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Title

Scaling Up Community ART Groups in Mozambique

SUMMARY

The ability of the health sector to respond to the pandemic in SSA has been compromised by severe human resource for health (HRH) shortages. To improve the accessibility and affordability of antiretroviral therapy (ART) the Provincial Directorate of Health and Médecins Sans Frontières piloted a community-based and patient-driven model for HIV care in Tete province, Mozambique, to improve retention on ART. The Community ART Group (CAG) strategy was designed to empower patients to take responsibility for community ART delivery, and to overcome patient reported barriers to monthly drug refills. In this paper we will describe the stepwise implementation and roll out of 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 were 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 MOH and major partners to pilot the CAG strategy on a national scale. Success of scale up will depend on the between policymakers, donors, health-managers, caregivers, communities, and patients.

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Key words: HIV; antiretroviral therapy, highly active; task shifting; health services accessibility; patient participation; peer group

Introduction

Scale-up of antiretroviral therapy (ART) in sub-Saharan Africa (SSA) over the past decade has been nothing short of spectacular, but it is not enough. Of the region´s 10.5 million people in need of treatment, less than half are on ART. 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% and 65% at 24 and 36-months respectively.[2] All of the world's high HIV prevalence countries are saddled with severe human resource for health (HRH) shortages. The ability of the health sector to respond to the pandemic in SSA has been further compromised by the current provider-centered biomedical model for HIV care. While such models were designed to provide periodic, time-limited services such as vaccinations and manage acute diseases such as malaria, they are ill-equipped to support chronic disease programs and to ensure optimal patient retention.

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With these perspectives in mind, in 2011, the Mozambique Ministry of Health began reshaping the traditional model of HIV care through the development of a patient-centered model inspired by a Community ART Groups (CAG) pilot in Tete province. This community based strategy was designed in 2008 in Tete province to empower self-managed patient groups to deliver antiretroviral therapy. In this paper we describe the stepwise implementation of CAG in Mozambique, and how lessons learnt from an innovative small-scale intervention were exported to the national level, to become a national strategy. The data on CAG were obtained through a chart review and routine data-collection.

Background

From 2003 to 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

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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 complement traditional task-shifting schemes. 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.

Stepwise Implementation of CAG

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Tete Province has a large geographic area of 100,724 km^2 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 that would serve as a vehicle for community ARV distribution, adherence promotion, monitoring and reporting.

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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 adherence obstacles. 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

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142 and the clinician. During these meetings, experiences, difficulties and practical
143 solutions were shared, and counselors and nurses educated CAG on issues
144 such as the importance of unscheduled consultations whenever a member
145 became ill. In this way, the strategy created a feedback loop between the
146 provider and the community, assuring ownership by the communities, and
147 creating an opportunity for the health provider to empower CAG members and
148 guide the process of community participation. Once the first CAG were
149 established, newly initiating ART patients began presenting themselves to
150 CAG focal points in communities expressing their desire to become members.
151 In this rural and poor context the advantages of social support outweighed the
152 application of clinical inclusion criteria. PLWHA often joined CAG having not
153 yet completed six months on ART and with CD4 counts below 200 cells per
154 μL.

155

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

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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 ingection. 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 mangers consistent of 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 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 June 2012, the number of members enrolled in CAG increased

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substantially. These early results have been sustained over time, with 4700 (96%) of 4895 members still in care by June 2012 (routine project data) LTFU rates remained low, as CAG members knew each other´s whereabouts and reported deaths and adherence challenges to health staff as they occurred. The CAG dynamic is illustrated in Figure 1.

Figure 1 Link between the members of a Community ART Group and the health facility.

This simple patient-driven and community embedded ART care model had profound benefits for the patients and the health system. First, health workers reported reduced work burden resulting from CAG members sending representatives to retrieve pharmacy prescriptions on behalf of other group members. Second, both health workers and patients reported the improvement in the quality of patient/provider relationships. 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 then 1%. Communication between the provider and the patients in CAG was further enhanced through the CAG group card that recorded disease screening results performed by group members and submitted each month to the

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clinician seeing the monthly CAG representative. This effectively created an early warning system for disease identification and referral.

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. Throughout the provincial pilot, CAG also proved effective as a community-based mechanism for providing mutual psychosocial support and shared information on HIV care and self-management. This, in turn, strengthened the perceived value of health services while simultaneously reinforcing the primary objective of CAG - improved ART patient retention. The sharing of information at the community level not only proved beneficial for patients already initiated on ART but also for patients with unknown HIV serostatus. Frequently, CAG members, recognizing possible HIV symptoms among their peers, encouraged and even referred individuals to local health facilities for HIV testing and care.

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 Tete City to present the CAG model to clinical and community-based partners active in other provinces and

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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.

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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. The CAG development and implementation process is illustrated in Figure 2.

Figure 2. Timeline of the launch of Community ART Groups in Mozambique.

Discussion

As high burden countries tackle the enormity of the HIV pandemic, institutions responsible for treating HIV-infected patients in those countries must adapt and respond to the structural constraints inherent to weak public health systems as well as the daily realities faced by poor people living with HIV/AIDS. 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.[11,16,17,18]

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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]

ART care delivery models embedded in the community reduce geographic barriers to medication refill and service utilization. Community-based ART care models have the potential to improve accessibility and affordability of treatment, and to result in a significant decrease in patient volume at already overburdened health facilities.[20] Furthermore, such models allow clinical staff to dedicate their time to symptomatic patients, ART initiations, and patients with non-HIV-related illnesses. 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 from an estimated 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]

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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.

The proportion of CAG members LTFU were lower than reported in the literature.[2] 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.[14] 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.

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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.

The Government of Mozambique decided to scale-up nationwide the field experience of Community-Based ART and a national protocol was developed. Interested in the potential of the 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, CASG 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 CASG is

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expected to be a non-linear process, marked by uncertainties, and unexpected events. The cycle of planning, implementation, monitoring, and evaluation may result in new insights. And, to assure a successful roll out of this innovative model of community ARV-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]

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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Legend figure 1: Link between the members of a Community ART Group and the health facility.

Community ART Groups (CAG) consist of a maximum of 6 members. Interested patients can join voluntarily and agree to meet monthly to verify member adherence (evaluated via pill-count), update a group card, and send one representative each month to the health facility to pick up ART 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. When back in the

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community the representative will distribute the ART. During the next months the other members will conduct the trip to the health facility.

Legend figure 2: Timeline of the launch of Community ART Groups in Mozambique.

Community ART Groups (CAG) commenced in 2008 as a small-scale initiative in rural communities to overcome barriers related to distances and transport. In 2009 this patient driven dynamic was adapted to the context of semi-urban areas, where patients joined CAG to spend less time in the queue of the clinics. Retention rates as high as 97,5% after a median time of 13 months in CAG convinced the Ministry of Health of Mozambique to pilot this innovative patient-centered treatment strategy on national scale from 2011 onwards. To assure that this innovative strategy was well understood, all stakeholders including policymakers, managers, regulators, researchers, caregivers, communities, and patients met during a workshop. While a national protocol informed all provincial health teams, a mobile team consisting of health professionals and CAG representatives visited all the provinces and gave support based on their experiences.

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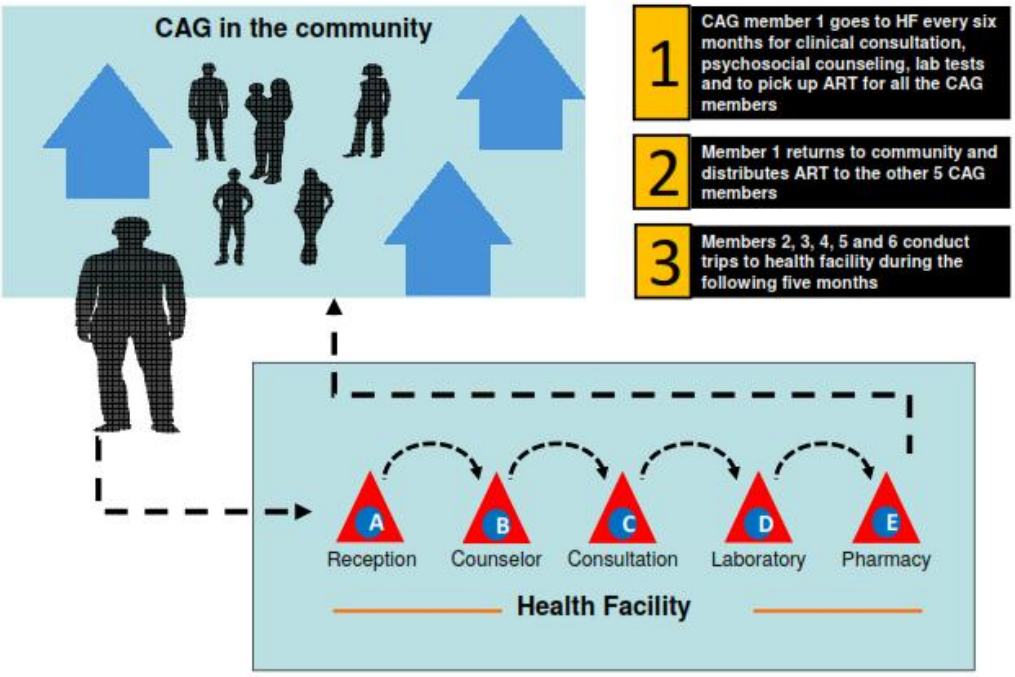
Figure 1 Link between the members of a Community ART Group (CAG) and the health facility.



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527 **Figure 2.** Timeline of the launch of Community ART Groups in Mozambique

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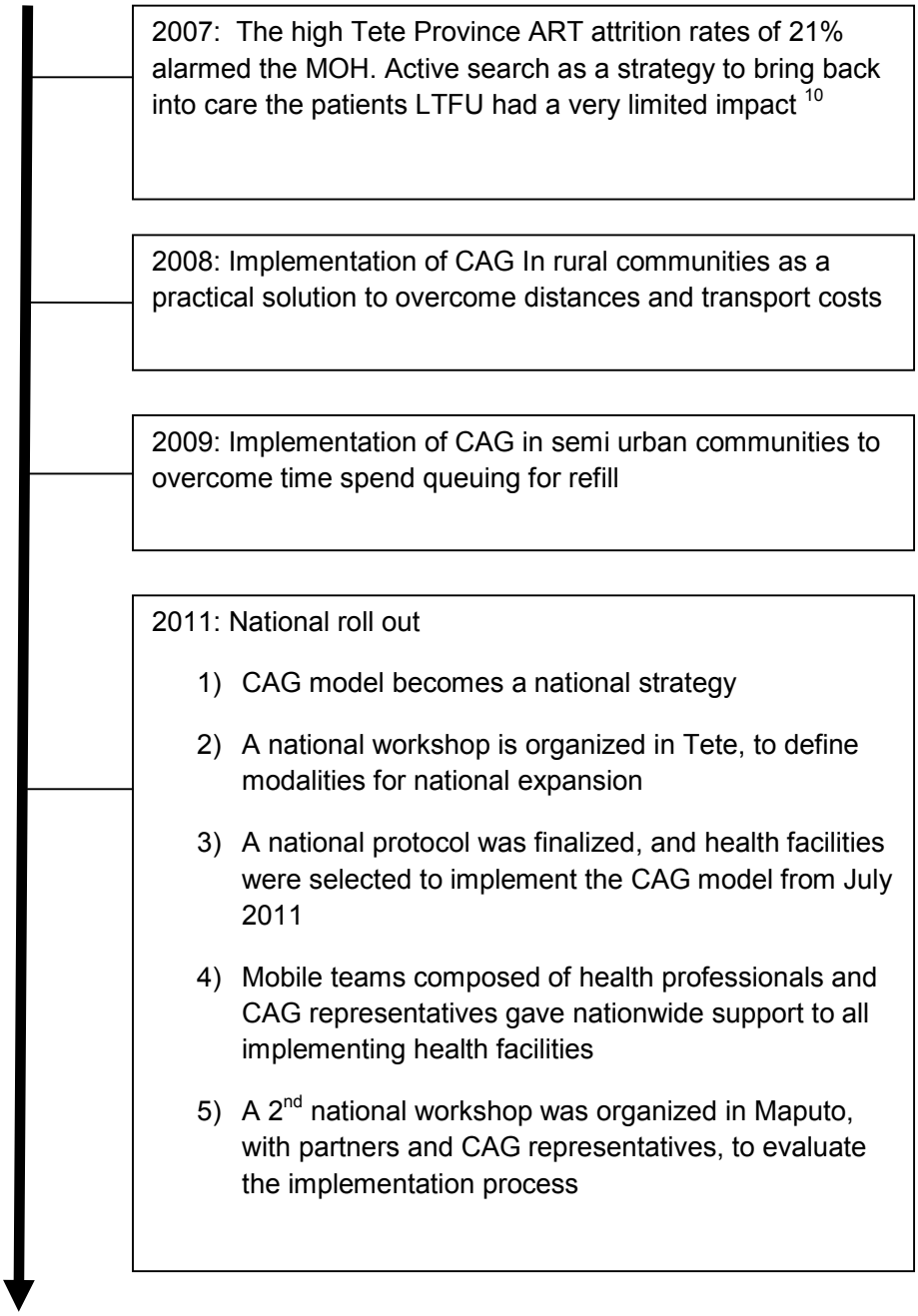

550 CAG: Community ART Group; LTFU: lost to follow up; MOH: Ministry of Health

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