



Feasibility of a Pilot Communication Intervention to Promote Linkage to HIV Clinic After Routine HIV Testing in Nakivale Refugee Settlement in Uganda

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Scholarly Report, Harvard Medical School

Date: 1 March 2017

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Scholarly Report Title: Feasibility of a pilot communication intervention to promote linkage to HIV clinic after routine HIV testing in Nakivale Refugee Settlement in Uganda

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Feasibility of a pilot communication intervention to promote linkage to HIV clinic after routine HIV testing in Nakivale Refugee Settlement in Uganda

Background: In Nakivale Refugee Settlement, 54% of newly diagnosed HIV-infected clients link to HIV clinic. We evaluated the efficacy of a communication intervention on linkage to care.

Methods: From November 2014-July 2016, clients undergoing HIV testing in Nakivale were offered a communication intervention. Mobile phone access was required to participate. Enrolled clients were phoned weekly (up to 3 calls/week) to encourage clinic attendance; clients who could read also received weekly text message reminders. The primary outcome was an initial HIV clinic visit within 90 days. We used two-sample t test with equal variances and Pearson's chi-square test to evaluate characteristics of those willing to participate.

Results: Of 5,586 clients undergoing HIV testing, 2,901 (52%) were willing to participate in the communication intervention. Willingness to participate was higher among males than females (67% vs 37%, $p < 0.001$), Ugandan nationals than refugees (58% vs 49%, $p < 0.001$); and those living closer than further to clinic (average time to clinic 49min (CI 48-51) vs. 68min (CI 66-70), $p < 0.001$). Of those who did not participate, 2,470 (92%) reported the reason was lack of phone access. Of 209 HIV-infected clients, 102 (49%) eligible individuals participated; 48 (47%) were literate and received text messages. There was no difference in linkage to clinic within 90 days of HIV testing between the intervention and non-intervention groups (49% vs 51%, $p = 0.973$). Excluding clients who linked prior to the intervention ($n = 81$), there was a trend toward increased linkage in the intervention group (61% vs 39%, $p = 0.162$).

Conclusion: In Nakivale Refugee Settlement, males, Ugandan nationals and those living closer to clinic were more willing to participate in a communication intervention. Poor access to phones limited enrollment. Low literacy among participants restricted use of text messages. Nonetheless, the pilot communication intervention suggested a trend toward improved linkage to an initial HIV clinic visit.

Student Role:

I travelled to Uganda during my first year to help design the project.

I spent six weeks:

- 1) Meeting with partners: Medical Teams International (MTI) who runs the health programs at the Nakivale Refugee Settlement; UNHCR; and the Community Advisory Board (a group of representatives from each of the countries present in the Settlement – Democratic Republic of the Congo, Somalia, Rwanda, and Burundi).
- 2) Creating the tools necessary to gather data – operations manual; phone call and text message scripts; timelines and flow diagrams; phone call collection database.
- 3) Aiding in the training and hiring of participants involved in data collection.

After development of the project, data collection continued over the next year and a half. This data collection was done by refugee research assistants, whom I met with during my time in Uganda. While there, I presented the operations manual and scripts so that the research assistants would be prepared to implement the intervention. After the data collection was complete, and with input from statisticians and my mentor, I analyzed the data and wrote the manuscript.

A pilot phone call and text message intervention to promote linkage to HIV clinic after routine HIV testing in Nakivale Refugee Settlement in Uganda

Introduction

Approximately 26 million HIV-infected individuals live in sub-Saharan Africa (1). Antiretroviral therapy (ART) can markedly reduce morbidity and mortality, slowing the progression of the disease and reducing transmission. However, poor adherence to ART can result in drug resistance and treatment failure. Currently, substantial attrition across the HIV care cascade exists worldwide - less than 50% of HIV-infected individuals are on antiretroviral therapy (1). Many patients experience difficulties in adhering to ART. This is particularly true for populations living in low resource settings including refugees, some of whom lack access to healthcare, face food insecurity, stigma, and supply shortages (2). In Nakivale Refugee Settlement only 54% of newly diagnosed HIV-positive clients link to HIV clinic within 3 months of diagnosis, and only 6% are initiated on ART (3).

Both the World Health Organization and UNAIDS have made it a priority to encourage the use of new technology in resource-limited healthcare settings, such as Nakivale Refugee Settlement (4, 5). Cell phone technology is often the primary source of communication in these settings (6). It has been used in numerous studies to enhance communication between the health care providers and HIV-infected clients (7). Two studies in rural Uganda found that overall phone access was high, privacy and confidentiality concerns rarely deterred participation (8), and mobile phone interventions resulted in a significant increase in adherence for patients who missed appointments (9). In particular, inexpensive text message reminders have been shown to be acceptable and effective, leading to an increase in ART adherence (10, 11, 12, 13, 14). A study on improving HIV clinic visits for HIV-positive children in Cameroon found that phone calls, text messages, and phone calls with text messages all improved clinic attendance (15).

We developed a communication intervention for newly diagnosed HIV-infected clients to improve linkage to care in a refugee settlement. This study explores who in a refugee setting can participate in an intervention of phone calls and text messages, and the efficacy of such communication tools in improving clinic attendance.

Methods

Site and Subject Selection:

Run by United Nations High Commissioner for Refugees (UNHCR) and established in 1960, the Nakivale Refugee Settlement hosts 68,000 refugees in southwest Uganda. In 2014 when the study began, the population living in Nakivale originated from a number of different countries; the Democratic Republic of the Congo represented 54% of the refugees in the Settlement, Somalia 17%, Rwanda 14%, Burundi 13%, and Eritrea, Ethiopia, Sudan, South Sudan, Kenya, Tanzania, and Liberia represented the remaining 2%. Though not given land ownership rights permitting them to live within Nakivale, Ugandan nationals have been reported to live illegally within the Settlement, as well as travel to the Settlement for work and personal reasons. Clients were enrolled at the Nakivale Health Center, which included both refugees and local Ugandan nationals living in and around the settlement. Operated by the non-governmental organization Medical Teams International, the health center offers free HIV testing, CD4 counts, and ART for eligible clients. Clients may also access pre-ART services at four satellite clinics throughout the settlement.

Eligibility criteria included adults of age 18 years or older, capacity to give informed consent in English, Kinyarwanda, Runyankore, or Kiswahili, not known to be HIV-infected, and access to a phone.

Study Outcomes:

The aim of the study was to develop and evaluate a communication intervention using phone calls and text messages. The primary outcome was linking newly diagnosed HIV-infected clients to HIV clinic for an initial appointment within 90 days. Additionally, the acceptability and feasibility of the intervention was assessed by evaluating willingness to participate among eligible individuals and HIV-infected individuals.

Data Collection:

From November of 2014 to July of 2016, counselors with experience in community health work enrolled adults in the waiting area of the Outpatient Department at the Nakivale Health Center.

The counselors offered free HIV testing for all eligible adults. Prior to receipt of their HIV test result, clients were asked if they would be willing to participate in a follow-up communication intervention if found to be HIV-positive. All clients were surveyed to obtain demographic information, including contact information, date of birth, gender, country of origin, marital status, education level, and distance to clinic. Enrolled clients were also asked why they agreed to participate.

Newly diagnosed HIV-positive clients enrolled in the intervention were contacted within 2-5 days by phone to encourage HIV clinic attendance. The personal phone calls were conducted by a research assistant trained in HIV counseling who could answer questions about HIV/AIDS and stress the importance of enrolling in care at the HIV clinic. Literate clients also received weekly text message reminders, after consenting to receiving written information regarding clinic information on their personal phone. For all calls, the identity of the client was verified by checking full name and age. Participants who were not initially reached by phone were contacted three consecutive times. If three attempts were not successful, they were contacted again weekly if they still had not presented for care. After three consecutive months, the participant was considered to have not linked to care. Data elements were obtained prospectively on a weekly basis from written clinical registers in Nakivale Clinic, and in the four satellite clinics where pre-ART services are offered.

Statistics:

Participant characteristics were reported as frequencies (percents) or means (with confidence intervals), as appropriate. We used Pearson's chi-square test to evaluate characteristics of willingness to participate and to compare enrolled HIV-positive clients to those not enrolled. Two-sample t test with equal variances was used to compare between means. Two-tailed values were considered statistically significant if the p-value was less than 0.05. Statistical analyses were performed using SAS 9.4 (Cary, NC, USA) and r version 3.1.1 (www.r-project.org).

Results

Of 5,586 clients undergoing HIV testing, 2,901 (52%) were willing to participate in the communication intervention. The majority of the participants were male, refugees, lived in Nakivale, with an average age of 30 (CI 30-31), currently married, had not attended secondary school, and traveled to clinic by foot. Of those who did not participate, 2,470 (92%) reported the reason was lack of phone access.

Table 1 presents baseline characteristics of the eligible participants and demonstrates the proportion of those willing to participate within each demographic. Willingness to participate was higher among males than females (67% vs. 37%, $p < 0.001$) and among Ugandan nationals than refugees (58% vs. 49%, $p < 0.001$). Those participants living closer to clinic were more likely to participate; the average time to clinic for those who participated was 49min (CI 48-51) vs. 68min average time to clinic (CI 66-70) for those who did not participate ($p < 0.001$).

Of the 209 newly diagnosed HIV-infected clients, 102 (49%) were willing to participate. Of the participants, 48 (47%) were literate and received text messages. For HIV-infected clients, willingness to participate was not significantly different by gender ($p = 0.257$), but was significantly higher among Ugandan nationals than refugees (56% vs. 34%, $p = 0.003$), (Table 2). Those who lived closer to clinic were more likely to participate than those who lived farther away, with an average travel time of 55min (CI 47-63) for those who participated vs. 72min (CI 61-83) for those who did not ($p = 0.013$).

There was no significant difference in linkage to an initial clinic visit within 90 days of HIV testing between the intervention and non-intervention groups (49% vs. 51%, $p = 0.973$). However, 37% of HIV-infected clients linked to care on day 0, before the intervention could take place.

Excluding clients who linked prior to the intervention ($n = 81$), there was a trend toward increased linkage in the intervention group (61% vs 39%, $p = 0.162$).

The most common reasons for testing among all eligible participants were “want to know” (98%), “convinced by advertisements” (23%), and “feeling sick” (6%). The most common reasons for testing among HIV-infected individuals were “want to know” (96%), “convinced by advertisements” (21%), “feeling sick” (22%), and “if I am HIV-infected, I want to start taking HIV medications” (6%).

Discussion

At Nakivale Refugee Settlement, the majority (52%) of clients undergoing HIV testing were willing and eligible to participate in a communication intervention that consisted of phone calls and text messages. Males, Ugandan nationals, and those who lived closer to clinic were more willing to participate. However, 92% of those who did not participate cited lack of phone access as the reason; thus, males, Ugandan nationals, and those closer to clinic are more likely to have phones and more likely to benefit from any communication intervention that uses mobile phone based reminders.

This pilot communication intervention demonstrated a trend toward improved linkage to an initial HIV clinic visit for participants who did not immediately link to clinic after diagnosis. Because the majority of newly diagnosed HIV-infected patients were walked to their first clinic appointment directly from the testing area, most patient linked to care before the intervention was implemented. After excluding these individuals, the power of the study indicated a trend and not a statistically significant benefit of the intervention for a first visit. Additional research is needed to assess whether retention is improved by such communication interventions. Furthermore, non-clinic testers, such as home-based testers, may benefit more greatly from communication interventions since these testers will not link to clinic the day of testing.

Given the resource constraints of a refugee settlement, it may be tempting to rely on cost-effective text messages as the primary method of mobile communication, especially in light of previous studies in sub-Saharan Africa (7, 9, 10, 11) which indicate text messaging is efficacious in enhancing adherence to ART. However, it is worth noting that the majority (53%) of the participants in this study were illiterate and unable to benefit from text message support. While not the most efficient method, combining phone calls with text messages is likely the most effective in this setting. Another viable option might be to incorporate automated voice messages instead of text messages to overcome literacy barriers while keeping costs to a minimum.

Our study should be viewed in the context of certain limitations. In addition to low literacy restricting the use of text messages, poor access to phones also limited enrollment. Future studies may consider offering cell phones to HIV-infected clients. The study population was drawn from one refugee site in southwest Uganda, which may not be wholly representative of other refugee populations. Future studies on mobile phone interventions, especially when using text messages that can be read by other parties, should be cognizant of breach of privacy

concerns. Participants in low resource settings often share phones, and discussion of the consequences of contacting a participant through phone messages should be clarified during the consent process.

As HIV-testing and ART become increasingly available in sub-Saharan Africa, promoting ART adherence is the next step in halting the progression of the disease. In a refugee setting with no hand-delivered mail, landlines, or internet access, mobile phone calls and text messages help improve interaction between health care providers and patients. Use of phone technology is acceptable and feasible among refugees, and shows promise in improving linkage to HIV clinic care among HIV-positive patients in a refugee setting.

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Tables

Table 1. Baseline characteristics of eligible participants and proportion of those willing to participate within each demographic

Variable	Overall (N=5586) % (n/N)	Willing to Participate / Total n in each category	P-value*
Gender			<0.0001
Female	51.1% (2851/5580)	37.4% (1067/2851)	
Male	48.9% (2729/5580)	67.2% (1833/2729)	
Age category			<0.0001
18-19	10.9% (607/5586)	38.6% (234/607)	
20-24	24.0% (1340/5586)	54.9% (735/1340)	
25-29	20.1% (1124/5586)	55.6% (625/1124)	
30-34	15.2% (846/5586)	55.9% (473/846)	
35-39	10.6% (594/5586)	53.0% (315/594)	
40-44	7.5% (418/5586)	50.5% (211/418)	
45-49	5.1% (283/5586)	56.2% (159/283)	
≥50	6.7% (372/5586)	39.8% (148/372)	
Missing	0.04% (2/5586)	50.0% (1/2)	
Refugee Status			<0.0001
Refugee	67.1% (3737/5572)	49.0% (1830/3737)	
National	32.9% (1835/5572)	58.1% (1066/1835)	
Live in Nakivale			<0.0001
Yes	85.1% (4752/5586)	50.2% (2383/4752)	
No	14.6% (816/5586)	63.4% (517/816)	
Missing	0.3% (18/5586)	5.5% (1/18)	
Country of origin			<0.0001
Uganda	33.1% (1848/5586)	57.9% (1069/1848)	
Rwanda	26.2 % (1466/5586)	36.8% (540/1466)	
DRC	21.3% (1191/5586)	59.7% (711/1191)	
Burundi	16.8% (940/5586)	51.4% (483/940)	
Somalia	0.9% (50/5586)	78.0% (39/50)	
Eritrea	0.2% (11/5586)	100.0% (11/11)	
Ethiopia	1.0% (55/5586)	74.6% (41/55)	
Sudan	0.1% (5/5586)	80.0% (4/5)	
Other	0.0% (2/5586)	50.0% (1/2)	
No Response	0.0% (1/5586)	0.0% (0/1)	

Variable	Overall (N=5586) % (n/N)	Willing to Participate / Total n in each category	P-value*
Missing	0.3% (17/5586)	11.8% (2/17)	
Relationship status			<0.0001
Currently Married	59.2% (3306/5586)	48.4% (1600/3306)	
Never Married	27.3% (1525/5586)	63.4% (967/1525)	
Divorced/separated	10.2% (569/5586)	44.6% (254/569)	
Widowed	2.2% (120/5586)	39.2% (47/120)	
Not married, living with partner	0.8% (42/5586)	64.3% (27/42)	
No response	0.1% (3/5586)	33.3% (1/3)	
Missing	0.4% (21/5586)	23.8% (5/21)	
Education			<0.0001
No school	15.3% (854/5586)	27.3% (233/854)	
Some primary school	43.2% (2411/5586)	43.3% (1043/2411)	
Completed Primary School	15.5% (865/5586)	59.9% (518/865)	
Some Secondary School	15.0% (840/5586)	72.6% (610/840)	
Completed Secondary School	5.2% (291/5586)	81.1% (236/291)	
Some Vocational School	0.2% (12/5586)	83.3% (10/12)	
Completed Vocational School	0.3% (19/5586)	73.7% (14/19)	
Some Certificate Program	0.5% (25/5586)	68.0% (17/25)	
Completed Certificate Program	1.4% (77/5586)	89.6% (69/77)	
Some Bachelors	1.6% (87/5586)	86.2% (75/87)	
Completed Bachelors	1.4% (76/5586)	90.8% (69/76)	
Some Post Graduate	0.1% (6/5586)	50.0% (3/6)	
Completed Post Graduate	0.1% (4/5586)	50.0% (2/4)	
No response	0.0% (1/5586)	0.0% (0/1)	
Missing	0.3% (18/5586)	11.1% (2/18)	
Mode of Transportation			<0.0001
By foot	66.5% (3715/5586)	47.3% (1757/3715)	
Public bicycle	0.2% (9/5586)	66.7% (6/9)	
Private bicycle	9.2% (516/5586)	50.4% (260/516)	
Public boda boda	16.0% (894/5586)	61.7% (552/894)	
Private boda boda	4.9% (274/5586)	75.9% (208/274)	

Variable	Overall (N=5586) % (n/N)	Willing to Participate / Total n in each category	P-value*
Taxi	1.5% (81/5586)	64.2% (52/81)	
Private car	0.7% (38/5586)	86.8% (33/38)	
NGO car	0.8% (42/5586)	73.8% (31/42)	
Missing	0.3% (17/5586)	11.8% (2/17)	

Note: Denominators vary due to participant non-response

Abbreviations: DRC: Democratic Republic of the Congo; NGO: Non-profit organization

* P-value based on Pearson's chi-square test.

Table 2. Baseline characteristics of HIV Positive Participants and proportion of those willing to participate within each demographic

Variable	Overall (N=209) % (n/N)	Willing to Participate / Total n in each category	P-value*
Gender			0.257
Female	58.9% (123/209)	45.5% (56/123)	
Male	41.1% (86/209)	53.5% (46/86)	
Age category			Not calculated
18-19	4.8% (10/209)	40.0% (4/10)	
20-24	19.6% (41/209)	51.2% (21/41)	
25-29	21.5% (45/209)	57.8% (26/45)	
30-34	20.6% (43/209)	48.8% (21/43)	
35-39	9.1% (19/209)	42.1% (8/19)	
40-44	9.6% (20/209)	55.0% (11/20)	
45-49	6.7% (14/209)	50.0% (7/14)	
≥50	8.1% (17/209)	23.5% (4/17)	
Refugee Status			0.003
Refugee	31.3% (65/208)	33.9% (22/65)	
National	68.8% (143/208)	55.9% (80/143)	
Live in Nakivale			0.077
Yes	67.9% (142/209)	54.9% (78/142)	
No	31.1% (65/209)	41.5% (27/65)	
Missing	1.0% (2/209)	100.0% (2/2)	
Country of origin			0.087
Uganda	68.9% (144/209)	54.9% (79/144)	

Variable	Overall (N=209) % (n/N)	Willing to Participate / Total n in each category	P-value*
Rwanda	14.4 % (30/209)	33.3% (10/30)	
DRC	8.6% (18/209)	38.9% (7/18)	
Burundi	6.7% (14/209)	35.7% (5/14)	
Eritrea	0.5% (1/209)	100.0% (1/1)	
Missing	1.0% (2/209)	0.0% (0/2)	
Relationship status			0.049
Currently Married	55.5% (116/209)	55.2% (64/116)	
Never Married	11.0% (23/209)	47.8% (11/23)	
Divorced/separated	25.8% (54/209)	38.9% (21/54)	
Widowed	5.3% (11/209)	27.3% (3/11)	
Not married, living with partner	1.4% (3/209)	100.0% (3/3)	
Missing	1.0% (2/209)	0.0% (0/3)	
Education			<0.0001
No school	24.4% (51/209)	23.5% (12/51)	
Some primary school	47.9 % (100/209)	49.0% (49/100)	
Completed Primary School	12.9% (27/209)	74.1% (20/27)	
Some Secondary School	8.6% (18/209)	77.8% (14/18)	
Completed Secondary School	4.3% (9/209)	55.6% (5/9)	
Some Certificate Program	0.5% (1/209)	100.0% (1/1)	
Completed Bachelors	0.5% (1/209)	100.0% (1/1)	
Missing	1.0% (2/209)	0.0% (0/2)	
Mode of Transportation			0.001
By foot	48.8% (102/209)	35.3% (36/102)	
Public bicycle	0.5% (1/209)	100.0% (1/1)	
Private bicycle	6.7% (14/209)	57.1% (8/14)	
Public boda boda	30.6% (64/209)	70.3% (45/64)	
Private boda boda	9.6% (20/209)	55.0% (11/20)	
Taxi	2.4% (5/209)	20.0% (1/5)	
Private car	0.5% (1/209)	0.0% (0/1)	
Missing	1.0% (2/209)	0.0% (0/2)	

Note: Denominators vary due to participant non-response

Abbreviations: DRC: Democratic Republic of the Congo

* P-value based on Pearson's chi-square test.