affiliations:

1. Uganda Tuberculosis Implementation Research Consortium, Makerere University, Kampala, Uganda
2. Clinical Epidemiology Unit, Makerere University, Kampala, Uganda
3. Department of Epidemiology of Microbial Diseases, Yale School of Public Health, New Haven, Connecticut, USA
4. Pulmonary, Critical Care, and Sleep Medicine Section, Yale School of Medicine, New Haven, Connecticut, USA

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Corresponding Author:
Mari Armstrong-Hough, MPH, PhD
Epidemiology of Microbial Diseases Department
Yale School of Public Health
Yale University
60 College St
New Haven, CT 06520
Mari.armstrong-hough@yale.edu

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Abstract (263 words)

Background Home-initiated tuberculosis (TB) evaluation could improve test uptake and linkage to care among at-risk contacts of active TB index patients. However, there is a need to systematically explore why contacts accept, decline, or are unable to complete these services. We sought to describe the barriers to home-based sputum collection as part of enhanced household contact investigation for TB in Kampala, Uganda.

Methods Using a parallel convergent mixed-methods design, we collected quantitative data describing home sputum collection among 82 household contacts of active TB patients and qualitative interviews from a sub-sample of 19 of those contacts. Data were analyzed in parallel to produce a more complete picture of the underlying barriers to home sputum collection.

Results Men were significantly more likely than women to provide sputum when eligible (p=0.04). Contacts who reported risk factors for or symptoms of TB but no active cough where significantly less likely to provide sputum (p=0.05). Education level was not associated with differences in home sputum collection success. In interviews, contacts pointed to support from and for the index patient as a facilitator. Contacts were particularly enthusiastic about the convenience of home-based sputum collection compared to visiting a clinic. Lost or insufficient sputum containers, difficulty producing sputum on demand, and shame emerged as barriers to collecting sputum at home.

Conclusions Uptake of sputum collection might be improved by addressing opportunity barriers prior to the visit, possibly through equipment checklists and improved community health worker

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training. More research is needed on the effects of TB stigma on willingness to produce sputum, even in the privacy of one's own home.

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Introduction

Active case-finding for tuberculosis (TB) has the potential to expand detection of prevalent cases in high-burden settings and reduce incident cases by interrupting transmission.[1-5] One important tool for active case-finding is household contact investigation.[6] However, case-finding through contact investigation depends on contacts' ability and willingness not only to complete screening for TB symptoms and risk factors, but also to complete TB evaluation if referred. In a previous study of contact investigation and clinical follow-up for household contacts of pulmonary TB patients, we showed that only 20% of symptomatic or high-risk contacts referred for TB evaluation eventually completed evaluation.[7]

Home-initiated TB evaluation could improve test uptake and linkage to care among at-risk contacts of active TB index patients because it is more convenient, more private, and less expensive for contacts. However, there is a need to systematically explore why some contacts are unable or unwilling to initiate TB evaluation at home by producing sputum. We sought to determine the barriers to home-based sputum collection as part of enhanced routine household contact investigation for TB in Kampala, Uganda.

Methods

Study setting

The study took place in Kampala, Uganda from July 2016 to July 2017. Uganda has a high TB burden with an estimated annual incidence of 202 per 100,000 population.[8] The Uganda National TB and Leprosy Programme (NTLP) introduced contact investigation for household contacts of index TB patients in 2013.

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Design

This study employs a parallel convergent mixed-methods design. We collected quantitative data describing sputum collection offered as part of a household-randomized, controlled trial testing the implementation of enhanced household contact investigation for TB. We also collected qualitative interviews from a sub-sample of individuals who were asked to give a sputum sample during the trial. Data were analyzed in parallel to produce a more complete picture of the underlying barriers to home sputum collection.

Qualitative sampling and study participants

Trained lay health workers enrolled index TB cases at six Kampala Capital City Authority primary health centers and one general hospital in Kampala, Uganda. They then visited the homes of index patients to carry out household contact investigation for TB. During the home visit, lay health workers screened household members for TB symptoms and risk factors. They offered home-based sputum collection to adults and older children who were symptomatic or living with HIV. Adult household contacts who were offered the opportunity to submit sputum for examination were eligible for a follow-up interview two weeks later.

We purposively selected 20 household contacts offered home-based sputum collection during contact investigation, approximately half of whom had successfully given sputum and half of whom had failed to give sputum. Selected participants were contacted by phone and asked to participate in an in-depth interview (IDI) lasting approximately 30 minutes within a month following the home visit. The interview was scheduled at a location of the participant's choosing.

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Qualitative data collection

The semi-structured qualitative interview guide consisted of four sections. Respondents reflected on the events of the day of the contact investigation, their household context, their experience giving sputum, and the outcome of those services. After coding for facilitators and barriers to successful TB evaluation completion, we linked the qualitative data to individual- and household-level data collected during contact investigation.

We invited participants to interview in their preferred language, English or Luganda. All interviews were conducted by a bilingual, native Luganda-speaking researcher. Semi-structured interview responses were recorded on a digital recorder, translated if necessary, transcribed, and entered into Atlas.ti, an application for qualitative data analysis.

Analysis

We produced descriptive statistics for the total population of contacts who were offered home sputum collection. We then took a grounded theory approach to the interview data. First, we used conventional semi-structured content analysis to code, describe, and interpret the qualitative data.[9] Excerpt blocks were fixed at the level of the full response to a single question or prompt. During open coding, codes were generated inductively from the interview responses. After discussion, the list of open codes was refined to form a codebook. Two researchers, a Ugandan (JG) and a non-Ugandan (MAH) applied codes from the codebook and resolved differences by discussion. Codes were applied to whole excerpts; code co-occurrence was permitted.

After inductive coding was complete, we located the emergent codes within Capability, Opportunity, Motivation, and Behavior (COM-B) model components.[10,11] We then linked the coded qualitative data to individual- and household-level data collected during contact investigation and clinical follow-up data that show which contacts completed clinical evaluation for TB.

Human subjects and ethics approval

Each participant or their parent/guardian provided written informed consent. Participants <18 years old also provided written assent. The School of Medicine Research and Ethics Committee at the Makerere College of Health Sciences, the Uganda National Council for Science and Technology, and the Human Investigation Committee at Yale University approved the study (#1505015812).

Results

More than half of the sample (68%) were women and a quarter (26%) reported that they were living with HIV (Table 1). Most (65%) reported an active cough; the remainder had sputum collection indicated because they had other TB symptoms or were living with HIV. Men were significantly more likely than women to provide sputum when eligible (p=0.04). Contacts who reported risk factors for or symptoms of TB but no active cough where significantly less likely to provide sputum (p=0.05). Education level was not associated with differences in home sputum collection success.

The 19 interview respondents ranged in age from 17 to 61 years. Fourteen (74%) were female, reflecting sex differences in the probability of being invited to and successfully producing sputum. About half (9, 47%) had been unable or unwilling to produce sputum during the home visit; the remainder gave at least one sputum sample.

Key enablers

Support for (and from) the index patient. Contacts saw enthusiastic cooperation with contact investigation, including giving sputum, as a way of demonstrating for their sick household member, the index patient. However, index patients were also a source of support for contacts who had been asked to produce sputum themselves. A young mother explained,

> "I liked the fact that I was tested for TB because my partner, ever since he was diagnosed TB-positive, he has always wanted to take me for TB evaluation but I hadn't had the opportunity together with my baby. But as I was still planning I received a call that a [LHW] was coming to test us and we gave up on going to the clinic and we had it done from home." (R32, female, provided sputum)

The index patient's experience with the logistics of TB diagnosis was also an asset. Having seen her husband complete evaluation for TB just a few days earlier, the idea of providing sputum was not new to this contact: "When [the LHW] requested me to do the same I did it and I never had worries around it."

Perception that home services are convenient. Second, as hypothesized, many contacts who gave sputum cited the perception that it was convenient—it saved them the time, money, and stress required to visit a clinic. Even respondents who did not successfully provide sputum described its convenience:

> "It makes it convenient in a way that one doesn't have to use transport; you just have to wait for your results." (R29, male, did not provide sputum)

Most contacts had negative perceptions of clinics and preferred to be spared the need to visit one.

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Expectation of home-based treatment services. A few contacts pointed to a misperception that home sputum collection would entitle them to home-based treatment services. For example, one man explained:

"[Home sputum collection] helped me because I was found at home… It happened at home. And when my results come back, I will not walk… they will treat me from home in case I accept, so that I do not get exhausted." (R1, male, provided sputum)

Key barriers

Lost or insufficient sputum collection containers. The most important barrier was an opportunity barrier due to lost or insufficient sputum collection containers. Most contacts who did not provide sputum said they were not given the opportunity to be evaluated at home despite willingness to participate. Five contacts said the lay health worker never asked them to provide sputum, usually because there were insufficient containers. In two more cases, contacts said the lay health worker left a sputum container at the home for later pickup, but that the container was subsequently lost. For example,

> "[The LHW] actually tested us as well. You know, when she came on that day I had a cough and she provided a sputum mug to me which go lost and when she asked for it the cough had already cleared and I wasn't able to provide it." (R13, female, unable to produce sputum)

In some cases, like the one above, contacts did not understand that this meant they were never tested.

Difficulty producing sputum. The problem of lost sputum collection containers was related to difficulty producing sputum. Producing sputum can be difficult and time-consuming, leading health workers to leave a sputum container in the home for later pickup. Some contacts said they were simply unable to produce sputum:

> "[The LHW] asked for it but it wasn't productive. I cough in the morning but still I can't produce sputum." (R9, female, unable to produce sputum)

TB stigma. Finally, some contacts who did not give sputum described concern about TB stigma. For example, the woman who had lost the sputum container said of being asked to provide sputum, "In a way, it felt shaming." (R13)

Discussion

Household members are eager to cooperate with community health workers during contact investigation, may receive support from the index patient, and are pleased with the convenience of home sputum collection compared to visiting a health facility. However, producing sputum can be time-consuming or difficult. When a sample is not forthcoming, lay health workers leave sputum containers for future pickup, which are easily lost. Moreover, at least one interview respondents described a sense of shame when she tried to produce sputum. It is possible that TB stigma or negative associations with sputum could decrease the length of time for which household contacts are willing to try to produce sputum during the home visit, reducing the likelihood that a sputum sample can be collected.

Uptake of sputum collection might be improved by addressing opportunity barriers prior to the visit, possibly through equipment checklists and improved community health worker training. More research is needed on the effects of TB stigma on willingness to produce sputum, even in the privacy of one's own home.

The qualitative sample presented here has some limitations. In particular, women are overrepresented in the interview sample. This occurred as a result of our sampling strategy, which required that individuals who were unable or unwilling to produce sputum during the household visit make up half the interview sample. While only 46% of males in the population of all eligible contacts did not produce sputum, 70% of females did not produce sputum.

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Figures and Tables

Table 1. Characteristics and distribution of contacts eligible for sputum collection

	Total eligible (n=82)	Sputum not collected		
		No (n=51)	Yes (n=31)	p-value
Sex				
Female	56 (68%)	39 (70%)	17 (30%)	0.04
Male		12 (46%)	14 (54%)	
HIV status				
PLHIV	21 (26%)	16 (76%)	5 (24%)	0.13
Not LHIV	61 (74%)	35 (57%)	26 (43%)	
Cough				
Cough	53 (65%)	27 (51%)	26 (49%)	0.05
No cough	29 (35%)	24 (83%)	5 (17%)	
Education				
Primary	17 (50%)	13 (76%)	4 (24%)	0.45
Post-primary	17 (50%)	11 (65%)	6 (35%)	