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Authors

Maeri, Irene

Eyul, Patrick

Getahun, Monica

et al.

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Nothing about us without us: Community-based participatory research to improve HIV care for mobile patients in Kenya and Uganda

Irene Maeri^{a,*}, Patrick Eyul^b, Monica Getahun^c, Khalela Hatchett^d, Lawrence Owino^a, Cecilia Akatukwasa^b, Harriet Itiakorit^b, Sarah A. Gutin^g, Jason Johnson-Peretz^c, Sarah Ssali^e, Craig R. Cohen^c, Elizabeth A. Bukusi^a, Moses R. Kanya^{b,f}, Edwin D. Charlebois^g, Carol S. Camlin^{c,g}

^aCentre for Microbiology Research, Kenya Medical Research Institute, Nairobi, Kenya

^bInfectious Diseases Research Collaboration, Kampala, Uganda

^cDepartment of Obstetrics, Gynecology & Reproductive Sciences, University of California San Francisco, San Francisco, USA

^dDepartment of Community Health Sciences, University of California Los Angeles, Los Angeles, USA

^eSchool of Women and Gender Studies, Makerere University, Kampala, Uganda

^fSchool of Medicine, Makerere University, Kampala, Uganda

^gDepartment of Medicine, Center for AIDS Prevention Studies, University of California San Francisco, San Francisco, USA

Abstract

Background: Population mobility is prevalent and complex in sub-Saharan Africa, and can disrupt HIV care and fuel onward transmission. While differentiated care models show promise for meeting the needs of mobile populations by addressing care cascade gaps, the voices of mobile populations need to be included when designing care delivery models. Moreover, mobile individuals are faced with care challenges such as non-adherence to clinic appointments and HIV medication, poor referral systems, lack of social support, stigma, and non-disclosure that complicate their health outcomes. Mobility includes not only permanent migration but patterns of movement from place to place by mobile populations. We assessed the unmet needs of mobile populations and engaged mobile stakeholders in the design and implementation of service delivery to improve care outcomes for mobile people living with HIV (PLHIV). Involving mobile community stakeholders in community-based participatory research (CBPR) demonstrated that it is a powerful tool for engaging communities in designing services responsive to the needs and priorities of mobile populations.

*Corresponding author. Kenya Medical Research Institute, Centre for Microbiology Research, RCTP P.O. Box 614 - 40100, Kisumu, Kenya. imaeri@kemri-rctp.org (I. Maeri).

DECLARATION OF INTERESTS

We declare no competing interests.

Methods: CBPR was conducted in 12 rural communities in Kenya and Uganda participating in a mobility study within the Sustainable East Africa Research in Community Health (SEARCH) test-and-treat trial (NCT# 01864603) from 2016–2019. Annual gender-balanced meetings with between 17–33 mobile community stakeholders per meeting were conducted in local languages to gather information on mobility and its influence on HIV-related outcomes. Discussions were audio-recorded, transcribed and translated into English. Findings were shared at subsequent meetings to engage mobile stakeholders in interpretation. At three years of follow up, intervention ideas to address mobile populations’ needs were elicited. After refinement, these intervention options were presented to the same communities for prioritization the following year, using a participatory ranking approach.

Results: Key nodes where population mobility patterns intersect with one another were identified as desirable service locations. These nodes included transit hubs, trading centers, and beach sites. Communities prioritized mobile health ‘cards’ (to access services at multiple health facilities) with electronic medical records and peer-delivered home-based services. Mobile health clinics, longer anti-retroviral pill refills, and 24/7 services were less desirable options. Elicited challenges to care included: a lack of transfer letters to other clinics; and inability to adhere to scheduled appointments, medication regimens, and monitoring of treatment outcomes while mobile. This was compounded by the lack of social support and HIV-related stigma if care services were accessed when traveling to new communities.

Conclusions: Iterative discussions with mobile community stakeholders elicited communities’ health priorities and identified challenges to achieving HIV care cascade outcomes among mobile populations. To optimize HIV interventions and create more robust healthcare systems, understanding the mobility patterns and unique needs of mobile populations through responsive community engagement is critical. Simple iterative voting by the affected community on preferred interventions is one model to achieve this engagement.

Keywords

Community Based Participatory Research; HIV care; mobility; mobile populations; differentiated care; Kenya; Uganda

BACKGROUND

Annually, mobile individuals are faced with care and treatment barriers due to their mobility [1]. Population movement patterns such as rural-urban, urban-rural and circular migration flows (e.g. traders moving to different towns to buy/sell stock before returning home), collectively termed ‘mobility patterns’, contribute to losses at each step of the HIV care cascade, which are steps that people living with HIV (PLHIV) go through from learning their HIV status to achieving and maintaining viral suppression through care and treatment [1, 2, 3]. Further, concurrent sexual partnerships among this population remains a social feature which challenges the global effort to end the HIV epidemic, since without adequately maintained HIV treatment, concurrent sexual partnerships can fuel HIV transmission [1,3,4,5,6,7]. To date, in-depth population-specific needs assessments for HIV care adaptations within mobile populations have received limited attention [2,8]. It is critical

to include mobile populations in research to identify population-appropriate HIV care and treatment solutions.

While tremendous success in HIV prevention and antiretroviral (ARV) treatment coverage has continued to advance, the epidemic is still concentrated in sub-Saharan Africa (SSA) where in 2019 roughly 25% of new infections were among members of key populations, such as mobile individuals and their sexual partners [9, 10]. Access to care and treatment for mobile populations is challenging, as mobility disconnects individuals from established care systems. Mobile individuals often face disruptions in ARV treatment due to the challenges of obtaining transfer letters to other clinics [11,12], the experience of poor retention in HIV care or loss to follow up, and by developing drug resistance and resultant surges in viral load, any one of which can lead to poor health outcomes and higher HIV-related mortality [1,4,13–14]. The distance traveled by mobile clients for HIV care, non-disclosure of HIV status, and experiences of HIV stigma while mobile further complicate care engagement [14].

Migrants and mobile populations are a recognized key population for HIV prevention activities within the global AIDS response [15–16]. However, a focus on scaling up HIV prevention and ARV coverage among key populations has only been achieved in easier to reach populations [1, 17–18]. Without focused attention on hard to reach populations such as mobile PLHIV, the attainment of UNAIDS 95–95–95 goals for treatment (95% of PLHIV learning their HIV status, 95% of PLHIV enrolling in ARV treatment, 95% of PLHIV on ARVs reaching viral suppression) may remain out of reach by 2030 [19].

Health researchers have applied community-based participatory research (CBPR) to improve health outcomes by addressing health disparities through community empowerment [20–23]. CBPR is a participatory approach that includes both the community members and researchers in all phases of the research process. These partners share in the decision-making and ownership of the research process, and each partner's expertise is acknowledged. CBPR endeavors to enhance knowledge with action to achieve societal transformation that aims to eradicate health inequalities by expanding health outcomes that are beneficial to community members [24]. This approach is critical to improving health among marginalized, underserved, and vulnerable communities [25–26]. The existence of mutual respect and trust, capacity building, empowerment and ownership in participatory research approaches distinguishes it from non-participatory collaborative or action-oriented research. Involving community members in identifying and suggesting solutions to HIV care challenges has the potential to produce more relevant, successful, and impactful interventions [20–23]. As mobile populations are underserved and vulnerable to heightened HIV risk and care engagement disruptions, establishing mutual respect and trustworthy relationships is essential to addressing the social and health conditions of mobile populations [27–28].

While most CBPR approaches to resolve HIV intervention gaps have been applied in the United States, resource limited countries, particularly eastern African countries, are lagging behind on using CBPR to address HIV cascade gaps, especially with mobile populations. In North Carolina, USA, CBPR was employed to pilot CyBER/testing, a culturally congruent

intervention designed to increase awareness, reduce HIV risks, and promote HIV testing among men who have sex with men (MSM) within existing Internet chat rooms. As a result, more chatters tested for HIV, something that ordinarily was difficult to achieve with traditional HIV prevention interventions [29]. This pilot test illustrated the fundamental role partnership with community members played in ascertaining the feasibility and significance of the intervention. Project Salud also engaged migrant communities in Miami-Dade County (USA) in a CBPR to culturally adapt an HIV prevention intervention in the Latino migrant worker (LMW) community. It not only demonstrated the willingness of LMW to be included in an HIV prevention intervention, but also underscored the significance of LMW participation in an intervention that is culturally relevant, respectful, and responsive to their lived experiences [30]. Further, the CBPR approach was used to develop and implement church-based HIV interventions with African-American churches in Kansas City (USA). The approach capitalized on the input of the church community in assessing their HIV testing and awareness-needs to shape the intervention strategies that led to the project's acceptability by the wider church community [31].

Our study employed a CBPR approach with mobile community stakeholders to: (a) gather information about mobility and its associated challenges in communities from their perspectives and personal experiences; (b) involve them annually in interpreting study findings; and (c) in the final year of the study, work collaboratively to develop plans based on those findings for HIV prevention and care interventions which address the needs of mobile populations.

METHODS

We conducted qualitative community-based participatory research in 12 communities in western Kenya, eastern & south-western Uganda, embedded within the five-year study "Understanding Mobility and Risk in SEARCH Communities (R01MH104132), in a universal test and treat trial" (NCT# 01864603).

Sampling

Mobile community stakeholders sampled from 12 communities (n=6 in Kenya and n=6 in Uganda) were purposively sampled from various mobile groups: fisherfolk, transport sector workers (*boda boda/motorcycle and truck drivers*), artisanal gold miners, sex workers, traders, religious leaders, pastoralists, youth, and other opinion leaders, including community health extension officers and village elders. The study team together with mobile community stakeholders were involved in all phases of research between 2016 and 2019 as shown in image 1.

Data collection

During each year of the research period (2016–2019), a team of eight researchers trained in qualitative research methods facilitated gender-balanced community discussions with between 17 to 33 community members from each community (Image 1). Due to the mobile nature of the community members, their participation in subsequent community meetings was highly unlikely. The study therefore maintained in all meetings at least three to five

community members that acted as key mobilizers for subsequent community discussions. Thus each year, the community engagement meetings involved a mix of some previous members and a majority of new members. Further, the study team created good rapport with local opinion leaders and that helped to maintain links to the participants.

Prior to the start of community meetings, the study staff engaged opinion leaders in key informant interviews to gain context about each community, including the role of mobility as well as to identify key individuals from mobile populations to engage for the community meetings. Engaging these leaders allowed the study to explore each community's problems, strengths, weaknesses, and people community members turn to for guidance. While taking into considerations each communities' social and cultural aspects, the information contributed heavily in designing the CBPR tool and it further assisted in identifying key mobilizers for the community engagement activities. The CBPR explored the typology of mobile groups, mobility patterns, forces driving mobility, destinations or transit hubs, consequences of mobility, mobility-related health challenges and in the fourth year, the solutions to the challenges. The study team encouraged partnership throughout the CBPR process such that community members were involved in identifying mobility challenges, solutions to these challenges, and in applying these solutions to establish tailored intervention options. These ongoing partnerships strengthened trust and the relationship between the study team and the community members throughout the study period. Rather than obtaining individual informed consent, attendees gave verbal consent to participate and to be recorded prior to start of the discussions. Semi-structured guides were used during community discussions that lasted between 2–3 hours. The discussions were audio recorded, transcribed, and translated into English.

During the first three annual meetings, researchers facilitated discussions that explored population mobility and its associated HIV care challenges. Data collection summaries from each annual meeting were translated into local languages for discussion in the subsequent meetings. Researchers together with mobile community stakeholders carefully examined summaries from each annual meeting to confirm if the previous discussants gave a true reflection of the community's perspectives. Case studies from the community discussions were shared with and validated by the mobile community stakeholders. During the first three years of the study (2016–2018) discussion guide prompts focused on mobility-related health challenges, identified care challenges faced by mobile clients, and ways that service delivery could be improved. The investigators and study team members reviewed and synthesized the literature on service delivery models and interventions, integrating some of the community members' ideas that included; stationing mobile clinics at transit hubs, interfacility data linkage (i.e. sharing data between facilities), services offered between 8am to 5pm to accommodate more people, treating co-morbidities, mobile health cards to be used in any clinic, health education, and homebased services, among others. The study team refined these ideas to a set of five distinct service delivery care models. These included a mobile health 'card' that could be used to access services at multiple facilities, community-based health worker/peer-delivered services, mobile health clinics, longer ARV refills/more ARV pills, and '24/7' and/or moonlight (after-hours) services.

During year four of the study (2019), the service delivery care models (Figure 1 to 5) were presented to the mobile community stakeholders for a rigorous voting exercise, with the aim of identifying the most preferred intervention options to meet the care needs of mobile persons living with HIV.

Voting procedure

Mobile community stakeholders present at the final annual meeting identified their preferred intervention options through a voting exercise. Five intervention options to choose from were displayed on the wall (as shown in Fig.1 to 5). Mobile community stakeholders selected their three most preferred intervention options in three rounds of mutually exclusive voting. That is, in each round of voting, community members were given one voting card to select one preferred option (Image 2). The votes were counted and tallied to establish the most desired option at the end of each voting round. The intervention option with the most votes was acknowledged as the mobile community stakeholders' top preference in each round, and then removed from subsequent voting options.

Ethical approval

Ethical approval was obtained from Makerere University School of Medicine Research and Ethics Committee (2015–040), the Kenya Medical Research Institute (KEMRI/SERU/CMR/3052), the Uganda National Council for Science and Technology (HS 1834) and the University of California, San Francisco Committee on Human Research (14–15058). Permission was also obtained from the sites where the study was conducted. Informed consent forms were signed by the participants and appropriate measures were undertaken to ensure confidentiality.

RESULTS

Care challenges

The discussions held in each successive year of the engagement meetings confirmed that care challenges for mobile individuals were similar and consistent across regions. Thus, each year, new discussants voiced care challenges similar to the ones discussed in previous engagement meetings. The study therefore established that personal, community, and health factors complicate care access for mobile individuals. Non-adherence to clinic appointments and HIV medication were found to be common among this group. This was further exacerbated by poor referral systems and unfavorable clinic hours when mobile. These challenges threaten the ability of mobile populations to be retained in care and to achieve and sustain viral suppression.

“When [truck] drivers are moving, they may move with drugs [ARVs] for only 2 days but on reaching where they are going, the program changes and they have to proceed with the journey but they cannot go back home to pick more drugs -- yet they can't access ARV drugs from any other clinic. So this leads to poor clinic and medication adherence which could also end up in death.” *Community member, Uganda*

“I am seeing that sex workers may get challenges when they go to new beaches because they will lose market if they are discovered to be HIV-positive. Somebody may be getting care in Nyamrisra and she moves to Kisegi when fish is in plenty. She may take ARV drugs with her for the period she will be away, but because she cannot dictate how long fish will be available, her drugs get over before she finishes her business in Kisegi. Because she is somebody who is depending on the availability of fish she will not leave Kisegi to go back to Nyamrisra for her clinic since she may lose market while away. She will stay on without drugs because she can't go to Kisegi health centre where she might be publicly recognized and lose market. She will end up defaulting and the viral load will go up and that will risk her health.” *Community member, Kenya*

Moreover, care engagement for mobile individuals is thrown into disarray when they lack their accustomed social support while mobile:

“In families where partners have shared their HIV status there is normally support that this partner gets from the other family members when it comes to drug adherence. For example, reminding him about time for taking drugs and just ensuring that he is under treatment all the time. This support may be missed by a fisherman who keeps on moving from one beach to another and lacking family support may make him not to maintain care and treatment.” *Community member, Kenya*

“For those who get care support from Community Health Workers (CHWs), they miss the care whenever they move to other places where there are no CHWs. Gaining trust of new CHW in the new place will be hard; hence they lose a treatment buddy. With no treatment buddy, their HIV care and treatment is usually disrupted.” *Community member, Kenya*

Similarly, anticipated HIV stigma and non-disclosure while in transit to new communities exacerbate care access for this group, posing challenges for linkage to care, receiving and being retained in HIV care and maintaining viral suppression.

“I am a fisherman; I have moved from Ragwe to Sena. In Sena I have found a *jaboya* [sex for fish relationship] and I have not told her that I am HIV-positive and she has also not told me that she is on ARV drugs, in case she is HIV-positive. I want to hide my drugs from her and I can't take the drugs at the right time because she is with me most of the time. Secondly, if she is not HIV-positive and one day when cleaning the house she comes across my ARV drugs, because I did not disclose to her my HIV status and she has come across my ARVs, she decides to punish me by hiding them from me. When I will come back from fishing to take my drugs, I will miss them and I will not even know where to start from. I will end up defaulting because I can't go back to the clinic before the appointed time. So the viral load will go high just because I can't share my HIV status.” *Community member, Kenya*

“Another issue is being rejected by the new community. There was a casual laborer on ARV pills but she got fired by the firm manager. The firm manager said ‘she might infect my children with HIV.’” *Community member, Uganda*

“Movement for HIV-positives results to non-disclosure. By not disclosing, this person goes without drugs and his viral load goes up as well. Again, this person may end up posing as a new tester when he finally presents himself at the clinic – thus beginning afresh in HIV treatment.” *Community member, Uganda*

Distant clinics coupled with lack of transport to and from these clinics make it harder for mobile individuals to maintain clinic appointments, affecting retention in care

“Sometimes you are taking drugs in Nyamrisra and you are schooling in Mbita and transport cost may be a problem to students who board at school; hence they end up defaulting in keeping appointments.” *Community member, Kenya*

“Many mobile individuals living with HIV die due to poor medication adherence, long distances in accessing drugs, and transport challenges. Also, challenges with transfer letters or referrals.” *Community member, Uganda*

While these individuals are on the move, they are faced with an inability to obtain transfer documents to other clinics and link to care. The referral system rarely provided options for patients who were transferring from other facilities. Most mobile people presented at clinics and newly tested in order to access care while mobile.

“There are many health related challenges faced by the HIV-positive mobile people. You travel when you are not prepared. There could be places where you can get emergency drugs [short ARV refills] but they [health providers] cannot help you because they will ask you for a transfer letter, which you won’t be having. So if you leave this place going to Gulu without a transfer letter, you won’t call this side [primary clinic] that they send it to you on a bus. They can’t send it on mail. So they will definitely ask for a transfer letter. So you end up defaulting treatment and begin thinking that you will definitely die. You lose hope.” *Community member, Uganda*

“Some HIV positive people forget their documents home when they move to a new place and when they go to get medication at the new places, they are forced to start treatment afresh; they face HIV discrimination at the new places... they face difficulty in accessing treatment from another place because of lack of referral letter. They also experience lack of counseling support and lack of treatment follow ups, poor feeding leading to drop down in CD4, and having many partners leading to many health risks.” *Community member, Uganda*

“One thing that presents a challenge to fishermen on medication adherence: it is not easy to get a referral letter to collect drugs in the nearest health facilities due to frequent movements. You move from Tom Mboya to Ringiti to Remba so many times – so you cannot get proper medication due to that movement.” *Community member, Kenya*

Monitoring one's own viral load becomes a challenge due to high levels of missed clinic visits and this may affect long term viral suppression.

“When one is under care, he is visited and monitored by providers, and when he moves to another place, all these services he will miss.... like monitoring CD4 and viral load. When he moves to another place he will miss these services, and counselors will not visit him to encourage him if he misses appointment. This person may miss the support he was even getting from the family.” *Community member, Kenya*

“There is this person called *jamapara* (fish hunter). He may carry drugs when going to hunt for fish for three days. When it accidentally drops in the lake he will miss taking it for the days he will be in the lake. A fisherman that had been enrolled in care in Sena, when he moves to a place like Remba may not come back to Sena for his appointments – especially when it is high season for fishing. For somebody who minds about his health, he may go for refill in Remba but most of them don't. Some of them go hunting for fish all the way in Uganda and even Tanzania where health policies are different from ours; hence they will just default.” *Community member, Kenya*

Finally, some expressed concern that mobile individuals intensify HIV transmission.

“I am seeing that mobility may increase HIV transmission. A sexual worker will move from here to Takawiri, from Takawiri to Lolwe, then to another island. This sex worker will end up infecting others and this will continue because she is a temporary resident in all the places she is moving to. Especially ladies who have spruced themselves, they have bleached their skin and [are] looking attractive. She will even entertain 8 men in one day.... (Laughter) she will therefore spread the infection to many people.” *Community member, Kenya*

The above care challenges resulted in voting exercises by mobile community stakeholders to rank intervention options meeting care needs of mobile patients.

Voting results and patterns in ranking intervention options

Identifying the above challenges fostered consideration of plausible intervention options for meeting the care needs of mobile patients. These options were then ranked (Table 1). The two most preferred interventions were 1) mobile health cards for use in multiple facilities or for instant referrals, and 2) community-based health workers or peer-delivered services. Longer ARV refills, mobile health clinics stationed at roaming sites, and 24/7 and/or moonlight (after hours) services received less recognition.

Regional differences were evident in the ranking patterns. Kenyan communities opted for mobile health cards, community-based health workers, and mobile health clinics, while Ugandan communities preferred community-based health workers, mobile health cards, and longer ARV refills as their top three intervention options. Similarities in ranking options within regions included 6/6 communities in Kenya and 4/6 communities in Uganda giving priority to mobile health cards. This voting pattern depicted a commonality in evaluation of

the most preferred solution to meet the care needs of mobile patients across communities within a given region.

Reasons for the preferences

1. Mobile health card (MHC)—Voting patterns revealed the most preferred option, with 10/12 communities favouring a mobile health card. The card resonated with mobile community stakeholders because it helps avert any interference with care access due to mobility patterns, promotes instant referrals and reduces the waiting time at clinics, thereby allowing mobile patients to enjoy non-interrupted ARV treatment.

“I am talking as a fisherman. The card can really help us. Sometimes we go for fishing in other islands and get stuck in certain islands when the fish stocks are high that we can't leave at that point. But you will find that one of us needs to refill his drugs. This card will really help us in two ways: one, we can conduct our fishing activities without worrying about interruption of treatment; secondly, our fishing activities will not be interrupted by frequent travels of going back [to primary clinic] for refills.” *Community member, Kenya*

Besides reducing double data entry from mobile patients posing as new HIV testers in other clinics, MHC were seen as a way to reduce anticipated HIV stigma, especially among youth who want to access care in clinics where they will not be recognized.

“The reason why I am supporting this card is because as a youth, I know that if I go for my clinic at Humanist Health Centre, I will find people who know me; so I'd rather go to a clinic that I can't be recognized. With my card I will just go to Mbita and get my drugs (ARV) where nobody will identify me... (Laughter)... It helps to reduce stigma, as no one knows where you go to get your drugs.” *Community member, Kenya*

Furthermore, the discussants applauded the card's potential to address transportation challenges when accessing care in distant clinics.

“I chose number one [MHC card] because for us mobile people; say you are in Kampala and have been getting your treatment from Mitooma [350 km away] and you have no transport to come back -- you can use your card anywhere else to access treatment.” *Community member, Uganda*

However, perceived drawbacks with MHC included the possibility that the card may be lost, and without it, access to clinics would be impossible. Discussants also suggested it could become a promoter of HIV stigma and domestic violence in circumstances where the card is identifiable.

2. Community-based health worker (peer delivered services)—Mobile community stakeholders valued the community-based health worker model since it caters specifically to offsite needs, insulating mobile patients from the structural challenges and negative provider attitudes experienced with clinic-based services.

“So working with CHWs will help us so much when they bring to us drugs at the household or places of our convenience. I can call one when my drugs are over

to bring for me instead of going to the clinic, where patients are [so] many you'd think that there was a community meeting...(Laughter). It will even encourage me to adhere to drugs even when I am feeling tired of taking drugs. The CHWs are among us and they are people we know and reaching them will be much easier."

Community member, Kenya

"Why I am supporting CHWs -- there are people who live very far from the clinics, hence they default whenever they don't have transport to visit the clinics. CHWs will therefore get drugs from the facility and because they are living near patients, will take to them drugs at home hence preventing defaulting that might have arisen because of lack of transport." *Community member, Uganda*

The counseling skills and courteous approach offered by CHWs were met with approval from discussants. CHWs provide a good support system for highly stigmatized HIV patients, strengthening ARV adherence by winning patient trust while observing concerns around privacy and confidentiality.

"... Since CHWs are good in counseling, they will support the HIV patients that could still be stigmatized. They help HIV patients to accept their status and teach them the benefits of being in ARV treatment. I have seen CHWs that have brought many defaulters back to ARV treatment. I even saw one giving a patient her own money to use as transport to his primary clinic to get a transfer letter so that his ARV treatment could continue without interruptions that would put his health at risk." *Community member, Uganda*

"CHWs know how to approach people. They talk with people very well and they know how to keep secrets. And then, we are being told that being free and open about HIV status helps you in regaining your health fast enough, thus prolonging your life. Now when a CHW brings to you drugs she will also counsel you on adherence therefore encouraging you to continue with drugs and not to default."

Community member, Uganda

Achieving success with any health intervention at the community level demands smooth community entry. CHWs understand community issues and are better placed to propose and implement feasible options to address the problems experienced by individuals in a given community.

"...There are people who may not embrace any new health idea being implemented in the community. Since the CHWs are known in the community and people tend to believe in them, any new health intervention will be embraced if it is communicated by the CHWs. A stranger cannot come to the community with a good idea that will help the community and it's just accepted easily. Unless this person is seen with a CHW when selling this idea is when the community members will embrace it."

Community member, Kenya

According to the mobile community stakeholders, this care model is restricted to non-clinical services since CHWs are not medical practitioners. The discussants also noted that seamless delivery of services through this approach can only be achieved with proper training and consistent supervision of CHWs.

3. Longer ARV refills—Some mobile community stakeholders acknowledged the comfort that longer ARV refills or more ARV pills offer to mobile patients by allowing mobile patients to conduct their economic activities without any interruption and sparing them transportation costs to and from clinics. Similarly, longer ARV refills benefit patients who experience community stigma by decreasing the frequency of clinic visits normally associated with HIV.

“Longer refills are good because movement to clinics every month is shortened. It also helps you in being free to move as much as you want especially to a fisherman. So you can move to different beaches without worries of how you will get your drugs -- more so if you are in a beach far from a health facility. It can also be bad because you might forget about your clinics and because of lack of monitoring by providers you might get other infections in the process. It is better for shorter periods to allow for proper frequent monitoring by the health providers.”
Community member, Kenya

“Presence of stigma is evident in the community – that is why longer refills would come in handy at this time. You find people going all the way to Kisumu for their clinics, so if this person is given longer refills then frequent travels to Kisumu can be curtailed and somebody will just take drugs comfortably without any stress.”
Community member, Kenya

The only disadvantage voiced by discussants about this option was its inability to support frequent monitoring of other health measures like viral load.

4. Mobile health clinic—A few communities opted for mobile health clinics because of their ‘beyond boundaries’ approach, reaching many patients who were challenged in accessing health facilities. Mobility patterns determined desirable service locations: transit hubs, market and trading centres, *boda boda/motorcycle* stations and beach landing sites. This model was therefore viewed as the most appropriate for rotating services at those places.

“Mobile clinics will make it easy for many people to reach it. Even people who are busy selling *omena* may get time to attend especially when it goes to the trading centres.” *Community member, Kenya*

“People like fishermen hardly visit health facilities, so if mobile clinic is stationed at the beaches then the fisherfolk can really benefit.” *Community member, Kenya*

“I think that if mobile clinics are many, even the market traders who may leave markets late can easily access health care services if they hear one is in their neighbourhood.” *Community member, Uganda*

Some shortfalls to mobile health services included the need for implementation resources. The rough terrain and inaccessible roads within communities were also cited as a major deterrent.

5. 24/7 or moonlight (after hours) services: Proponents of increased service hours supported the flexibility of offering care to mobile individuals, who are ordinarily busy

during the day, so as to avoid the long queues synonymous with daytime clinic services and consequent absence from livelihood work.

“I want to speak as a fisherman: I can go to fish during the day and come back in the evening at 8pm and get services -- and don't you see it's advantageous to a fisherman?” *Community member, Kenya*

“At night is when all these people will come for services. You might be shocked when you find the longest queue you have never seen... (Laughter).” *Community member, Kenya*

Nevertheless, even communities which opted for this model voiced more disadvantages than benefits. Concerns over security in the community at night (muggings), poor working conditions for providers, rape cases for teenage girls when accessing care at night, and promotion of sexual engagements among youth (youth meeting in the bushes to have sex at night away from the view of parents/adults) deterred mobile stakeholders from giving more support to this option.

“Differentiating the genuine patients and thugs at night is not easy. Thugs can therefore take advantage in the night.” *Community member, Kenya*

“It can bring rifts in marriages, my wife can lie that she is sick and going for moonlight services while she is going to see her lover... (Laughter). Again it can be a threat to the community when young girls seeking health services at night fall victims of rape. The young girls can also lie that they are going for health services while going to meet with their male partners for sexual engagements since no one can keep an eye on them at night.... Night is not very safe with adolescent girls.” *Community member, Kenya*

In order to attain maximum health benefits from these options, mobile community stakeholders emphasized the integration of intervention options. For instance, discussants suggested blending mobile health cards with longer periods between ARV refills, or the availability of all options to patients and tailored provision based on a careful evaluation of the patient's needs and ability to benefit from particular services.

DISCUSSION

This study demonstrated that CBPR successfully led to the identification of care challenges for mobile patients, and the resulting partnership between researchers and mobile community stakeholders pinpointed solutions aimed at improving care access and treatment for this population. Information gathered about mobility and its associated challenges within communities, and working collaboratively with mobile stakeholders in interpreting findings, generated intervention ideas to address the care needs of mobile populations.

Heterogeneity among mobile populations participating in this study was displayed during voting exercises for preferred intervention options. The variability in voting patterns highlighted the difficulties of accommodating competing and divergent needs between unique communities; what works in one community may not work well in another [33]. In this study, mobile health cards were strongly supported by Kenyan communities. The

ability of the card to offer instant referrals and facilitate easier care access in multiple clinics was possibly recognised by these communities given its potential to address the transfer documentation challenges mobile patients often face. In contrast, Ugandan communities mostly desired a community-based health worker option, possibly to mitigate social support challenges and stigma-related issues mobile patients there face in the communities they travel to. This variability not only highlights the capacity of each community to generate solutions for its particular care needs but also the essential role each community can play in helping public health officials decide which interventions to deploy.

By the same token, when all communities displayed uniformity in voting outcomes, the common experiences shared by all, or nearly all, mobile populations was brought to the fore. The almost across-the-board preference for the mobility health card may suggest designing certain basic structures to provide the foundation for a more robust system that addresses the needs of these communities across the board. This calls for creativity in designing care models that are culturally relevant, respectful, and responsive to lived experiences (i.e. the knowledge gained by an individual through direct encounter with a phenomena) [20]. Additionally, this study mirrors other approaches in demonstrating that community members are often interested in giving their support and playing a role in participatory approaches, ensuring interventions are tailored to their needs [29–31].

The care challenges faced by mobile populations reported in this study are consistent with other findings that report care barriers for mobile populations [1,4,11–14]. The findings reveal evidence of potential gaps in the health care system especially for mobile patients. It demonstrates that a one-size-fits-all approach is incompatible with mobile populations, who are hard to reach and often subjected to unpredictable movement timing. Further, this study corroborates other findings in confirming the complexity of obtaining transfer documentations to other clinics [11–12], underscoring the struggles that mobile patients undergo to maintain care while mobile. Poor management of this process may increasingly interrupt HIV treatment and heighten HIV care defaults. Similarly, mobile patients may progressively undertake ‘silent transfers’ or pose anew in other clinics to enable care access. Concerted efforts are needed to characterize patient transfer experiences across clinics, identify challenges encountered, and explore options to improve the process.

The destinations of mobile populations are often dictated by their livelihood needs [32]. Occasionally, movements for livelihood take them beyond the borders of their countries. This study has established that fishermen in Lake Victoria often cross borders between Kenya and Uganda to hunt for fish. This is likely to threaten continuity of care not only because of long distances from primary clinics but also because of the different health care systems practiced in the respective countries visited. Feasibility of care access across neighbouring countries is essential to support and improve care access among mobile populations that may discontinue HIV treatment whenever they find themselves in countries other than their own. Additionally, the temporary habitation associated with mobile populations in transit hubs may intensify HIV transmission when they are disengaged from HIV care, as mobility is associated with higher risk sexual behaviours [4]. It may also create difficulties in monitoring treatment outcomes such as viral loads in mobile patients. Failure to enhance virologic monitoring among mobile patients could possibly result in virologic

failure and drug resistance [1,4,13–14], again calling for implementing intervention options aligned with the movement patterns of mobile patients.

Limitations.

Although this study did not apply the techniques involved in a fully implemented CBPR, the consultative process proved vital in determining intervention options that were responsive to communities' needs. The process also provided an opportunity for mobile community stakeholder voices to be heard, and ensured that the proposed interventions were acceptable, accessible, and had the potential to create a sense of ownership and sustainability [33–35]. It showed that CBPR is a powerful tool for engaging communities when designing interventions that can yield specific improvements to reduce health disparities among the vulnerable population concerned [36–38].

Recommendations.

Interventions designed to align care engagement with livelihood mobility may influence uptake of and retention in HIV care and treatment among mobile populations [32]. Differentiated care models which integrate co-interventions [39–40] offer substantial benefits for mobile populations. Examples of co-interventions include facilitating easier care access in multiple clinics, or care access points that offer instant referrals with the provision of more ARV pills, or peer-led models which factor in desired service locations. Since mobility patterns include seasonality, travel routes significantly determine desired HIV service locations. Participatory research has the potential to generate such tailored interventions integrated according to community priorities and thereby empower communities to determine their destiny in regards to HIV care programs.

Similarly, strategies safeguarding mobile populations from HIV stigma and discrimination while mobile [3] ought to be incorporated in these models. Some church-based studies have successfully addressed HIV stigma as part of intervention activities in diverse communities [31]. Referral system management for mobile patients must provide options for patients who may want to access care or transfer to other clinics while mobile.

CONCLUSION

The importance of CBPR for this study went beyond including mobile community stakeholders in the research. In order to critically understand a phenomenon and yield impactful interventions, science must be blended with lived experiences. This study combined lived experiences with rigorous science to understand community issues, care access challenges, and generate appropriate, positive, and more likely to be sustained health interventions as a result. Iterative discussions with mobile community stakeholders uncovered communities' health priorities likely to address care challenges they face. Given that mobile individuals may iteratively transisiton in and out of care, it is important to recognize efficient and effective models that facilitate diagnosis to viral suppression. The annual discussions identified substantial gaps in the HIV care cascade and subsequently generated varied intervention options to address HIV care challenges for mobile populations. Asking the communities to vote for their preferred intervention priorities illustrates one

successful adaptation of community participation models. These models hold promise for sustained care engagement among populations, such as those with high mobility, which experience critical health care challenges within the current healthcare system .

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Mobile health clinics *stationed at roaming sites* (transit hubs, markets, beaches, bodaboda stages)



Figure 1:
Care delivery model/Intervention option

Mobile health cards *for multiple facilities/instant referrals*

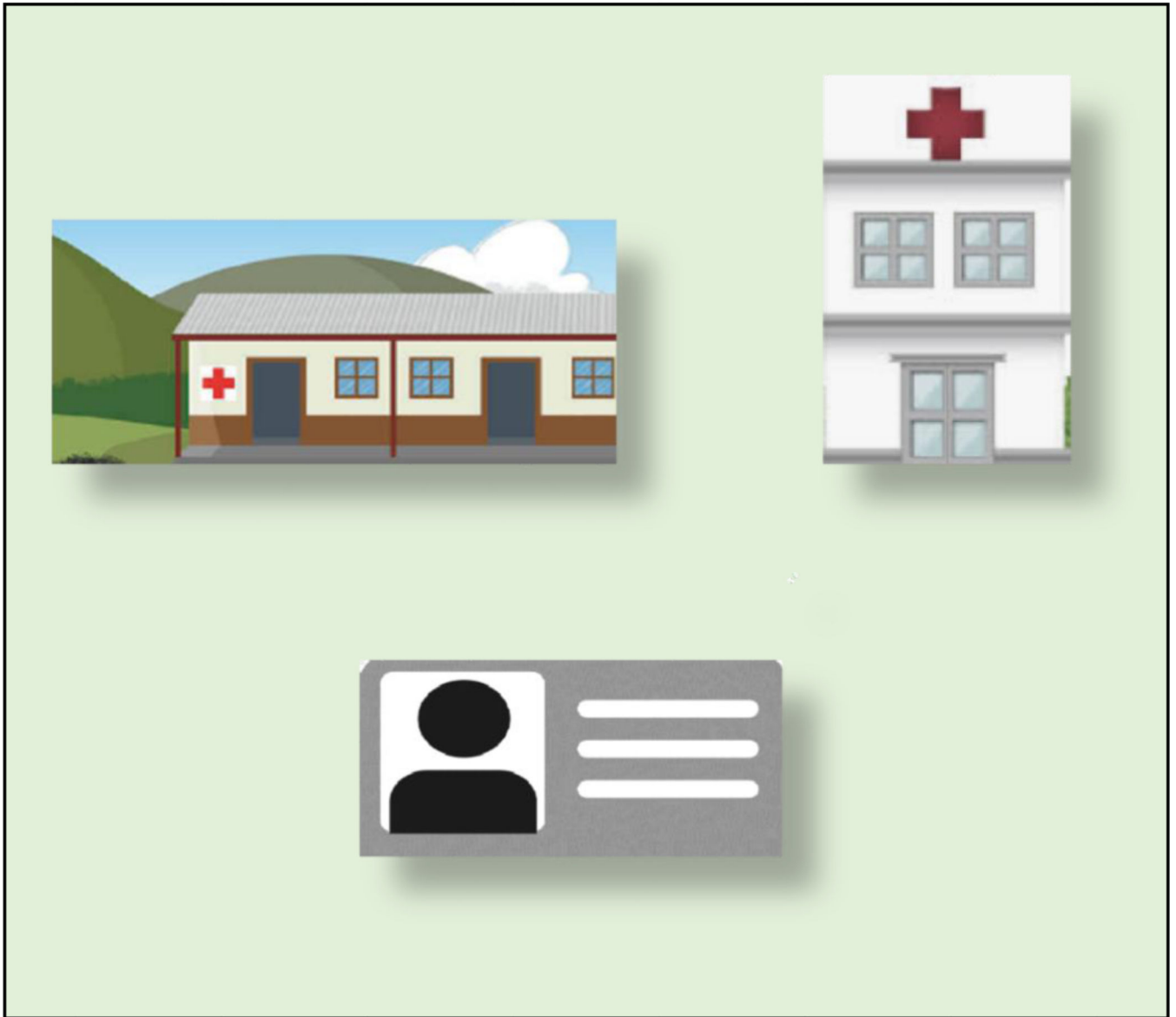


Figure 2:
Care delivery model/Intervention option

24/7 and/or moonlight (after hours) services

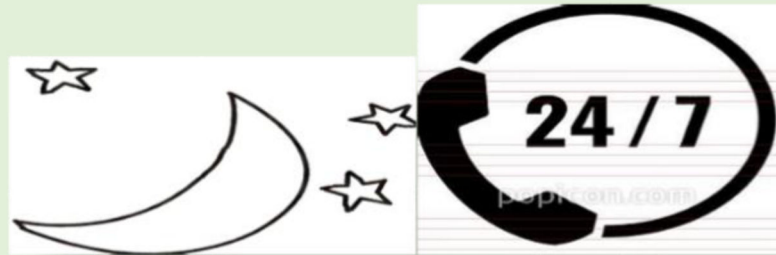


Figure 3:
Care delivery model/Intervention option

Longer TCA/more ARV refills



Figure 4:
Care delivery model/Intervention options

Community-based health workers (peer-delivered services)



Figure 5:
Care delivery model/Intervention options



Image 1:
Community discussion with mobile community stakeholders in eastern Uganda, 2017.



Image 2:
Community member voting for preferred intervention option in Kenya.

Table 1:

Ranking process showing how community members ranked their preferred intervention options. Numbers represent the votes cast in favor of an intervention option; the percentage of votes in that community associated with an intervention, rounded to whole numbers, is placed in parentheses. For ease of interpretation, the top-ranking intervention per community for each of the three rounds is bolded.

	Kenya						Uganda						
	First ranking												
Intervention options	Tom Mboya	Ogongo	Nyamrisra	Sena	Ongo	Sibuoche	Mitooma	Rugazi	Rubaare	Bugono	Kadama	Kameke	
Mobile health card	22 (67)	19 (59)	22 (69)	21 (70)	21 (66)	17 (53)	11 (46)	8 (28)	11 (24)	1 (5)	8 (38)	4 (15)	
CHW- peer delivered services	5 (15)	8 (25)	5 (16)	0 (0)	7 (22)	7 (22)	5 (21)	4 (14)	12 (38)	13 (65)	13 (62)	7 (27)	
Mobile health clinic	3 (9)	1 (3)	5 (16)	5 (17)	0 (0)	3 (9)	6 (25)	2 (7)	1 (3)	5 (25)	0 (0)	11 (42)	
24/7 and/or Moonlight services	0 (0)	1 (3)	0 (0)	2 (7)	4 (13)	2 (7)	1 (4)	9 (31)	4 (13)	0 (0)	0 (0)	0 (0)	
Longer ARV refills	3 (9)	3 (9)	0 (0)	2 (7)	0 (0)	3 (7)	1 (4)	6 (21)	4 (13)	1 (5)	0 (0)	4 (15)	
Total number of participants	33 (100)	32 (100)	32 (100)	30 (100)	32 (100)	32 (100)	24 (100)	29 (100)	32 (100)	20 (100)	21 (100)	26 (100)	
	Second ranking												
Mobile health card									10 (34)	24 (75)	13 (65)	15 (71)	11 (42)
CHW- peer delivered services	16 (49)	24 (75)	18 (56)	4 (13)	26 (87)	19 (59)	11 (46)	6 (21)				2 (8)	
Mobile health clinic	6 (18)	4 (13)	5 (16)	16 (53)	0 (0)	9 (28)	5 (21)	5 (17)	1 (3)	1 (5)	6 (29)		
24/7 and/or Moonlight services	1 (3)	0 (0)	0 (0)	6 (20)	6 (19)	0 (0)	5 (21)		4 (13)	0 (0)	0 (0)	0 (0)	
Longer ARV refills	10 (30)	4 (13)	9 (28)	4 (13)	0 (0)	4 (13)	3 (13)	8 (28)	3 (9)	6 (30)	0 (0)	13 (50)	
Total number of participants	33 (100)	32 (100)	32 (100)	30 (100)	32 (100)	32 (100)	24 (100)	29 (100)	32 (100)	20 (100)	21 (100)	26 (100)	
	Third ranking												
Mobile health card												19 (73)	
CHW- peer delivered services				6 (20)						13 (45)			5 (19)
Mobile health clinic	10 (30)	30 (94)	20 (63)		23 (72)	10 (31)	14 (58)	4 (14)	2 (6)	3 (15)	6 (29)		
24/7 and/or Moonlight services	6 (18)	1 (3)	0 (0)	17 (57)	2 (6)	5 (16)	8 (33)		16 (50)	4 (20)	0 (0)	2 (8)	

	Kenya						Uganda					
	First ranking											
Intervention options	Tom Mboya	Ogongo	Nyamrisra	Sena	Ongo	Sibuoche	Mitooma	Rugazi	Rubaare	Bugono	Kadama	Kameke
Longer ARV refills	17 (52)	1 (3)	12 (38)	7 (23)	7 (22)	17 (53)	2 (8)	12 (41)	14 (44)	13 (65)	15 (71)	
Total number of participants	33 (100)	32 (100)	32 (100)	30 (100)	32 (100)	32 (100)	24 (100)	29 (100)	32 (100)	20 (100)	21 (100)	26 (100)

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