The Community Adherence and Support Group Strategy in Niassa Province, Mozambique: A Process Evaluation of Group Formation Dynamics

Jama Joy Bernard

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Committee:

James Pfeiffer

Kenneth Sherr

Gabrielle O'Malley

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ABSTRACT

In Mozambique, where 11.5% of the population is infected with HIV, there is an ongoing struggle to scale-up HIV care and treatment including the expansion of ART access and improvement of coverage rates. The health system in Mozambique, as in other high HIV prevalence countries in SSA, must contend with a crippling health-care workforce shortage and weak infrastructure, among other challenges. To achieve the ambitious goal of scaling up ART coverage (while assuring high rates of ART adherence and retention in care), it is necessary to explore new models for HIV service delivery that account for practical challenges such as understaffed health facilities and physical and non-physical barriers to patient access and adherence to ART. A new model known as the Community and Adherence Support Group (CASG) strategy, which involves stable patients on ART forming groups to share treatment distribution responsibilities, was piloted by the Ministry of Health in 2010. This research was a part of a process evaluation that generated formative, qualitative data around group formation dynamics at 3 study sites of the national pilot. This research took place in Niassa Province.

University of Washington

DEDICATION

I would like to dedicate this manuscript to my family and friends in the US and in Mozambique.

This work would not have been possible without the love and support of many people.

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A number of individuals contributed to this study that deserve appreciation. I would like to thank my colleagues in Mozambique for their inspiration and tireless efforts in the face of great challenges, as well as the study participants for their patience and openness in sharing their experiences. I would also like to thank my thesis chair, James Pfeiffer, for guidance, as well as my committee members, Kenneth Sherr and Gabrielle O'Malley. Lastly, this study would not have been possible without the generous support of FHI360, and a special thanks to Joshua Volle, for his outstanding leadership and mentorship.

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INTRODUCTION

Highly Active Antiretroviral Therapy (HAART, or commonly known as ART) has been scaled-up across sub-Saharan Africa (SSA) during the past decade, with an estimated 6.2 million patients accessing ART in 2012 (UNAIDS, 2012). Despite great achievements in scaling-up ART access, coverage includes only 56% of the ART-eligible population in SSA (UNAIDS, 2012). In Mozambique, where 11.5% of the population is infected (INSIDA, 2010), there is an ongoing struggle to scale-up HIV care and treatment including the expansion of ART access and improvement of coverage rates. The health system in Mozambique, as in other high HIV prevalence countries in SSA, must contend with a crippling health-care workforce shortage and weak infrastructure, among other challenges (WHO, 2006). The estimated ART coverage in Mozambique is 47% overall (52% for adults and 22% for children), with more than 300,000 people on ART at the end of 2012 (Mozambique *Ministério da Saúde*, 2012).

These figures demonstrate the achievements of the national ART scale-up that was initiated in June 2004, when ART was first made available in the public sector in Mozambique. According to Ministry of Health (MOH) national ART data, only a few thousand people were accessing ART in 2004-2005. During the initial phase of national ART scale-up, services were delivered in vertical, targeted HIV care facilities in larger towns and cities. In 2006 the MOH began providing integrated HIV care and treatment services based at health facilities within the public sector primary health-care (PHC) system. This integrated approach enabled the public sector to provide improved coverage for HIV services, including ART (Pfeiffer et al., 2010) and promoted retention in care for ART patients (Lambdin et al., 2013).

Patient adherence and retention in care prove to be great challenges in the continued expansion of ART coverage across SSA, and serious threats to sustainable ART scale-up in

Mozambique (Micek et al., 2009). Measuring retention can be complicated due to poor national surveillance infrastructure, though data from clinical implementing partners, which are non-governmental organizations (NGOs) supported by the President's Emergency Plan for AIDS Relief (PEPFAR), provide an estimate. This aggregated reporting data, which accounts for 70% of ART patients in Mozambique, indicates patient retention figures at 12, 24 and 36 months to be 72%, 61%, and 48% respectively (PEPFAR, 2012).

The Mozambican government has committed to reach 80% of the ART-eligible population by 2015 via the United Nations General Assembly Special Session (UNGASS) declaration (UNGASS, 2009). To achieve this ambitious goal of scaling up ART coverage (while assuring high rates of ART adherence and retention in care), it is necessary to explore new models for HIV service delivery that account for practical challenges such as understaffed health facilities and physical and non-physical barriers to patient access and adherence to ART. Practical challenges such as distance from a health facility, transportation costs, work and family responsibilities have been shown to cause patients to miss appointments or abandon treatment entirely (Miller et al., 2010; Tuller et al., 2010). Long waiting times due to understaffed and overcrowded health facilities may also threaten patient adherence. As Mozambique has a severe shortage of skilled health workers (WHO, 2006), sustainable models of ART provision must include a cascade of task-shifting and task-sharing among doctors, nurses, community health workers and ultimately patients themselves. Increased patient involvement and self-management of their lifelong ART care is essential for rapid and sustainable ART scale-up.

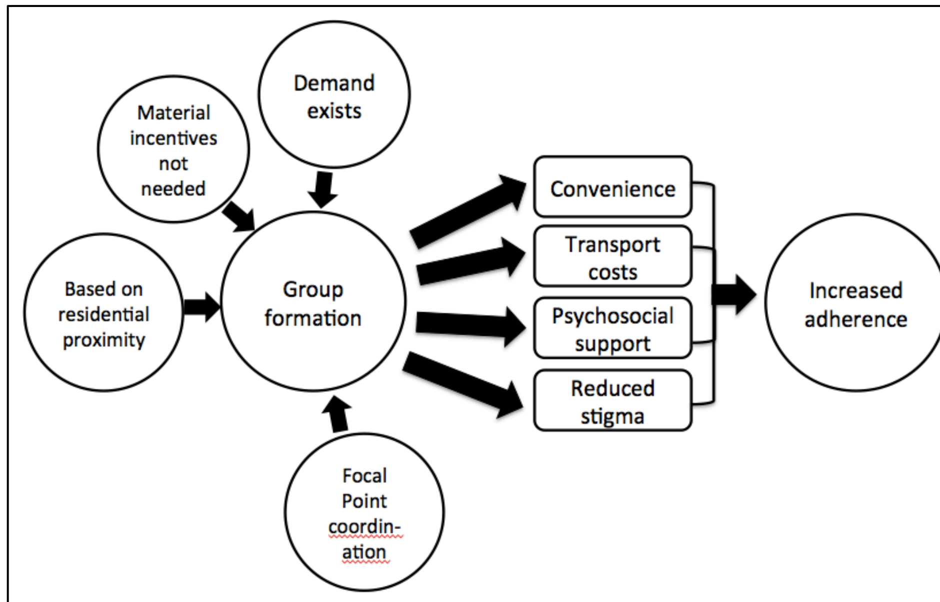
With these challenges in mind, *Médecins Sans Frontières* (MSF) collaborated closely with health facility staff and people living with HIV (PLHIV) in Tete Province to develop an intervention where stable patients on ART were given the opportunity to form a "community

adherence group" (CAG) of 2-6 members (eligibility criteria: > 15 years old and stable, healthy and adherent on ART for > 6 months) (Decroo et al., 2009). The group shares the burden of monthly visits to the health facility, as one member goes to the health facility each month to collect ART for all group members. During the visit the patient also receives an individual clinical consultation and reports on the adherence and health status of other group members. MSF reported great success in terms of improving adherence and retention in Tete Province, (Decroo et al., 2011) which led the Mozambican MOH to adopt the Community Adherence and Support Group (CASG) model (*Grupos de Apoio a Adesão Comunitária* or "GAAC" in Portuguese) as a national pilot strategy in 2011 (Mozambique *Ministério da Saúde*, 2011). With the support of USAID, the CASG strategy was implemented at 30 sites across the country (3 sites in each of the 10 provinces). Pilot strategy operations have been managed by provincial health authorities, in coordination with PEPFAR clinical implementing NGO partners. FHI360, formerly known as Family Health International, has supported the pilot operations at the 3 sites in Niassa province, located in northwestern Mozambique, where this study took place.

The model below (Figure 1) demonstrates the theory of change associated with the basic principles of the CASG strategy intervention and how group formation presumably leads to improved adherence. There are several key assumptions that guide the approach to group formation: These include that 1) there is substantial patient demand for a group approach to ART acess, 2) patients will form groups based on residential proximity, 3) material incentives will not be needed to attract and retain group members, and 4) the clinical officer acting as a Focal Point (FP) at each site will provide leadership in the coordination of CASG strategy activities. The presumed benefits of group formation that are anticipated to ultimately lead to increased patient adherence to ART are 1) greater convenience for patients, 2) reduced transport costs associated

with travel to the health facility, 3) increased psychosocial support among members, and 4) reduced stigma in the community.

Figure 1: Theory of Change



The purpose of this study was to explore the dynamics of group formation at the 3 pilot sites in Niassa province, with the following research question and specific aims:

Research question:

- Which underlying principles of group formation in the original theory of change are most important in the group formation experience, according to those closely involved in the process?

Specific aims:

- Identify and describe CASG participant perspectives on positive attributes and challenges to group formation and maintenance.
- Identify and describe health worker perspectives on positive attributes and challenges to group formation and maintenance.

The study contributes to a process evaluation of the intervention by capturing perspectives of those closely involved in the on-the-ground operations of the strategy, particularly regarding group formation dynamics. A process evaluation approach was utilized to provide an essential first step in ensuring membership experience outcomes aligned with intentions, and thus capable of informing future programmatic decision-making and translation of findings to similar settings. The study did not seek to evaluate the impact of the CASG strategy on adherence, though this would be an important area for future evaluation research. As the research question and specific aims were exploratory in nature and focused on perceptions of key individuals, it was essential to prioritize the utilization of qualitative methods throughout the research process.

METHODS

Study Setting

This study was conducted at the 3 CASG strategy pilot sites in Niassa province: Cuamba, Mandimba, and Mecanhelas districts. In compliance with MOH recommendations, the 3 pilot sites were selected to achieve a balance of rural (Mecanhelas), semi-rural (Mandimba), and urban (Cuamba) settings, based on ART patient enrollment figures (rural: ≤500, semi-rural: 500-1,000, urban: ≥1,000) (Mozambique *Ministério da Saúde*, 2011). Cuamba is the urban center and economic corridor of southern Niassa, with an estimated 100,000 inhabitants (Mozambique Census, 2007). Mandimba has a smaller population than Cuamba, but exhibits some features of an urban center, as it is a porous border town to neighboring Malawi. Mecanhelas is also close to the Malawi border, but is a much more rural community, presenting significantly less movement across the border than Mandimba. Due to practical reasons, the vast majority of patients interviewed for this study reside within the town limits of each site. Despite limited

time and transportation resources, the research team made a concerted effort to travel to distant outlying communities where CASG participants reside, in order to capture a diversity of patient experiences.

Study Sample

The study sample includes the following groups as outlined in Figure 2 below. The sample includes 48 participants in individual interviews (IDIs) and a total of 8 focus group discussions (FGDs) with 3-12 participants in each FGD.

Figure 2: Study Sample

Individual Interviews	Cuamba	Mandimba	Mecanhelas	Total
CASG Strategy Participants	15	15	15	**45**
CASG Focal Point	1	1	1	**3**

Focus Group Discussions	Cuamba	Mandimba	Mecanhelas	Total
Activistas	1	1	1	**3**
Clinical Staff	1	1	1	**3**
NGO Staff	1	1	0	**2**

CASG Strategy Participants

This group included HIV+ patients on ART that have participated as a member of a CASG strategy group for at least 6 consecutive months. The 45 CASG participants interviewed (from 22 distinct groups) represented 18% of all CASG participants (250) and 37% of all existing groups (59 total) across the 3 sites in Niassa province. At the time of data collection (December 2012), there were 8 groups in Cuamba, 24 groups in Mandimba, and 27 groups in Mecanhelas. In Cuamba, 6 distinct groups were included in the sample, whereas in Mandimba and Mecanhelas, 8 distinct groups from each site were included.

CASG participants were recruited via purposive snowball sampling, where participants were identified through established social networks, specifically through trusted *Activistas*

(community health workers) and the Focal Points at the health facility at each site. As research has shown that HIV disclosure is a sensitive issue due to pervasive stigma in Mozambique (Pearson, C. et al, 2009), the research team determined that it was necessary to recruit via purposive sampling in order to emphasize the voluntary nature of participation, as well as to prevent potential HIV status disclosure. This sampling strategy was also conducive to producing information-rich interviews with participants willing to discuss sensitive issues (Miles & Huberman, 2013), in this case related to respondents' positive HIV status. As CASG participants were recruited via *Activistas*, the sample may be biased toward patients that have sustained contact with *Activistas* or are *Activistas* themselves, which suggests the sample may be more socially connected and less alienated than the general population of PLHIV on ART at the study sites. See Figure 3 in the Results section for key demographic information of the 45 CASG strategy participants who were interviewed for the study.

CASG Focal Point

At each pilot site, one CASG Focal Point (a clinical officer of psychiatry) was appointed by the provincial health authorities to coordinate strategy activities in his or her respective district involved in the pilot. Each of these 3 Focal Points participated in key informant interviews, which provided a coordinator perspective and enhanced richness of data gathering regarding group formation at the 3 sites.

Clinical Staff

This group included an array of clinical staff involved with the CASG strategy: medical doctors, clinical officers, nurses, pharmacists, and administrative staff. These individuals were recruited at the health facility, in coordination with health facility leadership, to participate in one FGD at each of the 3 sites.

HIV/AIDS Activists (*Activistas*)

Known as *Activistas* in Portuguese, these individuals have a range of training and experience as community health workers in their communities, where they provide care and support for PLHIV. Many of these individuals are HIV+ themselves and function in an "expert patient" or peer educator role in their community, which has included promotion of the CASG strategy at the community level. *Activistas* were selected through purposive snowball sampling and were recruited through established social networks of community-based organizations (CBOs) that provide social services and basic care for PLHIV. This sampling strategy was necessary due to aforementioned issues with HIV disclosure and stigma in the community.

NGO Staff

This group of NGO staff with involvement in the CASG strategy included FHI360 employees that had worked on the strategy at all 3 sites (all resided in Cuamba), as well as *Estamos* (a Mozambican NGO) staff based in Mandimba. Mecanhelas did not have significant NGO presence to warrant a FGD.

Data Collection

A team comprised of 2 study coordinators and 6 trained data collectors (2 locals from each site) completed data collection activities over a period of 5 weeks at the 3 sites, during November and December of 2012. Structured individual interview and FGD guides were piloted and translated into locally spoken languages (Macua, Jaua, and Nyanja) prior to initiation of data collection. Written consent was obtained from all participants prior to initiation of individual interviews and FGDs, where participants were also assured of confidentiality and the voluntary nature of participation. Respondents did not receive any direct benefit or compensation for participating in

the study. All interviews and FGDs were recorded with a digital audio recording device, and audio files were destroyed immediately following transcription.

CASG participants were asked at the beginning of the interview whether they preferred to speak Portuguese or a locally spoken language, and the data collector followed accordingly, first interpreting questions into local language for the participant, and then interpreting the participant's answers into Portuguese for the study coordinators. Basic demographic information of CASG participants was collected following the consent process and prior to recording the interview. Interviews with the CASG Focal Points and all FGDs were conducted in Portuguese. Interview and FGD topics included group formation dynamics, incentives and barriers to membership, patient/provider satisfaction with the groups, and the roles of various stakeholders in driving group formation.

Data Analysis

The unit of analysis for this study was the site, as the study was a comparative analysis of the three pilot sites. Following transcription and translation of interviews and FGDs, qualitative data was coded using ATLAS.ti to identify emergent themes (Miles & Huberman, 2013; Bernard & Ryan, 2010). The principal investigator collaborated closely with another MPH student coder at the UW to develop a working codebook of themes, in the interest of enhancing inter-coder agreement and optimizing validity of findings. This process involved a series of meetings where the investigator and the collaborator coded materials independently, followed immediately by an in-depth discussion of emergent themes with the ultimate aim of creating a codebook of themes. American and Mozambican investigators collaborated remotely throughout the entire analysis process via email and phone contact. Feedback was solicited from the Mozambican research

team to support the development of the codebook, as well as to guide preliminary findings and final analysis results.

RESULTS

Demographics

While age and male to female ratios of CASG participant interviewees were fairly consistent across sites, a predictable difference in education level attained and Portuguese language skills can be seen between the sites: Cuamba (urban), Mandimba (semi-urban), and Mecanhelas (rural). While the vast majority of CASG participants in Niassa province are female (60-70%), in line with indication that females are higher users of HIV services than men in SSA, our sample included an even higher level of female participation (88.9%), due to challenges recruiting men to participate in the study. The research team attempted to approach roughly the same number of men as women, though finding men through established social networks of trust proved to be challenging, and men also refused participation at a higher rate than women. It is unclear why more male CASG participants declined participation than females.

Figure 3: Demographics of CASG strategy participants

	Cuamba	Mandimba	Mecanhelas	Average
Average age (years)	38.1	38.7	33.3	36.7 (range: 21-64)
% Female	86.7%	93.3%	86.7%	88.9% (40 women, 5 men total)
Average highest grade level achieved	7.5	5.4	3.8	5.6
% Interviews in Portuguese	60%	40%	13.3%	37.8%

Interviews with CASG participants revealed that the most commonly reported affiliations between members were based on residential proximity (neighbors), colleagues, domestic

partners, relatives, and group members that met at the health facility. "Colleagues" in this context refers to fellow HIV+ *Activistas* that work together at the same community-based organization (CBO), where their job is to provide HIV outreach in the community (with donor support of FHI360 and USAID). In Mandimba "met at the health facility" refers to patients that met at a *Chá Positiva* monthly meeting at the health facility, which is an ongoing forum where local PLHIV are invited to provide regular feedback to clinical staff regarding HIV services and related issues. Mecanhelas and Cuamba currently do not have active *Chá Positiva* meetings. Other patients that met at health facilities in Mecanhelas and Cuamba did so through the FP or another clinical staff member, or met each other in the waiting area of the health facility.

In Cuamba, nearly all of the 6 groups sampled were composed of *Activista* colleagues and also included other PLHIV they had cared for in the past as part of their role as an *Activista.* In Mandimba, this type of group was also common in the 8 groups sampled, as was initiation through the *Chá Positiva* meetings at the health facility. In Mecanhelas, more than half of the 8 groups sampled included a married couple (for the purposes of this study, defined as a domestic partnership), and other affiliations included neighbors, *Activista* colleagues and relatives.

Themes

From the data, the research team identified 4 distinct themes in relation to the dynamics of group formation that were demonstrated across the study sites. As postulated in the theory of change, the underlying principles of group formation that elicited significant findings were: 1) convenience, 2) preexisting networks of trust, 3) coordination, and 4) the role of resources.

Theme 1: Convenience

In terms of the basis of demand for the CASG strategy, interview data confirmed that demand does exist, and convenience is the principal driver of that demand. Convenience was reported as

the primary incentive for group formation. CASG participants only have to go to the health facility every 2-6 months (depending on number of members in the group) rather than monthly, which was reported as a major incentive for patients to participate. Nearly every CASG participant reported that the relief of travel and avoidance of long days spent at the health facility were enthusiastically welcomed by all. CASG participants reported the benefits of being able to focus on their daily activities and responsibilities (child-rearing, other family obligations, cooking, cleaning, socializing, working their fields, and other income-generating activities) and to "have a rest" from going to the health facility every month. Once they are part of a CASG group, they no longer have to worry about picking up their medication if they have to travel unexpectedly for work or a special event, take care of a sick child, or attend a funeral, as they know that another member will go to the health facility.

> *It is good to have the group because when you are busy or your child is sick, if or you are alone, or something else happens… you have a friend that can go and get the medication.*
>
> CASG Participant, Mandimba

As funeral attendance (even for a distant contact) is very important in the local culture, ability to attend funerals was mentioned as a direct incentive by several participants:

> *If I need to travel… I don't have to worry. Sometimes… the date is arriving that you had marked to do a consult… sometimes a funeral happens. Now, you cannot miss the funeral just to go to the hospital. This is a problem… people only talk about funerals here….and so when I spoke of this [to others], they thought that this thing here [CASG] is a good thing.*
>
> CASG Participant, Mecanhelas

The initial assumption by strategy designers and implementers was that convenience (particularly residential proximity) would be the primary driver of group formation, but the findings from this study revealed other important motivating factors that exist.

Theme 2: Preexisting Networks of Trust

The most visible theme was the importance of preexisting networks of trust in the initial formation and ongoing maintenance of CASG groups. Closely tied to this was a significant finding that many CASG participants discussed how they (and other PLHIV they know) were not disclosing their HIV status to their partners, relatives, neighbors, friends, and other social networks. This collective lack of disclosure made it difficult for a PLHIV to know whether another person is HIV+ (and thus potentially eligible to join a group with them), unless there was some reason or mechanism for prior status disclosure. A commonly reported experience where this disclosure happened was in the *Activista*-patient relationship, where an *Activista* had provided care for the patient in the past, and there subsequently existed an established relationship based on mutual trust, spanning an extended period of time. Many groups across sites were formed by an *Activista* with former patients, as the quote below demonstrates.

> *The other members [in my group]… I took care of them… they were patients that I had helped. So… we created a group. When [the FP] explained CASG [at the health facility] and said that we should find neighbors or people that live nearby, or colleagues… I went to speak with my neighbors that I had cared for. They accepted and we registered our names.*
>
> *Activista*, Mandimba

Activistas experienced in home-based care in their communities have a multitude of personal ties with PLHIV that they have provided direct care for in the past, likely when the patients were newly diagnosed with HIV or very ill. If these patients were discharged from the home-based care program the *Activistas* operate, it is possible that many of them are currently stable on ART and eligible for CASG participation. Many of these experienced *Activistas* are in an ideal position to facilitate group formation via their established social networks of PLHIV potentially eligible for CASG in an environment where stigma continues to be pervasive. An *Activista*

discusses stigma and the social support and peer educator role that the *Activista* provides:

> *There are people who were afraid who are now free. [Before they were]… feeling ashamed that they have AIDS… [people say] they are a prostitute, a whore. But as* Activistas *we are supporting them… saying, you shouldn't be afraid… let's go. You see me? I am taking the medication and I am not ashamed… we are in the same situation. And with [the group], it helps people be contented, free, without fear… they follow their treatment more [diligently].*
>
> *Activista,* Mandimba

Also many *Activistas*, being mutually trusting and "out" to each other as HIV+, formed groups amongst themselves, sometimes also including a domestic partner or a former patient. For *Activistas* who are known to each other as PLHIV, and for the patients they once cared for, personal disclosure of HIV status between these individuals is less of a concern because status has already been revealed by nature of the relationship. Other relationships that lack this established preexisting networks of trust prove more challenging to navigate in regard to group formation, which inherently is preceded by disclosure.

Other groups had been formed by family members, domestic partners, and neighbors, though rather than residential proximity as the driving force (as was thought), we found preexisting networks of trust to be much more important for groups to initially come together and stay together. As detailed below, some participants recalled feelings of uncertainty as to whether they could trust their fellow group members to maintain confidentiality, and ultimately concluded that due to the shared nature of the secret, the success of the group depends on preexisting networks of trust between all members.

> *I was afraid to enter the group… if I enter there, are they going to disclose [my status]? I was afraid… are they going to talk badly about me? That… I have [HIV] also. But later, that fear went away…I am here, what am I going to do? There is no fear…[the group] is family, we help each other. This here is my sister…this is my mother. Is she going to talk if she has it too?*
>
> CASG Participant, Mandimba

Before, I was hesitant in my heart. I thought that if 3 or 4 people got together to take this medicine… maybe one of us would break the silence [by disclosing another's status]… but no one has done that. We all know that we are equal in that sense… taking this medication… everyone has a secret. So, one cannot reveal the secret of another member.

CASG Participant, Cuamba

Patients, *Activistas*, FP's and other clinical staff discussed in FGDs and interviews how patients will see someone they know, often a neighbor, at the health facility and recognize that they appear to be in the "same situation" (in regard to HIV status and ART regimen), likely due to lack of privacy at the health facility. Several CASG participants described a similar story of the group coming together in the health facility waiting area:

We all met each other at the hospital and realized that we are all in the same situation… so, from then on we knew [each other's status]. Each person was approached by another and from there we began to form the group. For me it was a neighbor that approached me.

CASG Participant, Mandimba

It is not uncommon for a group to include a married couple. Several groups reported being created by married couples that (prior to CASG strategy implementation) were already coordinating with health facility staff to collect their ART on the same date. With the initiation of the CASG strategy, these married couples invited a trusted neighbor or relative to join them in forming an official CASG group.

Participants of groups that included married couples described both positive and negative experiences regarding the dynamics between the married couple and other group members. For married couples with a healthy relationship grounded in mutual trust, CASG membership provided an opportunity to expand their circle of trust with other PLHIV that were already known to them as trusted neighbors, relatives or colleagues. When married couples struggled to

trust each other, the conflicts that would arise seemed to often involve other group members. Several participants reported that another member's husband was not being adherent or refused to pick up the medication for the group. A participant described how it has been difficult for her to navigate conflict resolution within the group in this situation, as she feels like it is not her place to intervene in marital disputes:

> *I work well with my [female] colleague, but the man always complicates things [by refusing to pick up medication]. In terms of making changes to the group, specifically regarding the man… it's up to her. I cannot decide. I can't say anything because there is nothing to say… they are married. I can't say anything because they are married. The husband, as head of the family…. I can't interfere in their home. If the woman becomes tired of her husband's behavior… then we may decide to do something, but the decision is hers to make. After she decides, we could expel the man from the group and see how things go.*
>
> CASG participant, Mecanhelas

Participants also described scenarios where a group member is married and has not disclosed her HIV status to their domestic partner (all reported cases of this type were females who had not disclosed to their husbands). In this setting, trust between group members is particularly essential, to protect the confidentiality of the woman. There were some instances reported where women were in abusive situations at home, where the threat of gender-based violence made partner disclosure impossible. In these cases, the other group members organized a secure location to store the woman's medication, usually at the home of another member, the woman's mother or another trusted relative or friend. A participant discusses why her group could not have meetings due to a female member's abusive partner:

> *What causes us to not meet… is confidentiality. One of the women [in the group] is severely controlled by her husband… and [he] cannot know what this group is about. Even [the woman's] medication is with a friend.*
>
> CASG Participant, Cuamba

Related to preexisting networks of trust is the ongoing psychosocial support involved in lasting relationships based on mutual trust. Groups in Cuamba, for example, referred to themselves not as CASG, but as *seis amigos* or "six friends" and many participants spoke of the camaraderie and psychological relief from isolation that the group provides.

> *You can't know and do everything alone…you should have a person that knows your secret… it can't just be you that has everything to keep inside.*
>
> CASG Participant, Cuamba

> *I am happy because [in the group] a person isn't isolated… a person feels normal… one can even forget about their disease. It's great! Because sometimes what happens, what increases people's suffering, is isolation… they are sad. But now with this group we are happy, we have our songs, we are content, consoled. We are doing well! We wait for the appointments and the days are passing.*
>
> CASG Participant, Cuamba

Theme 3: Coordination

The importance of coordination was another recurring theme that emerged from the data. Strong Focal Point leadership was identified as a key driver of group formation, as the Focal Point must champion the strategy and coordinate with multiple stakeholders to ensure that operations run smoothly. Many study participants observed that successful group formation and maintenance relied on solid leadership of the Focal Point, who must coordinate with both *Activistas* and with clinical staff, who evaluate patients to determine whether they meet the eligibility criteria for CASG participation. As the Focal Points are clinical officers of psychiatry, it is other clinical staff that regularly see PLHIV patients and would clinically assess whether the patient meets the strategy criteria. The Focal Point also functions as a mediator when intra-group conflict is not resolvable among members:

> *I feel bad for our colleague, a man who is not adhering to treatment. I discussed this issue with the Focal Point and he then approached our colleague… now it is in the hands of the Focal Point.*
>
> CASG Participant, Mandimba

Prior to initiation of the CASG strategy, FHI360 organized a training in Cuamba for key health facility staff to be involved in the CASG strategy from health facilities at the 3 sites. The information from this training was to be disseminated to other health facility staff involved in the implementation of the strategy. In Mandimba and Mecanhelas, this was achieved through Focal Point efforts to coordinate with other health facility staff. In Cuamba, there were significant coordination challenges reported, which seemed to result in a lack of information and misinformation among health facility staff regarding the strategy. Nearly all of the health facility staff and CASG participants in Cuamba, for instance, believed that the groups must be comprised of exactly 6 members (whereas in reality groups may have 2-6 members). This widespread misinterpretation of key components of the strategy reflects poor communication and coordination during the early stages of implementation.

The data also revealed that during initial training and message dissemination, engaging *Activistas* was essential to ensure that they understood the strategy and their vital role in facilitating group formation. There was some confusion expressed regarding the role of the *Activista* within the implementation of the CASG strategy in Cuamba, where group formation has not taken off the way it has in Mandimba and Mecanhelas. Cuamba, which has the greatest number of patients on ART (>1,500), reported 8 groups formed, whereas Mandimba and Mecanhelas, which have lesser patients on ART (500-100 and <500), reported 24 and 27 groups (as of December 2012). This low uptake may be attributed to poor coordination between the health facility staff, Focal Point, and *Activistas* in Cuamba. When the strategy was first

introduced in Cuamba, many key PLHIV leaders and *Activistas* were minimally engaged by the Focal Point and thus struggled to understand the strategy. Some *Activistas* reported confusion and feelings of fear related to potential status disclosure and future job insecurity, as some *Activistas* working with FHI360 projects receive a stipend of roughly $50 per month to provide community-based care services for PLHIV. As the quote below demonstrates, an *Activista* was at first doubtful about the CASG strategy, as she had heard about it second hand and felt her job security threatened by its arrival. Only later did she come to understand the advantage of forming a group as an *Activista,* and begin to facilitate formation of other groups.

> *In the beginning, as an* Activista *I was doubtful. What would happen if I created a group… perhaps I would be finished with my professional work [as an* Activista*]? But later I saw that no… the groups are meant to improve the community itself… and not being a required program, it is a beautiful strategy that way… people enter the group with willingness, with all their heart. Now every* Activista *has [initiated] groups.*
>
> *Activista,* Cuamba

The Focal Point must also manage conflict resolution between health facility staff members. In Mecanhelas, there was tension reported between the Focal Point and the clinical staff, as the Focal Point was receiving an extra per diem to do field supervision work and the clinical staff were not. This created significant resentment on the part of the clinical staff, as they were doing the "extra work" of eligibility evaluations yet not receiving the additional funds that the Focal Point received. To resolve this conflict, the Focal Point decided to divide up his per diem to share with his colleagues to get them on board for the strategy to move forward.

Theme 4: Role of Resources

The role of resources in relation to formation and maintenance of groups was mentioned in nearly every interview and FGD, raising key questions related to trust and sustainability of the

CASG strategy. The role of resources was described in the following three distinct ways: 1) the sharing of resources among group members, 2) requests for donation of material resources to established groups (to be used for income generation activities), and 3) an uneasiness regarding potential destructive effects of injection of funds into groups.

Particularly for patients living in outlying communities (>10 miles from the health facility), the sharing of resources was reported as a strong incentive for group participation, along with the relief of the financial and physical burden of traveling long distances (sometimes walking) to reach the health facility. Some groups reported sharing a bicycle (if a member owns one) or if an owned bicycle is in disrepair or is lost, members pooled their resources to rent a bicycle for the day (reported to be $10-20, a significant amount of money in a setting where formal employment is scarce). No motorized vehicle transportation is available to these outlying communities that were sampled.

> *In our group not everyone has transportation, the only person who does… we depend on him, on his bicycle. So, when someone goes to [the health facility] to pick up medication, they take the bicycle.*
>
> CASG Participant, Mecanhelas

Groups also reported contributing funds to purchase a backpack, to be jointly owned and used each month to discreetly pick up the several bottles of medication from the health facility. Several participants reported that they have organized a contribution among members following a rotating savings club model. In some instances, this pool of funds was reserved in the event that a bicycle would break down, though the vast majority of participants interviewed were able to walk to the health facility and did not require a bicycle for transportation.

In one reported example, a group was formed and the group leader promptly began demanding that members make weekly contributions of 10 *Meticais* (roughly $0.33, not an

insignificant amount for someone who has no income). She proposed that the group create a pool of funds to buy snacks for meetings and to collect a small amount to give to the member who goes to the health facility to receive each month. Two of the group members chose to immediately leave the group and join another, due to their lack of desire (and inability) to contribute weekly. In this instance, the requirement of weekly monetary contributions was a disincentive for joining that group, undermining a basic principle of the CASG strategy (that the benefit to the member lies in belonging to the group itself and no material resources are required).

Many CASG participants requested funds during the interviews, unprompted, and many noted the abundance of resources available through organizations like FHI360 or the government. Even in outlying communities, residents at the study sites were attuned to how resources for HIV/AIDS programs are flowing through their communities. Many participants' comments alluded to expectations of types of "assistance" (money, loans, food, bicycles, etc.) that are not uncommon to receive in other HIV/AIDS programs. The CASG Focal Point in Mecanhelas explains this phenomenon:

> *Knowing our culture… [the patients] thought that the CASG… would come with some sort of assistance on the part of the government or the hospital… but we explained that no… the advantage of CASG is for you. And it is for that reason that the groups are formed from within the community… this group is simply meant to improve your own process. Do not expect to receive support in the form of sugar or oil… many people had this expectation but we explained this during our supervising visits. And now it is clear… they thought so during the first phase of CASG… but now it is clear.*
>
> CASG Focal Point, Mecanhelas

Some participants noted how creating long-term dependency on donated resources actually undermines sustainable community development. The following *Activista* used an

example of a patient of hers refusing to continue on ART after she stopped receiving a monthly *sexta básica,* a "basic basket" containing rice, flour, oil and fresh produce, which is meant to provide short-term nourishment for the patients most in need of nutritional supplement to their diet.

> *A [similar thing] happened to me… a patient, when she stopped receiving* a sexta básica, *she also stopped taking medicine. She said if I don't receive food… how will I take medicine without food? I said, just eat the food [that you normally] used at home… you eat that and then take the medication, even if it's just porridge you're eating. The* sexta básica *was only intended to develop your body a bit… it's not permanent.*
>
> *Activista,* Mecanhelas

Another *Activista* spoke of how expectations of material incentives may limit expansion of CASG:

> *It's just that the [CASG] groups here in Mandimba, we are not going to continue to develop because people have that thing of saying, "So… what about us? What sort of assistance are you going to give us? We don't have anything."*
>
> *Activista,* Mandimba

Many people made requests for funds to be used for small loans or grants to spur income-generation within their CASG group. Alongside this, though, was also indication of hesitancy, that this type of injection of funds into a group could undermine that trust which is the foundation of the group's success.

A CASG participant spoke about why other PLHIV may choose not to participate in CASG, due to resentment and perceived notions that HIV/AIDS program employees are gaining material wealth and benefitting from their misfortune ("eating with my name"). Other references indicate that it is common knowledge in these communities that there are significant material resources floating around for HIV-related work, as this quote demonstrates.

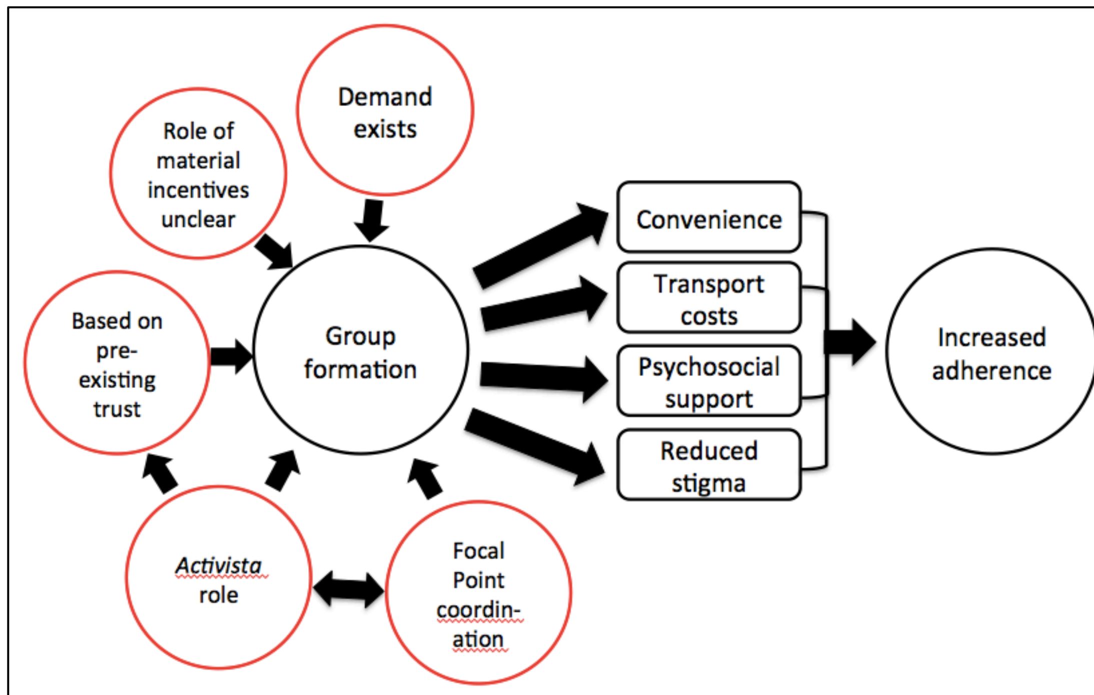
People are still saying [about CASG], "Not for me… what will I gain there?" For him, he does not gain anything… who eats is someone else. And so it's true… the one who eats is someone else. So they eat with his name. "They travel in cars, they eat well… with my name. They walk around and reveal my [HIV] status there because they know that with this HIV/AIDS… that these people bring money. So they eat with my name." So these people begin to say these things. "It's better if I just go there [alone], I am getting the medication and I am taking it alone… it's better than to be fooled."

CASG participant, Mandimba

DISCUSSION

Revisiting the theory of change demonstrates that findings revealed the following: demand does indeed exist among the CASG eligible population, the role of material incentives is unclear, and formation is not necessarily based on residential proximity (as was presumed). Formation appeared to be much more tied to preexisting networks of trust, which was reported to be largely navigated by *Activistas*, who had developed trusting relationships amongst themselves and with former patients their cared for in their community health worker role. An important discovery was how the focal point interfaced with the *Activistas* to access this population eligible for CASG, which led to greater uptake at the sites where the coordination was stronger. The role of the focal point in coordination of the CASG strategy was found to be essential to smooth strategy implementation, as expected.

Figure 4: Theory of Change (revisited)



RECOMMENDATIONS

The first overarching recommendation is that more research is needed. An important area of future research is to examine whether the public sector (with minimal external NGO support) can support this model in terms of sustainability and scalability. A mixed methods study is currently being undertaken by the MOH to evaluate impact of the CASG strategy across the 30 pilot sites. This study will provide a baseline for future research, though more qualitative and participatory research is needed to better understand *how* group formation influences patient adherence. The findings from this study revealed key issues to consider for CASG strategy scale-up beyond the pilot phase:

1. Meaningful involvement of PLHIV is essential, as preexisting networks of trust were found to be so important in successful group formation and maintenance. The findings suggest that *Activistas* played a critical role in facilitating uptake of the CASG strategy.
2. Strong leadership of Focal Point to promote coordination between other health facility staff and community-based health workers (*Activistas)* is also essential.
3. Message dissemination needs to focus on non-Portuguese (illiterate) populations, with a particular focus on men, who are greatly underrepresented in the CASG participant population.
4. Great care should be taken to assess whether utilizing material resources is appropriate to incentivize established groups or CASG-eligible patients to form or join groups. There was some indication that involvement of money could undermine the trust that is so essential for group formation and maintenance, as disclosure is still rare and stigma is pervasive.

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