



Scaling Up Community ART Groups in Mozambique

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Authors' contributions

Author TD, the guarantor of this paper, wrote the first draft, which was critically reviewed and improved by all the co-authors. All the authors have seen and approved the final version.

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ABSTRACT

Aims: To describe the stepwise implementation and roll out of Community ART Groups (CAG) in Mozambique.

Study Design: Descriptive study

Place and Duration of Study: Mozambique, between February 2008 and December 2011.

Methodology: Description of the stepwise implementation of a model for Anti-Retroviral Therapy (ART) delivery based on the principles of peer support and self-management. The program data on CAG were obtained through a chart review and routine data-collection.

Results: To overcome patient reported barriers to monthly drug refills for ART the Tete Provincial Directorate of Health and Médecins Sans Frontières developed a community-based ART model or patient-centered model, through peer support groups named CAG. The first CAG commenced in 2008, in rural health facility catchment areas, where members of CAG shared transport costs to overcome distances to the ART clinics. In 2009, lessons learnt were exported in Tete province and CAG model was launched in semi-urban contexts to decrease time spent in the clinics. In 2011, retention rates as high as 97,5 % convinced a joint task force that included Ministry of Health and major partners

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to pilot the CAG strategy on a national scale.

Conclusion: To respond to staggering attrition rates Ministry of Health in Mozambique and partners piloted an innovative patient-centered model for HIV care and exported good practices from local to provincial and national level. Success of scale up will depend on the collaboration and interaction between policymakers, donors, health-managers, caregivers, communities, and patients.

Keywords: HIV; antiretroviral therapy; highly active; task shifting; health services accessibility; patient participation; peer group.

1. INTRODUCTION

Scale-up of Anti-Retroviral Therapy (ART) in sub-Saharan Africa (SSA) went beyond what was estimated as feasible a decade ago, but it is not enough. Of the region's 10.5 million people in need of treatment, less than half are on ART [1]. The pandemic has decimated the ranks of farmers, teachers, doctors, nurses, young entrepreneurs and the future leaders of many nations, with a staggering 1.2 million HIV attributable deaths in SSA in 2010 alone [1]. The high mortality is the result of low treatment coverage and poor retention of patients initiated on treatment. A recent meta-analysis from over 17 countries in SSA revealed that patient retention was 70.0% and 64.6% at 24 and 36-months respectively [2].

From January 2003 to December 2011, 397,671 patients started life-saving ART therapy in Mozambique and as of December 2011, 273,561 remain active on treatment [3]. This marks an exponential increase in access to ART, undoubtedly saving thousands of lives. However, with national-level studies estimating 12-month patient attrition at 26%, there are serious concerns about the current health care model's ability to retain patients on treatment in the long-term[4]. A study done in Mozambique documented significant loss to follow-up (LTFU) observed at each step from HIV testing to treatment - also known as the leaking cascade. Only 56% of Mozambican patients testing positive enrolled in HIV care, and only 31% of patients living with HIV/AIDS (PLWHA) eligible for ART started treatment within 90 days of eligibility[5]. Studies examining the principal barriers to accessing ART in Mozambique have identified long distances to health facilities, transport constraints, food insecurity, low levels of knowledge around HIV, and lack of access to health facilities as the most commonly cited reasons for ART discontinuation[6]. One study conducted in central Mozambique highlights the challenges health facilities confront in attending burgeoning patient populations. In this study, high volume ART sites were found to have greater attrition than lower volume sites and a dose-response effect was identified associating levels of health facility staff and patient retention[7]. As in many countries, these problems have been addressed in Mozambique through adoption of task-shifting strategies, including non-physician medical technicians taking over the administration of ART traditionally handled by medical doctors, thus mitigating the effects of the HRH shortage[8].

These strategies, however, are unlikely to adequately address the challenges of an ever-growing ART population in a country that has goal of providing universal access to ART for PLWHA by 2015. It is imperative to develop out-of-clinic approaches to facilitate ART refill for healthy patients in the community. One such strategy based on a pilot model in the central Mozambique province of Tete proposes shifting key aspects of care and treatment responsibilities to Community ART Groups (CAG), a patient-centered model inspired by a local experience in Tete province. In this paper we describe the stepwise implementation of

CAG in Mozambique, and how lessons learnt from an innovative local small-scale intervention were exported to the national level, to become a national strategy. The program data on CAG were obtained through a chart review and routine data-collection.

2. STEPWISE IMPLEMENTATION OF CAG

Tete Province has a large geographic area of 100,724 km² and a population of 2.1 million inhabitants, of which approximately 7.5% are HIV-infected [9]. With over 90% of the population living in rural settings and only 32 of 105 official MOH health facilities offering ART, access to HIV/AIDS care and treatment services is a major obstacle for ART initiation and long-term retention. After noticing alarming rates of attrition from the ART program in 2007, health officials in Tete conducted a bottleneck analysis, which revealed a 21% LTFU rate among ART initiates who started treatment between May 2002 and August 2007[10]. Even more alarming was the subsequent finding that over half of the successfully traced LTFU population had died[10]. Despite significant investment in training volunteers, liaising with community-based organizations, and working to improve the quality of facility-based counseling services, retention of patients remained low.

Realizing that a fundamental modification was necessary, the provincial health team in Tete, supported by Médecins Sans Frontières (MSF), began to look at ways to address the underlying barriers to patient retention. Drawing on the robust body of chronic care literature and contemplating the potential implications and impact of a model designed to empower patients to care for themselves, the CAG strategy emerged[11,12,13]. To overcome barriers to monthly prescription pick-ups, stable patients on ART would be encouraged to form CAG, peer support groups of maximum 6 members, that would serve as a vehicle for community ARV distribution, adherence promotion, monitoring and reporting.

2.1 Phase One: First Experiences with CAG in Rural Contexts

In February 2008, the provincial pilot commenced in rural health facility catchment areas where ART was not yet available and LTFU rates were high. Local nurses, volunteers and community leaders were asked to invite known PLWHA to a community meeting with counselors to explore and document barriers to HIV service uptake. These discussions revealed three principal obstacles: 1) distances to health facilities, 2) costs of transport; and 3) availability of transport options. Noticing that the PLWHA enjoyed the social nature of the discussions and were, to a large extent, from the same communities, a suggestion was made to work as a team to overcome the obstacles to ART. PLWHA were asked to invite other known HIV positive individuals including family members, friends and neighbors to a follow-up meeting. There, the CAG strategy materialized as PLWHA began forming groups based principally on members' natural affinity (belonging to the same social network), and common needs as patients. A maximum of six members per group were registered on CAG group cards, one copy of which would be held by the members of the group themselves and the other of which would remain at the health facility for use by care providers. The CAG agreed to meet monthly to verify and register member adherence (evaluated via pill-count) on the group card and to send one representative each month using pooled resources to the health facility to retrieve ARV prescriptions for all group members. At the health facility, the representing CAG member would communicate to the clinician or counselor any important events occurring in the lives of the other members, have a routine consultation, and receive a treatment refill for all the group members of his or her CAG. Every six months groups met locally in the community or at the health facility with the counselor and the clinician. During

these meetings, experiences, difficulties and practical solutions were shared, and counselors and nurses educated CAG on issues such as the importance of unscheduled consultations whenever a member became ill. The CAG dynamic is illustrated in figure 1.

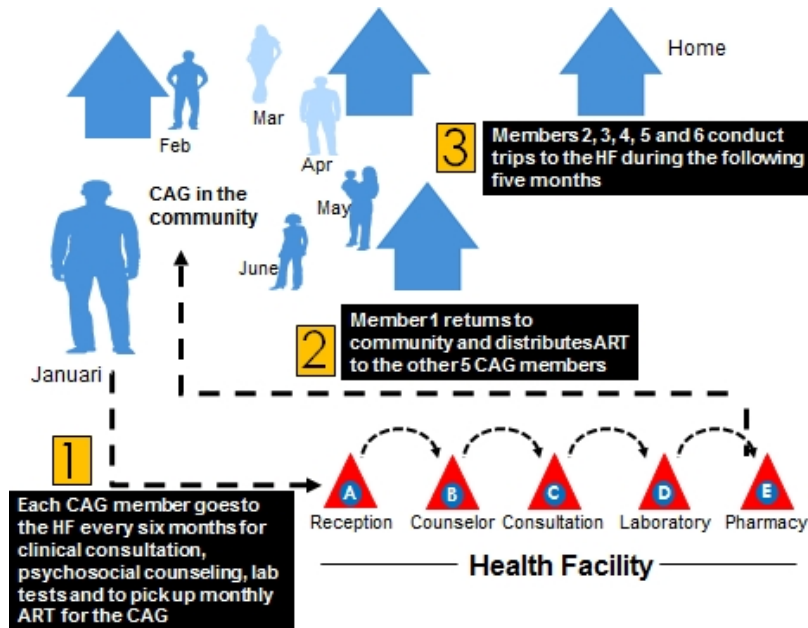


Fig. 1. Link between the members of a CAG and the clinic
 CAG = Community ART Group; ART = Anti-Retroviral Therapy

In this way, the strategy created a feedback loop between the provider and the community, assuring ownership by the communities, and creating an opportunity for the health provider to empower CAG members and guide the process of community participation. Once the first CAG were established, newly initiating ART patients began presenting themselves to CAG focal points in communities expressing their desire to become members. In this rural and poor context the advantages of social support outweighed the application of clinical inclusion criteria.

2.2 Phase Two: Provincial Roll out of CAG

Drawing on this first CAG experience, health officials in Tete subsequently extended the option to participate to patients living in semi-urban communities in closer proximity to major ART sites. While this demographic did not experience the same adherence barriers as their rural counterparts (transport costs and long distances to health facilities), CAG was a mean of reducing time spent at health facilities and the stigma tied to frequent clinic visits. Health officials implemented CAG in major ART sites using a process similar to that employed in the rural context: lay counselors met with patients to understand perceived barriers to ART follow-up and subsequently proposed CAG as a mean to facilitating long-term adherence to treatment. In semi-urban communities access was less problematic than in rural communities, and clinical inclusion criteria were applied. Participation in CAG was offered to

clinically stable patients. Interested candidates were screened to ensure they were more than six months on ART, had a CD4 count more than 200 cells per μL , and without active opportunistic infection. Each group was registered on a CAG group card similar to one that had been successfully employed in the rural context.

To assure consistency and proper monitoring, a mobile team composed of provincial CAG program managers, a senior counselor and a senior clinician visited each health facility implementing CAG on a monthly basis, providing technical support as needed. Provincial health partners also met regularly to review and discuss obstacles and achievements as well as to fine-tune implementation details such as inclusion criteria, data collection and monitoring tools.

To document this innovative strategy a chart review was conducted as part of a retrospective cohort study. Of the adult 1301 patients enrolled in 291 CAG between February 2008 and May 2010, 1269 (97.5%) were remaining in care, 30 (2.3%) had died, and 2 (0.2%) were lost to follow-up. Median follow-up time within a group was 13 months. The chart review confirmed that all patients that had died or that had abandoned treatment had been reported by the CAG members. The results of this retrospective cohort study and a description of the CAG monitoring tools were published elsewhere [14]. By the end of December 2012, the number of adult members enrolled in CAG increased substantially, and retention was sustained over time. Of the 5729 adult members, 5506 were active (includes 207 members who were transferred out), 209 (3.6%) died, and 14 (0.2%) were LTFU after a median follow-up time of 19 months (IQR: 10-29). Attrition was 2.2 per 100 person-years, with a mortality rate of 2.1 per 100 person-years and a LTFU rate of 0.1 per 100 person-years. LTFU rates remained low, as CAG members knew each other's whereabouts and reported deaths and adherence challenges to health staff as they occurred.

2.3 Phase Three: National Roll Out of CAG

Based on the successes of the CAG model in the province of Tete, in 2011 the Mozambican MOH began investigating how the strategy could be adapted for use at the national level. A task force composed of MOH officials and selected partner organizations drafted a national strategy, implementation protocol and monitoring tools to guide the expansion of CAG for the national pilot. In addition, a workshop was hosted in TeteCity to present the CAG model to clinical and community-based partners active in other provinces and to provide national health authorities the opportunity to observe the model in the field and interact with patient members.

Since mid-2011, the start of the national pilot phase, CAG were implemented in 30 health facilities throughout Mozambique. Careful selection of pilot facilities ensured participation of three ART sites of various patient volume stratifications in each of ten provinces excluding the province of Tete. Pilot health facilities were selected for each of three patient volume stratifications in each province. The volume stratification included one site with >1000 ART patients, one with between 500-1000 ART patients, and one with < 500 patients. All health facilities were selected based on the following inclusion criteria: Availability of TB services, pre-ART and ART services for at least 6 months, at least one nurse and one doctor on site, and access to CD4 testing (either on-site or off-site). The evaluation of the national pilot will focus on three key areas: (1) patient outcomes (alive and on therapy, LTFU, transferred out, stopped); (2) health facility workload (number of registered ART patients seeking services before and after CAG implementation); (3) cost implications of the CAG. In addition the CAG

experience for patients and healthcare workers will be evaluated through qualitative interviews and focus-group sessions [15].

At the end of 2011, three mobile teams, each composed of health managers, lay counselors and CAG members visited all of the health facilities participating in the national pilot to support the implementing health facilities. Questions at both the provincial and health facility level related to the objectives of CAG, mode of implementation, and use of monitoring tools with practical solutions proposed by the mobile team members. The team interacted with the direct implementers and the patients in the waiting area of each health facility. Health facility results, successes and difficulties were shared at a national workshop led by the Mozambique MOH and attended by implementing partners and the members of the mobile teams. As such, a formal feedback loop was created to analyze and direct the national CAG roll out. Early results show that the CAG strategy was well accepted. Treatment outcomes of CAG members compared favorably with outcomes of patients in conventional care. Moreover patients of neighboring districts began to ask to form CAG [16]. The rigorous evaluation of the national pilot will guide the future development of this community based ART model. The CAG development and implementation process is illustrated in figure 2.

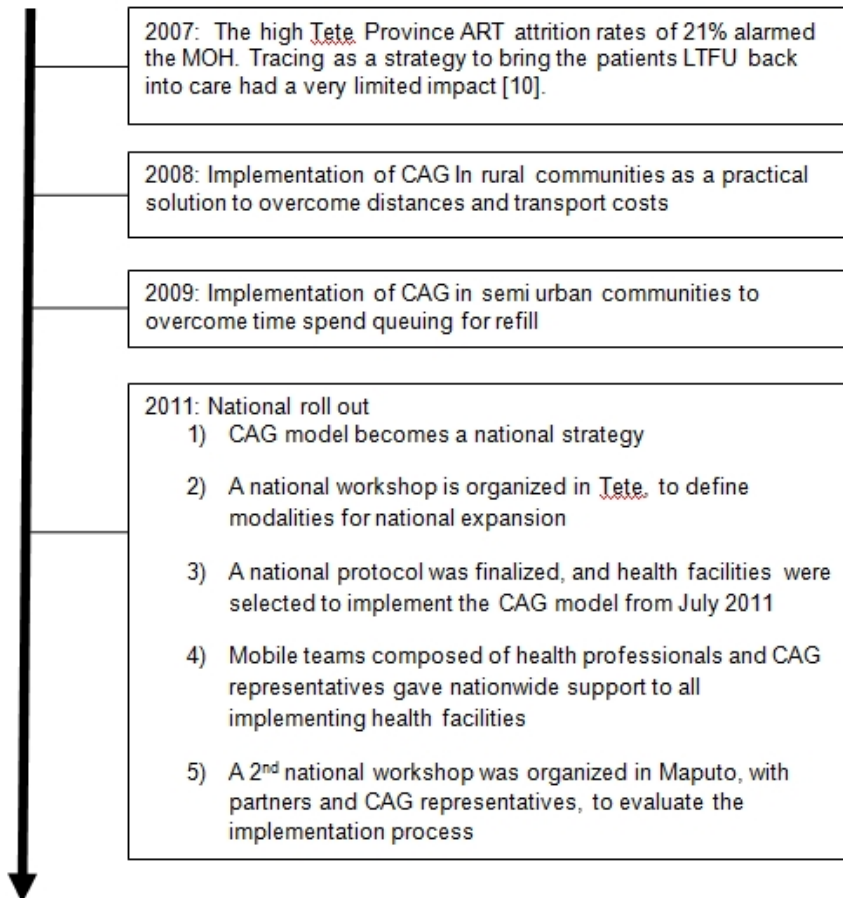


Fig. 2. Timeline of the launch of Community ART Groups in Mozambique
CAG: Community ART Group; LTFU: lost to follow up; MOH: Ministry of Health

3. DISCUSSION

The Government of Mozambique decided to scale-up nationwide the field experience of community-based ART delivery, in which ART patients are engaged in peer support groups to distribute ART and provide mutual adherence support. This simple patient-driven and community embedded ART care model had profound benefits for the patients and the health system. First, the work burden for health workers reduced resulting from CAG members sending representatives to retrieve pharmacy prescriptions on behalf of other group members. Second, the patient/provider relationships changed profoundly now patients became responsible for ART delivery and adherence monitoring. Third, CAG members' timely and accurate reporting on patient outcomes and adherence challenges led to the availability of more accurate information for use in program planning, management and indicator reporting. Deaths that occurred in the community didn't pass unnoticed, and were reported by fellow CAG members to the clinic staff. As a result of the proportion of patients with unknown treatment outcome among CAG members was less than 1%. Moreover an early warning system for disease identification and referral was established. Finally, at the community level, a cycle of information sharing was created with PLWHA accessing information through the CAG social network and transmitting knowledge and support to other peers over time.

Innovative approaches for models of ART care need to be designed with the reality of sub-Saharan Africa in mind. This includes adaptations to conform to the context of limited resources, diverse cultural factors and social integrity, as well as application of adherence promoters such as increased understanding of the importance of adherence, increased sense of self-worth, reminder tools, and community and peer support[11,17,18]. To optimally leverage all available resources, increased attention must be given to initiatives that partner with patients and established patient communities. This process involves standardization and simplification of treatment protocols and elimination of strategies not specifically focused on reaching the primary objective of initiating and maintaining patients on ART. Successful implementation of these programs could result in a substantial portion of the ART management workload being shifted to patients and communities, allowing the medical staff to focus on clinical case management, training, and supervision[12,19,20].

In Uganda and Kenya community-based ART care provided by lay staff proved to be as effective as health facility-based care as measured by retention and response to treatment. Additionally clinic visits were reduced 50% to 75%[21,22,23]. A study in Uganda found that community-based ART was associated with multiple positive social outcomes such as emotional support and relationship strengthening, and did not increase the stigma in the community[24]. This is consistent with other studies that have recognized community support as a determinant for improved treatment response and reduction of stigma[17,25, 26].

The community-based ART model in Mozambique differed from the care models in Uganda and Kenya. In Uganda and Kenya the community ART provider functioned as an extension of the health facility provider but within the community. In Mozambique, PLWHA organized themselves in a social network of small community support groups, and performed critical functions such as ARV distribution, outcome reporting, referral, and adherence support, motivated by health and psychosocial benefits, without any financial incentive.

A meta-analysis of attrition in sub-Saharan countries documented an attrition of 5 per 100 person-years among patients more than two years on ART [2]. The latter can be considered

as a threshold for attrition among stable patients. The outcomes among members in CAG, with 2.2 attritions per 100 person-years, compare favorably. However, the eligibility criteria that requires patients to be clinically stable and to have been on ART for 6 months before being able to join the program limit the comparison due to survivorship bias. Moreover, the data presented are program data and as such are subject to a number of limitations common to observational studies that threaten the validity and generalizability of the findings. While the low rate of attrition in this program suggests that the approach described herein has clear potential in supporting long-term ART management, questions remain regarding the impact of the CAG model in urban settings, how CAG members interact socially, and the impact of stigma on CAG-uptake in communities. A rigorous quantitative, qualitative and costing evaluation of the pilot will attempt to answer some of these questions. Adaptations of the CAG model are planned to reach particularly vulnerable groups, such as pre-ART patients, children, pregnant woman and patients being treated for tuberculosis.

Another concern is that the link between the community and the clinics was assured by counselors, remunerated by MSF. Counselors played an important role in the development of CAG, as they catalyzed the enrolment of patients in CAG and voiced the needs of the patients. A solution will need to be found for the dependency of the professional category of counselors, which has not yet been established in Mozambique.

Interested in the potential of the CAG strategy the governments of Malawi, Zimbabwe, Swaziland, Lesotho and South-Africa have sent delegations to visit Tete, and plan to adapt the CAG model to their context. In Tete, CAG were implemented as a response to local challenges. Can the strategy that was successful in Tete be applied to other social, cultural and political contexts, inside and outside of Mozambique? Considering that the process of implementation is as important as the evidence on which new protocols are built, Paine and Peters proposed to look at the health system as a complex adaptive system when scaling up effective and efficient health interventions[27]. Health systems are compromised of many interacting components and actors, such as policymakers, managers, regulators, researchers, caregivers, communities, and patients. Diverse socio-cultural and political factors, changing evidence, characteristics of delivery systems, characteristics of the users, and implementation capacity determine the complexity of the scale up of health interventions in developing countries. The scale-up of CAG is expected to be a non-linear process, marked by uncertainties, unexpected events and may result in new insights. And, to assure a successful roll out of this innovative model of community ART-delivery through patient networks, PLWHA need to be involved continuously during implementation, as community participation for HIV care can only be successful when driven and owned by the patients and the communities[28].

4. CONCLUSION

A sequence of events has catapulted a patient-driven community delivery ART care model from a small-scale intervention in central Mozambique to a national strategy being supported by the MOH and their partners. Neighboring countries are exploring how to implement CAG and adapt it to their environments. However, success of scale up and expansion of CAG will depend on the collaboration and interaction between policymakers, donors, health managers, caregivers, communities, and patients.

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CONSENT

Not Applicable

ETHICAL APPROVAL

Not Applicable

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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