


How Follow-Up Counseling Increases Linkage to Care Among HIV-Positive Persons Identified Through Home-Based HIV Counselling and Testing: A Qualitative Study in Uganda

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Abstract

We investigated how follow-up counselling had increased linkage to HIV care in a trial of referral to care and follow-up counseling, compared to referral to care only, for participants diagnosed as HIV-positive through home-based HIV counselling and testing. We carried out a cross-sectional qualitative study. Using random stratified sampling, we selected 43 trial participants (26 [60%] in the intervention arm). Sample stratification was by sex, distance to an ART facility, linkage, and nonlinkage to HIV care. Twenty-six in-depth interviews were conducted with participants in the intervention arm: 17 people who had linked to HIV care and 9 who had not linked after 6 months of follow-up. Home-based follow-up counseling helped to overcome worries resulting from an HIV-positive test result. In addition, the counseling offered an opportunity to address questions on HIV treatment side effects, share experiences of intimate partner violence or threats, and general problems linking to care. The counselling encouraged early linkage to HIV care and use of biomedical medicines, discouraging alternative medicine usage. Home-based follow-up counseling also helped to promote HIV sero-status disclosure, facilitating linkage to, retention in and adherence to HIV care and treatment. This study successfully demonstrated that home-based follow-up counselling increased linkage to care through encouragement to seek care, provision of accurate information about HIV care services and supporting the person living with HIV to disclose and manage stigma.

Keywords

sociology of health & illness, HIV, linkage to care, counselling, Uganda, medical sociology, sociology, social sciences

Introduction

Home-based HIV counselling and testing (HBHCT) have been shown to achieve high HIV testing uptake in several settings in sub-Saharan Africa (Armstrong-Hough et al., 2018; Doherty et al., 2013; Fylkesnes et al., 2013; Hensen et al., 2014; Mutale et al., 2010; Sabapathy et al., 2012; Sekandi et al., 2011; Shanaube et al., 2017; Tumwesigye et al., 2010). HBHCT reduces inequalities in access to services (Mutale et al., 2010) and facilitates early HIV diagnosis (Wachira et al., 2012). However, in the absence of interventions to facilitate referral uptake, nearly 70% of the people living with HIV (PLHIV) identified through HBHCT do not link to care (Fox et al., 2010, 2016; Hensen et al., 2014; Sharma et al., 2015; Tumwesigye et al., 2010). A systematic review published in 2015 reported that linkage to HIV care ranged from between 18% and 36% of the individuals diagnosed HIV positive when HBHCT was not

accompanied by interventions, such as community-based counselling (Sharma et al., 2015). Other earlier studies have also shown a need for interventions to address linkage to care barriers (Fox et al., 2010, 2016; Govindasamy, Kranzer, & Ford, 2014; Govindasamy, Meghij, et al., 2014; Van Dyk & Van Dyk, 2003).

Although some interventions have been used to increase linkage to care after HBHCT, few have been evaluated in randomized trials (Ruzagira et al., 2017). In this article, we report on a qualitative study, conducted in the context of a cluster-randomized trial in Masaka District, southern

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Uganda. The trial showed that counselling provided 1 and 2 months after HBHCT was associated with a twofold increase in the odds of linking to HIV care among participants (linkage was 51% in the intervention arm vs 33.3% in the control arm) (Ruzagira et al., 2017). We utilized qualitative data collected in the context of this trial to examine how the counselling intervention increased linkage to HIV care, guided by the theoretical framing of the Health Belief Model. For the purposes of this article, we drew on the core constructs from the Health Belief Model: perceived severity, susceptibility, and the cues for taking action, and benefits of taking action against perceived barriers (Rosenstock, 1974).

Methods

Overview

This was a cross-sectional qualitative study nested in an open-label cluster randomized controlled trial. The aim of the trial was to evaluate the effectiveness of a counselling intervention on linkage to HIV care. Linkage to HIV care in this study was defined as a confirmed registration with an HIV clinic within 6 months of HIV diagnosis after HBHCT. The trial was conducted between March 2015 and March 2016. Twenty-eight rural communities were randomly allocated (1:1) to intervention (HBHCT, referral and home-based counselling at one and two months) or control (HBHCT and referral only).

At enrolment, participants received standard HIV counselling and testing (HCT) including pre-test and post-test counselling, with an option for couples-HCT for those that were married/cohabiting. Post-test counselling included a discussion of HIV risk reduction strategies, disclosure plans, partner testing, care and support services and referral for HIV care. In the intervention arm, counselors visited participants' homes at 1 and 2 months after enrolment and referral to provide counselling, aiming to encourage linkage to HIV care. The content of the counseling included a discussion of the individual's acceptance of HIV diagnosis, fear of, or experience of, stigma, plans to seek care, importance of HIV status disclosure and availability of psychosocial support for linkage to and retention in care; and information about local HIV care services, antiretroviral drugs, and rationale for early linkage to HIV care. The counseling sessions were also used to address specific issues, for example, family or marital discord arising after disclosure of HIV status, occurrence of adverse effects following initiation of cotrimoxazole prophylaxis and/or antiretroviral therapy. Six months after HBHCT and referral for HIV care, counselors visited participants' homes and interviewed each participant about linkage to HIV care. For participants who reported that they had linked to HIV care, a member of the study team visited the clinic to verify linkage. Only participants whose records were found at the clinics were considered to have linked to HIV care.

Sampling and recruitment

For the qualitative study, the sample consisted of randomly selected individuals from the intervention arm of the trial. To ensure representation of all participant sub-groups, sampling was stratified by age (18–30 years and ≥ 31 years), gender, distance from an ART provider clinic (≤ 5 km and > 5 km), and linkage status (linked and not-linked).

Data collection

In-depth interviews were conducted with 43 (21 linkers; 22 non-linkers) trial participants, the majority of whom (26/43) had received follow-up HBHCT (the intervention). The in-depth interviews were conducted using a topic guide. Each interview covered the following issues: (a) Awareness of HIV services and their availability in the participants' communities; (b) experiences of HIV services utilization, including HBHCT and the counselling intervention; (c) perceptions and reactions to HIV test results; (d) linkage to or inability to link to HIV care services; and (e) facilitators and barriers for linkage and non-linkage. Interviews were conducted in participants' homes by two Ugandan interviewers (a man and a woman), both with experience in qualitative data collection methods and analysis. The interviews were conducted in the local language (Luganda) and lasted up to 1 hr. Besides audio-recording the interviews, interviewers took field notes.

Data management

The interviewers wrote full interview transcripts and translated them into English. The transcripts were reviewed throughout the course of the study by a senior social scientist, to oversee quality and provide continuous feedback on interview content and format.

Data analysis

A thematic content analysis approach, guided by the constructs listed above from the Health Belief Model, was used to distil key concepts from the interviews. At the first level of analysis, the interviews were read repeatedly by the interviewers and the senior social scientist. Each interview script was summarized to a "testing and linkage" or "testing and non-linkage to HIV care" story. From these narratives, we identified factors/reasons that encouraged (cues and benefits of action) as well as those that discouraged (barriers to) linkage to HIV care.

Ethical approval

All information about the study was provided in the trial protocol and informed consent documents. The protocol and informed consent documents were approved by the Uganda Virus Research Institute Research Ethics Committee (reference number: GC/127/14/12/491), the London School of Hygiene & Tropical Medicine Ethics Committee (reference

Table 1. Participants' Socio-Demographic Characteristics.

Variable	Linked to HIV care	Did not link to HIV care	All
	n (%)	n (%)	n (%)
Total enrolled	17 (65.4)	9 (34.6)	26
Sex			
Male	7 (41.2)	6 (66.7)	13 (50)
Female	10 (58.8)	3 (33.3)	13 (50)
Median (IQR)	33 (14)	34 (12)	33.5 (12.8)
Age (Years)			
18–30	5 (29.4)	4 (44.4)	9 (43.6)
≥31	12 (70.6)	5 (55.6)	17 (65.4)
Marital status			
Married/in a relationship	10 (58.8)	5 (55.6)	15 (57.7)
Divorce/separated	4 (23.5)	2 (22.2)	6 (23.1)
Single	2 (11.8)	1 (11.1)	3 (11.5)
Widowed	1 (5.9)	1 (11.1)	2 (7.7)
Religious affiliation			
Christian	14 (82.3)	8 (88.9)	22 (84.6)
Moslem	3 (17.7)	1 (11.1)	4 (15.4)
Education level			
Nil	1 (5.9)	1 (11.1)	2 (7.7)
Primary	12 (70.6)	6 (66.7)	18 (69.2)
Secondary	4 (23.5)	2 (22.2)	6 (23.1)
Distance to ART clinic			
Within 5 km radius	14 (82.4)	7 (77.8)	21 (80.8)
Over 5 km radius	3 (17.6)	2 (22.2)	5 (19.2)

number 8833), and the Uganda National Council for Science and Technology (reference number HS 1732). Written informed consent was obtained from each participant. The trial was registered at ClinicalTrials.gov (NCT02497456).

Results

Participant characteristics

A total of 149 PLHIV participants were enrolled in the intervention arm of the trial. Of these, 43 (29%) were sampled for the qualitative study, 29 (19%) were located and invited to participate, and 26 (17%) accepted. All the 26 (17 linkers, nine non-linkers) PLHIV that accepted to participate were included in the final analysis: their median age was 33.5 years (IQR =12.8), 13 (50%) were female, 15 (58%) were married or in a relationship, 22 (85%) were Christians, and 18 (69%) had only primary school education (Table 1). Of the 14 sampled participants who were not located, 7 (50%) had moved to distant places either for marriage and or in search of work, while the rest were untraceable.

Findings

Overcoming worries and doubts over HIV test results accuracy

Most of the participants reported that at first, they doubted the accuracy of the HIV test; testing HIV positive

had worried them. The participants explained that the HIV testing process used very little blood, and it took a very short time to determine a person's HIV sero-status, which made them doubt the credibility of the test. However, some who had linked to care reported that during the follow-up counselling, counsellors helped them to overcome their mistrust of the HIV testing process and the HIV positive test results. The participants explained that the counsellors reassured them that the HIV testing process was very accurate. They also added that counselors comforted them and explained to them that they were not to worry, because they were not the first ones to test HIV positive. The counselors also encouraged them to link to care to take good care of their health. The participants commented that some of them linked to HIV care expressly because the counselors had encouraged them to. In addition to this, some participants added that they sought HIV care because the counsellors had promised them that if they did, they would have an opportunity to confirm their HIV status through retesting:

When I tested HIV positive, I got worried. I even shed tears, but the counsellor comforted me. Even when she visited me again, she comforted me more. She told me that I was not the first one to get infected and that the most important thing was for me to go for HIV care. That is when I went to seek HIV care. (26-year-old male participant in the intervention arm [linked to care])

Interestingly, none of the non-linkers in the intervention arm reported doubts about HIV test accuracy or expressed worry as being their reasons for not linking to HIV care.

Encouraging early linkage to HIV care seeking

Several asymptomatic participants reported that they were reluctant to seek health care because they were asymptomatic. However, some participants in the intervention arm reported that they eventually sought HIV care due to the counsellors' encouragement during the follow-up counselling. The participants in the intervention arm who had linked to care further explained that during the follow-up counselling, the counsellors re-emphasized that it was better to seek health care before one became symptomatic. The counsellors also added that linking to HIV care early helped to prolong one's life. Eventually, some participants in the intervention arm said they had linked to HIV care because of repeated exposure to information about early linkage to care benefits:

I did not go to the health facility (seek health care) immediately after testing HIV positive because I was not feeling weak or sick. When the health workers (counsellors) came back, they asked me whether I had gone to the health facility as instructed. I told them I had not gone to the health facility yet. They told me that HIV drugs (ART) work best for those who seek care early before becoming weak. Then I decided to go after one month. (31-year-old female participant in the intervention [linked to care])

However, there were a few intervention arm participants who reported that they had not linked to HIV care because they felt no pain or sickness and were strong:

When I tested (HIV positive) I never sought care soon because I was not feeling any sickness or pain. The counsellor went ahead and visited my home twice. I told him that I will go but I was still feeling no sickness or any pain. (50-year-old male intervention arm participant [did not link to care])

Encouraging HIV sero-status disclosure and enlisting psychosocial support

Some participants in the intervention arm reported that during follow-up counselling, counsellors encouraged them to disclose their HIV status to their significant others. Some participants in the intervention arm, who had linked to care, added that the people they disclosed their HIV status to offered them psychosocial support. Psychosocial support highlighted by the participants included listening to them, encouragement, and reassurance that things will get better. The psychosocial support in return motivated them to seek HIV care. In addition to psychosocial support, some of the people to whom study participants disclosed their HIV status

provided material and financial support which enabled the disclosing participants in the intervention arm to seek HIV care. Only married women reported that HIV sero-status disclosure offered them the basis to seek permission from their husbands to leave home and seek HIV care. Additionally, disclosure empowered these women to ask for transport fares from their spouses. Almost in all cases, the participants who had disclosed their HIV status were reminded, encouraged, and supported to keep clinic appointments and adhere to treatment:

The counsellor advised me to disclose to my partner and when I did, he also took an HIV test. He was found HIV-negative but he is very supportive. Sometimes, I would be thinking deeply and appear worried, but he asks me why I am worried. He comforts me not to be worried any more. He supports me in all ways let it be providing transport to collect drugs and reminds me to swallow (my drugs). (35-year-old female participant in the intervention arm [linked to HIV care]).

However, HIV sero-status disclosure among the intervention participants who had linked to HIV care was not only to spouses. Some participants reported that they disclosed to their parents, siblings, or friends. Those disclosed to often offered psycho-social support in return, which helped to facilitate linkage and retention in care as well adherence to treatment:

There is a fellow community member I told about my HIV test results because the counsellor had advised me to share my test results with the friends I trusted. They had tested him as well and he had also started taking HIV drugs. He advised me to go the health facility. I told him I will not go. If it is dying, let me die. He went away. When he came back after two months, I agreed with him that I had to go to the health facility. I decided to go. Come rain come thunder. I am not the first one to be found HIV positive. If the community talks about me, let them do so but I have made up my mind. (30-year-old male participant in the intervention arm [linked to care])

However, there were some, mainly female, participants who reported that they did not disclose their HIV sero-status to their significant others despite their exposure to follow-up counselling. Because of non-disclosure, such participants did not get any psycho-social, material, or financial support to enable them link to HIV care:

I am still planning how to go to the health facility without telling him (husband) why I have to go. But I fear what if he gets to know? How will he react? He might quarrel and end up beating me. (40-year-old female intervention arm participant [did not link to care])

Overcoming intimate partner violence/threats

Some female participants reported that follow-up counselling helped them to overcome threatened partner violence.

These participants explained that they had been threatened by their partners when they attempted to seek HIV care. As a result, they delayed seeking HIV care. However, during the follow-up counselling, the counsellors advised the individuals subjecting or threatening their partners with violence to also test for HIV and to support the PLHIV partners' health seeking attempts. Some of those partners accepted to undergo HIV testing and supported their PLHIV partners to link to HIV care:

My husband had stopped me from going to seek health care. When the counsellor visited and asked why I was not accessing care, he (husband) was around and he told the counsellor that I would be going to the health facility. The next day, I went to the health facility and he neither abused nor beat me up. (25-year-old female participant in the intervention arm [linked to care])

However, there were a few cases where the follow-up counselling had not overcome the experienced or threatened partner violence by the time the trial ended. Some female participants reported that they had not sought HIV care because their partners refused to allow them to go, threatening violence if they went without their consent/approval:

I wanted to go there (health facility). When I told my husband about it (going to the health facility), he threatened me: 'if you attempt to go there, you will see what will happen. (40-year-old female intervention arm participant [did not link to care]).

Overcoming the fear of treatment side effects

Many participants taking part in the trial reported that fear of HIV drug side effects deterred them from seeking care early. However, some participants in the intervention arm who had linked to care reported that during follow-up counselling, the counsellors advised them to focus on the benefits rather than the side effects of HIV drugs and pointed out that the side effects would be short lived. The participants reported that this motivated those who had not yet linked to HIV care services to do so:

the counsellor encouraged me every time she came back not to worry about the drug side effects, that these would go if I took my drugs as instructed by the health care workers. (20 year old female participant in the intervention arm [linked to care])

However, some participants remained worried and fearful of HIV treatment side effects despite the follow-up counselling. A third of the participants who had failed to link to HIV care reported fear and worries about HIV treatment side effects as their only barrier to HIV care linkage:

When the health care worker came back and asked me why I had not gone to the health facility as asked to, I told her that I was very fearful of the HIV drugs side effects. She comforted me that not everyone on HIV drugs treatment, experiences side effects. I am still planning to go to the health facility. (25-year-old female intervention arm participant [did not link to care])

Encouraging and discouraging use of biomedical and alternative medicine

Some participants reported that they were using alternative medicine to treat illnesses like cough and fever. However, the participants who had linked to HIV care added that during the follow-up counselling, the counsellors strongly discouraged the use of alternative medicine to treat HIV. Instead, the counsellors encouraged participants to seek biomedical HIV care. This, the participants explained, motivated those who had not yet sought biomedical care to do so:

When the counsellor came back to check on me, she found me weak, advised against using traditional medicine and encouraged me to go to the health facility to access modern HIV drugs. When I went, I was initiated on HIV treatment, the fever and general body weakness stopped. (26-year-old male participant in the intervention arm [linked to care])

By the end of the trial, several participants who had not linked to care reported that they were using herbs to treat HIV. These participants explained that they obtained herbs from the people who sold traditional medicine and that these herbs had helped them to remain strong despite being infected with HIV. They also added that when they become weaker, they would seek biomedical care:

I never went to the health facility because I am using traditional medicine to treat illnesses I get. I still feel strong without any pain. (50-year-old male intervention arm participant [did not link to care])

Reissuing referral letters

Some trial participants reported that they had delayed seeking HIV care because they had lost/misplaced their referral letters. A few participants added that during the home-based follow-up counselling, the counsellor re-issued them with new referral letters replacing the ones that had got lost/misplaced.

While the counsellors re-issued referral letters to some participants who reported losing/misplacing them, there were a few who were very fearful about reporting the loss:

He (counsellor) gave a letter to present to the health facility but I lost it. When he came back, I did not tell him that I lost the letter he gave me. I was afraid to tell him that held me back from seeking health care. (30-year-old female intervention arm participant [did not link to care])

Linkage to care barriers that were not addressed by the intervention-home based follow-up counselling

Participants, mainly those who had not linked to care by the end of the trial, reported other barriers that could not be addressed by the counselling intervention. These barriers

included food insecurity, lack of transport fares, and not having decent clothing to put on to go out in public. It was mainly male participants who reported that they feared to seek care because of lack of food. These participants explained that they had learnt through listening to radio programmes and colleagues that to be adherent to HIV treatment, one needs to be food secure, because treatment increased one's appetite. They added that they were willing to seek care, but they did not have food to take along with the treatment:

if you had collaborated with organizations which give us material support and we had enough supplies of maize flour, beans, rice and sugar, as we grow enough of our own food, we would have taken the drugs (HIV treatment) freely and hopefully. I can't accept to take daily HIV drugs when I have no food security. (33-year-old male intervention arm participant [did not link to care])

Other intervention arm participants of both sexes who did not link to HIV care, reported that they had not sought HIV care yet because they lived far away from health facilities and had no money to pay for their transport to health facilities. These participants explained that they had understood everything they had to do but had not taken any action because they could not afford the transport fares to the health facilities.

Only a few participants who had linked to care by the end of the trial reported that they had not sought care because they did not have decent enough clothing to put on while seeking care. These men and women explained that they feared to appear at the health facility when poorly dressed. They claimed that they would seek care after acquiring decent clothing.

Discussion

The current study shows how a counselling intervention provided after HIV diagnosis and referral increases linkage to HIV care. Our findings show that home-based follow-up counselling improved linkage to care through promotion of positive living for the persons that tested HIV positive, provision of accurate information about HIV and HIV care services including ART. The intervention also supported individuals to overcome intimate partner violence and self-perceived stigma through sero-status disclosure. However, not all of those who received follow-up counselling overcame the barriers they faced and linked to care.

The findings of this study are similar to those of previous studies in south-western and eastern Uganda (Muhamadi et al., 2011; Ware et al., 2016), and South Africa and western Kenya (Doherty et al., 2013; Knight et al., 2015; Low et al., 2013; Naik et al., 2015, 2018; van Rooyen et al., 2013) that also explored how post HIV diagnosis follow-up counselling helps to improve linkage to HIV care. These studies reported that home-based counselling and testing with or without

follow-up counselling improved HIV and care awareness. In addition, couple counselling and early linkage to care through information giving and emotional support were important in facilitating care.

Our study findings also revealed that linkage to HIV care is a process where people need time to receive and accept an HIV positive result, and then process the linkage to care decision and work towards achieving the goal of linking to care, a finding corroborated in other research (Adekeye, 2011; Kawuma et al., 2018; Seeley et al., 2019). Linkage to HIV care does not happen in a vacuum but in an environment full of inaccurate information about HIV testing and results, HIV drugs, and competing health systems. All these factors work together to cause worries and mistrust of HIV positive results and to cast doubt on the effectiveness of the HIV biomedical drugs. Family support has the potential to trigger linkage to HIV care and could be enlisted through disclosure of PLHIV status. Studies in Tanzania, Uganda, Lesotho, and South Africa on home-based counselling with and without follow-up counselling, showed how counselling encouraged HIV sero-status disclosure and improved linkage to HIV care (Bogart et al., 2016; Doherty et al., 2013; Labhardt et al., 2016; Mulogo et al., 2011; Plazy et al., 2016; Sanga & Mukumbang, 2019; Tabana et al., 2013). Addressing intimate partner violence was one of the ways of overcoming barriers to linkage to HIV care (Bukonya et al., 2017; Naik et al., 2018).

Although the current study showed that post-HIV diagnosis follow-up counselling addresses some of the barriers to linkage to HIV care, we also demonstrated that there are other important barriers to HIV care linkage that require other interventions. These barriers have been reported previously (Bukonya et al., 2017; Lubogo et al., 2015; Nakigozi et al., 2013; Tuller et al., 2010; Weiser et al., 2010) and include transportation difficulties and food insecurity. Hence, follow-up counselling would need to be applied in combination with other linkage to care strategies to ensure success (Ruzagira et al., 2017; Seeley et al., 2019; Tuller et al., 2010).

Strengths and limitations

The sample for this study was obtained through a stratified random sampling technique making the results applicable to a wide range of trial participants. Nevertheless, qualitative research does not aim at generalizability, we aimed at gaining an in-depth understanding of how follow-up counselling helped to improve linkage to care. We were able to successfully trace over 80% of the linked to care sampled trial participants one year after the initial HIV test. The study also demonstrated other things that could be done in addition to home-based follow-up counselling to further improve linkage to care. This was more so for the patients faced with the challenges of access and affordability of basic needs (food insecurity and decent clothing in addition to affording transport). The study was done among a poor and peri-urban

population, covering a broad geographical area where care is provided by government and NGO clinics with no or little additional support. The linkage to care mechanism (facilitators and barriers) identified, represent common experiences of diagnosed HIV-positive people linking to care in this Ugandan setting.

The study had some limitations. First, the study only investigated the perspective of the end user (patients' perspective) of the health system. There were no attempts to include the health care workers who staff the health care system and the policy makers or the counsellors who delivered the intervention. Second, the study applied only in-depth interviewing as the data collection tool. Third, the evaluation of the intervention impact on linkage to care was carried out after a 6-month follow-up. Linkage to care is a process where one is required to test for HIV, receive, and accept HIV positive results and then process the decision to link to care or not. Such a decision is made in an environment involving other players (disclosing to significant others, alternative health systems) who might discourage linkage to care through stigma, threatening/exerting violence, and/or promotion of alternative medicine. Besides this, individuals take different routes to link to care. While some easily navigate through the linkage to care stages others take more time and may struggle to overcome barriers to care.

Conclusion

Successful scale-up of linkage to HIV care interventions that are shown to be effective in research studies will require a comprehensive understanding of how they work, as well as understanding their limitations. This study demonstrated how follow-up counselling, an increasingly used linkage strategy, promoted linkage to care through promotion of positive living, provision of accurate information about HIV and HIV care services, and empowering identified PLHIV persons to overcome stigma. The study also highlighted the limitations of the counselling intervention and the need for more linkage to care interventions.

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Ethical approval

All information about the study was provided in the trial protocol and informed consent documents. The protocol and informed consent documents were approved by the Uganda Virus Research Institute Research Ethics Committee (reference number: GC/127/14/12/491), the London School of Hygiene & Tropical Medicine Ethics Committee (reference number 8833), and the Uganda National Council for Science and Technology (reference number HS 1732). Written informed consent was obtained from each participant. The trial was registered at ClinicalTrials.gov (NCT02497456).

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