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## “Wan Kanyakla” (We are together): Community transformations in Kenya following a social network intervention for HIV care



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## ABSTRACT

**Background:** In sub-Saharan Africa, failure to initiate and sustain HIV treatment contributes to significant health, psychosocial, and economic impacts that burden not only infected individuals but diverse members of their social networks. Yet, due to intense stigma, the responsibility for managing lifelong HIV treatment rests solely, and often secretly, with infected individuals. We introduce the concept of “HIV risk induction” to suggest that social networks of infected individuals share a vested interest in improving long-term engagement with HIV care, and may represent an underutilized resource for improving HIV/AIDS outcomes within high prevalence populations.

**Methods:** In 2012, we implemented a ‘microclinic’ intervention to promote social network engagement in HIV/AIDS care and treatment. A microclinic is a *therapy management collective* comprised of a small group of neighbors, relatives, and friends who are trained as a team to provide psychosocial and adherence support for HIV-infected members. Our study population included 369 patients on ART and members of their social networks on Mfangano Island, Kenya, where HIV prevalence approaches 30%. Here we report qualitative data from 18 focus group discussions conducted with microclinic participants ( $n = 82$ ), community health workers ( $n = 40$ ), and local program staff ( $n = 39$ ).

**Results:** Participants reported widespread acceptability and enthusiasm for the microclinic intervention. Responses highlight four overlapping community transformations regarding HIV care and treatment, namely 1) enhanced HIV treatment literacy 2) reduction in HIV stigma, 3) improved atmosphere for HIV status disclosure and 4) improved material and psychosocial support for HIV-infected patients. Despite challenges, participants describe an emerging sense of “collective responsibility” for treatment among HIV-infected and HIV-uninfected members of social networks.

**Discussion:** The lived experiences and community transformations highlighted by participants enrolled in this social network intervention in Western Kenya suggest opportunities to reframe the continuum of HIV care from a secretive individual journey into a network-oriented cycle of engagement.

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## 1. Introduction

In sub-Saharan Africa, despite tremendous progress and increasingly widespread access to antiretroviral therapy (ART), significant numbers of HIV-infected individuals still do not receive adequate treatment (Rosen and Fox, 2011). Countless others continue to be lost to follow-up at various stages along the ‘cascade’ of HIV care (Fox and Rosen, 2010). The sub-optimal provision and/or maintenance of treatment severely curtails the vast potential of ART to improve individual morbidity and mortality (WHO, 2013), and prevent new infections (Cohen et al., 2011; Hontelez et al., 2013).

A number of strategies have been tested to address gaps in implementation of ART, largely targeted at HIV-infected individuals (Cheever, 2007). Yet, in many high-prevalence populations, it is not only HIV-infected individuals alone, but also their informal networks (i.e. large extended families) and formal “community groups” (Campbell et al., 2013) (i.e. small businesses, agricultural co-ops, faith-based groups, self-help groups, etc.) that bear the psychosocial, health, and economic burdens of AIDS-related illnesses (Chimwaza and Watkins, 2004; Kaschula, 2011; Miller et al., 2006; Nyambedha et al., 2003; Were et al., 2008). As such, these HIV-affected social networks have a vested interest in sustainable treatment solutions, and may represent an important yet underutilized resource in sub-Saharan Africa for optimizing HIV/AIDS outcomes.

In 2012, our group implemented a quasi-experimental trial of a social network intervention, known as the “microclinic” model, among 369 patients on ART living within highly HIV-prevalent fishing communities on Mfangano Island, Lake Victoria, Kenya. Incorporating both patients on ART and members of their social networks, the intervention contributed to significant improvements in long-term engagement in HIV care within intervention communities. Among other outcomes, patients residing in intervention communities experienced one-half the rate of absences from care greater than 90-days compared to patients living within control communities over 22 months of follow-up (adjusted hazard ratio 0.48, 95%CI = 0.25–0.92) (Hickey et al., 2015).

Here, we report qualitative data from focus group discussions that we conducted with microclinic participants, including local Kenyan program staff and community health workers, one year after the conclusion of the intervention. We document lived experiences of participants to better understand how social network interventions like microclinics may impact the ways that members think and behave regarding long-term engagement with HIV care.

### 1.1. In rural Africa, HIV is a collective burden managed in secret by individuals

Diverse research has documented the devastating socio-economic effects of HIV infection in high-prevalence communities across sub-Saharan Africa, highlighting reduced adult work productivity, the increased burden of orphans and vulnerable women, overstrained health systems, food insecurity, and economic hardship (Heymann and Kidman, 2009; Rugalema, 2000). In these settings, HIV/AIDS illness emerges as a collective adversity impacting both HIV-infected and HIV-uninfected members of dense social networks.

Since 2008, our group has been conducting ethnographic fieldwork among remote Kenyan fishing communities on Lake Victoria, where general adult HIV prevalence has exceeded 25% for over a decade (County Service Delive, 2013). Conceptually, we rely upon Tim Ingold’s definition of an individual “organism” as a “locus of growth and development within a continuous field of relationships” to explore the social ecology of HIV/AIDS at the community-

level (Ingold, 1990). Individuals in rural Kenya, as elsewhere, rely on their “web of relationships” to activate important forces for health including *social capital*, *social influence*, and *social support* (Heaney et al., 2008). Unfortunately, our experience in Western Kenya suggests that HIV-infected individuals often struggle to mobilize these crucial social forces specifically for issues relating to HIV illness and treatment (Salmen, 2009; Merten et al., 2010; Tsai et al., 2013; Nagata et al., 2014). Despite the reality that HIV represents a collective health burden, paradoxically, the responsibility for managing HIV infection too often falls solely and silently on the shoulders of infected individuals.

In most treatment contexts in Africa, HIV status disclosure continues to be a difficult and potentially dangerous process for many newly diagnosed individuals to initiate without assistance and reassurance (Greeff et al., 2008). Moreover, when individuals are diagnosed with HIV, rarely do their providers have training or tools to effectively bring members of a patient’s support network into the treatment plan. As a result, family and friends lack education, confidence, and resources to participate in the treatment process. Consequently, HIV-infected individuals continue to endure intense stigma in isolation across rural Africa, often forced to seek care in secret, consume antiretroviral regimens covertly, and navigate challenging healthcare and economic decisions on their own (Mbonu et al., 2009; Simbayi et al., 2007).

Effectively, stigma serves HIV-infected individuals with both “gag” and “restraining” orders, cutting them off from the social capital that would otherwise be readily available as a resource for other serious financial or health problems. Numerous studies have documented the adverse impact of stigma on treatment outcomes (Merten et al., 2010; Dlamini et al., 2009; Watt et al., 2009). When individuals are unable to engage social support from their networks, their ability to access lifesaving ART, and then adhere to lifelong treatment, is compromised (Ware et al., 2013). In rural African communities where networks demonstrate high degrees of relational density (Kohler et al., 2001), when HIV-infected individuals fail to access or maintain ART, HIV weakens not only their individual immune systems, but simultaneously threatens the overall resilience of many people across a wide web of relationships (Allison and Seeley, 2004).

### 1.2. ‘HIV risk induction’

From a biological standpoint, we know that uncontrolled viral loads contribute to increased infectivity and risk of transmission (Montaner, 2006). From a social network standpoint, we have observed along the shores of Lake Victoria that uncontrolled HIV/AIDS can increase socioeconomic vulnerability and susceptibility to high-risk HIV behaviors for many people associated with seropositive individuals (Salmen, 2009). Christakis and Fowler, in their groundbreaking social network analyses of the Framingham Offspring Study, define the network phenomena of “induction” as the “spread of a behavior or trait from one person to another” (Christakis and Fowler, 2007). In the context of HIV in rural Kenya, we have begun to apply the concept of “HIV risk induction” to describe the propagation of socioeconomic hardships and high-risk behaviors through social networks as a result of AIDS-related morbidity and mortality.

Within impoverished Kenyan fishing communities on Lake Victoria, the significant costs of AIDS-related illness can generate an economic spiral of reduced productivity, food insecurity, decreasing income, and missed educational opportunities for school-going children (Allison and Seeley, 2004). In our context, where “transactional sex is an economic reality” (Westaway et al., 2007), women and girls within HIV-affected households are particularly vulnerable, and often find themselves in sexual relationships based on

financial dependence with male breadwinners. A dramatic example is illustrated in the practice of *jaboya*, frequently translated as “fish-for-sex”. Many suspect the prevalence of *jaboya* has increased over the past three decades, with recent estimates of up to 10% of women and 34% of men in one fishing community having participated in *jaboya* (Fiorella et al., 2015), linked to the economic impact of HIV/AIDS across the gendered fishery economy (Béné and Merten, 2008; Mojola, 2011). Due to high HIV prevalence among migrant Nile perch fisherman (Allison and Seeley, 2004), participation in *jaboya* relationships greatly increases the risk of HIV exposure (Camlin et al., 2014). Ultimately, AIDS-related economic hardship both increases the likelihood that members of HIV-affected households participate in transactional sex, like *jaboya*, and simultaneously undermines the ability of vulnerable women and girls to negotiate condom use, monogamy, family planning, and other safer sexual behaviors (Camlin et al., 2013).

While specific high-risk sexual behaviors remain the vehicles for HIV transmission, the actual drivers of new infections stem from the ripple effects of AIDS-related hardship and economic vulnerability that reverberate through these dense networks. As such, the intensity and reciprocity of relationships described in many African settings have become, paradoxically, double-edged swords for people in HIV-prevalent communities trying to support one another (Setel, 1999). The same reciprocity that facilitates lifelines of material and emotional support can also tie many members of HIV-affected networks to the heavy, sinking stones of lost livelihoods, medical expenses, vanishing school fees, depression, substance abuse, and desperate economic choices, creating a vicious cycle.

Along the taught lines of induced risk, the compounding socio-economic impacts of an individual HIV infection can increase the likelihood that associated network members experience exposures to HIV and subsequent sero-conversion, even unbeknownst to one another. Within interdependent networks where multiple individuals may become infected, all members, regardless of current HIV status, have much to gain by working together to improve treatment for those infected and stabilize mutual vulnerabilities. Breaking the cycle of HIV risk induction may unlock additional network benefits of “treatment as prevention” above and beyond viral load suppression. By improving resilience of the network as a whole, we suggest, it may be possible to slow the induction of HIV risk from infected individuals to affected networks. Consequently, limiting the number of infections within dense networks may also improve care for those already infected, freeing up limited resources and energy to support people living with HIV.

### 1.3. Network approaches for HIV care

A growing body of research has documented the important role that social capital and social support play in improving HIV/AIDS outcomes. In Uganda, Tanzania, and Nigeria, Ware and colleagues have reported on the social determinants of access to HIV care, arguing that in the face of economic scarcity, patients relied heavily on important relationships for the resources necessary to access care. In return, these supporters expect good adherence as a way to maintain health and get a good “return on investment” (Ware et al., 2009). Other research has demonstrated the role of social supports to improve voluntary HIV testing and antenatal care (Mohala et al., 2011) as well as sustained engagement in ART adherence (Dlamini et al., 2009; Weiser et al., 2003; Geng et al., 2010), including interventions built around patient support groups (Madiba and Canti-Sigaqa, 2012; Mundell et al., 2012; Visser and Mundell, 2008), and adherence “companions” or “partners” (Foster et al., 2010; O’Laughlin et al., 2012; Stubbs et al., 2009).

Though helpful, we argue that interventions that prescribe new support structures may ultimately be less sustainable than approaches that engage extant networks of both HIV-infected and HIV-uninfected members that have prior standing within a community. Because social networks are woven into the very fabric of community life, particularly in rural Africa, these networks hold untapped potential to enhance and sustain treatment support forces for people on lifelong ART (Heaney et al., 2008; Carlson et al., 2012). In South Africa, Pronyk et al. have demonstrated that social capital within existing community groups can be “exogenously strengthened” to augment HIV and other health initiatives. (Pronyk et al., 2008). In Zimbabwe, Skovdol et al. argue that formal and informal networks may serve as “critical enablers” (Skovdal et al., 2013) of HIV/AIDS interventions. Campbell and colleagues suggest that existing “community groups” may be the key players in fostering “HIV competent communities” (Campbell et al., 2013), where social norms and practices reinforce healthful behaviors regarding HIV treatment and prevention.

### 1.4. The microclinic model

Our group has adapted a social network strategy, known as the “microclinic” model, to address HIV/AIDS within Lake Victoria fishing communities in Kenya. The microclinic model was first developed to address diabetes and metabolic disease in Jordan, India, and Kentucky, USA (Ding et al., 2013; Zoughbie, 2009). A microclinic is not a small medical facility, but rather a “therapy management collective” comprised of a small network of 5–15 neighbors, relatives, and friends. Members of microclinics are trained as a team to provide psychosocial, nutritional, and adherence support for members who are struggling with life-threatening chronic diseases.

## 2. Methods

### 2.1. Study population and study design

HIV prevalence among the 200,000 residents of Mbita Sub-county (formerly Suba District) has been consistently surveyed between 25% and 40% over the last decade, marking this region as one of the most severely HIV-impacted populations in East Africa (County Service Delive, 2013). At particularly high risk are the approximately 26,000 residents who live in remote fishing communities of Mfangano Island Division with limited electricity and health care infrastructure. Since 2006, HIV care and treatment services in the region have scaled-up through a PEPFAR-funded partnership between the University of California, San Francisco (UCSF), the Kenya Medical Research Institute (KEMRI) and Ministry of Health (Kulzer et al., 2012).

In 2012, we initiated a quasi-experimental trial called the Mfangano Island Healthy Networks Impact Study (MIHNIS), to evaluate a social network approach for improving engagement with HIV care. All adult HIV-infected patients currently enrolled in ART at the Sena Health Center, the Government of Kenya’s only Level 3 facility on the island, were eligible to enroll in the study during the enrollment period of November 2011 through February 2012. The microclinic intervention was then implemented within a single sub-location on Mfangano Island (Mfangano East, hereafter referred to as the Intervention community). All Sena Health Center patients on ART residing within the 5 villages of Mfangano East sub-location comprised the intervention arm and were invited to recruit members of their social networks to form microclinic groups. All Sena Health Center patients residing in separate but highly similar neighboring communities in the Sub-locations of North, West and South comprised the Control arm.

Quantitative methods and outcomes relating to engagement with care and medication adherence among patients in intervention versus control communities are reported elsewhere (Hickey et al., 2015). In order to better understand lived participant experiences one year after the completion of the intervention, patients on ART who joined microclinic groups, social network members of patients on ART who joined microclinic groups, community health workers, and local Kenyan program staff were recruited to participate in focus group discussions. All study procedures were approved by ethical review committees at both UCSF and KEMRI.

## 2.2. Microclinic intervention

Within intervention communities, microclinics were referred to as “*kanyaklas*” meaning “team” in Dholuo. Each *kanyakla* of 5–15 people was enrolled through one of two recruitment avenues:

- 1) Community health workers invited pre-existing “community groups” (Campbell et al., 2013), such as church groups, cooperatives, self-help groups, “merry-go-rounds”, etc. to enroll en bloc as *kanyaklas*.
- 2) Program staff assisted patients on ART to recruit informal patient-centered groups comprised of family, friends and neighbors upon whom they normally rely for support.

Rather than forming de novo “patient support groups”, the registration process incorporated preexisting networks comprised of both HIV-infected and HIV-uninfected men and women who agreed to work together to improve community health in general. Ultimately, most but not all microclinics (42/44 groups) included at least one HIV-infected member, with a median number of 2 patients on ART per group (Hickey et al., 2015). While peer-to-peer support among patients was encouraged, mixed group composition was specifically promoted to avoid stigma and unwanted disclosure previously associated with exclusively HIV-positive patient support groups. Importantly, participants were not required to disclose HIV status to other group members at the time of registration, and all members were encouraged to help one another regardless of status.

Once enrolled, each participant was registered in one microclinic only, and each microclinic was assigned a local Community Health Worker (CHW), previously trained by the Ministry of Health (Kenya Essential Package, 2007). These CHW's attended biweekly trainings to serve as group facilitators for the duration of the program. Microclinic participants then progressed through ten biweekly facilitated workshops at individual locations and times selected by their own group. Concurrently, health seminars at a local community center and vernacular radio broadcasts reinforced salient curriculum topics for the community at-large. In this way, many actors engaged with the training in varying degrees of depth (see Fig. 1). All sessions and lessons were developed in a participatory process to address HIV/AIDS treatment issues relevant to Lake Victoria fishing communities (Salmen and Campbell, 2012). Microclinic participants progressed sequentially through sessions on basic HIV/AIDS biology and antiretroviral medication, confidentiality and group support, community outreach and linkage to care strategies. Instead of didactic lectures, lessons were designed as group discussions, interactive role-plays, and learning games to boost knowledge of HIV treatment and secondary prevention, catalyze conversations, and above all, create a supportive atmosphere for confidential status disclosure among members (see Fig. 2).

At the conclusion of the ten sessions, each microclinic was invited to an optional group HIV counseling and testing session based on Kenyan Ministry of Health group testing guidelines.

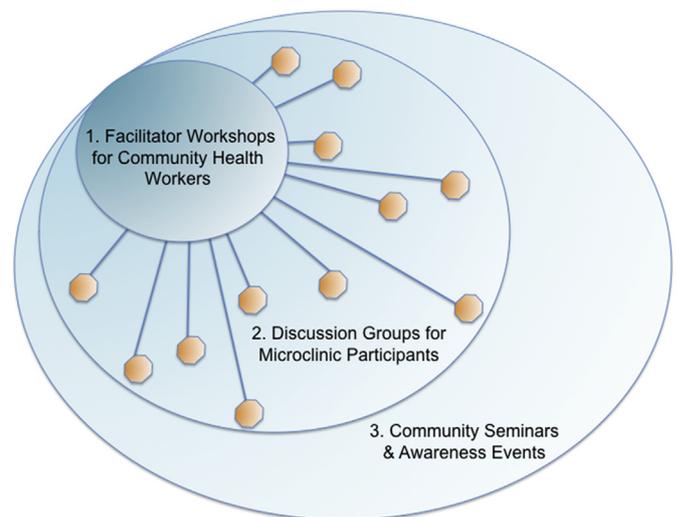
Following group testing, members sat for a group discussion facilitated by program staff that allowed participants to disclose status confidentially to all the other members of their microclinic group only. Throughout the training, program staff emphasized the voluntary nature of the final group testing and disclosure session. Groups that completed all the sessions were given commemorative “*Kanyakla*” T-shirts of a color chosen by the group, and were recognized at an official graduation ceremony.

## 2.3. Focus group discussions and analysis

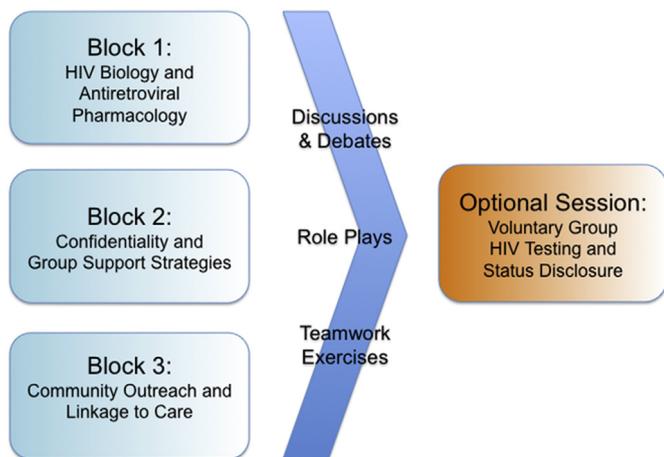
Within intervention community of Mfangano East, local research staff recruited a convenience sample of 161 focus group respondents via group and individual invitations from research staff, as well announcements at the participating local community health center. Each session, comprised of 5–12 adult participants, was conducted over 1.5–2 h and was facilitated by a trained moderator in local Dholuo and/or English depending on group preference.

Each discussion sought to explore participant experiences and observations regarding changes in attitudes and behaviors following microclinic intervention. Four broad discussion guides were developed to facilitate conversations about HIV stigma, HIV testing, ART adherence, and linkages to care, respectively. At least one focus group with each discussion guide was conducted separately with male and female participants, CHW's and program staff. In total we conducted five discussions with male microclinic participants ages 29–69 ( $N = 31$ ), five discussions with female microclinic participants ages 23–67 ( $N = 51$ ), four discussions with mixed male and female community health workers ages 26–52 ( $N = 40$ ), and four discussions with mixed male and female Kenyan microclinic program staff from the participating local community center ( $N = 39$ ).

Each session was recorded with digital recorders, transcribed and translated into English, and then reviewed for linguistic accuracy by local Kenyan research staff. Using grounded theory methods (Strauss and Corbin, 1998), a master list of 47 emergent themes was developed by a designated committee of local and international researchers. These themes were then used to manually code all focus group transcripts. Based on inductive analysis of this dataset,



**Fig. 1.** Microclinic training formats. 1. Biweekly “Train-the-Trainer” facilitator workshops for Community Health Workers (CHWs). 2. Biweekly Microclinic discussion groups of 5–15 people facilitated by CHW facilitators at self-selected times and locations (homes, schools, churches, etc.). 3. Monthly HIV-related Awareness Events and vernacular radio broadcasts for community at-large.



**Fig. 2.** Microclinic curriculum. Microclinic groups advanced through ten (10) training sessions. Sessions 1–3 (Block 1) focused on HIV biology, ART, adherence; 3–6 (Block 2) focused on confidentiality, communication and group support, and 7–10 (Block 3) focused outreach, mobilization and linkages to care strategies. At the conclusion of these sessions, each microclinic was invited to participate in voluntary Group HIV Counseling and Testing and a facilitated HIV status disclosure session.

participant responses that spoke to perceived transformations in local behavior and attitudes following microclinic intervention were grouped into 5 broad categories, reported below. All coding and categorization was reviewed for accuracy and reliability by both English and Luo speaking members the focus group committee.

### 3. Results

#### 3.1. Microclinic participation and status disclosure

During the implementation phase, we observed high levels of participation and acceptance among intervention communities. Local staff enrolled a total of 536 residents from within Mfangano East into 44 self-selected microclinics, incorporating 66% (113/171) of all patients currently on ART within the intervention catchment of Sena Health Center (Hickey et al., 2015). Importantly, 86% of registered participants (461/536) graduated the microclinic program and chose to participate in the voluntary group counseling and testing and HIV status disclosure sessions, including 97 patients on ART. This figure represents 56% of all patients on ART within a catchment area of over 5000 people. To our knowledge, this is the first community-wide voluntary HIV status disclosure intervention of this scale in East Africa.

#### 3.2. Focus group responses

Based on inductive category construction, we organized participant responses to highlight four overlapping community-level transformations following microclinic intervention, namely 1) enhanced HIV treatment literacy 2) reduction in HIV stigma 3) encouragement and support for HIV status disclosure, and 4) improved access to material and psychosocial support for HIV-infected patients. Taken together, these focus group responses illustrate an emerging sense of “Collective Responsibility” for care and treatment among both HIV-infected and HIV-uninfected members of microclinic groups. Participants also note several concerns and pitfalls, as detailed below.

##### 3.2.1. HIV treatment literacy

Respondents reported widespread understanding of basic HIV prevention facts prior to microclinic intervention (“ABC’s of

Prevention”, etc.) thanks to decades of HIV awareness campaigns in the region. However, many focus group respondents reported ongoing confusion regarding details of HIV pathophysiology, the mechanisms of action of antiretroviral treatment, possible side effects of ART, opportunistic infections, and healthy lifestyle strategies for PLWHA. Participants also reported the persistence of local illness constructs relating to the etiology of HIV infection, namely witchcraft and a regional wasting affliction known in DhoLuo as “chira”. Following the microclinic intervention, respondents spoke of changes in common myths and misconceptions about HIV.

*In our kanyakla, people think that HIV is just like any other disease, unlike in the past when there were misconceptions that it was chira. (Respondent C4-5, 34-year-old Female Microclinic Participant)*

At the same time, participants suggested an increased familiarity with concrete information regarding HIV biology, antiretroviral pharmacology and adherence.

*Kanyakla has encouraged me a lot because first kanyakla has enabled me to know that the virus can play with the drug to an extent of one developing drug resistance if a poor adherer. (Respondent D3-6, 35-year-old Female Microclinic Participant)*

Overall, participants spoke of an increased sense of confidence to take an active role in their own care, asking questions, and actively engaging with providers in treatment decisions.

*Another thing was a change of perception on being an active patient, whereby you can talk to the doctor unlike before, when people were not free ... But when we were in kanyakla, we realized that we are to be active patients, to ask even the diagnosis, even the drugs that we have been given. (Respondent C6-1, 37-year-old Female Local Staff)*

##### 3.2.2. HIV stigma

Respondents commented on the pervasive stigma faced by people living with HIV/AIDS prior to the intervention. Respondents described the persistent association between HIV and promiscuity or sin, and fears of HIV contagion. Others spoke of the common belief that infected individuals represent a “lost cause” economically because HIV/AIDS is invariably fatal. Following intervention, respondents spoke of a change in attitudes about HIV, not only among participants in the microclinic program, but also among other community members influenced by relatives and friends who had joined microclinics. Respondents appreciated the mixed composition of HIV-infected and HIV-uninfected members, rather than groups composed of only infected patients:

*Kanyakla has made us to be free with those who could not sit together ... It has made us to share with those with and without HIV virus and even eat together. (Respondent D1-7, 35-year-old Male Microclinic Participant)*

In particular, many respondents spoke of a new sense of openness, whereas previously, HIV treatment had been a furtive endeavor, with many patients seeking treatment on the mainland for fear of being seen at FACES-supported clinics on the island, many patients were now were able to openly engage in care and treatment, taking medication in public, and being seen at the clinic on Mfangano:

*In the past when somebody knew that he or she is positive and had started taking medication, she was not free to disclose her status .... When she was going to the facility for medications, she would hide for people not to see her. But after kanyakla training, people do not hide. If you ask them, they will tell you, I am going for my medication. (Respondent B2-3, 30-year-old Female Microclinic Participant)*

*I can thank the people who brought the program because of what it has done in my life. Before, I was fearful, but after I realized that it was a good thing because I came to know my status. Before it was started, people were taking their medication from outside the island because of stigma. Today, the facility on the island is full because all who were taking their medication from outside are now back. (Respondent A1-4, 53-year-old Male Microclinic Participant)*

### 3.2.3. HIV status disclosure

Participants reported previous desires to disclose HIV status to family and friends, but faced challenges when trying to initiate the disclosure process on their own due to stigma, mistrust, social isolation, and fear of rejection/reprisal. Focus Group discussions suggest that the microclinic program enabled many patients to overcome seemingly insurmountable barriers to disclosure. In particular, participants spoke of several factors that created a more conducive atmosphere for HIV testing and disclosure. Respondents spoke of a growing sense of collective momentum during the 6 month training that motivated them to participate in the final group testing and facilitated disclosure session with fellow microclinic members:

*I got courage that all the members were to go, so I asked myself if I remained behind and the rest are tested, then I'll be alone. So we did go together for group VCT. (Respondent A2-8, 38-year-old Female Microclinic Participant)*

Respondents indicated that testimonials and role modeling from people living with HIV gave many the courage to disclose. Similarly, HIV-infected participants reported a desire to disclose in order to encourage others living in secret with HIV to disclose:

*Being that there are people who are not adhering to their medication, this can force you to disclose your status in order to help and encourage them that are suffering, and tell them the benefits of adhering to drugs. (A1-4, 53-year-old Male Microclinic Participant)*

Most importantly, numerous respondents highlighted the impact of the confidentiality training sessions that were an integral part of the curriculum, including the development of ground rules among many groups for enforcing breaches in confidentiality. For many, this confidentiality training was the deciding factor in securing their resolve to share such personal information within the groups:

*When I heard about group VCT, I was a little bit nervous, and I felt like leaving kanyakla because I did not trust that the other members could keep my secret. But after the training, and more so the session on keeping confidentiality, I was encouraged to go for group VCT because this could help us. (Respondent A1-1, 54-year-old Male Microclinic Participant)*

Several respondents expressed specific concerns regarding the group testing and disclosure process. Despite extensive confidentiality training, several staff respondents pointed to instances in

which unwanted disclosures occurred when a group member was unable or unwilling to keep information confidential:

*Breach of confidentiality was experienced. Some kanyakla members shared the HIV status of other members of their group. This caused discomfort. (Respondent A6-6, 38-year-old Female Local Staff)*

Local program staff also indicated some unease regarding a sense of peer pressure or coercion influencing group members' decisions to participate in "optional" group testing and the subsequent disclosure session. Despite the voluntary nature of these sessions that was explicitly discussed throughout the program, staff respondents suggest that perceptions of material gain (i.e. program T-shirts) and the ground rules established by specific groups may have exerted undue influence on some members' decisions to participate. Other challenges include participants who dropped out of the program, despite open invitations to continue, after they were unwilling to disclose their HIV status. Group discussions also revealed a few instances in which participants faced threats of rejection and reprisal following the disclosure session. In the situations that were reported, however, respondents emphasized that microclinic members were able to provide crucial physical and emotional support during these periods of potential crisis:

*Kanyakla has helped even those who did not join. It has also helped solve some domestic affairs like there was a case where a woman went for group VCT and was found to be HIV positive, so her husband heard this from someone else and he wanted to chase his wife away, as kanyakla members we talked to him and they are now living together happily. (Respondent D4-10, 30-year-old Female Community Health Worker)*

Respondents report that navigating these challenging situations empowered participants, and encouraged several groups to take a more active role in facilitating disclosure conversations even among discordant couples and non-Kanyakla members, a process that had been impossible for many HIV-infected individuals to initiate alone:

*Kanyakla has helped in this case where we got problems with couples who did not want to disclose their status to their partners. As a kanyakla we had to come up with a better ways of improving disclosure system among couples by going as a kanyakla and assisting this person to disclose his/her status. (Respondent D4-6, 37-year-old Female Community Health Worker)*

### 3.2.4. Material and psychosocial support

According to many respondents, the microclinic process unlocked a great deal of support that had previously been blocked by stigma and secrecy. Respondents indicate improved access to instrumental forms of support (food, funds, labor, etc) following group disclosure:

*We started a saving and loaning program so that we can help members. And during the meetings, we also educate ourselves about HIV. (Respondent C4-4, 37-year-old Female Microclinic Participant)*

*A kanyakla member asked another one to help her in the farm the next day while she went for her medications. Disclosure made this possible, because the woman knew why she needed to go on that particular day. (Respondent D5-5, 27-year-old Female Local Staff)*

Others spoke of increased emotional and appraisal support (encouragement, love, advice, counseling, etc):

What kanyakla has brought is love and relationships and one can help the other in case of difficulty. (Respondent A3-2, 36-year-old Male Microclinic Participant)

The discussions have made us free with one another. We always meet in homes of members and when we are coming to your home, and we realize that you don't look healthy, we encourage and counsel you continue being healthy. (Respondent B1-5, 31-year-old Male Microclinic Participant)

### 3.2.5. Collective responsibility for care and treatment

Focus groups indicated that both HIV-infected and HIV-uninfected members of microclinics embraced new, collective responsibilities for various aspects of the HIV continuum of care following the microclinic intervention:

Okay, I learned that going for care and treatment can also be a collective responsibility ... Reminding each other of their schedules and also accompanying their friends to go get medication ... I now know that a friend can help a friend to continue with care and treatment. (Respondent C4-11, 23-year-old Female Local Staff)

Group members described new confidence in facilitating initial linkages and helping members initiate antiretroviral treatment:

Our kanyakla helped a family where the husband was taking medication but did not disclose to the other members. We counseled that family, and when their child was tested, he was also found positive. Today, they are on medication. (Respondent C4-4, 37-year-old Female Microclinic Participant)

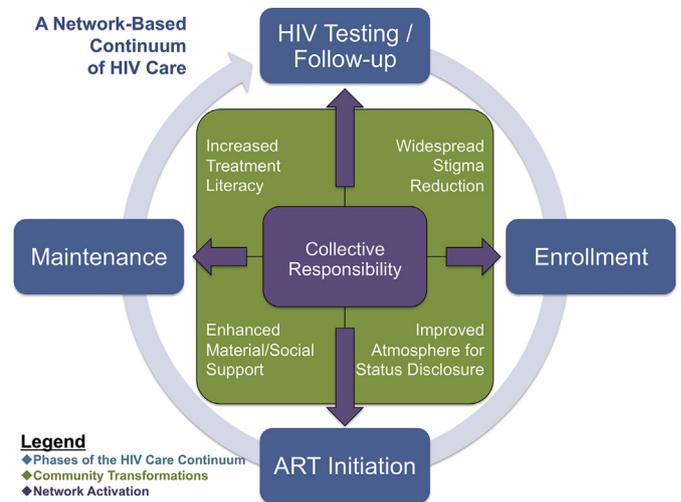
In some cases microclinics report engaging in direct outreach and mobilization within their community:

In our kanyakla, we moved even to the village to encourage and counsel members of the community. During that time, there is a family that tested positive and was helped to seek care and treatment. (Respondent C4-1, 27-year-old Female Microclinic Participant)

Respondents also describe increased involvement in helping group members maintain therapy, going so far as to trace treatment defaulters among microclinic members as well as other community members at large. Regular group interactions appeared to provide recurrent opportunities, both formal and informal, to support and maintain enrollment, as well as monitor those who leave care, and encourage re-engagement:

I happen to have a friend who was on drugs but was swayed by religious beliefs. She met some people who prayed for her and told her she was healed, thus should not continue with the drugs. It did not take long when the lady fell sick and was bedridden. We went to her home with few kanyakla members and took her to the hospital. The lady is really doing very well today. (Respondent D3-2, 50-year-old Female Microclinic Participant)

According to respondents, the “collective responsibility” for care and treatment fostered within microclinics eventually spilled over into the community at large, in some cases, driven by outreach activities initiated by microclinic groups themselves. Ultimately, focus group responses suggest that the microclinic approach helped reframe the HIV continuum of care from an individualized hardship into a network-based cycle of engagement, summarized in Fig. 3.



**Fig. 3.** Transforming the HIV continuum of care. Respondents describe lived experiences with four broad community transformations associated with the microclinic social network intervention on Mfangano Island, broadly categorized as 1) increased treatment literacy, 2) reductions in stigma, 3) improved atmosphere for disclosure, and 4) enhanced social support. By activating social networks to promote “collective responsibility” for HIV care and treatment, these transformations help reframe the phases of the HIV continuum of care from an individual “cascade” into a network-oriented cycle of engagement.

## 4. Discussion

On Mfangano, we have observed that the microclinic social network intervention has potential to catalyze direct, community-wide participation in HIV prevention and treatment activities. Based on our observations, this process was facilitated through two overlapping phases. First, longitudinal group training on issues of HIV, teamwork, and communication, led to improvements in HIV literacy and reductions in stigma. By moving the discourse around HIV away from a secretive and shameful “death sentence” towards a comprehensible, common challenge, participants were able to engage with the second phase: group HIV testing and disclosure. A facilitated atmosphere for group testing and disclosure in turn, unlocked a great deal of social support that had previously blocked by HIV stigma. Instead of a lonesome “cascade” through care, with individually experienced hardships and frequent interruptions (Kilmarx and Mutasa-Apollo, 2013; Hallett and Jeffrey, 2013), microclinics have potential to transform our leaky continuum of care into a network-oriented cycle of engagement.

### 4.1. Limitations and challenges

Limitations of our study relate primarily to nature of the study design, in which focus group discussions were conducted only among microclinic intervention participants one year after the conclusion of the training. Microclinic responses provide a view into their lived experiences, however they remain subject to recall bias, and make it difficult to draw definitive causal conclusions regarding intervention impacts.

Focus Group participants also revealed isolated cases of harm relating to the intervention, mostly regarding loss of confidentiality following group testing and disclosure, and associated risks of rejection and reprisal. Focus group responses, particularly among local staff, do raise some questions regarding the extent to which group testing sessions can be considered fully “voluntary” when the impact of peer pressure and group dynamics are taken into consideration. As voiced by the respondents, this session

represents the *critical* component of the curriculum both in terms of its importance for opening new avenues of support and in terms of potential pitfalls for participants.

Our study suggests that any social network approaches that utilize facilitated disclosures of this kind will need to pay careful attention to factors influencing members' decisions to participate and ensure adequate systems are in place for follow-up and ongoing support should problems arise. In our setting, careful monitoring by trained local staff and intensive confidentiality training may have helped keep reports of confidentiality lapses and reprisal incidents to a minimum, yet certainly unreported occurrences may also have contributed to unknown harms. However, we also heard from many participants that the experience of group testing and HIV status disclosure was ultimately positive and led to substantive assistance from microclinic members with disclosure to others outside the group. Longitudinal microclinic training appears to both lower the activation energy required for HIV-status disclosure, while simultaneously providing a crucial safety net of group support throughout this difficult process.

#### 4.2. Conclusion

Our work among the Kenyan fishing communities on Lake Victoria is premised on the idea that we can further augment emerging "treatment as prevention" strategies (Montaner, 2006) by redefining the unit of intervention from the HIV-infected individual to the HIV-affected network. Because of the socioeconomic impacts of HIV infection, amplified and propagated by network phenomena such as risk induction, friends and family of HIV-infected individuals may be more vulnerable to an array of HIV-related risks. By engaging the network as a whole to improve care for infected members, we may be able to improve overall resilience, thus deflating the socioeconomic pressures that often drive high-risk behaviors for women and girls and limiting the number of new infections within the network. By reducing the number of infections among family and friends, networks may be able to direct more support for those already living with HIV. At the same time, by opening up dialogue and disclosure among infected members, unexpected avenues of peer-to-peer support may arise for patients within their own preexisting community networks.

A growing number of voices support social network involvement in HIV treatment and prevention efforts. Coates advocates for an expansion of *combined* HIV treatment and prevention approaches beyond individual behaviors to address the "behavior of many actors and systems." (Coates, 2013). Similarly, Johnson et al. have described a Network Individual Resource model, arguing that "HIV prevention efforts themselves will be more successful when they rely on trusted networks or become trusted networks themselves" (Johnson et al., 2010). Campbell and colleagues suggest that we can foster "HIV competent communities" by facilitating interventions that engage both formal and informal community groups, "nesting them within wider comprehensive responses, and supporting them through strong partnerships with service providers." (Campbell et al., 2013). Clearly, as Campbell et al. argue, these approaches require great sensitivity and careful participatory implementation to ensure that powerful network forces do not further entrench harmful gender norms, myths and misperceptions about HIV, and instead promote positive behavior change.

We believe that network oriented interventions will be important not only for improving HIV/AIDS outcomes specifically (Hickey et al., 2015), but also because these types of interventions hold potential to establish enduring social infrastructures that build resilience and facilitate a broad range of community health interventions. By organizing established local stakeholders, under the banner of a disease specific challenge (i.e. HIV/AIDS), social

networks can become highly efficient dissemination and follow-up platforms for subsequent health, education, economic, agriculture and livelihood programming. By recruiting established community groups, utilizing highly flexible training schedules, and empowering local community health workers as facilitators, we suggest that network interventions can be easily adapted and scaled into different contexts. By leveraging social network forces, we may be able to simultaneously address myriad socio-economic and ecological factors underpinning HIV transmission in sub-Saharan Africa.

Further implementation research in the field is required within the rural fishing communities of Lake Victoria as well as across diverse global contexts. We need to better understand and articulate ways in which similar community-based approaches can be harnessed to sustainably reinforce the inherent resilience of social networks and catalyze normative transformations across wider fields of relationships.

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