

**Community-based ART in sub-Saharan Africa: lessons learnt
from Community ART Groups in Tete province,
Mozambique**



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Table of content

Prologue	13
1. General introduction	15
How to control the HIV epidemic?	15
90-90-90 targets	15
Performance of ART programmes	16
ART roll out in Mozambique	17
Peer-led ART delivery, in Tete, Mozambique	18
2. Objectives	25
3. Methods	27
4. Results	31
Chapter one: Challenges with decentralization of ART to primary health care facilities in Tete	31
Chapter two: Retention in care in Community ART Groups, a peer-led ART delivery model, in Tete	37
Chapter three: Transferability of lessons learnt from Community ART Groups in Tete to other settings	69
Chapter four: Community-based ART in sub-Saharan Africa	89
Chapter five: Spill over effect of participation in ART delivery on utilization of other health services	105
5. General discussion and conclusion	129
Facility-based ART delivery: insufficient to cover ART needs	129
Peer-led ART delivery in Tete: high retention on ART	131
Peer-led ART delivery: transferable to other settings	133
Community-based ART: a key component of differentiated care	136
Peer-led ART delivery: uptake of other health services remains low	139
Strengths & limitations of the methodological approach	141
Communities and HIV care: the way forward	145
Community engagement is key to achieve 90-90-90	145
Community-based comprehensive HIV care: a proposal	146
Conclusion	149

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Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
CAG	Community ART Groups
CBART	Community-based ART
HIV	Human Immunodeficiency Virus
LTFU	Lost to follow-up
MOH	Ministry of Health
MSF	Médecins Sans Frontières
PLHIV	People Living with HIV
SSA	sub-Saharan Africa
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

Glossary of terms

Community-based ART delivery (CBART): model of care whereby ART is delivered to patients in the community. For this thesis the definition is restricted to lay provider-led CBART. Lay providers include community health workers, volunteers, and PLHIV.

Community-based comprehensive HIV care: model of care whereby all the key components of HIV care, such as HIV testing, ART initiation, and ART refill are delivered in the community.

Community engagement (or community participation) in medical care: process whereby community stakeholders (including patients, community leaders, community health workers, thought leaders) are involved in designing, planning, and implementing medical activities.

Patient participation (in medical care): Patients are not passive receivers of care, but are responsible for one or more medical tasks which are essential for achieving and maintaining a healthy status.

Peer-led ART delivery: a form of CBART, whereby peer groups are responsible for ART delivery.

Peer support: The support received from peers, living with the same (chronic) condition and experiencing the same challenges.

Retention on ART: Patients active in care and on ART. The opposite is attrition, and includes those who died or were LTFU.

Self-efficacy (being autonomous): Patients use their expertise of living with a chronic condition and acquired knowledge and skills to achieve and maintain a healthy status. Patients are responsible for the day-to-day management of their chronic condition.

Beknopte samenvatting

Wereldwijd leven naar schatting 36,7 miljoen mensen met HIV . In juni 2016 namen 18,2 miljoen een antiretrovirale therapie (ART). De epidemie is nog niet gecontroleerd: in 2015 werden 2,1 miljoen nieuwe infecties en 1,1 miljoen doden gerapporteerd. Om HIV overdracht en HIV gerelateerde sterfte te controleren zullen de meeste mensen met HIV ART moeten nemen. Dit is een grote uitdaging, vooral in sub-Saharaans Afrika, de regio met de hoogste HIV-prevalentie.

Dit proefschrift evalueert benaderingen die gericht zijn op het verbeteren van de toegankelijkheid en het gebruik van ART programma's. In Mozambique werd ART gedecentraliseerd naar eerstelijns gezondheidscentra. Het tekort aan gezondheidswerkers, een gebrekkige infrastructuur, een gebrek aan coördinatie, en grote afstanden tussen gemeenschappen en gezondheidscentra beperkten de impact van dit decentralisatie proces. Zodoende bleef de grote meerderheid van mensen met HIV nog steeds zonder behandeling. We leerden dat ART decentralisatie niet zou volstaan. Bovendien stopte een hoge proportie van mensen met HIV hun behandeling.

Hoe kan ART toegankelijk worden in elke gemeenschap, en hoe kunnen patiënten gemotiveerd worden om ART te starten en de behandeling levenslang te nemen? In 2008, in de rurale uithoeken van de provincie Tete, stelden we patiënten voor om zelfhulpgroepen te vormen. Deze zelfhulpgroepen, CAG genaamd, werden verantwoordelijk voor ART bedeling in hun gemeenschap. Retentie was hoog. CAG leden meldden een vermindering van directe en indirecte behandelingskosten, en voelden zich opgelucht door de gemakkelijk en zekere toegang tot ART. Ervaringen met CAG in andere provincies van Mozambique, en in Lesotho, toonden aan dat het CAG model kon aangepast worden aan verschillende contexten. Een systematische literatuurstudie bevestigde dat niet medisch geschoolde zorgverleners effectief waren in het bedelen van ART in verschillende landen. Bovendien bereikten programma's die ART bedelen op gemeenschapsniveau patiënten die voorheen geen toegang hadden tot de regulier gezondheidszorg.

Deelname van patiënten aan ART bedeling leidt niet automatisch tot een beter gebruik van alle beschikbare gezondheidszorgdiensten. Minder dan de helft van de familieleden van CAG leden deed een HIV test. Bovendien werd moeder- kind zorg niet goed gebruikt door de CAG leden en hun familie. Anderzijds, wanneer het routinematig opvolgen van de virale lading beschikbaar werd in Maputo, was het gebruik van deze test hoger bij CAG leden dan bij patiënten die niet lid waren van een CAG. Hoe op een meer systematische manier gemeenschappen te betrekken bij medische zorg dient verder onderzocht te worden.

De observationele studies van dit proefschrift hebben een aantal belangrijke beperkingen, die inherent zijn aan de observationele methode. Anderzijds weerspiegelen de bevindingen van operationeel onderzoek de realiteit van het programma. Bovendien bevestigden de resultaten van kwalitatief onderzoek de kwantitatieve bevindingen. Resultaten van opeenvolgend onderzoek resulteerden in aanvullende inzichten.

Gemeenschapsparticipatie voor medische HIV zorgverstrekking wordt steeds meer erkend als een stimulus voor het gebruik van beschikbare zorg. Het effect van participatie op het hele continuüm van HIV-zorg is echter nog niet onderzocht. Dit is een belangrijk onderwerp voor toekomstig onderzoek. Bovendien zal ART niet volstaan op de HIV epidemie onder controle te krijgen. Een uitgebreid pakket van preventieve, diagnostische en therapeutische interventies zal moeten verankerd worden in het dagelijkse leven van gemeenschappen met een hoge HIV prevalentie.

Executive summary

Globally an estimated 36.7 million people are living with HIV (PLHIV). By June 2016, 18.2 million were enrolled on ART. The epidemic is not yet controlled: 2.1 million new infections and 1.1 million deaths were reported in 2015. Higher levels of ART coverage are needed to control HIV transmission and reduce mortality. Therefore, barriers to ART will need to be removed maximally. This is a major challenge, especially in sub-Saharan Africa (SSA), the region with the highest HIV prevalence.

This thesis evaluates approaches which aimed at improving accessibility and utilization of the ART programme. In Mozambique, to reduce geographical barriers to ART and to increase the absorptive capacity of the health system, ART was decentralized to primary health care clinics. But the implementation of ART decentralization was slowed down due to a shortage of health care workers, inadequate infrastructure, and a lack of coordination. Although more patients were enrolled on ART, coverage of ART needs remained low. Moreover, distances remained a major barrier to ART. We learnt that facility-based ART would not suffice to achieve and sustain high levels of ART coverage. Moreover, high attrition (defined as patients being either death or loss-to-follow-up) rates showed that successful ART provision entailed more than enrolling patients on ART.

How to bring ART delivery closer to the patient's home, and motivate PLHIV to use these services? In 2008, in the rural communities of Tete province, we proposed patients stable on ART to join peer groups, and engage in community ART delivery. These peer groups were named Community ART Groups (CAG). Early and long term retention on ART in CAG was high, and higher than in individual care. The better the peer group functioned, the higher the retention on ART. CAG members reported a reduction of direct and indirect treatment costs, and felt relieved by the secured supply of ART. Experiences with CAG in other provinces of Mozambique, and in Lesotho, showed that the CAG model could be adapted and transferred to other settings. A systematic review included in this thesis confirmed that different lay provider-led community-based-ART delivery models were effective in retaining patients on ART. Moreover, such community delivery models make ART accessible to PLHIV

who would not be able to travel periodically to a health facility. To achieve and sustain ART coverage programs will need to differentiate, and offer patients the possibility to switch from one delivery platform to another, in the facility or in the community.

Patient participation in ART delivery doesn't lead to a better utilization of all available health services. Although CAG members were perceived as co-providers of the ART program, surprisingly less than half of the family aggregate was tested for HIV. Moreover, mother and child health services were not well used by the CAG members and their family aggregate. On the other hand, when viral load monitoring was implemented in Maputo, the uptake of viral load monitoring was higher in CAG than in individual care. What motivates communities to use available health services, and eventually engage in medical care? Multiple determinants are at play, including the patient-level, society-level, and health system-level factors, and the characteristics of the medical intervention. How to involve communities in a more systematic manner in medical care should be further investigated.

The observational studies included in this thesis have some important limitations, inherent to the observational design. On the other hand, the findings of operational research represent the reality of the programme. Qualitative data confirmed quantitative findings. Results of consecutive research initiatives resulted in complementary insights.

Community engagement is increasingly recognised as an enabler of uptake, linkage, retention, and adherence. However, the performance of programmes that engage community actors along the whole continuum of HIV care has not yet been studied. This is an important topic for future research, and will require collaboration of researchers from different domains. Moreover, it will take more than treatment to control the HIV epidemic. In high prevalence contexts a comprehensive package of preventive, diagnostic, and therapeutic interventions will need to be embedded in daily life. When barriers are removed and communities are motivated to use available services, HIV control may become feasible, even in resource constrained contexts.

Prologue

In 2007, when I was working with Médecins Sans Frontières as the coordinator of an HIV clinic, I read “expert patients and AIDS care” (1). The authors, Katherina Kober and Wim Van Damme, hypothesized that experiences with self-management for chronic disease care could inform HIV care: PLHIV gain expertise in the day-to-day management of their chronic condition, and become experts in living with HIV and its treatment. Hence, PLHIV could use this expertise and become involved in medical care, and become less dependent of psychosocial and medical HIV care.

The lecture of this manuscript was my first contact with the concept of “experts patients”. It was a milestone in my professional development. Previously, between 2003 and 2006, in Mozambique, I had witnessed how much ART impacted on the prognosis of severely immunosuppressed patients (also described as the Lazarus effect). However, access to ART was poor, as ART scale-up was hampered by the extreme workforce gap and the poor geographical health care coverage. To increase the absorptive capacity of the health system lay health care workers were recruited to do HIV testing and to prepare patients for lifelong daily ART. Unexpectedly, they guided medical doctors in prescribing and monitoring ART (in the early days of the ART scale-up most medical doctors had no experience in HIV care).

The concepts provided in “expert patients and AIDS care” and my experiences with lay counsellors convinced me that medical tasks, if simplified and standardized, could be transferred to PLHIV. In 2007, when I became the “padrinho” for scaling up ART in the peripheral primary health care facilities of a rural district, Chiuta, we visited these health facilities two-weekly. We observed how social obligations or work impeded some patients to adhere to the scheduled ART consultations. During the many hours spend in the care, I discussed with Sergio Dezembro, chief counsellor, how we could involve PLHIV in ART, and secure their ART delivery. We agreed to explore the concept of “expert patients”. We invited interested patients to form a peer network, and to represent one another at the clinic during the ART consultations. On public holidays we met with patients,

counsellors and Ministry of Health nurses from different clinics, and discussed challenges and lessons learnt. The groups were called “Grupos de Apoio TARV”, or “Community ART Groups (CAG)”.

Quickly ideas and practices from Chiuta expanded to five additional districts in Tete province. The work that is presented here is the result of a process of “learning by doing” in a programmatic context. Findings were shared during conferences, and were promoted by WHO and UNAIDS as good practices. I feel it was a privilege to participate and witness this long journey, during which a practical solution for a concrete problem in a remote corner of Tete province became a recommendation for implementers and policymakers working in high prevalence settings.

My role changed over time: from implementer, to researching implementer, to researcher. The Master in Public Health, specific short courses, and working in a research oriented environment with MSF (Operational Research Unit) and the ITM (Unit of HIV/AIDS & Infectious Diseases) were conducive in this process. What didn’t change, is my passion for the topics addressed in this thesis.

1. General introduction

Globally an estimated 36.7 million people are living with HIV (PLHIV). By June 2016, after more than a decade of antiretroviral therapy (ART) scale-up, 18.2 million were enrolled on ART (2). The epidemic is not yet controlled. Although overall HIV transmission and AIDS related mortality decreased, 2.1 million new infections and 1.1 million deaths were reported in 2015 (2). The vast majority of PLHIV live in sub-Saharan Africa (SSA). In SSA the coverage of ART needs is 47.4%: out of 25.5 million PLHIV about 12.1 million were receiving ART (3).

How to control the HIV epidemic?

To reduce HIV transmission and AIDS related mortality programmes will need to ensure that preventive, diagnostic, and therapeutic services will be widely accessible and continuously used (4). Preventive measures include condom use, male circumcision, pre-exposure prophylaxis, prevention of mother-to-child transmission, and ART initiation at any CD4 count (5). Individuals with an unknown or negative HIV status need to test for HIV periodically. Those who test positive will need to start early to have a maximal effect of ART on the reduction of HIV transmission and mortality (6). Therefore ART has to be very accessible, and PLHIV will need to be motivated to seek and adhere to daily ART. When large proportions of PLHIV in a community are enrolled on ART, are retained in care, adhere to ART, and subsequently achieve an undetectable viral load, both mortality and HIV transmission will be reduced within that community (6). The coverage of ART needs is thus an important indicator of HIV control in a population.

90-90-90 targets

Global targets for ART coverage have evolved over time. The first target, “three by five”, aimed at 3 million on ART by 2005 (7). In that era, most programmes in sub-Saharan high prevalence countries offered ART exclusively to the most immunosuppressed patients, with CD4 levels below 200 cells per microliter (8). When evidence showed important benefits of ART in less immunosuppressed patients treatment guidelines became more inclusive. In 2010 the WHO recommended a threshold of 350

cells/ μ l (9), and in 2013 a threshold of 500 cells/ μ l (10). In 2011 the United Nations proposed a new target :“15 million on ART by 2015”. This target was met 9 months earlier than scheduled. Since 2015, WHO guidelines recommend ART initiation at any CD4 count (11). Currently the World Health Organization (WHO) endorses the 90-90-90 UNAIDS targets: by 2020, 90% of people living with HIV should know their HIV status. Of those, 90% should be on ART, and 90% of people on ART should have a suppressed viral load. Or, when combined as a single indicator, 73% of all PLHIV should have a suppressed viral load (12).

Performance of ART programmes

In sub-Saharan Africa (SSA), the implementation of HIV care is hampered by structural barriers, such as the health workforce gap and the inadequate infrastructure of health facilities (13). Hence, health policies had to adapt to enrol millions on ART during the past decade. Many tasks were standardized and shifted from doctors to nurses, from nurses to lay workers, and from lay workers to patients. Nurses became involved in ART prescription, lay workers became involved in HIV testing and adherence counselling, and patients were invited to join peer groups to share treatment experiences (14). Simultaneously treatment was decentralized from specialized HIV clinics to peripheral primary health care facilities. All these policies aimed at increasing the absorptive capacity of resource constrained health systems and increase the geographical accessibility of ART (15).

However, successful ART provision entails more than including patients on ART. High levels of attrition on ART (defined as patients being either death or loss-to-follow-up (LTFU)) reversed some of the advances made. A recent systematic review of ART outcomes in African countries showed attrition rates of 18%, 24%, and 31% at six months, one year, and two years ART, respectively (16). Structural, health system, patient, and social factors explain high LTFU rates (17). Structural factors include distances between communities and health facilities, transport costs, and lack of regular transport. Health system factors include lack of health care workers, long waiting times at the health facilities, and lack of trust between patient and health care workers. Patient and social factors

include work responsibilities, family commitments, stigma, and discrimination (18). Implementers understood that innovative approaches would be needed to reduce barriers to ART refill (19,20). Proposed measures included fast tracking of healthy patients to the pharmacy (in many programmes patients had to queue every month consecutively at the reception, the counselling room, the clinical consultation room, and finally at the pharmacy), spacing of appointments for clinical consultations at the clinic, and community-based ART pick-up (18, 21).

ART roll out in Mozambique

Mozambique, one of the sub-Saharan countries with a high prevalence, counts 23.9 million inhabitants, out of which 1.5 million are infected with HIV (2). The government began providing antiretroviral therapy in 2003 (22). By the end of 2015 more than 802,000 individuals were reported to be on ART (3). This was an enormous achievement for a country with one of the worst health workforce gaps on earth (0.03 doctors and 0.21 nurses per 1000 inhabitants) (23,24). In addition, many patients had to travel monthly to fetch their ART refill at the health facility. In Mozambique, the distance between the communities and the nearest health facility is more than 10 km for more than 50% of the population (23).

Initially, ART was provided in HIV clinics, supported or managed by non-governmental organizations, and located in the larger agglomerations. In 2005, out of Mozambique's 1338 health facilities, 36 were providing ART, or an average of 3 health facilities per province. Between 2003 and 2005, the first three years of the ART programme, 19,000 PLHIV started ART (22). In that period most PLHIV had no access to HIV care. For them AIDS remained a deadly condition. Between 2006 and 2008, HIV care was decentralized to rural nurse-led health care facilities. The number of health facilities providing ART increased from 36 to 140 facilities in 2006, and 213 facilities in 2008. Between 2006 and 2015, the yearly number of individuals starting ART was 80,000, on average (22).

However, many patients who started ART were LTFU or died. One study showed an overall attrition rate of 37 per 100 person-years (25). Another study showed that half of those who started ART were

either dead or LTFU at 3 years follow-up (26). Barriers to retention-in-care reported by patients included distances, lack of information, queuing at the health facilities, and stigma associated with regular presence in the health facility (27,28). Attrition was worse in overloaded health facilities (29)

In the central Province of Tete, with a population of two million inhabitants, 24 out of 105 health facilities provided ART in 2008 (22). In health facilities supported by Médecines Sans Frontières (MSF) about one in five patients on ART was LTFU (30). Attrition was even worse in health facilities without support from MSF. Home visits of patients LTFU were unsuccessful in bringing patient back to care (30). Patients were hard to trace due to incomplete addresses in the patient files, and distances between the facility and the patient's home. When a patient's home was localized, frequent explanations for not returning to the health facility included death and moving to another community. Some patients found it hard to reengage in HIV care, because of social or work obligations, time spend travelling to the clinic, time spend queuing at the clinic, lack of public transport, and costs of public transport (30). As a reaction to the high levels of attrition the provincial MOH halted further decentralization of ART.

Peer-led ART delivery, in Tete, Mozambique

In 2008, the care model was very provider-driven, with little space for patient participation. The focus of the early years of the ART programme was on scaling up ART initiation. This focus shifted in 2008. How to retain those who started ART in a context characterized by structural challenges worried the MOH and their partners.

How to adapt HIV care delivery to fit better patient needs? On the one hand, many patients were still presenting with AIDS, and were in need of referral clinical care. For them HIV was still a severe and often deadly condition (31). On the other hand, PLHIV stable on ART had to be treated as people living with a chronic condition (1). But, in Tete province none of the actors was experienced in providing large scale chronic disease care.

Unprecedented challenges require innovative approaches. The literature on chronic disease care showed that an increased level of self-efficacy can enhance behavioural change, which is key to adhere to a lifelong treatment (1). Given this evidence, the beneficial effect of peer support on health service utilization (32), and the social constructs of identity in Africa, whereby personal views and actions are strongly correlated with collective views and priorities (33), we proposed patients on ART to join a peer group dynamic in which they would be responsible for community ART delivery. These peer groups were named Community ART Groups (CAG). Patients interested in joining a CAG contacted their peers in the community, proposed them to form a peer group, and returned together to the health facility to be registered as a CAG. Each CAG consisted of maximally six members. Monthly members in CAG indicated a group representative to pick up ART at the health facility. CAG members took turns in representing their CAG at the health facility. When representing the CAG at the clinic the group representative had a clinical consultation. When back in the community the group representative distributed ART during a peer group meeting. When sick, CAG members went for an unplanned consultation to the health facility, as any other patient on ART who developed symptoms in between two appointments.

First, this thesis describes the challenges with ART decentralization, which motivated us to consider PLHIV as co-providers. Second, it describes early and long term retention on ART in CAG, and compares retention in CAG with retention in individual care. Then it describes the expansion of CAG in Mozambique and Lesotho, and shows other experiences with community-based ART (CBART) in the sub-Saharan region. Finally, spillover effects of participation in ART distribution on the use of other HIV services and mother and child health care services are presented.

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2. Objectives

Rationale: In Tete, ART roll out was constrained by distances between communities and health facilities and high attrition. As a first response ART was decentralized to community-embedded primary health care facilities. The many constraints encountered during decentralization informed the first research question addressed in this thesis: “How did primary health care centres in Tete city perform when ART was decentralized?” The results boosted policy makers to “think out of the box”. Hence, the CAG model was proposed to stable patients. This was a novel approach. There was no literature on experiences with peer-led ART delivery that could guide us. Hence, the subsequent questions addressed in this thesis “Can patients in peer groups effectively participate in ART delivery”, “Are lessons learnt from community participation in ART delivery in Tete transferable to other contexts?”, and “Does community participation in ART have a positive impact on the utilization of other health services?” had a direct, practical relevance for ART programme managers of the setting where the studies were conducted, and policy makers working in other resource constrained high prevalence countries. As the studies were embedded within the regular HIV programme, the designs had to be feasible in a programmatic setting. Retrospective studies using descriptive and analytical methods were complemented with mixed methods studies. A systematic review was conducted to situate the findings in the literature on CBART.

General objective: The overall aim of this thesis is to evaluate the performance of CBART programmes in ART delivery in Mozambique and the sub-Saharan region.

Specific objectives:

- To describe the challenges with decentralization to community-based primary health care facilities, in Tete, Mozambique
- To describe the CAG model, the early and long-term results and estimate the effect on retention on ART, in Tete, Mozambique
- To study the transferability of lessons learnt from CAG to other settings, in Mozambique and in Lesotho
- To study effectiveness, cost and acceptability of community-based ART care for SSA through a review of published literature, and formulate recommendations for the future of community-based HIV care
- To study if participation in CAG in had a spillover effect on utilization of other health services such as mother and child health services in Tete and routine viral load monitoring in Maputo

3. Methods

The thesis includes a total of **nine studies**, listed here below, by specific objective. The methods used are summarized in table1.

To describe the challenges with decentralization to community-based primary health care facilities, in Tete, Mozambique

- (1) **Decroo T**, Panunzi I, das Dores C, Maldonado F, Biot M, Ford N, Chu K. Lessons learned during down referral of antiretroviral treatment in Tete, Mozambique. *J Int AIDS Soc.* 2009;12:6.

To describe the CAG model, the early and long-term results and estimate the effect on retention-in-care, in Tete, Mozambique

- (2) **Decroo T**, Telfer B, Biot M, Maikere J, Dezembro S, Cumba LI, et al. Distribution of antiretroviral treatment through self-forming groups of patients in Tete Province, Mozambique. *J Acquir Immune Defic Syndr.* 2011;56(2):e39-e44.
- (3) **Decroo T**, Koole O, Remartinez D, dos Santos N, Dezembro S, Joffrisse M, Rasschaert F, Biot M, Laga M. Four-year retention and risk factors for attrition among members of community ART groups in Tete, Mozambique. *Trop Med Int Health.* 2014;19(5): 514-21.
- (4) **Decroo T**, Telfer B, Das Dores C, Candrinho B, White RA, Dos Santos N, Mkwamba A, Dezembro S, Joffrisse M, Ellman T, Metcalf C. The effect of Community ART Groups on retention-in-care among patients on ART in Tete Province, Mozambique: a cohort study. *BMJ Open.* 2017; submitted.

To study the transferability of lessons learnt from CAG to other settings, in Mozambique and in Lesotho

- (5) **Decroo T**, Lara J, Rasschaert F, Bermudez-Aza EH, Couto A, Candrinho B, Biot M, Maikéré J, Jobarteh K. Scaling Up Community ART Groups in Mozambique. *Int STD Res Rev.* 2013;1(2):49-59.

- (6) Vandendyck M, Motsamai M, Mubanga M, Makhakhe S, Tungal S, Jonckheree S, Van Cutsem G, Shroufi A, **Decroo T**. Community-based ART resulted in excellent retention and can leverage community empowerment in rural Lesotho, a mixed method study. HIV/AIDS Res Treat. 2015;2(2):44-50.

To study effectiveness, cost and acceptability of community-based ART care for SSA through a review of published literature, and formulate recommendations for the future of community-based HIV care

- (7) **Decroo T**, Rasschaert F, Telfer B, Remartinez D, Laga M, Ford N. Community-based ART programs can overcome barriers to ART retention of patients on ART and decongest health services in sub-Saharan Africa: a systematic review. Int Health. 2013;5(3):169-79.

To study if participation in CAG in had a spillover effect on utilization of other health services such as mother and child health services in Tete and routine viral load monitoring in Maputo

- (8) Geelhoed D, **Decroo T**, Dezembro S, Matias H, Lessitala F, Muzila F, et al. Utilization of and barriers to HIV and MCH services among Community ART Group members and their families in Tete, Mozambique. AIDS Res Treat. 2013; 2013:937456.
- (9) Swannet S, **Decroo T**, de Castro SMTL, Rose C, Giuliani R, Molino L, et al. Journey towards universal Viral Load monitoring in Maputo, Mozambique: Many gaps, but encouraging signs. Inter Health. 2017;accepted for publication.

Contributions to additional publications, which added insights into the thesis topic, but not included in this thesis:

- Jobarteh K, Shiraishi RW, Malimane I, Samo Gudo P, **Decroo T**, Auld AF, Macome V, Couto A. Community ART Support Groups in Mozambique: The Potential of Patients as Partners in Care. PLoS One. 2016;11(12):e0166444
- **Decroo T**, Ford N, Laga M. Lifelong ART for 20 million people in sub-Saharan Africa: communities will be key for success. The Lancet Global Health. 2014;2(5):e262-e263.
- Rasschaert F, **Decroo T**, Remartinez D, Telfer B, Lessitala F, Biot M, Candrinho B, Van Damme W. Sustainability of a community-based anti-retroviral care delivery model – a qualitative research study in Tete, Mozambique. Journal of the International AIDS Society. 2014;17:18910.
- Rasschaert F, **Decroo T**, Remartinez D, Telfer B, Lessitala F, Biot M, Candrinho B, Van Damme W. Adapting a community-based ART delivery model to the patients' needs: a mixed methods research in Tete, Mozambique. BMC Public Health. 2014;14(1):364.
- Rasschaert F, Telfer B, Lessitala F, **Decroo T**, Remartinez D, Biot M, Candrinho B, Mbofana F, Van Damme W. A qualitative assessment of a community antiretroviral therapy group model in Tete, Mozambique. PLoS One. 2014; 9(3):e91544.
- Lynch S, Ford N, Van CG, Bygrave H, Janssens B, **Decroo T**, Andrieux-Meyer I, Roberts T, Balkan S, Casas E, Ferreyra C, Bemelmans M, Cohn J, Kahn P, Goemaere E. Public health. Getting HIV treatment to the most people. Science. 2012;337(6092):298-300.
- **Decroo T**, Van Damme W, Kegels G, Remartinez D, Rasschaert F. Are Expert Patients an Untapped Resource for ART Provision in Sub-Saharan Africa? AIDS Research and Treatment 2012;2012:749718.

Table 1: Methodological characteristics of the nine studies included in the thesis

Chapter	Location	Objective	Design	Study population	Data sources	Data analysis
1	Tete city, Mozambique (1)	Describe challenges with decentralization of ART to primary health care facilities	Descriptive study	Patients on ART	Prospectively updated database ART registers	Descriptive
2	Tete province, Mozambique (2)	Describe characteristics and early outcomes of patients in CAG	Retrospective cohort study	Patients in CAG	Prospectively updated database	Descriptive
	Tete province, Mozambique (3)	Estimate long-term retention in CAG Estimate predictors of attrition in CAG	Retrospective cohort study	Patients in CAG	Prospectively updated database	Descriptive Analytical
	Tete province, Mozambique (4)	Estimate the effect of CAG versus individual care on retention-in-care	Retrospective cohort study	Patients in CAG and in individual care	Prospectively updated database File review	Descriptive Analytical
3	Mozambique (5)	Describe the early uptake and process of national CAG roll-out in Mozambique	Descriptive study	Patients in CAG	Reports	Descriptive
	Nazareth, Lesotho (6)	Describe retention in CAG and in individual care Explore views and experiences with CAG implementation	Mixed methods	Patients in CAG and in individual care Health staff	File review Focus group discussions	Descriptive Thematic content analysis
5	Sub-Saharan Africa (7)	Review the literature for evidence on lay providers-led community-based ART	Systematic literature review	Patients receiving ART in their community	Systematic literature review	Descriptive
4	Changara district, Tete province, Mozambique (8)	Describe utilization of mother and child health care by patients in CAG and their family aggregates Explore experiences and perceptions of barriers to mother and child health care	Mixed Methods	Patients in CAG and their family aggregates	Review of patient cards Focus group discussion	Descriptive Thematic content analysis
	Maputo city, Mozambique (9)	Describe uptake and outcomes of routine viral load in Maputo	Retrospective cohort study	Patients on ART in Maputo	Prospectively updated database	Descriptive Analytical

ART: antiretroviral therapy; CAG: Community ART Group.

4. Results

Chapter one: Challenges with decentralization of ART to primary health care facilities in Tete

This chapter consists of one study, titled “*Lessons learned during down referral of antiretroviral treatment in Tete, Mozambique*”, which describes the challenges of ART decentralization to community-based primary health care facilities in Tete. ART transformed HIV from a deadly to a chronic disease. However, initially ART was only available in specialized HIV clinics. ART decentralization was the recommended strategy to reduce barriers to HIV care, to increase the size of the overall ART cohort, and to increase coverage of population-level ART needs.

Key messages

- Decentralization of ART increases the absorptive capacity, but required more investment in organization and infrastructure than forecasted.
- Structural health system bottlenecks limit the impact of ART decentralization on ART coverage.
- If health facility-based ART doesn’t suffice, innovative approaches are needed to meet the demand for ART.

Lesson Learned during Decentralization of HIV/ART Care in Tete, Mozambique

Authors and institutions

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Journal of the International AIDS Society 2009;12:6.

Abstract

As sub-Saharan African countries continue to scale up antiretroviral treatment, there has been an increasing emphasis on moving provision of services from hospital level to the primary health care clinic level. Delivery of antiretroviral treatment at the clinic level increases the number of entry points to care, while the greater proximity of services encourages retention in care. In Tete City, Mozambique, patients on antiretrovirals were rapidly down referred from a provincial hospital to four urban clinics in large numbers without careful planning, resulting in a number of patients being lost to follow-up. We outline some key lessons learned to support down referral, including the need to improve process management, clinic infrastructure, monitoring systems, and patient preparation. Down referral can be avoided by initiating patients' antiretroviral treatment at clinic level from the outset.

Introduction

As sub-Saharan African countries continue to scale up of antiretroviral treatment (ART), there has been an increasing emphasis on moving provision of services from tertiary to primary level care. Decentralization is an important strategy for improving access to ART, particularly in rural areas.

Decentralization is defined as the process of moving away from hospital-centered delivery of ART and into primary health clinics (PHCs), thereby improving access (proximity) to care, and greater retention in care (less defaulting) [1-3].

A recent review of loss-to-follow up in ART programs in resource-limited settings concluded that services that have smaller numbers of patients may have improved retention rates and that population coverage should be supported by smaller decentralized facilities rather than a few large programs [4]. Despite the logic and evidence supporting the decentralization of HIV/AIDS care to the PHC level, in many settings HIV care has initially

been provided only at hospital level. As hospital services become saturated there will be a need to "down refer", patients to lower levels of the health system.

However, this process of down referral must be carefully planned and executed to avoid overwhelming primary care services and to maximize patient retention. Reports from TB programmes have shown that almost a third of patients are lost on referral between the hospital and clinic [5]. This article describes the lessons learned from a large scale and rapid down referral of ART services in Tete, Mozambique.

Context

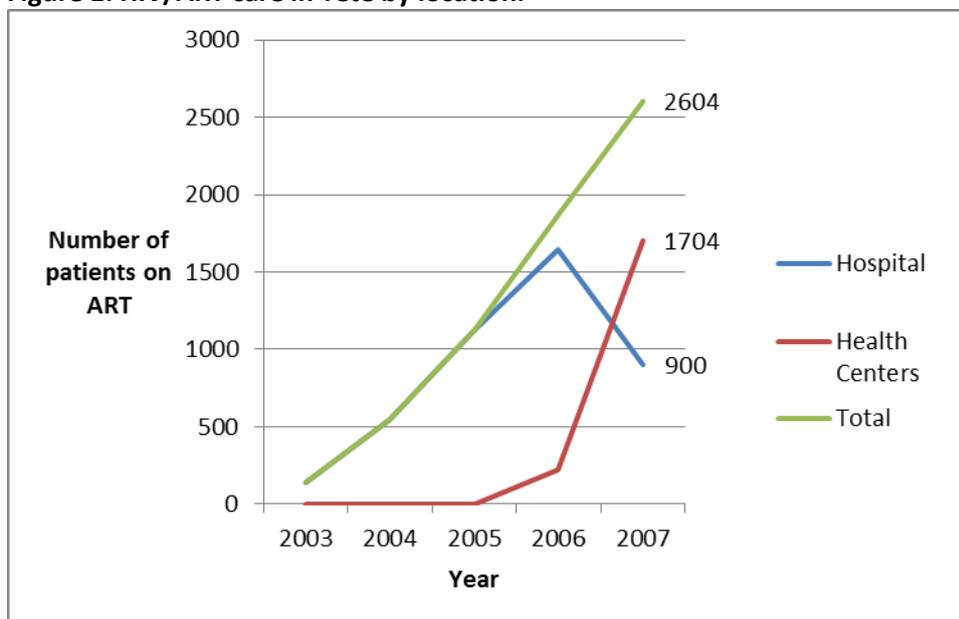
Tete is a rural province of Mozambique with a population of 1.8 million and an adult HIV prevalence of 19%. [6-7]. In 2003, the Provincial Health Department began, with support of Médecins Sans Frontières (MSF), an HIV/ART program at Tete Provincial Hospital. At that time, this was the only provision of ART in the province.

By the end of 2006, 2350 patients had been initiated on ART of which 1637 (70%) remained in care, resulting in hospital services strained to treat this many patients. In Tete, decentralization began slowly, with approximately 218 patients initiated on ART in the 4 urban PHCs by the end of that year.

In May 2007, the provincial health department issued a mandate to down refer 1000 patients (61%) of the patients followed at the provincial hospital. This was in

preparation for major reconstruction work at the hospital, which resulted in a six-fold reduction in consultation rooms for HIV. Due to the inadequate capacity of the clinics to manage so many new patients at that time, only stable patients (those on ART for at least six months and with no clinical complications) were considered for down referral. Within nine months, the number of patients managed at the clinics increased nearly eight-fold, from 218 to 1,704 patients (Figure 1).

Figure 1: HIV/ART care in Tete by location.



In 2007, a large scale down referral from hospital care to the primary health clinics decentralized much of HIV/ART care.

While down referral is a necessary step to integrate HIV/ART services into the PHC system, this process in Tete was particularly challenging. This was due to its rapid implementation, which resulted in more than 100 patients being lost to care (representing a loss to follow up rate of 30%). Capacity and human resources at the PHC level were rapidly overwhelmed until structural and human resource solutions were proposed and implemented.

Challenges

Management

The down referral process began before planning with all involved stakeholders had been completed because of the renovation of the hospital. Staff at the PHCs did not fully appreciate the extent of the services that would need to be provided. Until this point, ART services had been mainly provided at the tertiary care level; PHC staff, although trained in ART care, were not experienced enough to manage the large influx of patients on ART.

Although the criteria for down referral were well defined, some non-eligible patients were also down referred in the drive to move patient care out of the hospital. Finally, too many patients were referred at once, instead of a phased approach being implemented.

Primary Health Clinic Infrastructure

As a result of the influx of patients, the overall number of consultations (HIV and non-HIV) at each clinic more than doubled. Initially, each PHC clinic had only one ART consultation room. Consequently, other rooms, such as sterilization areas or changing rooms, were used for consultations.

Waiting time was often several hours, and waiting areas became overcrowded. The increased patient load put a severe strain on other clinic services: laboratories could not keep up with the increase in blood collections; and pharmacies became congested with long waiting lines as insufficient staff members were trained to dispense antiretrovirals (ARVs).

Drug supply management also became a problem as PHC clinics were not aware of the extent of referral numbers to expect and could not forecast consumption. When medications ran out, patients returned to the hospital to fill their prescriptions. Some patients initially asked to be transferred back to the hospital due to frustration with the chaotic process.

Patient Monitoring & Data Management

The transfer of patients between the hospital and the clinics was not well monitored. With many providers down referring, there was no master list of all patients to be transferred. Referral letters were supposed to accompany patients, but these were sometimes lost. The electronic database maintained at the hospital was not updated when patients were down referred. No systematic active tracing of these "loss to follow-up" patients was conducted until the following year. Lists of "loss to follow-up" patients were sent to the clinics in an attempt to trace and update the database, but the clinics had meanwhile issued new patient identification numbers, so

records did not match. Therefore, the true outcomes for those patients lost during referral remain unknown. As these were stable patients with no clinical complications, mortality is unlikely to have contributed to this rapid attrition over a short time period [8].

Patient Education

In the beginning, some patients were reluctant to be down referred as they did not fully understand the advantages (easier access to services) and disadvantages (less confidentiality due to closeness to their community) of follow-up at the PHC clinics. Consequently, they feared a decrease in the quality of care; several patients refused to be down referred or they decided, without informing the medical team, to self-transfer from one clinic to another.

Proposed solutions

The hospital and clinic staff, along with the provincial health department, identified the problems described here, and jointly proposed a number of actions (Table 1). A joint MSF and provincial health team, dedicated to assisting the clinics with the down referral process, was assembled. This team oversaw a number of actions, including the establishment of monthly quotas of patients to be down referred to prevent overwhelming the clinics. The actions allowed for: better stock forecasting; reorganization of clinic laboratories so that routine blood collection was done on specific days; training in stock management for the PHC pharmacists; and establishment of a buffer stock of ARVs and medications to treat opportunistic infections in case clinic stocks became depleted.

Human resources were also restructured: two nurses were moved from the hospital to the clinics, and receptionists were hired to register patients at the clinics and collect demographic data. The latter is an example of "task shifting" of work previously done by the clinicians or counsellors [9].

To improve patient flow, a fast track system was created for stable patients so that they only needed to come to the clinic every three months. A simplified data collection system was implemented for monitoring and evaluation, including the use of check lists of

patients to be down referred and of those who actually registered at the PHC clinics. Finally, counsellors at the hospital were trained to explain the reasons for the down referral, while counsellors in the PHCs were trained to receive the referred patients.

Table 1: Essential Steps in Tertiary to Primary Care Down Referral of HIV/ART Services

Planning
Joint tertiary and primary level care staff meeting to discuss feasibility of down referral
Down referral criteria strictly established
Phased implementation according to capacity
Establish dedicated team who will oversee down referral process
Primary Health Clinic Human Resources and Infrastructure
Well trained and adequate number of clinicians
Continued coaching and training during down referral
Receptionists and data managers to accurately register and track patients
Adequate clinic space (ie consultations rooms and pharmacy)
Ensure adequate supply of antiretroviral medications
Patient Flow and Education
Improve efficiency of patient care by establishing fast track and designated phlebotomy dates
Implement appropriate & simplified data collection tools
Standardize identification numbers between tertiary and primary care centers so tracing would be easier
Establish regular contact between tertiary and primary level level to ensure all transferred patients are enrolling at PHC level
Conduct lost to care tracing of patients who are down referred but are subsequently "lost"
Train counselors at the tertiary and PHC level on how to educate patients on the process of the down referral.

Conclusions

In other settings in southern Africa, decentralization has proven to be a successful strategy for supporting scale-up of antiretroviral therapy [1,3,10-12]. In particular, providing ART at the PHC clinic level increases the number of entry points to care, while the greater proximity of services encourages retention in care [1,4].

In Tete City, the majority of clients referred to clinic services continued their follow-up at clinic level. Down referral was, in the end, broadly accepted as these services were more accessible.

However, a number of issues should be considered to ensure that appropriate support is given to PHC clinics. The mass transfer of patients enrolled in care at the hospital level can quickly overwhelm minimally staffed clinics if appropriate steps are not taken. In addition to the extra workload, clinic staff may feel uncomfortable with their new level of responsibility, particularly if training and supervision mechanisms are not in place. The Tete experience serves to highlight a number of simple steps that can be taken to ensure a smooth transition from hospital-based to clinic-based care.

The short-term chaos has been outweighed by the broader benefits of establishing a decentralized programme. As of December 2008, more than 2,700 patients on ART were being followed in the four PHC clinics, compared to around 800 in the hospital. Most problems during down referral were successfully resolved through the creation of a team that worked across different areas of the health service to address a range of challenges, from drug supply to human resources. At the same time, a number of changes were made to reinforce the capacity and efficiency of the primary health care clinics.

Down referral requires careful planning, implementation over a realistic timeframe, and attention to monitoring at all levels. Perhaps the most obvious lesson is the need to take time to explain to the patients the reasons behind the decisions taken for the down referral, and explain that they would benefit from more proximal services without any compromise in care. Criteria for referral should ideally be determined in consultation with all stakeholders, including service users. Finally, given the growing evidence that most ART cases can be initiated at clinic level, the problems associated with down referral could have been avoided by initiating newly enrolled patients directly at PHC clinic level from the outset.

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Chapter two: Retention in care in Community ART Groups, a peer-led ART delivery model, in Tete

To overcome patient- and provider-level barriers to ART, patients joined CAGs in Tete province.

Although peer support was a known enabler for adherence, there were no earlier experiences with PLHIV involved in medical tasks. Therefore this chapter shows the results of the CAG pilot in Tete.

The paper titled “*Distribution of antiretroviral treatment through self-forming groups of patients in Tete Province, Mozambique*” describes the CAG model and its early results. The second paper of this chapter “*Four-year retention and risk factors for attrition among members of community ART groups in Tete, Mozambique*” shows long term outcomes and estimates predictors of attrition in CAG. In the third paper of this chapter “*The effect of Community ART Groups on retention-in-care among patients on ART in Tete Province, Mozambique: a cohort study*” retention in CAG is compared with retention in conventional individual care.

Key messages

- Peer-led ART delivery is feasible.
- Peer-led ART delivery is effective. Retention in care in Community ART Groups was high, was sustained over time, and was higher than in conventional care.
- Even though overall retention in CAG was high, some sub-groups, such as males or severely immunosuppressed patients, were more at risk to die or to be LTFU.
- If PLHIV can engage in medical tasks, and become more self-efficacious, the burden on overstretched health systems may reduce, especially in high prevalence countries.
- PLHIV can join peer groups, and close the gap between remote communities and the health system for ART refill. Moreover, higher levels of self-efficacy may motivate PLHIV to sustain adherence, and engage in additional medical tasks.

Distribution of antiretroviral treatment through self-forming groups of patients in Tete province, Mozambique

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Journal of Acquired Immune Deficiency Syndromes 2011;56(2):e39-e44.

Abstract

Background: As antiretroviral treatment cohorts continue to expand, ensuring patient retention over time is an increasingly important concern. This, together with capacity and human resource constraints, have led to the consideration of out-of-clinic models for the delivery of antiretroviral therapy (ART). In 2008, Médecins Sans Frontières and the Provincial authorities launched a model of ART distribution and adherence monitoring by community groups in Tete Province, Mozambique.

Programme approach: Patients who were stable on ART for six months were informed about the community ART group model and invited to form groups. Group members had four key functions: facilitate monthly ART distribution to other group members in the community, provide adherence and social support, monitor outcomes, and ensure each group member undergoes a clinical consultation at least once every six months. Group members visit the health centre on a rotational basis such that each group member has contact with the health service every six months.

Results: Between February 2008 and May 2010, 1,384 members were enrolled into 291 groups. Median follow up time within a group was 12.9 months (8.5-14.1). During this time 83 (6%) were transferred out, and of the 1,301 patients still in community groups, 1,269 (97.5%) were remaining in care, 30 (2%) had died, and 2 (0.2%) were lost to follow-up.

Discussion: The Community ART Group model was initiated by patients to improve access, patient retention, and decongest health services. Early outcomes are highly satisfactory in terms of mortality and retention in care, lending support to such out-of-clinic approaches.

Keywords: antiretroviral therapy, retention, community engagement, self-management

Introduction

The number of people receiving antiretroviral therapy (ART) in low-income countries continues to increase, with an estimated five million people on treatment as of July 2010. As treatment cohorts continue to expand and age, the question of how to ensure that patients initiated on ART are supported to remain in care is becoming an increasingly important concern.

A recent systematic review of programmes in sub-Saharan Africa reported that on average

almost a third of patients were lost to follow-up (LTFU) within two years of being initiated onto ART(1).

Several studies have indicated that practical challenges – distance to services and associated transport costs, work responsibilities, and family commitments – are associated with defaulting from care (2, 3). Barriers at the health facility level such as long waiting times, patient experience with the health system, stigma and discrimination, and lack of social support and information for adherence have also been reported as

reasons for defaulting (1). Thus, ensuring that ART services are accessible as close as possible to the community is an important way to improve access to and retention in care (4-6).

ART is a lifelong therapy and the number of patients entering treatment continues to increase, leading to concern that conventional health systems will become increasingly overwhelmed. The limited health workforce in high HIV-prevalence settings together with the need to provide ART at the community level has led to consideration of out-of-clinic models of care that would engage patients in essential tasks including ART distribution and peer support for adherence and social support (7).

Mozambique faces many problems common to high HIV-burden countries in southern Africa. The government began providing antiretroviral therapy in 2003 but the dire lack of human resources and infrastructure for health care provision has limited coverage: in 2007 it was estimated that only around one third of people in need of ART were receiving treatment (8), while overall, only around half of the population have access to an acceptable level of health care(9). Access to and retention in care is a major challenge in many parts of the country due to distances from to health facility, transportation costs, and long waiting times (10).

In 2008, in collaboration with patients and local health authorities, Médecins Sans Frontières (MSF) piloted a model of ART distribution and adherence monitoring by community groups to supplement the conventional mode of ART delivery in health clinics and hospitals. The model was initially proposed during problem-solving discussions between counselors and ART patients as a potential way to improve retention while giving patients greater responsibility for certain aspects of service provision.

In this article, we describe the implementation of the community ART group (CAG) model report preliminary outcomes.

Program description

Project setting

Tete Province lies in central Mozambique and borders Malawi, Zambia and Zimbabwe. Approximately 85% of the province's 1.8 million inhabitants live in rural areas. Adult HIV-prevalence is estimated at 13% (11). MSF has been supporting the health authorities in Tete Province since 2002 in the implementation and scale up HIV care and treatment. ART provision began in May 2003 at Tete Provincial hospital and was decentralized to selected peripheral health centres in 2006 (12). By mid-2010 one quarter of health facilities in Tete Province (28/105) were authorised to initiate ART.

Despite significant progress in increasing access to ART services through decentralisation of HIV care and task-shifting, about one in five ART patients in Tete are lost to follow up, and at least half of those LTFU are estimated to be dead (13).

Stakeholder consultation

Group discussions were conducted between patients and counselors at health facilities supported by MSF. Patients reported that the main barriers to ART access and retention on ART were transport costs and perceived stigmatization by attending health facilities, and time lost waiting in long queues at clinics, often just for refills.

Ministry of Health Guidelines state that patients stable on ART only need a clinical consultation once every 6 months, but ART supplies can only be given monthly. The practical consequence is that patients often travel long distances to pick up medications every month. The community ART group approach was proposed in consultation with patients as a way for patients to utilize existing social networks and pool resources to reduce the individual requirement to travel and queue at health centres each month for ART prescriptions and provide mutual support for adherence and social needs.

Participating clinics and group formation

Community ART Groups (CAG) were established in twelve health facilities in six districts (Chiuta, Changara, Moatize, Tete City, Cahora Bassa and Mutarara) of Tete Province. The estimated population of the six districts with CAGs was 900,666. As of May 2010, approximately 11052 people were active on ART, among whom half (5772) were attending health centres at which CAGs were established (13).

Participating health facilities were required to have the following minimum package of services: HIV counseling and testing, a clinician authorized to prescribe ART, a guaranteed supply of ART and opportunistic prophylaxis, and transport for CD4 samples and results.

At the group level, members had four key, practical functions: to collect and distribute ART each month to group members in the community; to provide community-based adherence support and treatment outcome monitoring; to establish a community-based treatment social support network, and to ensure each group member undergoes a clinical consultation at least once every six months. The group elected a group leader who would facilitate monthly group meetings, conduct monthly pill counts, and monitor group attendance.

CAGs were promoted in clinic waiting areas, during consultation and counseling sessions, and through information distributed within the community. In order to join a group, patients needed to be clinically stable on ART for a minimum of six months and have CD4 ≥ 200 cells/mm³. Interested patients were advised to form groups of up to six, elect a group leader, and present to their nearest clinic for eligibility assessment by a clinician. Counselors trained newly formed groups in the approach and in the roles and responsibilities of patients in a group, conducted monthly monitoring of groups of group representatives, and conducted group counseling and education sessions.

Community ART groups

Each month a group representative visits the nearest health facility to collect medicines for the group. Every member is expected to serve as the group representative on a rotational basis such that each patient has contact with a health centre every six months. Group members could still visit the health centre at any other time, for any reason if required.

A group meeting is held in the community before each clinic visit and the designated group leader counts each members' pills (adherence check). Any new signs or symptoms, adherence problems, or intention to relocate to another area or interrupt treatment are discussed and documented for each patient on the group-held group monitoring form. The group chooses a member who will represent and report on the group, and collect medications at health facility level, for that month. The patients give their appointment cards to the group representative to take them to the health facility.

At facility level, the group representative discusses each group member with a counselor or clinician, covering such issues as adherence (self-report and pill count), clinical status, and any action to be taken such as requesting a patient to attend the health facility for consultation, bloods, or adherence counseling. The group monitoring form (see below) is jointly reviewed. The group representative then meets with a clinician who prescribes ART and prophylactic drugs for each group member. The patient-held appointment cards are updated by the clinician or counselor. The group representative also undergoes a clinical consultation at this visit. The group representative then returns to the community and distributes ART and other medicines to each patient, returns the patient-held appointment cards and, where necessary, requests a group member to go to the health facility for follow up.

All members from different CAGs linked to the same health facility are invited six monthly for

a group session at the health facility or in the community. Health education and information updates on topics such as CAG dynamic, adherence, when to come for an unplanned consultation, tuberculosis, prevention of

mother to child transmission, opportunistic infections, and treatment issues are provided. A blood sample for CD4 is taken at the end of the session for all who are present. (Table 1).

Table 1. Summary of Community ART group (CAG) implementation steps

Consult stakeholders	<ul style="list-style-type: none"> • Hold group discussions with patients, health authorities and health facility staff
Select project sites	<p>Select sites according to, for example, size of ART cohort (urban sites), geographical isolation of surrounding population (rural sites), and whether a facility had the following features:</p> <ul style="list-style-type: none"> • HIV counseling and testing • Transport for CD4 samples & results • A clinician authorized to prescribe ART, follow patients, draw blood from patients for CD4 counts, and familiar with procedures for Community ART group project • A person to manage the groups (counselor, clinician, other) • A person to dispense ART and a secure supply of ART and opportunistic prophylaxis
Prepare health facilities to manage CAGs	<ul style="list-style-type: none"> • Design a guideline with health authorities, tailored to reality of each facility • Train facility staff in the CAG model and their flexible roles and responsibilities
Promote CAG model as voluntary option to conventional care for stable ART patients	<ul style="list-style-type: none"> • Provide patients with information on CAGs in health facility waiting areas, during consultations and counseling sessions • Ask patients who attended the health facilities to inform other ART patients known to them in their local area, about CAGs • Request patients to form groups of a maximum of six, and elect a group leader • Request groups to present to a facility to be screening for eligibility to join CAGs
Screen interested ART patients	<p>Eligibility criteria:</p> <ul style="list-style-type: none"> • Followed on ART at least six months • Taking first line ART with weight greater than 25 kilograms (kg) • Taking an alternative first line regimen containing Efavirenz with weight > 40 kg • Be clinically stable and without any active WHO Stage III or IV clinical condition • Have a CD4 count in last three months greater than 200 mm³ • Screening: By clinician or counsellor. Documentation in patient file
Train group members once screened	<ul style="list-style-type: none"> • Train and educate group members in the CAG model, the practical functions of group members, and the responsibilities of the group leader and group representative • Open two copies of the group monitoring form, one for the group, one for the facility
Every month groups meet in community, a group representative attends the health facility to report on the group and collect ARVs, to distribute in the community	<ul style="list-style-type: none"> • Groups meet in community each month to count pills, monitor adherence and outcomes, update the group monitoring form, and elect a group representative • The group representative for the month attends the facility to report on the group, collect ARVs for each group member, and to have an individual clinical consult. • Clinicians prescribe ART each month for individual patients in standard manner. The group monitoring form is updated, such as ARVs dispensed for each member • Group representative distributes ART to members in community • Patients can attend the facility at any other time they need, for any reason
Monitor patients and ART groups and provide ongoing support and quality improvement	<ul style="list-style-type: none"> • Monthly group meeting in community (intra-group monitoring) • Monthly feedback from group representative to facility (group-facility monitoring) • Monthly update of information on ART group monitoring form • Patient file, consultation registers and other standard monitoring tools updated • Monthly standard reports to health authorities and analysis of database • Every six-months all group members attend the facility for a group meeting/training, and to have blood collected for CD4 count • Activities conducted to audit the quality of functioning of CAGs, such as follow up of patients who died, were LTFU, returned to individual care, have adherence problems

Monitoring and evaluation

Three paper-based tools are used to monitor Community ART groups: the national patient-held appointment card, the clinic-based patient file, and a group monitoring form.

The patient-held appointment cards are given to the group representative prior to the health facility visit and brought together with the group monitoring form to the health facility. The next CAG refill dates are updated on appointment cards and then returned to each group member in the community along with a one-month supply of ART.

Paper-based patient files are kept in all health facilities and contain essential information on each patient: unique patient ID, name, contact details, age, sex, clinical history, CD4 results, clinical consultation findings, medications prescribed, adherence & counseling information, and other details.

The group monitoring form includes information on ART prescription and pill counts for all group members and acts as a group-specific cohort register. The group monitoring form contains basic background information including patient identification number), sex, age, date initiated ART, CD4 at ART initiation, count and date of last CD4, monthly dates of ART collection, monthly pill counts, date of next consultation, and a basic health check. One side of the form is updated by the group representative and group members (pill count and patient signature of approval) each month. The group representative takes this form (along with the patient-held cards) to the facility each month, where it is reviewed with clinic staff and updated with information such as number of ART dispensed to the group representative for each patient, date to next collect ART for the group and new CD4 results. A copy of the group monitoring form is held at the clinic.

Information from the three monitoring tools are encoded in an electronic database (Excel) by a trained data manager to evaluate the

following programme-level information: demographic and other baseline information, date of ART initiation, CD4 count at ART initiation, date each patient joined ART group, name of ART group, dates of ART distribution, dates of six-monthly CD4 blood collection and individual consultation, CD4 results, pill count at time of each ART distribution, number of pills dispensed, and standard patient outcomes. Data are analysed each month to track enrolment, patient follow up and outcomes, undertake data cleaning, and generate aggregate health centre outcome reports for Community ART groups.

Patient consent and protections

Community ART Groups were started as a programmatic response as solution to respond to the many obstacles patients encountered in accessing their monthly treatment and to alleviate overburdened health centres. A number of basic securities were put in place to ensure voluntary participation and patient data protection. From the beginning, participation in Community ART Group care has been voluntary. At the start of the programme basic information about the CAG approach, including eligibility criteria and roles and responsibilities of group members was made available in the local language through information sessions in health facility waiting areas and in discussion with patients who had defaulted from care. At any time, patients in CAG care could opt and return to standard care and follow up. No financial or material incentive was provided. The Community ART group electronic database is password-protected and locked and stored in a secure room according to normal standards. The programme was formally approved by local health authorities.

A number of processes were established to ensure the proper functioning of the groups. CAG members were encouraged to report to their clinician or counselor any serious problem experienced within a group, such as diversion or non-receipt of ARVs. Regular meetings were held with members at community and health facility level, to identify

any problems and counselors conducted ad hoc audits through brief, structured, interviews with group members at facility level. All adverse events such as death or defaulting were investigated and documented.

Results

The first CAG was established in February 2008. By 31 May 2010, 1,384 members had

been enrolled into 291 groups (Table 2). Group members had been on ART for a median of 22.3 months (IQR 9.7-34.2) at enrollment. Median age at enrollment into a group was 36 years and the majority (70%) were female, consistent with demographic characteristics of adults in conventional ART care in Tete province (12). Median follow up time within a group was 12.9 months (IQR 8.5-14.1) (Table 3).

Table 2: Baseline characteristics of Community ART group patients

Category	Value
Total	1384
Number of facilities with CAGs	12
Number of groups	291
Average number per group	5
Female, number (%)	968 (70%)
Age at enrolment (years), media (IQR)	36 (30-43)
CD4 count at ART initiation*, median (IQR)	176 cells/mm ³ (105-247)
Months on ART pre-CAG, median (IQR)	22.3 (9.7-34.2)

*data missing for 86 patients

Table 3. Outcomes of Community ART group patients, Tete Province, Mozambique

Outcome	Value
Total	1384
Months in CAGs, median (IQR)	12.9 (8.5-14.1)
Died: n, % (95%CI)	30, 2.2% (1.5-3.1%)
Lost to follow-up: n, % (95%CI)	2, 0.1% (0-0.5%)
Transferred out to other health facility: n, % (95%CI)	35, 2.5% (1.8-3.5%)
Transferred back to conventional care: n, % (95%CI)	48, 3.5% (2.6-4.6%)
Active in CAG: n, % (95%CI)	1269, 91.7% (90.1-93.1%)
CD4 gain while in CAG, median (IQR)**	478.5 cells/mm ³ (313.5-642)

** Data available for 78% (836) of patients: patients in CAGs at least nine months and who had a CD4 in last 6 months,

A review of documentation and meetings with facility staff and CAG leaders confirmed that all doses of ART were collected from the facility and delivered to patients. Adherence monitoring was successful, with 92% of patients (1173 of 1269 members as 31 May 2010) had their last two pill counts recorded correctly on the group monitoring form.

Adverse outcomes were reviewed for all patients. Of the 1,384 patients who had enrolled into a community ART group, 83 (6%) had been transferred either back to conventional care or to another treatment centre, in general due to patients changing

place of residence. Of the remaining 1,301 patients, 1,269 (97.5%) were remaining in care, 30 (2%) had died, and 2 (0.2%) were lost to follow-up.

Of 48 members that returned to standard care, 27 left due to change of residence, 3 due to poor adherence to ART, 12 for medical reasons, and 6 for social reasons unrelated to the group. Among the 30 CAG member who died, 3 died of acute, unknown circumstances at home, while the remainder had all had at least one clinical consultation related to their illness leading to death: 21 deaths due to HIV related causes, the remaining 6 due to non-

HIV related illness. The two instances of defaulting were due to change of residence and social reasons unrelated to CAGs or their care.

Finally, in terms of workload reduction, staff at health facilities reported that CAGs resulted in an approximately 4-fold reduction in consultations among patients in CAGs.

Discussion

The community ART group approach was designed together with patients in response to patient reported barriers to retention on treatment, and as such, was a highly acceptable alternative mode of service delivery for stable ART patients. For patients, community ART groups represent a way to decrease the financial and economical/social costs of their treatment, take greater responsibility for the management of their own health, and be active partners in health care delivery. Beyond simply reducing transport costs, the groups provides a means of encouraging greater patient responsibility for their own health and building and reinforcing social networks and peer support, which have been identified as important ways to support adherence to treatment (14, 15)

The proportion of patients lost to follow-up were lower than reported in the literature, in which rates of loss to follow-up at 12 months range from 1.2% to 26% (1). For Mozambique the national average rate of defaulting at 12 months is 15% (16). However, the data presented are programmatic data and as such are subject to a number of limitations common to observational studies that threaten the validity and generalizability of the findings. In particular, survivorship bias resulting from the eligibility criteria that requires patients to be clinically stable and to have been on ART for six months before being able to join the programme may limit generalizability. Nevertheless, the current low rate of defaulting and mortality in this programme suggests that the approach described herein has clear potential in

supporting long-term ART management, at least for stable patients.

Around five million people are currently receiving ART in developing countries, and another 10 million people are currently estimated to be in need of treatment (17). The growing number of patients on ART is not, however, being met by a commensurate increase in the numbers of clinics and clinic staff. High HIV-burden settings are usually chronically under-resourced to meet current needs: it is estimated that a seven-fold increase in health personnel is required in Mozambique to meet the health needs of the population (18).

In order for ART delivery to be sustainable and successful in the long-term, there is a need for models of care that separate clinical patient management (which requires trained health workers) and the dispensing of medicines (which does not), and address patient-reported barriers to treatment access and retention. A shift from acute to chronic care implies a greater emphasis on self-management of disease outside of a clinical setting, with patients assuming an active and informed role in managing physical, psychological, and social aspects of health (19).

In Western countries, chronic disease self-management programs are accepted as a way to improve patient outcomes and reduce the burden on healthcare systems for a range of chronic diseases including asthma (20), diabetes (21), arthritis (22), chronic obstructive pulmonary disease (23), and cancer (24). Non-physician led approaches such as repeat prescriptions(25) and patient held records (26) have been found to be of benefit to patients and health services.

For HIV care, the concept of chronic disease self-management has been proposed for almost a decade but has been largely confined to adherence support (27). More recently, out-of-clinic approaches to ART care have been piloted as a way to decongest overburdened health services and simplify

treatment for patients. A recent cluster randomized trial in Uganda found that home-based ART delivery was equivalent to facility-based ART delivery in terms of survival and virological suppression (28). In Tanzania, community-based volunteers and trained medical workers support mobile drug distribution by refilling prescriptions in the community, and this has anecdotally led to reduced loss to follow-up (29). In western Kenya, people living with HIV/AIDS have been trained and salaried to provide to follow up to clinically stable HIV patients in their communities and distribute ART and prophylaxis for opportunistic infections (30). The positive early outcomes of the Community ART Group approach presented here lend support to such out-of-clinic approaches.

Improving retention in care is just one challenge to health services in high-HIV prevalence settings. Substantial attrition has also been reported among patients diagnosed HIV positive and awaiting ART initiation, both in Mozambique (31) and elsewhere (32). Innovative approaches are also needed across the care cascade from HIV diagnosis to long-term retention.

The future refinement of the community ART group approach in Mozambique will include reflection on how this approach can support the health service and improving outcomes across the treatment cascade. For example, many Community ART groups have members who are not yet eligible for ART who join monthly group meetings in the community, and benefit from the social support and education. In this way, the CAG model may also help to minimize pre-ART defaulting, an issue of growing concern in ART programmes in southern Africa (32).

Another challenge lies in the need to develop adapted approaches for vulnerable subgroups as children, adolescents, pregnant woman, commercial sex workers and HIV/TB co-infected patients. Finally, the CAG program requires longer-term follow up and formal evaluation comprising both qualitative and

quantitative approaches to determine its effectiveness, acceptability, sustainability and generalisability.

While there remains an urgent need to continue to enroll patients onto ART as a medical priority, programme implementers must also begin to take the long view, including from the patients' perspective. HIV/AIDS is a chronic disease requiring lifelong treatment. With successful treatment, patients initiated on ART in resource-limited settings can expect to live around 30 years on treatment (33). The long-term management of ART in resource-limited settings will require out-of-clinic solutions, with patient-clinic partnerships, in particular for patients who are stable on ART. Community-based approaches represent an important dimension in this approach.

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Four year retention and risk factors for attrition among members of community ART groups in Tete, Mozambique

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Abstract

OBJECTIVE Community ART groups (CAG), peer support groups involved in community ART distribution and mutual psychosocial support, were piloted to respond to staggering antiretroviral treatment (ART) attrition in Mozambique. To understand the impact of CAG on long term retention we estimated mortality and lost to follow-up (LTFU) rates and assessed predictors for attrition. **METHODS** This is a retrospective cohort study. Kaplan-Meier techniques were used to estimate mortality and LTFU in CAG. Individual and CAG level predictors of attrition were assessed using a multivariable Cox-proportional hazards model, adjusted for site-level clustering. **RESULTS** Mortality and LTFU rates among 5729 CAG members were respectively 2.1 and 0.1 per 100 person-years. Retention was 97.7%, 96.0%, 93.4% and 91.8% at 12, 24, 36 and 48 months respectively. At individual level, attrition in CAG was significantly associated with: 1) immunosuppression when joining a CAG; and 2) being male. At CAG level attrition was associated with: 1) lack of rotational representation at the clinic; 2) lack of a regular CD4 count among fellow members; and 3) linkage to a rural or district clinic compared with linkage to a peri-urban clinic. **CONCLUSIONS** Long term retention in this community-based ART model compares favorably with published data on stable ART patients. Nevertheless, to reduce attrition further efforts need to be made to: 1) enroll patients earlier on ART; 2) promote health seeking behavior, especially for men; 3) promote a strong peer dynamic to assure rotational representation at the clinic and regular CD4 follow-up; and 4) reinforce referral of sick patients.

Key words:

HIV; antiretroviral therapy, highly active; health services accessibility; peer support; community participation

Introduction

In the past decade the scale-up of antiretroviral therapy (ART) was spectacular. In low- and middle-income countries 9.7 million people were reported on ART at the end of 2012. But still, it is not enough. Still 1.7 million people died because of AIDS in 2011 (World Health Organization 2013a). To reduce AIDS related deaths WHO recommends a new target of 25.9 million receiving ART in low- and middle-income countries, an unprecedented public health challenge (World Health Organization 2013b). A major bottleneck is attrition on ART, which includes

patients who died or who are lost to follow-up (LTFU). A meta-analysis from over 17 countries revealed a 24-month patient attrition of 30.0%, and 35.4% at 36-months (Fox & Rosen 2010). Transport costs and distance are the most frequent cited barriers to adherence (Govindasamy *et al.* 2012).

In Mozambique, with an adult prevalence of 11.5%, over 1.5 million Mozambicans are living with HIV (Ministry of Health Mozambique 2010). At the end of 2012, only 42% (308,577) of the 690,000 estimated in need were on ART (World Health Organisation 2012). Meanwhile almost one third of the

people living with HIV/AIDS (PLWHA) who had started ART were either dead, or LTFU (Ministry of Health Mozambique 2012a). The decentralization of ART care, which aimed to decrease the burden on overloaded clinics and increase accessibility for the patients, was hampered by a lack of infrastructure, a lack of human resources for health, and organizational challenges including the drug supply (Decroo *et al.* 2009; Ministry of Health Mozambique 2012b). Subsequently attrition at rural clinics was reported almost twice as high when compared with urban clinics (Lambdin *et al.* 2013).

To respond to the attrition community ART groups (CAG), peer support groups of maximum six members, were rolled out in the rural province of Tete since February 2008. Monthly, on the day of ART refill, CAG members meet in the community. During the meeting they verify each other's adherence, and choose a representative to collect ART for all the members. At the health facility, the group representative has a consultation, relates any important events which occurred in the lives of the other members and receives a treatment refill for all the group members of the CAG. The most frequently prescribed ART regimen contains zidovudine, lamivudine, and nevirapine. For each CAG a group card, containing data on the members and the dates of refill, is updated, with one copy held at community and one copy at clinic level. Then the group representative returns to the community to distribute the ART to the fellow group members. One month later, another group member is chosen to represent the CAG at the health facility. Early results showing a retention of 97.5% after a median follow-up time of 13 months convinced the national Ministry of Health to expand CAG first within Tete province, and then at national level (Decroo *et al.* 2012; Decroo *et al.* 2013). In this paper long term retention in CAG is analyzed. Moreover, individual and CAG level risk factors associated with attrition are estimated and the circumstances in which CAG members died are described.

Methods

Study design and data collection

This retrospective study uses program data to describe and analyze the retention among the adult members who joined the CAG program between February 2008 and December 2012. Data were encoded in an electronic database (Excel) from February 2008 onwards. The sources were clinic held copies of the group cards and patient files. Every month a data technician met one of the providers (nurse or counselor) of each clinic, who gave an update based on the information he/she had obtained from the CAG representatives. Variables were updated monthly, including recent CD4 results and the next day for ART refill. Periodically a file review was organized to verify the data from the database with the data recorded in the files.

The treatment outcomes reported were: active, dead, LTFU, transferred out, and returned to individual/routine care. LTFU was defined as being more than 2 months late for the last appointment or date for refill. Return to individual/routine care was defined as the exit of a member out of a CAG, and the return into normal individual/routine care, on the initiative of the patient or the clinician. In individual care the patient would have to visit the clinic on a monthly basis for ART refill. The type of clinics on which CAG members depend for ART provision were categorized as peri-urban clinics (CAG members living in the vicinity of a referral hospital providing specialized care with medical specialists, referral laboratory and radiology available), district clinics (CAG members living in the vicinity of a district hospital with a medical doctor and small laboratory available), or rural clinics (CAG members living in the vicinity of a health center providing primary health care with nurse based care). To understand better the circumstances in which some of the patients died or were LTFU the health staff (counselor or nurse) did efforts to obtain information from the fellow group members or the treating clinician, which was digitized as a short narrative in the database.

Data analysis

Explanatory variables included in this analysis are either at individual or at CAG level. Some numeric variables were categorized to facilitate the analysis. The median and interquartile ranges (IQR) were calculated for numeric variables, and proportions for categorical variables. Mortality and LTFU rates were calculated per 100 person-years. Kaplan-Meier techniques were used to estimate survival in CAG. Predictors of mortality were assessed using a multi-variable Cox-proportional hazards model, adjusted for site-level clustering. Missing data were handled using the missing indicator method.

Adjusted hazard ratios (aHR), 95% confidence intervals (CI), and p-values were calculated to estimate the association between attrition (mortality or LTFU) and variables at individual and CAG level. Patients alive on ART were censored on 31 December 2012. Members transferred out to another clinic were censored on the date of transfer out. Patients who returned to individual care and who were active on ART three months after leaving the CAG were censored on the day they left the group, independent of their final treatment outcome. Patients who returned to individual care and who died or were LTFU within three

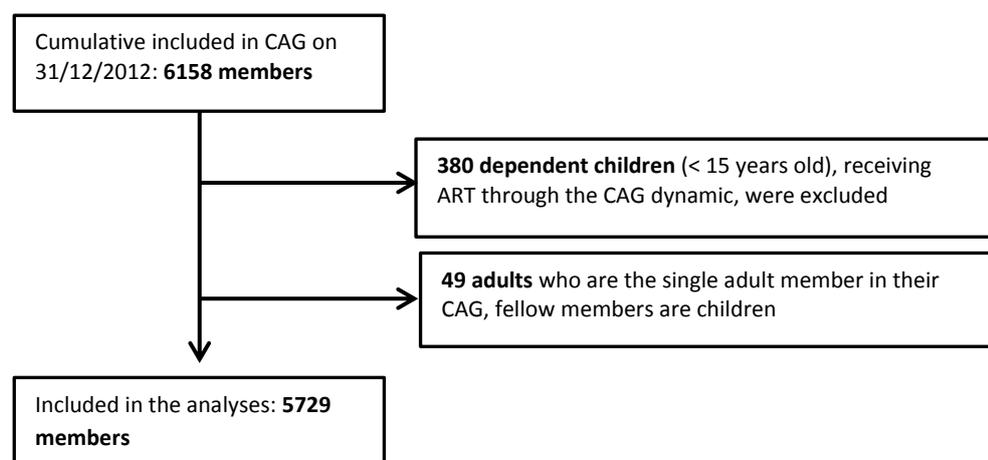
months after leaving the CAG were considered as having experienced the event. A multiple Cox-regression model was constructed using a hierarchical approach, including first individual level (p-value <0.1) and subsequently CAG level (p-value <0.1) characteristics. The model was simplified by stepwise backwards elimination until all individual level variables had a p-value <0.05, and consequently further simplified by deletion of CAG level variables until all CAG level variables had a p-value of <0.05. Analyses were performed with Stata (version 11.2).

Results

Characteristics of study population

Between February 2008 and December 2012 6158 patients had joined the CAG, among who 5729 adults. 380 dependent children and 49 patients who were the only adult member of a CAG were excluded from the analysis (Fig 1). Of the 5729 adult members, 5507 were active (includes 207 members who were transferred out), 208 (3.6%) died, and 14 (0.2%) were LTFU after a median follow-up time of 19 months (IQR: 10-29).

FIGURE 1: Members included in the analyses



ART: antiretroviral therapy; CAG: community ART group

The main characteristics of members in CAG are summarized by outcome in **table 1**. Median age when joining a group was 36 years (IQR 30-43) and 30% of the group members were male. The median CD4 count had improved since patients started ART, and improved more while they were member of a CAG. Median CD4 counts at ART initiation, at group enrolment, and the last value obtained were respectively 186 cells/ μ l (IQR 116-249), 389 cells/ μ l (IQR 266-563), and 426 cells/ μ l (IQR 285-598).

One fourth (28%) of the members shared the cost of transport to get to a clinic for the monthly ART refill. Half (50%) of the members were member of a group without a fluent rotational representation at the clinic. Moreover 77% of the members were member of a group in which not all members had an updated CD4 count. 12% of the members depended of rural clinics, run by nurses only, and without possibility for hospitalization.

TABLE 1: Characteristics of CAG members

	N= 5729 CAG members
At individual level:	
Male: n (%)	1746 (30)
Age when joining a group (years): median (IQR)	36 (30-43)
CD4 when starting ART (cells/ μ l): median(IQR)	185 (114-248) ^a
CD4 when joining CAG (cells/ μ l): median,(IQR)	385 (258-560) ^b
Last CD4 (cells/ μ l): median(IQR)	421 (277-593) ^c
At CAG level: member of a CAG..	
... with transport fee to go to the clinic: n (%)	1608 (28)
... without a recent CD4 count for all fellow members *: n (%)	4401 (77)
... without fluent rotational representation at the clinic: n (%)	2838 (50)
... consisting for more than 50% of young adults (< 30 year): n (%)	1166 (20)
... linked to a: n (%)	
• Peri-urban clinic	3394 (59)
• District clinic	1666 (29)
• Rural clinic	669 (12)

N: number; IQR: interquartile range; CAG: community ART group ; *recent CD4 = during last 24 months; ^a Data for 4406 (77%) members; ^b Data for 3983 (70%) members; ^c Data for 4020 (70%) members

Characteristics of members were similar at peri-urban, district or rural clinics (**table 2**), except that at rural clinics members joined CAG earlier, after a median of 7 months on ART. Furthermore, at district clinics and rural

clinics close to half of the members had to pay for transport to access the clinic, much more than the 7% of members at the peri-urban clinics.

Table 2: Characteristics of CAG members by clinic type

	Peri-urban 3394 members 840 CAG	District 1666 members 389 CAG	Rural 669 members 162 CAG
Male, n (%)	1019 (30%)	500 (30%)	227 (34%)
Age, median (IQR)	36 (30-44)	35 (28-41)	35 (29-42)
CD4 when starting ART, median (IQR)	189 (118-253)	186 (117-246)	162 (91-226)
CD4 when joining CAG, median (IQR)	411 (283- 584)	375 (251-547)	303 (173-468)
Months on ART when joining CAG	27 (12-44)	17 (7-32)	7 (3-20)
Nr of members per CAG, median (IQR)	4 (2-6)	4 (2-6)	4 (2-6)
CAG depending on transport to get refill, n (%)	140 (7%)	168 (43%)	72 (44%)

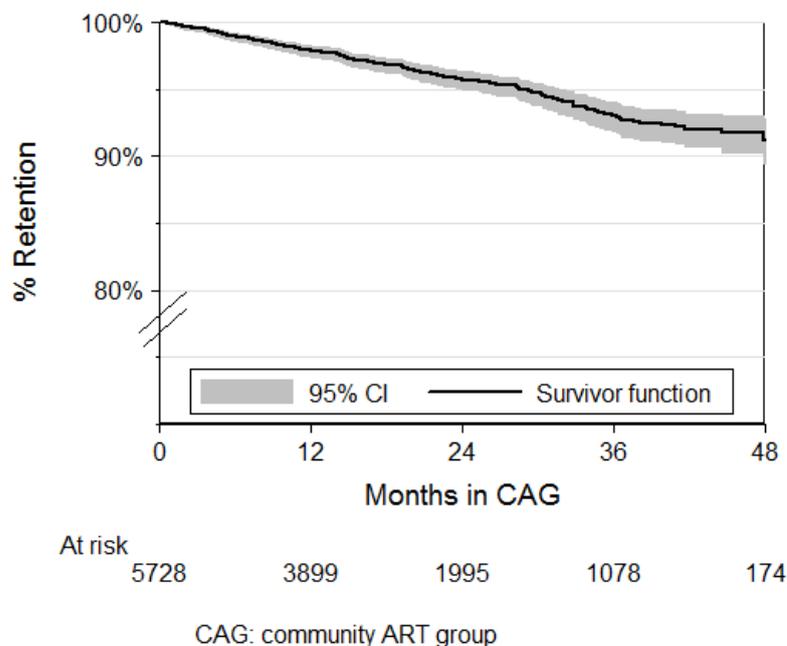
N: number; IQR: interquartile range; CAG: community ART group

Retention

Retention among CAG members on 31/12/2012 at one, two, three and four years on ART was respectively 97.7% (95% CI: 97.4-98.2), 96.0% (95% CI: 95.3-96.6), 93.4% (95% CI: 92.3-94.3) and 91.8% (95% CI: 90.1-93.2)

(**graph 1**). Overall, the attrition rate was 2.2 per 100 person-years among the 5729 adult members on 31/12/2012. The mortality rate was 2.1 per 100 person-years, and the LTFU rate was 0.1 per 100 person-years.

GRAPH 1: Retention in CAG on 31/12/2012



Factors associated with attrition

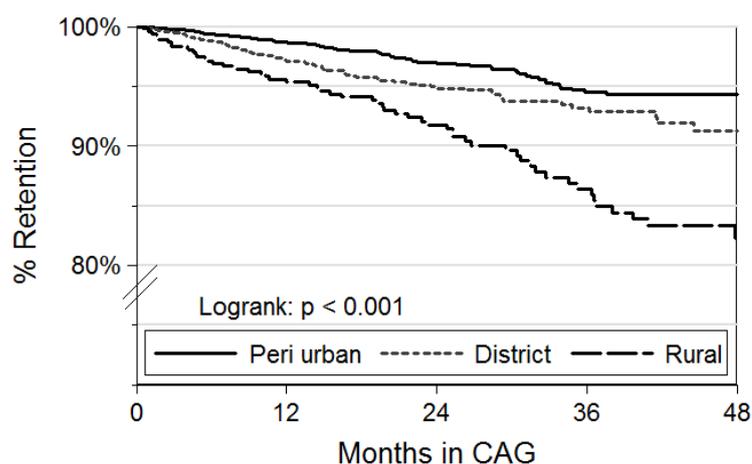
Factors associated with attrition in CAG were estimated. **Table 3** shows the final multivariate model and the adjusted hazard ratios for each of the factors (at individual or group level) associated at level 0.05 with mortality among members in CAG.

Risk factors associated with attrition at individual level were: 1) having a low CD4 (below 200 cells/ μ l) when joining a group (aHR 2.28; 95% CI, 1.60-3.24); and 2) being male (aHR 1.93; 95% CI, 1.48-2.51); and at group level: 1) being member of a group without a fluent rotational representation at the clinic to get a refill (aHR 1.72; 95% CI,

1.27-2.33); 2) being member of a group without a recent CD4 for all fellow members (aHR 1.88; 95% CI, 1.18-3.00); 3) being member of a group linked with a rural clinic (aHR 2.59; 95% CI, 1.81-3.70) or district clinic (aHR 1.57; 95% CI, 1.14-2.16) compared to being linked with a peri-urban clinic.

The retention rates among CAG members at the peri-urban clinics were 98.8%, 97.1% and 94.7%, at the district clinics 97.2%, 95.4% and 93.7% and for the rural clinics 95.8%, 92.2% and 87.3% at one, two and three years respectively (**graph 2**). The logrank test for strata according clinic type was significant (p -value < 0.05).

GRAPH 2: Retention in CAG stratified by type of clinic



At risk by clinic

Peri-urban :	3394	2240	1023	581	23
District :	1666	1244	687	321	85
Rural :	668	415	285	176	66

CAG: community ART group

TABLE 3: Factors associated with attrition among CAG members

Characteristics of members at individual or community ART group level	N	Attrition (death or LTFU)	HR (95% CI)	P	aHR (95% CI)	P
Total, n (%)	5729 (100.0%)	222 (100.0%)				
Male, n (%)	1746 (30.5%)	106 (47.8%)	2.07 (1.59-2.70)	< 0.001	1.93 (1.48-2.51)	< 0.001
CD4 when starting ART, n (%)						0.057
• ≥ 200 cells/μl	1931 (33.7%)	55 (24.8%)	1		1	
• < 200 cells/μl	2475 (43.2%)	140 (63.1%)	1.76 (1.29-2.42)	< 0.001	1.33 (0.96-1.82)	0.086
• Missing data	1323(23.1%)	27 (12.2%)	1.20 (0.70-2.05)	0.495	0.86 (0.53-1.40)	0.547
CD4 when joining CAG, n (%)						< 0.001
• ≥ 200 cells/μl	3402 (59.4%)	96 (43.2%)	1		1	
• < 200 cells/μl	581 (10.1%)	57 (25.7%)	2.97 (2.12-4.17)	< 0.001	2.28 (1.60-3.24)	< 0.001
• Missing data	1746 (30.5%)	69 (31.1%)	2.83 (2.05-3.91)	< 0.001	2.65 (1.92-3.66)	< 0.001
Member of a CAG without a recent CD4 for all fellow members, n (%)*	4401 (76.8%)	201 (90.5%)	2.49 (1.56-3.97)	< 0.001	1.88 (1.18-3.00)	0.008
Member of a CAG without a fluent rotational representation at the clinic, n (%)	2838 (49.5 %)	153 (68.9 %)	2.00 (1.48-2.71)	< 0.001	1.72 (1.27-2.33)	< 0.001
type of clinic, n (%)						< 0.001
• Peri-urban	3394 (59.2%)	84 (37.8 %)	1		1	
• District	1666 (29.1%)	78 (35.1 %)	1.56 (1.13-2.13)	0.006	1.57 (1.14-2.16)	0.006
• Rural	669 (11.7%)	60 (27.0 %)	2.85 (2.00-4.06)	< 0.001	2.59 (1.81-3.70)	< 0.001

N: number; LTFU: lost to follow-up; HR: Hazard Ratio; aHR: adjusted Hazard Ratio; CAG: community ART group; *recent CD4 = during last 24 months

Circumstances of stopping or dying in CAG care

Of the 5729 adult CAG members 208 (3.6%) died and 14 (0.2%) were LTFU after a median follow-up time of 19 months (IQR: 10-29). The most frequent cause for stopping treatment was travel, often to look for work. Some

female members feared to disclose their sero-status to a new partner and preferred to stop ART. Also information on the circumstances in which CAG members died was obtained.

When the patient died in the community in most cases the members of the CAG network

were able to give a feedback to the health workers. Only for 6 (3%) group members who died no explanation at all was reported. However, the information obtained on the circumstances in which patients died was mostly not specific. The majority of patients (73%; 151 patients) died after a prolonged period of illness, most likely due to an AIDS related condition. Major causes were treatment failure, tuberculosis, and anemia. For 42% (64/151) among them a big variety of non-specific symptoms were reported, and in most cases there was no clear diagnosis.

Discussion

The attrition among 5729 adult members stable on ART who joined a CAG between February 2008 and December 2012 was 2.2 per 100 person-years. Mortality and LTFU rates were respectively 2.1 and 0.1 per 100 person-years. The overall retention at one, two, three and four years on ART was respectively 97.7% (95% CI: 97.4-98.2), 96.0% (95% CI: 95.3-96.6), 93.4% (95% CI: 92.3-94.3) and 91.8% (95% CI: 90.1-93.2). The social network of CAG members and their close relatives was a very useful source to obtain information on the few patients LTFU. For the few patients LTFU mainly practical reasons (travel to work) and social behavior (secrecy towards new husband) interfered with compliance to ART care. The majority of the deaths occurred after a prolonged period of disease. The obtained data suggest that mortality is mainly HIV related, and often caused by preventable or curable conditions, and here improvement can be made. The outcomes, and especially the LTFU rates, among patients in CAG are every convincing in a context where 48.6% attrition at three years ART was reported (respectively 17.4% and 31.0% were death and LTFU at three years ART) (Wandeler *et al.* 2012). In another Mozambican study overall attrition since the start of ART was 19.8 per 100 person-years. After the first three months attrition on ART was 13.2 per 100 person-years (Auld *et al.* 2011).

How to interpret retention and attrition among CAG members? CAG consist mainly of stable patients on ART, and participation is voluntary (about 50% of patients on ART choose to join at the ART sites where the ART group dynamic was rolled out). It is probable that the patients who joined CAG have different psychosocial and biomedical characteristics than patients who chose to remain in individual care. First, patients were ought to be clinically stable on ART and immunologically recovering when they joined a CAG, and second they might have had a different adherence profile than those who preferred to stay in individual care. Subsequently findings cannot be generalized, and one has to be cautious when comparing outcomes of members in CAG with outcomes of other cohorts. On the other hand 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 (Fox & Rosen 2010). 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.

Attrition among CAG members depended on the immunological status, gender, the peer dynamic in the community and the level of care offered at the clinic. Members who joined the CAG with a CD4 below 200 cells/ μ l were at higher risk for attrition (aHR 2.28; 95% CI, 1.60-3.24). Immunosuppression is a known risk factor for attrition among PLWHA on ART (Gupta *et al.* 2011). Strategies need to be developed to enroll patients earlier on ART. Subsequently patients could join a CAG with a less depressed immunological status. Another risk factor at individual level was male gender (aHR 1.93; 95% CI, 1.48-2.51). This finding confirms what was described by other studies and in a review (Auld *et al.* 2011; Druyts *et al.* 2013; Mills *et al.* 2011). If men would prioritize utilization of health care services in an earlier stage of the HIV infection, and in an early stage during new episodes of illness, this could reduce the attrition among men (Auld *et al.* 2011). Moreover, treatment strategies are not yet

adapted to the specific needs of men, while for woman antenatal care services are an opportunity to increase uptake into care (Druyts *et al.* 2013; Mills *et al.* 2011). An opportunity could be the roll out of male circumcision, as part of a care package which could include a proposal for HIV testing (Mills *et al.* 2011).

At group level attrition was associated with a lack of rotational representation at the clinic (aHR 1.72; 95% CI, 1.27-2.33) and a lack of a regular CD4 count among fellow members (aHR 1.88; 95% CI, 1.18-3.00). Risk factors associated with the functioning of the CAG confirm that the CAG has to be more than a distribution system for ART. Interestingly, dependency on a transport fee to access ART (aHR 0.97; 95% CI, 0.72–1.31) was not significantly associated with mortality. This finding suggests that CAG were able to overcome the barrier of transport cost, as members share this cost.

Attrition among CAG members was also associated with linkage to a rural clinic (aHR 2.59; 95% CI, 1.81-3.70) or a district clinic (aHR 1.57; 95% CI, 1.14-2.16) compared with linkage to a peri-urban clinic. Retention in CAG at the rural clinics at one, two and three years on ART was respectively 95.8%, 92.2% and 87.3%. Attrition was 4.8 per 100 person-years. In our study attrition was mainly due to mortality, which is strongly associated with the type of clinic on which CAG members depend for clinical care. This association did not alter once adjusted for individual or CAG level factors, which suggests that the association between attrition and clinic type is mainly explained by health system factors, or the lower quality of clinical care provided at rural clinics. Our findings are consistent with a recent Cochrane review, which reported a higher mortality among ART patients attending rural clinics (Kredo *et al.* 2013). Another Mozambican study reported 23 attritions per 100 person-years among patients more than six months on ART at rural clinics in Mozambique, which was twice as high as the attrition at urban clinics (Lambdin

et al. 2013). However, the roll out of simplified and standardized ART care compares favorably with no care at all. From a public health perspective, the reduction of overall HIV/AIDS related deaths at population level through ART decentralization to nurse-based clinics outweighs the eventual loss due to a lower quality of clinical care at rural clinics (Kredo *et al.* 2013). Furthermore, when communities partner with rural clinics to deliver a standardized package of HIV care improved uptake, linkage and retention in care can be achieved (Rasschaert *et al.* 2011; World Health Organisation 2013b).

Some limitations limit the interpretation of our findings. First, WHO clinical stage and history of tuberculosis are known risk factors associated with attrition but data were unavailable for the analysis (Caluwaerts *et al.* 2009). Moreover, data for some variables were not available for all the patients, including CD4 counts and the date patients started ART. Many patients had no recent CD4 due to a limited access to CD4 (only 3 machines for the 32 ART sites in Tete province) and the periodical breakdown of the machine at the central site. Second, as mentioned above, patients were able to choose between joining a CAG and remaining in individual care. Selection and confounding bias would occur if one would compare the outcomes of patients in CAG with patients in individual care. An ongoing quantitative study will allow adjustment for collected biomedical variables; however adjustment for psychosocial factors will remain a challenge. Finally, as the data were collected from the members in CAG, and from the counselors, observation bias could have occurred. Rigorously a file review was organized in 2010, and periodically thereafter, to assure that the reported outcomes were the true outcomes. During this repetitive process no discrepancies were found when it comes to the reported treatment outcomes. Moreover, frequent visits of the counselors and a multidisciplinary supervision team to the communities allowed to understand well the dynamic, and to verify what was reported.

Conclusion

Long term retention in CAG was exceptionally high: 91.8% at 4 years of follow-up. To decrease further attrition among CAG members, efforts should be made to include patients earlier on ART, and earlier in CAG, with a less suppressed immunologic status. Strategies should be piloted to reach male patients earlier, and to support them to seek health care earlier when sick. The peer dynamic (rotation wise representation at the clinic, mutual follow-up of CD4) is associated with the treatment outcomes, and is a potential resource to build future strategies on, and promote uptake of HIV testing, linkage to care and retention in care.

The findings of our study confirm the results found by recent studies, which documented how community and peer support for ART care improve ART outcomes in sub-Saharan countries (Fatti *et al.* 2012; van Rooyen *et al.* 2013; Wouters *et al.* 2012). Recently proposed large scale ART roll-out will only be possible if all human potential available, including community health workers and PLWHA, is engaged to reach the target of sustained ART coverage in poor resourced high prevalence countries.

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The effect of Community ART Groups on retention-in-care among patients on ART in Tete Province, Mozambique: a cohort study

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Abstract

Background: High levels of attrition (death or loss-to-follow-up (LTFU) combined) on antiretroviral therapy (ART) indicate that delivery models need to adapt in sub-Saharan Africa. In 2008, patients on ART in Tete Province, Mozambique, began forming community ART groups (CAGs), and took turns to collect ART refills at the health facility. We conducted a retrospective cohort study to quantify the effect of CAG versus individual care on retention-in-care.

Methods: Data up to May 2012 was collected from patient records at eight health facilities. Survival analysis was used to compare retention-in-care among patients in CAG and patients in individual care, with joining a CAG treated as an irreversible time-dependent variable. Patients had to remain in care for at least six months after starting ART to be included in the analysis. Multivariable Cox regression was used to estimate the effect of CAG on attrition, adjusted for age, sex, and health facility type, and stratified by calendar cohort.

Results: Twelve-month and 24-month retention-in-care from the time of eligibility were respectively 89.5% and 82.3% among patients in individual care and 99.1% and 97.5% among those in CAGs ($p < 0.0001$). CAG members had a greater than five-fold reduction in risk of dying or being lost-to-follow-up (adjusted hazard ratio [aHR]: 0.18, 95% CI: 0.11-0.29).

Conclusions: Among patients on ART, retention-in-care was substantially better among those in CAGs than those in individual care. This study confirms that patient-driven ART distribution through CAGs results in high retention-in-care among patients who are stable on ART.

Introduction

Currently an estimated 36.7 million people are living with HIV (PLHIV), of whom seventeen million were on antiretroviral therapy (ART) at the end of 2015 (UNAIDS, 2016). Will it be feasible to achieve the UNAIDS target of having 73% of all PLHIV on ART and virologically-suppressed by 2020? Such an unprecedented undertaking will require innovative approaches, especially in sub-Saharan Africa (SSA), where the HIV burden is the highest, and health workforce gaps and other challenges hamper response (WHO, 2014). In addition, high levels of attrition (death or loss-to-follow-up (LTFU) combined) have hampered advances in care.

A recent systematic review reported attrition rates in ART programs in African countries of 18%, 24%, and 31% after six months, one year, and two years of ART, respectively (Fox, 2015). Distance to health facilities, transport costs, long waiting times at the health facilities, work responsibilities, and family commitments have been reported as reasons for defaulting treatment (Govindassamy, 2012). ART delivery closer to patients' homes is effective at augmenting retention-in-care (Govindassamy, 2012).

To enrol and retain millions on ART, health systems have had to adapt during the past decade. Several policies have been implemented to increase the capacity of

understaffed health systems. Treatment has been decentralized from specialized HIV clinics to peripheral primary health care facilities (Kredo, 2013). Tasks have been shifted from doctors to nurses, from nurses to lay health-workers, and from lay health-workers to patients (Callaghan, 2010). Additionally, in some countries delivery models have become increasingly patient-centered, allowing patients to combine lifelong ART refills with a normal social and economic life (Govindassamy, 2012; Duncombe, 2015).

Mozambique is one of the countries that has adopted a patient-centered ART delivery model. However, despite decentralization of ART provision, starting in 2006, LTFU rates remained unacceptably high (Lambdin, 2013; MOH, 2012). Strategies, such as home visits to patients LTFU, had been unsuccessful in bringing patients back to care (Caluwaerts, 2009). Patients reported that long distances, lack of information, queuing at health facilities, and stigma associated with regular clinic attendance, as barriers to retention-in-care (Posse, 2009).

To overcome these barriers associated with the conventional, clinic-based, individual-care approach to ART delivery, and drawing on published accounts of patient involvement in chronic disease care (Kober, 2006), the Health Directorate of Tete Province and Médecins Sans Frontières proposed that stable patients on ART be given the option of forming peer groups and becoming involved in ART delivery and monitoring.

Patients on ART are given the option of joining a peer group, or remaining in clinic-based individual care, and can move between the two models of care, according to their preference. These peer groups are named Community ART Groups (CAGs). To join a CAG, patients are required to be at least 15 years old, and to have been on ART for at least six months, and to be stable on treatment. Each CAG has a maximum of six members.

Members take turns to travel to the clinic to collect monthly ART refills for all group members. Every month, before the CAG representative attends the health facility to collect the ART refills, the group meets in their community to discuss their current health and treatment status and any travel plans. The CAG representative whose turn it is to collect the monthly ART refills, has a clinical consultation and reports on the status of the other group members (retained on ART in the group, died, travelled, etc.). This information is recorded on a group monitoring card, which is kept in the clinic, and updated each month. CAG members are advised to make unscheduled visits to the health facility between ART refill appointments if they develop health problems, as do other patients who develop health problems during the intervals between scheduled appointments. Giving patients a high level of autonomy, the CAG model is the most patient-driven, community-based ART delivery model described to date (Bemelmans, 2014).

The CAG model has previously been described in more detail (Decroo, 2011). CAG members reported several benefits including time and cost savings. They reported that less frequent clinic visits was associated with reduced experiences of stigma in the community, and viewed the CAG as a protective environment where they could share treatment experiences confidentially. Patients considered counsellors, lay health-workers trained in the basics of HIV care and psychosocial care, to be approachable. These counsellors played an important role in forming and monitoring CAGs (Rasschaert, 2014). Four year retention-in-care was 92% (Decroo, 2014). Despite this high retention on ART among patients in CAGs, these previous studies did not assess the relative effectiveness of the CAG model and the standard, clinic-based, individual care approach in retaining patients on ART. We conducted a study to quantify the effect of the CAG model relative to standard individual care, on retention-in-care among patients on ART.

Methods

Study design

We conducted a retrospective cohort study using programme data.

Study setting

Mozambique has a population of 23.9 million inhabitants, of whom more than 70% live in rural areas (WHO, 2009). HIV prevalence among sexually-active people is estimated to be 10.5%. Over 1.5 million people in Mozambique are living with HIV (UNAIDS, 2016b). The government began providing ART in 2003 (MOH, 2012). Due to an extreme shortage of human resources and limited infrastructure, it took more than a decade to attain 50% ART coverage, according to the ART eligibility criteria in effect at the time. By the end of 2015, ART coverage was about 53% (UNAIDS, 2016b).

The rural Province of Tete, in Mozambique, has a population of two million. An estimated 36% of the population has access to a health facility within 30 minutes of their home (WHO, 2009). HIV prevalence is estimated to be 7.5% (MOH, 2010). The province has 105 health facilities, spread across 15 districts. By mid-2012 only 32 of the 105 (30.5%) facilities in Tete Province offered ART (MOH, 2012). Decentralization of ART provision towards peripheral clinics, in order to increase accessibility of ART, has been hampered by infrastructural constraints, a shortage of medically-qualified staff, organizational challenges, and a lack of regulation to push for task-shifting from nurses to lay health-workers (Decroo, 2009).

Of the 32 facilities in Tete Province that were providing ART in 2012, 12 (37.5%) implemented the CAG model in 2008 or 2009.

Study sites and population

Of 12 health facilities that had implemented the CAG model by the end of 2009, eight (Manje, Changara, Songo, Chitima, Mutarara, Moatize, Zobue, and Boroma) were included in this study. The other four facilities were excluded because the majority of patients on ART (>80%) were enrolled in CAGs, leaving

few patients in standard care to serve as a comparison group.

In order to minimize survival bias, patients who started ART more than 6 months before the CAG model was introduced at the health facility that they were attending, and patients who transferred to the health facility more than 6 months after starting ART, were excluded from the analysis. Patients younger than 15 years, 60 years and older, with an unknown age at ART initiation, were also excluded from the analysis. Patients who remained in care for less than 6 months after starting ART were excluded because patients are required to be stable on ART in order to be eligible to join a CAG, and mortality is highest in the first 6 months after starting ART (Lawn, 2008; Gupta, 2011).

Study period

The start of the study period varied by health facility, starting on the date that the first CAGs were formed at the facility. Patients at all 8 study facilities were followed-up until the end of April 2012. For the purpose of this analysis, patients entered the cohort on the date on which they became eligible to join a CAG, defined as 6 months after starting ART.

Data collection and definition of variables

Patient-files and clinic-held copies of CAG cards were used as data sources. Data was abstracted during the second half of 2012 and 2013, and entered into a Microsoft Access database. CAG monitoring tools and processes have been described elsewhere (Decroo, 2011).

The information collected included patient socio-demographic characteristics (sex, age at ART initiation, date of ART initiation, CD4 results, date of joining a CAG, and date of returning to individual care, if applicable), treatment outcomes and dates. The following treatment outcomes were recorded: retained-in-care at the end of the study period (30 April 2012), dead, lost to follow-up (LTFU), and transferred out. LTFU was defined as being more than 2 months overdue for the most recent appointment or scheduled ART refill.

Health facilities were categorized as peri-urban or rural. The two peri-urban facilities (Moatize and Songo) have medical specialists, a referral laboratory and radiology facilities available, and the rural facilities (Manje, Changara, Chitima, Mutarara, Zobue, and Boroma) are primary health care facilities run by nurses.

Data analysis

The analysis was performed using Stata Version 14 (StataCorp, College Station, Texas, USA).

Some numeric variables were categorized to facilitate the analysis. Median and interquartile ranges (IQR) were calculated for numeric variables and proportions for categorical variables.

Survival analysis was used to compare retention-in-care among patients in CAG and patients in individual care. Joining a CAG was treated as an irreversible time-dependent variable, with patients included in the “not in a CAG” group until they joined a CAG, and in the CAG group from the date that they joined a CAG. CAG members who returned to individual care (n = 11), were retained in the CAG group in the survival analyses. Univariable and multivariable Cox regression were used to estimate crude hazard ratios (HRs) and adjusted hazard ratios (aHR) for attrition. The aHRs were adjusted for age, sex, and health facility type, and stratified by calendar period of ART initiation (six-month intervals).

Patients who remained in care at the end of the study period had their follow-up censored on 30 April, 2012. Patients who were LTFU, or who died during the study period, were considered as having experienced the outcome event (attrition), with the outcome date defined as the most recent date of contact with the health facility, either in the form of an individual clinic visit, or an ART

refill collected by another CAG member on the patient’s behalf. Patients who were transferred to another facility were censored on the date of transfer.

Ethics

This study was approved by the Ethics Review Board of Médecins Sans Frontières (Geneva, Switzerland) and the Mozambican National Bioethics Committee.

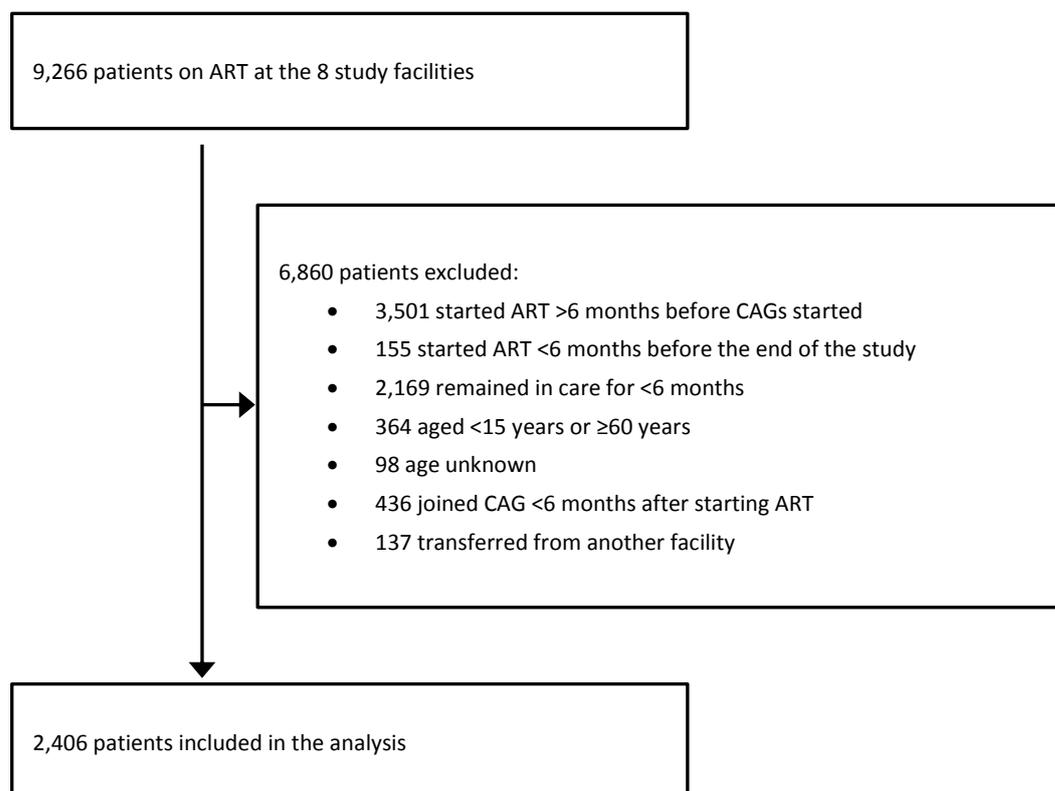
Results

During the study period, between 1 February 2008 and 30 April 2012, 9,266 patients were provided with ART in the eight health facilities. Of these patients, 6,860 were excluded from the analysis because they did not meet the eligibility criteria, leaving 2,406 patients in the analysis. The reasons for the exclusions are shown in Figure 1.

Of the 2,406 patients who satisfied the inclusion criteria, 901 (37.5%) joined a CAG during the study period (Table 1). Patients who joined a CAG had a longer follow-up time (median: 26 months, IQR: 18 to 33 months) from the date that they entered the cohort and the end of the study (30 April 2012) than those who did not join a CAG (median: 16 months, IQR: 7 to 27 months). Patients who joined a CAG were also more likely to be female (CAG: 70.3%; 631/901; non-CAG: 59.9%; 883/1505), and attending a rural clinic (CAG: 64.8%; 584/901; non-CAG: 57.3%; 862/1505).

CAG patients joined a CAG after a median of 8.3 (IQR 3.6 to 16.7) months from the time of eligibility (6 months after starting ART). Overall, 279 out of 2406 (12%) patients died or were LTFU by the end of the study period (30 April, 2012). Attrition was greater among those aged <25 years, males, and those who were not CAG members (Table 2), than among patients without these characteristics

Figure 1: Study flow diagram: inclusion of patients on ART in the study



CAG: Community ART groups; ART: antiretroviral therapy

Table 1: Characteristics of patients included in the analysis, by CAG status

	Did not join a CAG	Joined a CAG	Total cohort
Total (n, column %)	1505 (100)	901(100)	2406(100)
Sex [§] (n, column %)			
Fem ale	883 (59.9)	631 (70.3)	1514 (63.1)
Male	617 (41.1)	267 (29.7)	884 (36.9)
Age at ART initiation (years) (median, IQR)	32 (26 – 39)	33 (27 – 40)	32 (27 – 39)
Time in the study (months) (median, IQR)	16 (7 – 27)	26 (18 – 33)	11 (20 – 30)
Health facility type (n, column %)			
Peri-urban	643 (42.7)	317 (35.2)	960 (39.9)
Rural	862 (57.3)	584 (64.8)	1446 (60.1)

CAG: Community ART Group; [§] 8 (0.3%) patients did not have their sex recorded; Time in the study is defined as the interval between the date on which the patient entered the cohort and the end of the study period (30 April 2012), regardless of whether the patient left the cohort before the end of the study period.

Table 2: Retention in care from the time of eligibility to join a CAG, and factors associated with retention

Characteristic	12-month RIC % (95% CI)	24-month RIC % (95% CI)	HR (95% CI)	aHR (95% CI)
All (n = 2,406)	90.8 (89.5 – 92.0)	86.0 (84.2 – 87.6)	—	—
CAG status				
Not in a CAG (n = 2,406)	89.5 (87.9 – 90.8)	82.3 (79.9 – 84.5)	1.00 (reference)	1.00 (reference)
In a CAG (n = 901)	99.1 (97.3 – 99.7)	97.5 (95.4 – 98.6)	0.17 (0.10-0.28)	0.18 (0.11 – 0.19)
Age (years)				
15 – 24 (n = 371)	87.7 (83.5 – 90.9)	81.4 (75.9 – 85.8)	1.52 (1.09-2.11)	1.65 (1.17 – 2.32)
25 – 29 (n = 515)	92.7 (89.9 – 94.7)	87.1 (83.0 – 90.2)	0.98 (0.71-1.36)	1.04 (0.75 – 1.45)
30 – 39 (n = 945)	90.8 (88.6 – 92.6)	87.3 (84.6 – 89.6)	1.00 (reference)	1.00 (reference)
40 – 59 (n = 575)	91.2 (88.3 – 93.4)	85.8 (82.0 – 88.8)	1.09 (0.80-1.49)	0.98 (0.72 – 1.34)
Sex				
Female (n = 1,514)	92.4 (90.8 – 93.7)	88.9 (86.9 – 90.7)	1.00 (reference)	1.00 (reference)
Male (n = 854)	88.2 (85.6 – 90.3)	80.8 (77.4 – 83.8)	1.78 (1.41 – 2.26)	1.82 (1.42 – 2.33)
Facility type				
Peri-urban (n = 960)	90.9 (89.2 – 92.3)	85.6 (83.3 – 87.7)	1.00 (reference)	1.00 (reference)
Rural (n = 1,446)	90.8 (88.5 – 92.6)	86.6 (83.7 – 89.0)	0.97 (0.76 – 1.25)	0.90 (0.70 – 1.16)
Cohort				
2008 (n = 148)	93.1 (87.5 – 96.2)	88.0 (81.4 – 92.4)	1.00 (reference)	—
Jan – Jun 2009 (n = 229)	92.5 (88.1 – 95.2)	85.1 (79.7 – 89.2)	1.27 (0.77 – 2.10)	—
Jul – Dec 2009 (n = 389)	93.7 (90.8 – 95.7)	88.8 (85.1 – 91.6)	0.94 (0.57 – 1.56)	—
Jan – Jun 2010 (n = 352)	92.4 (89.0 – 94.8)	87.4 (83.3 – 90.5)	1.06 (0.63 – 1.78)	—
Jul – Dec 2010 (n = 382)	92.2 (88.9 – 94.5)	84.4 (80.2 – 87.8)	0.95 (0.55 – 1.64)	—

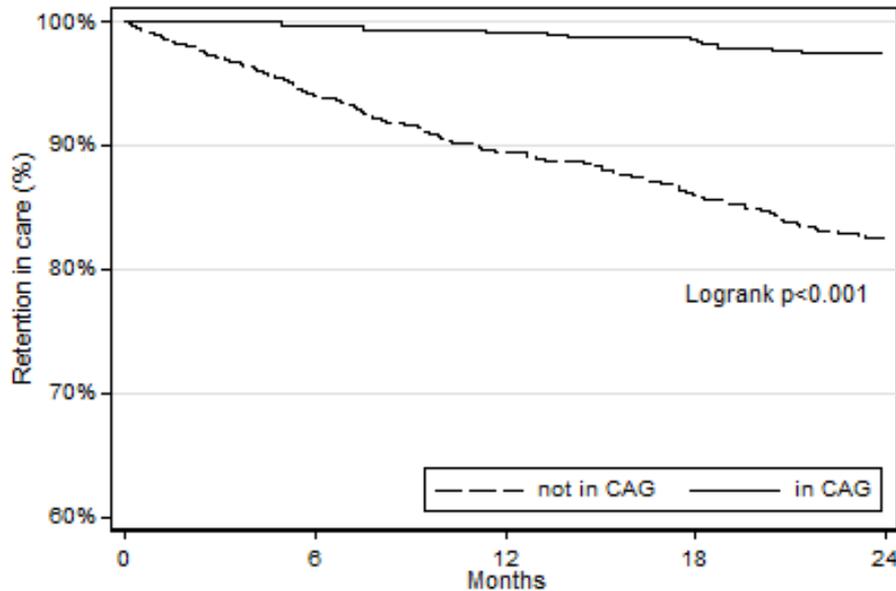
RIC: Retention in care; CI: Confidence interval; HR: Hazard ratio; Adjusted hazard ratio. Hazard ratios were adjusted for the other variables shown, and stratified by calendar cohort in 6-month categories. CAG status was a time-dependent variable. Patients were in the “not in CAG” group until they joined a CAG. Cohorts are defined according to the date on which patients became eligible to join a CAG. The multivariable Cox regression was stratified by cohort, so aHR’s were not determined.⁴

Overall, 12-month retention-in-care (RIC) from the date of eligibility was 90.8% (95%CI: 89.5% to 92.0%) and 24-month RIC was 86.0% (95%CI: 84.2% to 87.6%). RIC was significantly

greater among patients in CAGs than those not in CAGs (stratified log-rank test: $p < 0.0001$) (Figure 2). Twelve-month RIC was 99.1% (95% CI: 97.3 to 99.7%) among those in

CAGs and 89.5% (95% CI: 87.9 to 90.8%) among those not in CAGs (Table 2)

Figure 2 Retention-in-care by CAG status among 2406 patients on ART, between 2008 and 2012, in Tete, Mozambique



CAG: Community ART Groups

Adjusted for age, gender, health facility type, and stratified by calendar period of ART initiation, patients in CAG had a more than five-fold lower rate of attrition (aHR: 0.18, 95% CI: 0.11 – 0.29) (Table 3). The risk of attrition was higher among patients younger than 25 years compared to those aged 30 – 39 years (aHR: 1.65, 95%CI: 1.17 – 2.32); and among males compared to females (aHR: 1.80, 95%CI: 1.41 – 2.30) (Table 2).

Discussion

We found that RIC among patients in CAGs was substantially higher than among patients in individual care. After adjustment for age, gender, health facility type, and after stratification by calendar period of ART initiation, patients in CAG were more than five times less at risk to die or to be LTFU. Other studies on RIC in care in CAG and individual care showed similar findings. Reports of high retention in CAG in Tete province informed CAG pilots, in Mozambique, and in Lesotho.

The Mozambique national pilot showed 91.4% and 82.9% RIC in CAG and individual care, respectively. This study included patients from 68 health facilities, from 7 different provinces (not Tete province), a mix of urban and rural, and high and low volume ART clinics (Jobarteh, 2016). The MSF supported pilot in Lesotho showed 98.7% and 90.2% RIC in CAG and individual care, respectively (Vandendyck, 2015).

Overall, 12-month RIC from the date of eligibility (6 months after starting ART) was 90.8% and 24-month RIC was 86.0%. These findings are similar to what is reported by other studies conducted in Mozambique. In a study conducted in rural Mozambique, two-year attrition among patients more than 12 months on ART was 16.2% (Wandeler, 2012). Another Mozambican study showed late attrition rates (after 6 months on ART) of 15 patients per 100 person-years in urban clinics, and 23 patients per 100 person-years in rural clinics (Lambdin, 2013). A systematic review

analyzed data from eight Mozambican studies and found attrition of 17% at 6 months, 28% at 12 months, and 44% at 24 months (Fox, 2015).

The finding that attrition may be reduced by a patient-driven ART distribution model has important implications, especially in rural contexts. The high retention-in-care among patients who joined CAGs can be attributed to a combination of factors including: a reduced time spent travelling to and from the facility, and queuing at the facility; reduced health care-related transport costs; and enhanced information-sharing within the community and between the community and health-care workers (Rasschaert, 2014). Peer support and higher levels of self-efficacy have been identified as important enablers of successful lifelong HIV care (Langebeek, 2016). Peer support enhances utilization of health care services, and has a positive effect on quality of life (Bateganya, 2015). Rasschaert et al found that relationships between patients and healthcare providers changed profoundly after the CAG model was implemented. CAG members were perceived by clinic and community staff as co-providers because they took responsibility for medical tasks, served as a channel of communication between community members and healthcare providers, and reduced the workload of healthcare workers, especially in rural health facilities (Rasschaert, 2014b).

In 2008, when the CAG model was introduced, clinicians and healthcare workers were concerned about whether medical tasks such as ART distribution could be delegated to patients. The results of this study confirm that ART distribution can be delegated to patients, and demonstrates that patients can take responsibility for their lifelong HIV care, especially when supported by their peers. Earlier studies have shown the benefit of involving patients in peer-to-peer activities without remuneration, including counselling, tracing of patients LTFU, administrative tasks in health facilities, and income-generation projects (Wouters, 2012; Zachariah, 2006), but this study is the first to show that patients

can be involved in ART delivery without remuneration, motivated by their own health needs. Other community-based ART delivery models in Uganda and Kenya, have introduced ART delivery to patients' homes by paid lay healthcare workers, who are recognized and accountable as formal healthcare workers, and equipped with motorbikes and cell phones (Weidle, 2008; Jaffar, 2009; Wools-Kaloustian, 2009).

To achieve and sustain high ART coverage, health programs need to differentiate and adapt to the specific needs of different subgroups, including virologically suppressed patients on ART, clinically unstable patients, HIV/TB co-infected patients, and adolescents (Grimsrud, 2016; Philips, 2015). For those stable on ART less frequent clinic visits and out-of-clinic ART refill are recommended to reduce maximally the burdens on patients and rationalize the use of the scarce health workforce (WHO, 2015).

A strength of this study is the large number of patients, with diverse characteristics included in the analysis. Another strength is that all the study facilities gave patients the option between individual, clinic-based care and CAG, thus enabling the models of care to be compared under "real life" programmatic conditions. Therefore our findings are representative of the reality of the program in Tete. Another strength is our methodological approach. Patients entered the cohort after being on ART for 6 months, thus excluding patients who had not yet stabilized on ART. Among patients on ART, attrition has been found to be highest immediately after ART initiation, gradually declining over the following year (Fox, 2015). We minimized the potential for survival bias by excluding patients who had started ART more than 6 months before CAGs were introduced at the facility; starting follow-up 6 months after ART initiation in order to exclude patients who had not yet stabilized on ART; treating CAG status as a time-dependent variable to ensure that retention in care prior to joining a CAG was taken into account; and stratifying the Cox regression analyses by calendar period of

entry into the cohort to take into account potential interaction between CAG status and calendar period with respect to attrition.

However, there are also limitations to this study. The exclusion criteria that we chose may have resulted in some selection bias, making the findings less generalizable. There is also likely to be some inherent selection bias because this was an observational study and patients opted voluntarily to join a CAG or to stay in individual care. Patients who opted to join a CAG and those who remained in individual care may have differed with respect to hidden confounding factors which we did not take into consideration in the analysis. Potential confounders for which we were unable to adjust in the analysis, due to a lack of data, include distance of the patients' homes from the clinic, psychosocial characteristics, and health prognosticators such as CD4. There may thus be some residual confounding in the estimated risk of attrition associated with CAG status and the other factors (age, sex, facility type) that we considered in the analysis. In addition, we were unable to use viral suppression as an outcome because routine viral load monitoring was not available during the study period. Although we found high retention-in-care among patients in CAGs, we were unable to assess adherence to treatment. Further research is needed to compare viral load outcomes of patients in CAGs and patients in conventional care.

Currently CAG are rolled out nationally in Mozambique, and in neighboring countries such as Lesotho, Zimbabwe, and Malawi (Jobarteh, 2016; Vandendyck, 2015). In Tete Province the daily management of CAG strongly depended of facility-based lay counsellors (Rasschaert, 2014). Adaptation of this patient-driven delivery model, which was rooted in the rural community of central Mozambique, will be needed to be adapted to local contexts, needs of specific patient groups, available resources and national policies.

Conclusion

RIC was substantially higher among patients on ART in CAG than among those in individual care. Exclusion of the first six months on ART from the follow-up period, and the exclusion of patients who had been on ART for more than 6 months at the time that CAGs became available at the facility that they were attending, reduced the potential for survival bias but, as the study was observational in design, residual or unmeasured confounders may have contributed to the differences observed. Nevertheless this study confirms that patient-driven ART distribution through CAGs results in high RIC, and supports the Mozambique Ministry of Health in rolling out CAG nationally.

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Chapter three: Transferability of lessons learnt from Community ART Groups in Tete to other settings

CAG was implemented in Tete province, Mozambique. As there were no other experiences with PLHIV performing medical tasks it was not clear if CAG would work in other settings. Therefore experiences with CAG in other settings are shown in this chapter. *“Scaling Up Community ART Groups in Mozambique”* describes the process that resulted in the national roll out of CAG in Mozambique and it’s early results. The second study of this chapter, *“Community-based ART resulted in excellent retention and can leverage community empowerment in rural Lesotho, a mixed method study”*, describes retention in CAG and in individual care in Lesotho. Moreover, patients’ and health care provider’s views and experiences with CAG implementation were explored to understand better the CAG dynamic.

Key messages

- Patients played an important role in rolling out CAG in Mozambique, outside Tete province. They shared their experiences with policymakers and patients queuing at health facilities.
- CAG resulted in high retention in rural Lesotho. Retention on ART was higher in CAG than in conventional care. CAG members and health care workers reported that CAG reduced costs and induced peer support and a feeling of comfort and relief. Moreover, health care workers reported that the workload reduced in the health facility.
- Lessons learnt from peer-led ART delivery in Tete are transferable to other settings, if adapted to the local context.

Scaling Up Community ART Groups in Mozambique

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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: The Tete Provincial Directorate of Health and Médecins Sans Frontières developed a community based ART model or patient-centred model, through CAG, to overcome patient reported barriers to monthly drug refills for ART. 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 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. 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.

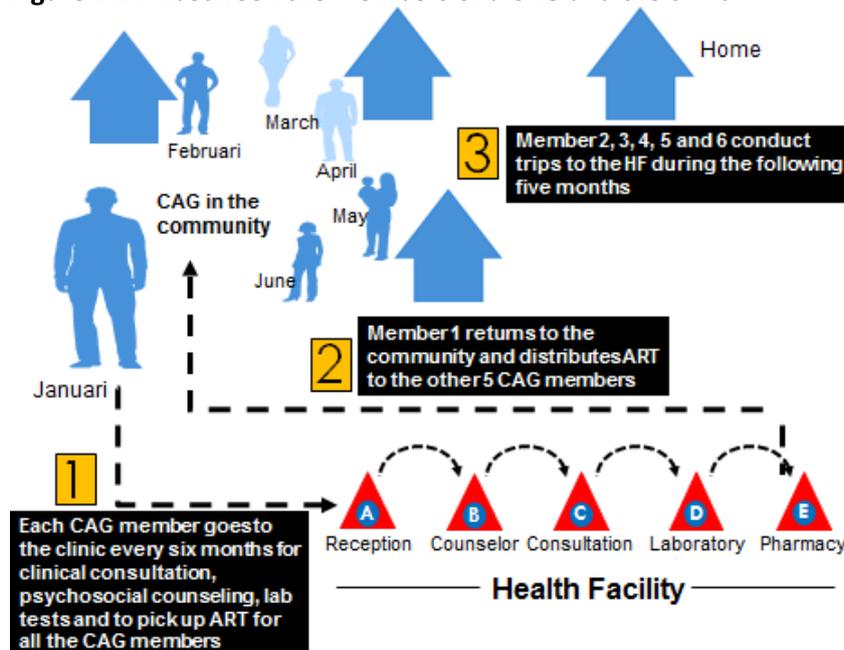
Realizing that a fundamental modification was necessary, the provincial health team in Tete, supported by Médecins Sans Frontières (MSF), began to look at ways to address the underlying barriers to patient retention. Drawing on the robust body of chronic care literature and contemplating the potential 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.

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

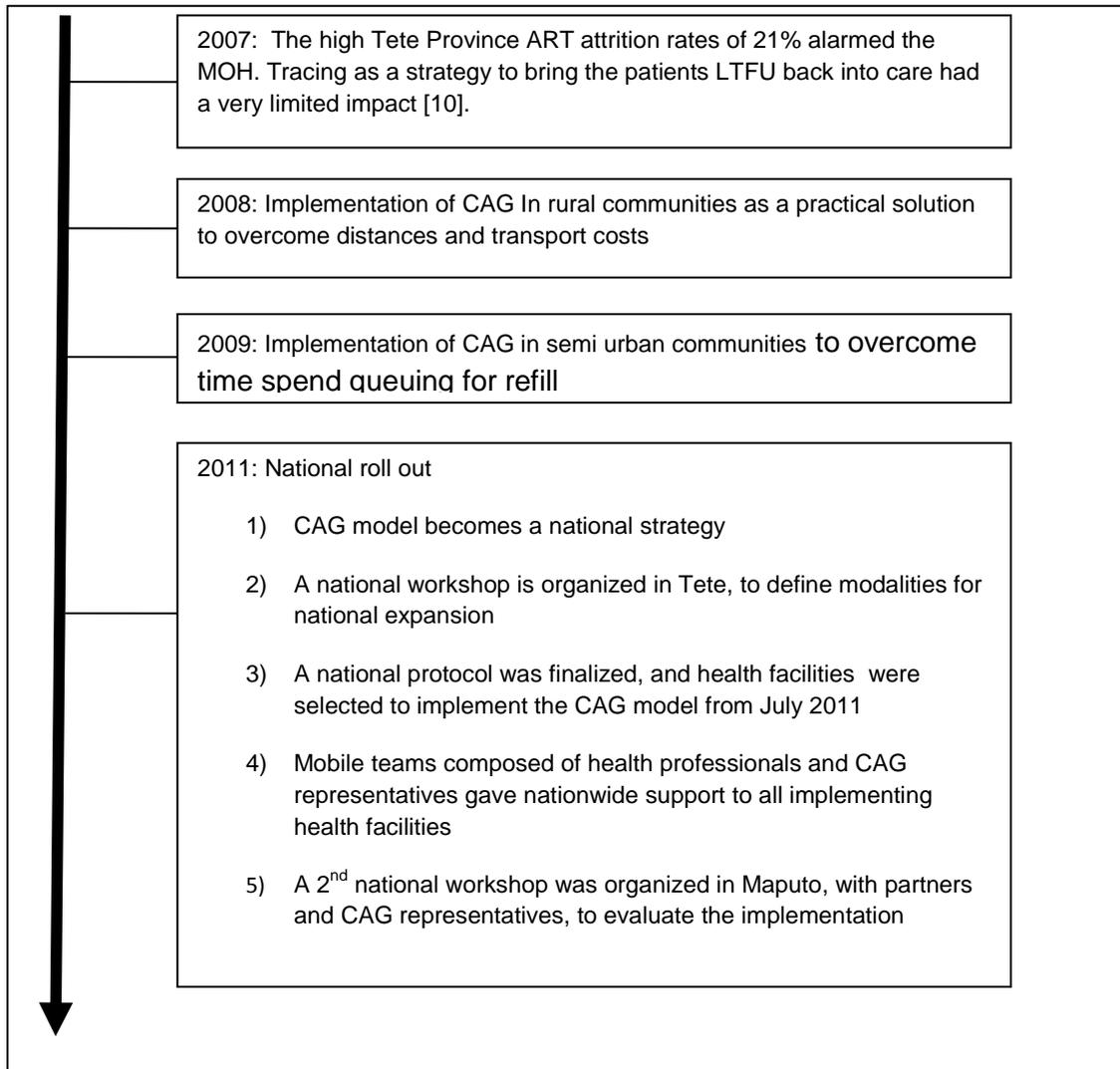
to provide national health authorities the opportunity to observe the model in the field and interact with patient members.

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. 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.

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



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 [11,16,17,18]. 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 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].

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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Community-based ART resulted in excellent retention and can leverage community empowerment in rural Lesotho, a mixed method study

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Abstract

Objectives: We conducted a mixed method study to evaluate the pilot of community ART groups (CAG's) in Lesotho.

Method: At the end of 2012 CAGs were piloted in Nazareth clinic, a facility in rural Lesotho. In CAG's stable patients take turns to collect antiretroviral therapy (ART) for fellow group members. Kaplan-Meier techniques were used to estimate retention among stable patients in CAG and not in CAG. Eight focus group discussions with 40 purposively selected CAG members, nine village health workers, six community leaders and nine clinicians provided insights in how CAGs are perceived by different stakeholders. The thematic analysis approach was employed for data analysis.

Results: Among 596 stable patients 199 (33%) had joined a CAG. One year retention among CAG members and patients not in CAG was 98.7% (95% CI, 94.9-99.7) and 90.2% (95% CI, 86.6-92.9) respectively. CAG members commented that membership in CAG: 1) reduced time, effort, and money spent to get a monthly ART refill; 2) induced peer support, which enhanced adherence, socio-economic support and empowered members to deal with stigma; and 3) resulted in a feeling of relief and comfort. Village health workers confirmed increased openness about HIV in their community. Community leaders added that CAG members promoted health seeking behaviour to community members. Clinicians reported a workload reduction.

Conclusion: Participation in CAG impacted positively on the lives of members, not only on their access to ART, but also on their life within the community.

Key words: HIV; antiretroviral therapy, highly active; health services accessibility; peer support; community participation

Introduction

The scale-up of antiretroviral therapy (ART) in the past decade was spectacular, but still, it is not sufficient. In 2013, close to 12 million were receiving ART in low- and middle-income countries. An additional 14 million are in need of ART [1,2]. Moreover, attrition is problematic. A meta-analysis from over 17 countries in sub-Saharan Africa revealed an attrition of 30.0%, and 35.4% at 24 and 36 months respectively [3]. Transport costs and distance are reported as the most frequent cited barriers to adherence, followed by stigma and fear of disclosure, staff shortages, long waiting times, fear of drug side effects,

male sex, younger age, and the need to take time off work [4].

Lesotho, a mountainous country with approximately 2,171,000 inhabitants, has the third highest HIV prevalence in the world (after Swaziland and Botswana) and is the poorest of the three [5]. In Lesotho one in four adults is infected with HIV. Of 280,000 estimated to be in need of ART, it is estimated that only 93,000 (33%) are currently accessing it [2]. Attrition is problematic; in rural Lesotho 55.4% were reported to be alive and on treatment at three years on ART, 13.5% had died, and 30.9% were lost to follow-up [6]. Scale-up of ART has been hampered by

chronic understaffing and inadequate infrastructure in the healthcare system [7].

In 2009, drawing on a care model rolled out in Mozambique [8,9], the Lesotho Ministry of Health decided to pilot Community ART Groups (CAG). CAG are self-formed peer groups, in which PLWHA engage to assure community ART distribution. The pilot started in December 2012 in Health Centre (HC) Nazareth clinic in Roma district, was supported by Médecins Sans Frontières (MSF), and by mid-2013 Lesotho Network of AIDS Services Organisations (LENASO) and Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) joint in. Here we study how the CAG dynamic was perceived by different stakeholders, and study retention among patients in conventional care and CAG members in HC Nazareth.

Methods

This is a mixed methods study. Qualitative methods were used to study the views and perceptions of different stakeholder. Quantitative methods were used to describe the characteristics and outcomes of patients in CAG and not in CAG.

Setting

HC Nazareth serves a population of 26,582 [10]. HIV care is provided integrated in primary health care services. Furthermore the Nazareth health team organizes outreach activities to four community embedded health posts (HP). The distance from HC Nazareth to the different HP ranges from 10 to 19 km. Medical services include HIV testing, CD4 testing and ART. In conventional HIV care patients visit HC Nazareth or one of the HP on a monthly basis.

Description of the CAG model

Since the end of 2012 the CAG dynamic was promoted. PLWHA stable on ART were invited to constitute a CAG. CAG members meet monthly in the community. During the meeting they verify each other's pill count (adherence), and choose a representative to go to the health facility. At the health facility,

the group representative has a consultation, relates any important events which occurred in the life of the other members, and receives a treatment refill for all the group members of the CAG. Then the representative returns to the community to distribute ART to the fellow group members. One month later, another group member is chosen to represent the CAG at the health facility.

Quantitative data collection and analysis

Quantitative data were collected on patients who started ART between 1/01/07 and 31/12/10. Data sources included the individual clinic-based patient files and the CAG group monitoring forms. Data on socio-demographic and clinical characteristics, participation in CAG, and treatment outcomes were recorded on a data collection form and then encoded in an electronic database (Excel).

The reported treatment outcomes include active, dead, defaulted, transferred out, and return to individual care. Patients are considered defaulters when they are more than 3 months late for ART refill. CAG defaulters are CAG members who didn't receive ART neither in the community, neither in the clinic. Attrition is the sum of the dead and defaulted. When a patient leaves a CAG to return to conventional individual care the outcome is "return to individual care". Stable on ART was defined as being an adult with a CD4 above 350 cells/ μ l, while more than 6 months on ART.

The median and interquartile ranges (IQR) were calculated for numeric variables and proportions for categorical variables. Kaplan-Meier techniques were used to estimate retention among stable patient in CAG and not in CAG. Analysis of data was conducted with STATA (version 11.2).

Qualitative data collection and analyses

Purposive sampling was used to identify key informants who were likely to provide rich data for the analysis. Key informants were invited from four categories of stakeholders (**table 1**).

Table 1: Key informants

	Aim	Participants of FGD
CAG members	To understand the impact of CAG on their health, their link with the clinic and life in the community	27 female and 13 male CAG members Each FGD was composed by members from different CAGs.
Clinicians dealing with CAG.	To understand the impact on patients, on staff, on the organization of care and clinician-patient relationships.	9 clinicians of HC Nazareth.
Village Health Workers dealing with CAG	To understand the impact on the organization of CAG at community level and VHW-patient relationships.	9 VHW
Community leaders (Chief and Community Councillors)	To understand the impact on the on the community at large.	4 Chiefs and 5 Community Councillors

VHW= Village Health Worker

Data were collected employing focus group discussions (FGD) in Sesotho, moderated by a trained interviewer. A note taker observed the group discussions, and took handwritten notes. Interim data analysis was conducted to adapt the initial question guide during the study process. A thematic analysis approach was employed to data analysis. Notes were read and coded. Relationships between coded data were explored. Clusters of linked codes grouped into categories. Categories of data were analysed for emergent themes or theories.

This study was approved by the Ethical review board of Lesotho. All interviewees were 18 years or older and provided an individual written informed consent prior to the data collection. No cost incurred to participants.

For the quantitative component of the evaluation, all analysis was done using routinely collected, de-identified data.

Results

Retention at HC Nazareth

Files of 900 patients of the 2007-2010 ART cohorts were retrieved. Characteristics and outcomes are resumed in **table 2**. Of the 900 patients, 111 (12%) were attending the Health Post, and 199 (22%) were enrolled in CAG. Of the 111 stable patients attending a Health Post, more than half (60; 54%) were CAG members. Retention at 12, 24, and 36 months ART was respectively 88%, 84%, and 80% (**figure 1**).

Table 2: Characteristics and outcomes of the 2007-2010 ART cohort of HC Nazareth

	2007-2010 ART COHORT
N	900
Male, N (%)	281 (31%)
Age, median (IQR)	38 (30-48)
Attended at a Health Post, N (%)	111 (12%)
In CAG, N (%)	199 (22%)
CD4 at ART initiation, cells/ μ l, median (IQR)	183 (102-273)
CD4, last value, cells/ μ l, median (IQR)	547 (354-746)
Follow-up on ART, months, median (IQR)	47 (32-64)
Retention at:	
1 year ART	88%
2 year ART	84%
3 year ART	80%
6 year ART	65%

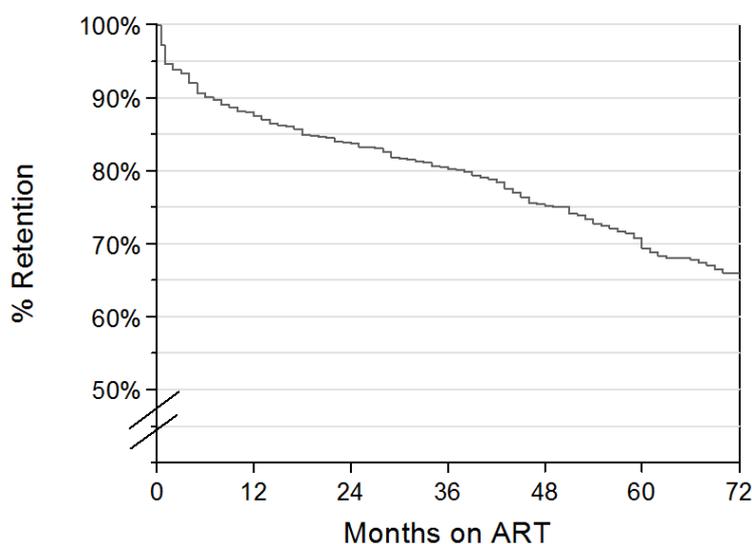
CAG: community ART group; ART: antiretroviral therapy; IQR: inter quartile range; N: number

One year retention in CAG and in conventional care

Among the 900 patients 596 patients were stable on ART. Among them 199 were in CAG and 397 in conventional care (**table 3**). The vast majority of stable patients in conventional care (29%) and in CAG (22%) were female. Median age was similar for patients in conventional care (41; IQR 33-50) and patients in CAG (38; IQR 33-50). Stable patients joined CAG when they were a median

of more than 54 months on ART. One third of CAG members were registered at a Health Post. The median values for CD4 at ART initiation, the first CD4 above 350 cells/ μ l, and the last obtained CD4 were similar among CAG members and patients in conventional care. One year retention was respectively 98.7% (95% CI; 94.9-99.7) and 90.2% (95% CI; 86.6-92.9) among CAG members and stable patients not in CAG (**figure 2**).

Figure 1: Retention on ART among the 2007-2010 ART cohort of HC Nazareth



Number at risk

900 764 705 656 433 306 84

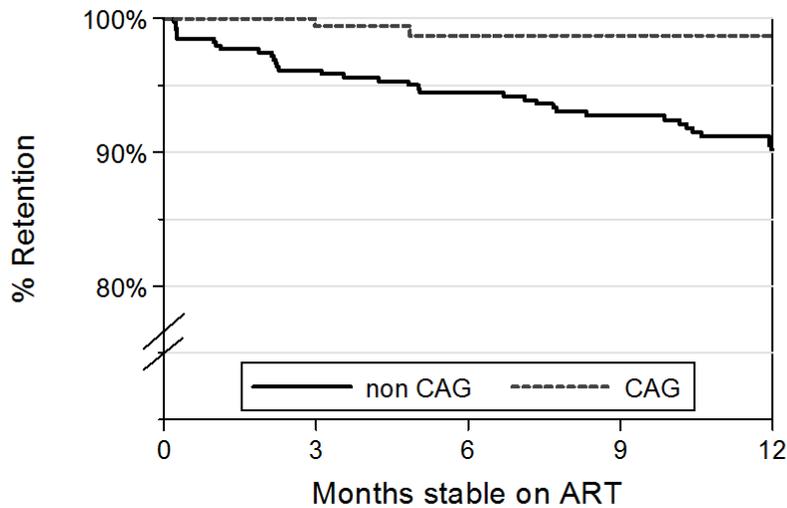
ART: anti-retroviral therapy

Table 3: Characteristics and outcomes among stable patients in CAG and in conventional care

	CAG	Conventional care
N	199	397
Male, N (%)	43 (22%)	116 (29%)
Age, median (IQR)	41 (33-50)	38 (31-49)
Time on ART prior to joining CAG or immune recovery (CD4 above 350 cells/ μ l), months, median (IQR)	54 (42-62)	21 (10-35)
Follow up at a Health Post, N (%)	60 (30%)	37 (9%)
History of tuberculosis, N (%)	23 (12%)	61 (15%)
CD4 at ART initiation, cells/ μ l, median (IQR)	202 (139-291)	209 (129-287)
CD4, first above 350, cells/ μ l, median (IQR)	485 (400-580)	496 (412-620)
CD4, last value, median (IQR), cells/ μ l	701 (543-910)	578 (457-751)
One year retention once stable on ART, % (95% CI)	98.7% (94.9-99.7)	90.2% (86.6-92.9)

CAG: community ART group; ART: antiretroviral therapy; IQR: inter quartile range; CI: confidence interval; N: number

Figure 2: One year retention on ART among stable patients in CAG and in conventional care (not in CAG)



Number at risk	0	3	6	9	12
non CAG :	397	356	336	308	277
CAG :	199	187	108	62	32

Logrank: p = 0.003

ART: antiretroviral therapy; CAG: Community ART Group

Access to treatment and care in CAG

Transport cost, walking distance, being absent from work, leaving other duties behind represent barriers for patients to access the clinic every month for refill and clinical consultation. CAG members can **save transport cost**: “I’m living in a rural village and therefore we are able to save money if we don’t go to the clinic every month”, or **avoid walking during long hours**: “It really helps because I leave very far from the clinic and I have to wake up very early and walk a long time to go there”. People who are working **don’t have to be absent**: “in my group, one member is a teacher, so when she needs to be the representative, she explains to the principal and go. Now she is no longer absent every month”. Others **can continue their others duties**: “I have different kind of jobs so I’m able to do them now as I only go to the clinic when I have to go”. As a consequence, “people feel happy because we don’t go to the clinic often now”. “At some point I was even giving my Bukana [treatment card] to others to bring treatment for me”.

Decongestion and reduction of workload

Health Facilities are **decongested**: ““If only one person goes, it will reduce the queue”. The Nurses confirmed: “I started with CAG in Ha Masupha (Health Post), the number of patients who attend the Health Post decreased”. Another Nurse said that “CAGs reduce my **workload** because a lot of the work including pill counting is done in the community”. She further stated that “when one has a group, you manage to do an examination of that patient when otherwise you wouldn’t be able to do this for every patient.”

Adherence support

CAGs members’ **support each other’s to adhere to their treatment**: “we talk about the challenges we encounter with our treatment and assist one another”. A CAG member explained: “I also support other members who suffer from the side effects from the pills because I’ve been having them. I tell them how I coped”. **Adherence barriers can be identified**: “we discovered that others are not taking treatment well when we are doing pill count”, and **action is taken** to support each other’s: “(...) we decided to pay her a visit.

After our visit we discovered that she is taking well the treatment”.

Network of peers

Being together, living in the same situation, bring the CAG to form a **network of peers**: *“I discovered that we help each other’s, we tend to love each other’s and we are working together”.* Members support each other’s **if one of them is sick**. A Chief explained: *“I’ve seen one member of the CAG sick. He is also very poor. One member gave him money to travel to the Health Centre. As a group, they also contributed R10 and gave him to buy food”.*

The support provided goes besides ART: *“our responsibility is to teach one another how to stay healthy”, “... to see that the group is together, to see that we are clean, that we eat good food”, “... that we behave well”.*

A Nurse explained that *“CAG members talk not only about treatment but **personal issues** as well”.* Confirmed by a CAG member: *“the setting is convenient for ourselves: it is happening in our homes, we are comfortable. When we receive our pills, we have still time to talk”.*

CAG members discuss **family and social problems**. *“We have many problems in the family, so when we go to the group we can share our experiences. Then we see that most of us share the same problems, so we are able to help one another”.* CAG member can even assist with **food**: *“we are poor so there are many members who don’t have food on their table. When we meet we are able to see how we can assist such members”.* A Chief said: *“what I’ve learned is that in other group they **started small projects**: they contribute R10 to buy the seeds and plant the field”.* **Support for funeral** is also of interest: *“we have formed a society whereby we contribute every month and use it if there is a funeral”.*

Openness

CAG allows the members to be more **open about their status**, towards their **family**: *“with the support of the group, some are able to open up with their families”*, or towards the

community: *“what I have discovered is that they were people hiding to take their treatment. Now we can take our treatment openly and are able to help others who are hiding”.* A Chief added: *“other community members are able to open-up about their status when they see that even the chief is HIV positive and a CAG member”.* Outside the CAG, CAG members reach **other community members on ART**: *“In my village they like to hide their status, with the CAG we have an opportunity to meet others”.*

A VHW stated that CAG is *“needed because people are able to counsel one another, especially **men** who hide their status”.*

Through the CAG, **pregnant woman** can also be supported: *“there was a pregnant lady who is not a member of the group but we paid her a visit as she refused to go to the clinic”.*

Some groups are supported by **local leaders**: *“we have the chief assistant, he is not taking ART but his wife does. During our sit-in he always visits us. He listens and gives support if needed”.* **Other community members** can also support: *“there is another lady, who lost her daughter in law from HIV, who join us, though she is not on ART. She is there to support us”.*

Family members provide support as well: *“we are supported by our families and even my wife is very happy. She is asking if she can be a member of the group. Even when I’m not around, she is attending the meeting and tells me what happened”.*

Role model

“We see the CAG members, they are clean and they look healthy, and some are becoming fat”. (Community leader)

A Chief explain how CAG members can have a positive impact on the health of the community by being a **role model**: *“what I would like to see is member of CAGs able to go to the community and tell them that you can live a positive and healthy life with HIV”.*

Another Chief added: *“I do support the idea that CAG members can go to other people from the community who lives with HIV. Last week we buried a young man who passed away. He was living with HIV and didn’t opened-up. Maybe if he had opened-up and joined a CAG, he wouldn’t have died”.*

Uptake of HIV Testing and linkage to counselling

CAG members can also help liaising with other people in the community to increase **uptake to HIV Testing and Counselling**. *“People used to talk about us when we meet. They were shocked as we don’t look sick. So I think we influence people about knowing their status”*. Through the network of the CAGs, women can now encourage their partners to be tested: *“Many men want to test now, especially husbands, as we are doing well on treatment with the CAG”*. The network can also ensure **continuity** from testing until retention and adherence: *“A neighbour on treatment visited me when I was sick. That is how I know others on treatment in my village. There were taking ART and encouraged me to go to the clinic as I was sick. I tested positive and even afterwards they assisted me. Today we form a CAG together”*.

Stigma

Even though, in some area, CAG members **don’t face any stigma**, *“In my village, there is no stigma; we work together as it seems that we are all infected in the community”*, it is **still reported as a challenge** by other CAG members: *“in the group we don’t have stigma, but we still have it outside”*.

CAG Members can **share with each other their experience of stigma**: *“I work in the village in another woman’s house. I told her I’m HIV positive. The next day, she brought gloves that I can use to wash the dishes and clean the house. I shared with my group and a man went to talk the husband. Eventually the husband told her to stop”*. Being together **allow people to face stigma**: *“parents were going to transfer their child for treatment in Maseru to avoid to be seen at the clinic. Today they are in a CAG, go to Nazareth clinic and are open about the status of their child”*, or **decreasing their perception** of the stigma: *“I also joined because there are people who stigmatized us so when I get to the group I talked about it and get relieved”*.

Psychological comfort

Finally, participation in CAG seems to give a **psychological comfort** *“I want to stay in CAG because I don’t have issues there. I always go to the group and share. Therefore I’m relieved”*, also explained by this member: *“it is important to be a member of the group because if I’m hurting inside I’m able to open up with members of the group. From there I feel healed”*.

“Forming a group assisted me so much that now I consider my group members as my friends”.

Discussion

Overall, three year retention was 80% at HC Nazareth, better than the 55% three year retention reported elsewhere in Lesotho [6]. Furthermore, one year retention among treatment experienced CAG members at HC Nazareth was excellent (98.7%). Members reported multiple collateral benefits and commented that membership in CAG: 1) reduced time, effort, and money spent to get a monthly ART refill; 2) changed the perception by clinic staff as now they represent a group of patients; 3) induced peer support among fellow members, resulting in reports of improved adherence, home visits when a fellow member was sick, family and socio-economical support, empowerment to deal with stigma, 4) increased the openness with which people can adhere to their treatment; 5) generated interest and promoted health seeking behaviour of other community members, including community leaders; and 6) resulted in a feeling of relief and comfort. Rare conflicts, when appearing mostly on personal ground, were resolved with support from the clinic staff.

The findings of our study confirm the results of another recent study of retention in CAG which showed exceptionally high four-year retention in CAG with 91.8% at 4 years of follow-up in Tete, Mozambique [9]. In the same project a qualitative study showed that peer support resulted in a better understanding of treatment, improved adherence and retention on ART. Moreover,

the group dynamic created a protective environment where patients discuss problems, exchange experiences and support each other. Empowerment resulted in a new role for patients, who instead of being ignored or excluded became considered as a source of information by the community and as a partner by the health care workers [11]. Separation of monthly ART refill from clinical assessments benefited patients and programmes in different sub-Saharan countries [12, 13]. A recent WHO report outlines how patients and community health workers can take responsibilities in ART care to complement services provided by medical staff [14]. Especially in contexts where the absorptive capacity of the health system is limited community-based ART entails an opportunity to reduce barriers to retention, to reduce the burden on health systems of growing ART cohorts and enhance the scale-up of antiretroviral therapy (ART) by reaching those most in need [13,15,16]

Despite the potential benefits for patients and providers several challenges were faced during the scale-up of community-based ART. Critical enablers include: 1) a reliable drug supply system to ensure access to ART; 2) appropriate number of community health workers and lay counsellors to support the formation, training and monitoring of CAGs; 3) clear mechanisms to trigger support or referral back to clinic care to ensure patients and groups in need receive appropriate care; and 4) a simplified monitoring system to avoid increased administrative workload [12,14,17].

There are some limitations inherent to the design of our study. We used a purposive sampling method to identify key informants among patients on ART, which may have resulted in reporting bias. People in favour of the CAG model might be more eager to participate and talk positively about their experiences and opinions related to the CAG model. In addition, our quantitative findings are built on 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.

Finally, when estimating the association between membership in CAG and attrition, we were able to adjust for biomedical factors; however we had no data on psychosocial factors. Still, the results among CAG members were very encouraging in a context where attrition is a major bottleneck for ART roll out. Towards the future we recommend to include pre-ART patients and patients in the early phase of ART in the CAG dynamic.

Conclusion

Participation in CAG impacted positively on the lives of members, not only on their access to ART, but also on their life within the community. In the CAG model patients were empowered to take responsibility and to support each other. In the rural context of Lesotho the network of peers, community health workers and community embedded Health Posts has the potential to leverage increased uptake of HIV testing, linkage to care and retention on lifelong treatment.

Acknowledgment

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Chapter four: Community-based ART in sub-Saharan Africa

How to situate experiences with peer-led ART delivery in Tete in the literature? In “*Community-based ART programs can overcome barriers to ART retention of patients on ART and decongest health services in sub-Saharan Africa: a systematic review*” the characteristics and outcomes of lay provider-led CBART programmes in sub-Saharan Africa are described.

Key messages

- Lay providers, including lay health care workers and patients, can be effective in CBART delivery. All CBART programmes resulted in high retention and, when measured, in high virological suppression.
- CBART is acceptable to those involved. Data on the effect of CBART on stigma are scarce. Where reported, findings suggest that CBART is associated with more positive than negative social outcomes.
- To enrol additional PLHIV on ART, CBART is not more costly than facility-based ART.
- The CAG model is the only ART delivery model that depends of non-remunerated PLHIV, in sub-Saharan Africa.
- Engaging community health workers and patients in ART delivery may be an important strategy to increase coverage of ART needs, especially in high prevalence resource constrained contexts.
- Policy-makers need to provide multiple delivery platforms, tailored to the needs and expectations of different subgroups. CBART should be a key component of such a differentiated care approach. Some patients may prefer facility-based ART. Other patients may prefer CBART.

Community-based ART programs can overcome barriers to retention of patients on ART and decongest health services in sub-Saharan Africa: a systematic review.

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Abstract

In sub-Saharan Africa models of care need to adapt to support continued scale up of ART and retain millions in care. Task shifting, coupled with community participation has the potential to address the workforce gap, decongest health services, improve ART coverage, and to sustain retention of patients on ART over the long-term. The evidence supporting different models of community participation for ART care, or community-based ART, in sub-Saharan Africa, was reviewed. In Uganda and Kenya community health workers or volunteers delivered ART at home. In Mozambique people living with HIV/AIDS (PLWHA) self-formed community-based ART groups to deliver ART in the community. These examples of community ART programs made treatment more accessible and affordable. However, to achieve success some major challenges need to be overcome: first, community programs need to be driven, owned by and embedded in the communities. Second, an enabling and supportive environment is needed to ensure that task shifting to lay staff and PLWHA is effective and quality services are provided. Finally, a long term vision and commitment from national governments and international donors is required. Exploration of the cost, effectiveness, and sustainability of the different community-based ART models in different contexts will be needed.

Keywords: HIV; antiretroviral therapy, highly active; health services accessibility; task shifting; community participation

Introduction

In sub-Saharan Africa (SSA) 23.2 million people live with HIV, and more than 10 million are in need of antiretroviral therapy (ART). With ART coverage in SSA at around 50% of the need, health systems are faced with the dual challenge of having to increase the rate of enrollment for those still in need while at the same time continuing to care for the millions of people who are currently on treatment.¹

There are considerable challenges to managing this ever growing caseload. A critical shortage of clinically qualified staff to provide clinical care places considerable pressure on the scarce medical workforce.² In rural Africa, the low geographical density of health structures creates a heavy burden on patients who may have to travel long

distances to seek care, and patients may have to choose between cost of food and cost of transport fees to the ART clinic. In urban settings, competing activities such as work and social life interfere with time spent queuing in overburdened health facilities with large patient cohorts. Moreover, long waiting times are a key driver of attrition among patients on ART.³ A meta-analysis from over 17 countries in SSA revealed that patient attrition on ART was 30% and 35% at 24 and 36-months respectively.⁴ Attrition included patients who died or were lost to follow-up (LTFU) while on ART, and is the opposite from retention (i.e. $1 - \text{attrition}$).⁴

One way to overcome the shortage of health staff is task shifting, which aims to obtain an optimal skill mix among the different professional categories within local health teams in order to increase capacity to deliver

services.^{5,6} Lay workers, communities and people living with HIV/AIDS (PLWHA) can also be engaged and deliver basic essential care functions to decrease the pressure on the scarce medical cadres.⁷ In particular, treatment adherence strategies such as peer support and community participation in care can increase the autonomy for day-to-day decision making of patients and their families.⁸

Task shifting, coupled with community participation, has the potential to address the workforce gap and make effective HIV care more widely available and closer to the communities.^{5,7} This paper reviews the published evidence for approaches and impact of engaging lay people (including volunteers, community health workers (CHW) and PLWHA) in ART delivery, a strategy that has the potential to be expanded and sustained in the resource scarce context of SSA.

Methods

A search strategy was developed combining key terms associated with community-based ART (CBART) programs. : "HIV" OR "Antiretroviral Therapy" AND "Africa" AND "Community" OR Communit* OR "Self Care" OR "Home" OR Volunteer* AND "Treatment Outcome" OR "CD4 Lymphocyte Count" OR "HIV Infections/mortality" OR "Survival Rate" OR "Patient Dropouts" OR "Acceptability" OR "Affordability" OR "Cost" OR "Patient Acceptance of Health Care" OR "Social Stigma". The Cochrane Collaboration and Pubmed databases were searched in February 2013. Moreover, websites of non-governmental organizations, such as Médecins Sans Frontières (MSF) and The AIDS Support Organization (TASO), were assessed to identify relevant documentation. Google scholar was searched with key words of the string, and reference lists of relevant papers were checked. No language or study design restrictions were used.

All retrieved abstracts were reviewed in duplicate (FR and TD). Articles were retrieved if they 1) reported original data on effectiveness, acceptability or cost of CBART, and 2) engaged lay workers, volunteers or PLWHA in community ART delivery (ART defined as treatment with at least three antiretroviral medications).

Articles without original data on effectiveness, acceptability or cost of CBART were excluded. Articles documenting direct observed therapy (DOT) programs were excluded, as the DOT strategy is not compatible with the principles of empowerment and self-management for chronic disease care.⁸ Moreover DOT has already been established by other reviews to offer little or no benefit over self-administered treatment.⁹

Results

Our search identified 1133 records, among which 1091 were excluded after reading the title and/or abstract, 42 records were read in full, and 18 were retained for review (Figure 1). The 18 retrieved records published outcomes of 6 different programs from 3 countries (Table 1). All articles were published between 2006 and February 2013. The 18 records comprised two cluster randomized controlled trials (RCT), 11 prospective or retrospective observational cohort studies, two qualitative studies, one cost-effectiveness study, one activity report from a non-governmental organization, and one abstract (table1, table2).

The different models described in the literature can be divided in two categories: 1) health service outreach to support home-based ART delivery by CHW, peer CHW or volunteers, in Uganda and Kenya; and 2) patient-led community ART dispensing, in Mozambique.

FIGURE 1: Flow of information through the different phases during the review of published work related to community-based ART (CBART).

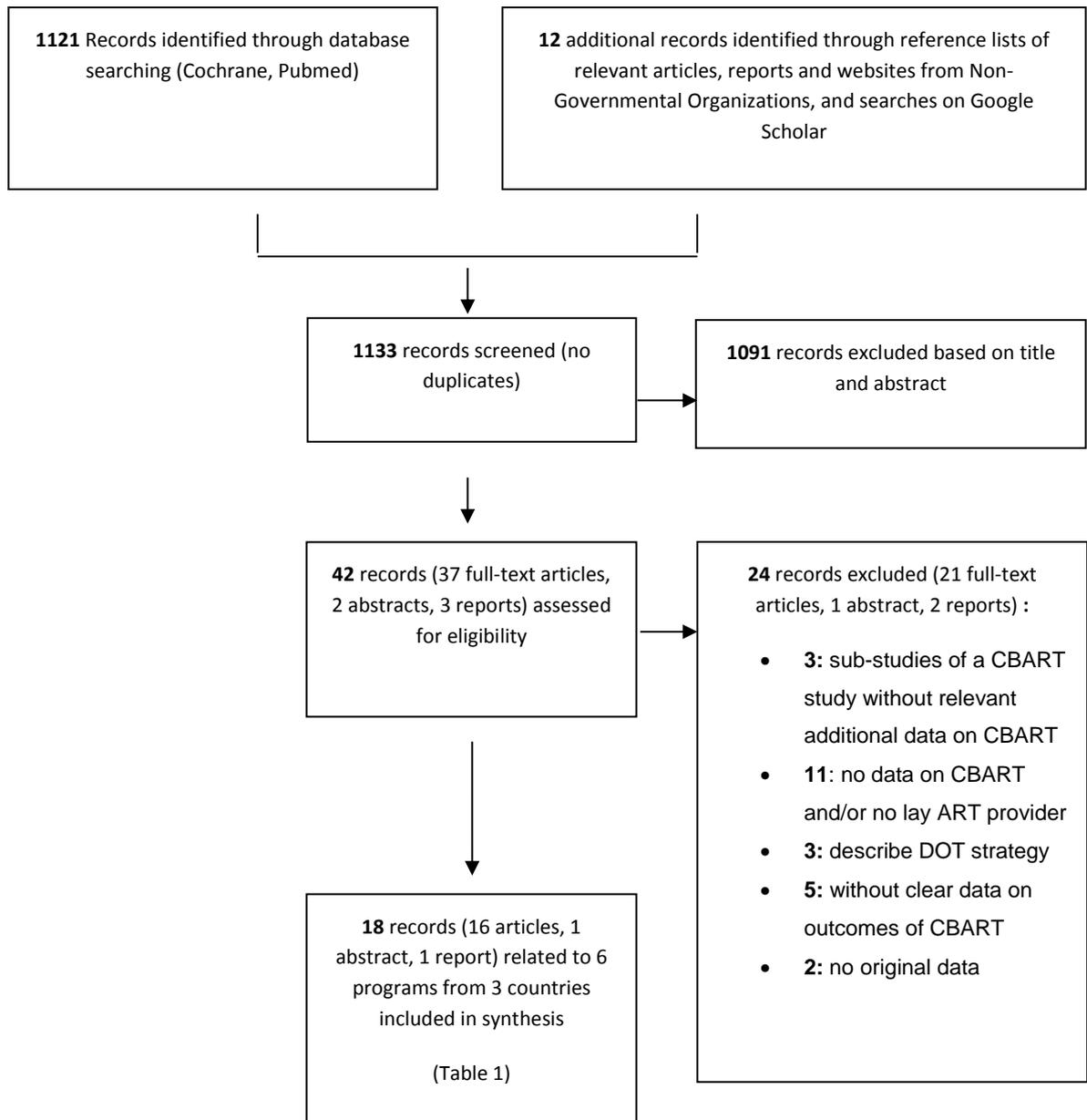


TABLE 1: Characteristics of the studies documenting CBART programs

Study	Study design	Country	CBART model and type lay ART provider	Nr of participants	Contains data on
Weidle et al, 2006 ¹⁰	Prospective cohort study	Uganda (Tororo & Busia districts)	Home-based ART delivery by CHW (field officer)	987 (CBART)	. Treatment response . Treatment outcomes
Apondi et al, 2007 ¹¹	Qualitative study			654 (CBART)	. Social outcomes
Mermin et al, 2008 ¹² Moore et al, 2011 ¹⁴ Mermin et al, 2011 ¹⁵	Prospective cohort study	Uganda (Tororo, Busia, & Mbale districts)		. 1045 . 1094 . 1132 (all in CBART)	. Treatment response . Treatment outcomes
Marseille et al, 2009 ¹³	Cost-effectiveness study			. 1045	. Cost effectiveness of CBART
Amuron et al, 2007 ¹⁶ Jaffar et al, 2009 ¹⁷ Amuron et al, 2011 ¹⁸	Cluster RCT	Uganda (Jinja district)		1453 . 859 CBART . 594 FBART	. Treatment response . Treatment outcomes . Cost
Mpiima et al, 2012 ¹⁹	Retrospective cohort study (activity report)			3457 . 2155 CBART. . 1302 FBART	. Treatment outcomes
Kipp et al, 2010, 2011, 2012 ^{20,22,23}	Prospective cohort study	Uganda (Kabarole district)	Home-based ART delivery by volunteers	385 . 185 CBART . 200 FBART	. Treatment response . Treatment outcomes
Alibhai et al, 2010 ²¹	Qualitative study			130 (CBART)	. Health related quality of life
Wools-Kaloustian et al, 2009 ²⁴ Selke et al, 2010 ²⁵	Cluster RCT	Kenya	Home-based ART delivery by peer CHW (CCC)	208 . 96 CBART . 112 FBART	. Treatment response . Treatment outcomes
Decroo et al, 2011,2012 ^{26,27}	Retrospective cohort study	Mozambique	Patient led community ART dispensing in peer groups (CAG)	1301 (CBART)	. Treatment outcomes

RCT = randomized controlled trial; CBART = community-based ART; FBART = facility-based ART; CHW = community health worker; CCC = Community Care Coordinators; CAG = Community ART Group

1. Health service outreach to support home-based ART delivery

1.a. Home-based ART delivery by CHW in Uganda

In Uganda, CHW were engaged in three different CBART programs to deliver ART at home, provide adherence support, detect side effects and opportunistic infections, and refer sick patients to the clinics. Each CHW was responsible for 35 to 40 PLWHA on ART. CHW were lay people, and received 4- 6 weeks training and a basic salary to provide simple standardized medical tasks. They were equipped with a motorbike, and had access to

a cell phone to ask advise from health facility-based medical staff when needed.

Questionnaires and checklists were used for guidance and monitoring. Patients were enrolled in the CBART program straight after ART initiation. Routine visits to the clinic were scheduled every six months, or not at all. During regular meetings with all stakeholders information was provided and difficulties were discussed, which resulted in the development of a partnership between the patients, the community and the service provider (Table 1 & 2).¹⁰⁻¹⁹

TABLE 2: Characteristics of described CBART models

CBART model and type lay ART provider	Training	Salary or other motivation	Equip-ment	Inclusion criteria clients CBART	Nr of clients/ lay provider	Frequency com-munity distribution	Frequency clinic visits
Home-based ART delivery by CHW ¹⁰⁻¹⁹	. Four to six weeks theoretical training . Refresher courses	Salary	. Motor-bike . Cellphone	. From initiation ART . Positive adherence plan for some studies	35-40	Weekly or monthly	Range: no regular visits – every six months
Home-based ART delivery by volunteers ²⁰⁻²³	Two day training and monthly meetings	. Social recognition . Non-monetary incentive	. Bike cycle . boots . Raincoat	. From initiation ART. . willing-ness to receive home-visits	5	. Monthly for ART . Weekly for other support	Every 6 months
Home-based ART delivery by peer CHW ²⁴⁻²⁵	. One week theoretical . Two months practical	Salary	. Motor-bike . Cellphone . Electronic device	. 3 months on ART . Clinically stable	11	Monthly	Every 3 months
Patient led community ART dispensing in peer groups ²⁶⁻²⁷	6 monthly meetings	. Health benefits . Peer support	No equipment	. 6 months on ART . Clinically stable	Peer groups (CAG) of 6	Monthly	Every 6 months

CHW = Community Health Worker; CCC = Community Care Coordinators; CAG = Community ART Group

In a first CBART program, in Jinja, Uganda, a cluster RCT compared outcomes at 12 and 36 months on treatment of a CBART cohort with a facility-based cohort, and found a viral load below 500 at 12 months in 84% of the CBART cohort, and 83% in the facility-based cohort. At 12 months mortality rates were 11% in both arms, LTFU was 1% in the CBART and 2% in the facility-based cohort.¹⁷ After 36 months follow-up, mortality rates were 14% in the CBART and 13% in the facility-based arm.¹⁸ Time and money spent accessing HIV care were reduced drastically as patients only invested to go a clinic when sick.¹⁷ Overall, CBART was found to be no more expensive than facility-based ART, as the costs of the home visits were offset by the savings from reduced health service utilization.¹⁷

Prospective studies conducted at two other CBART programs sites in Uganda found similar results at 12 and 24 months.^{10,12,14,15} Compared with no intervention, mortality decreased with 95% among PLWHA who accessed ART in the CBART program.¹²

Program data reported 8,7% and 22,4% attrition respectively among 2155 patients in CBART and 1302 patients in the facility-based cohort.¹⁹ CBART was associated with multiple positive social outcomes such as increased social support at community level and decreased discrimination.¹¹ Patients who before CBART had no access to HIV care were enrolled on ART together with multiple family members.¹⁰

1.b. Home-based ART delivery by volunteers in Uganda

Another study piloted a home-based ART delivery model, run by community volunteers. Volunteers had a two day training. Each volunteer visited weekly no more than five PLWHA to deliver ART, support and monitor adherence, and refer sick patients to the clinic. The volunteers were motivated by social recognition and non-monetary incentives. During monthly meetings problems were reported and solutions sought. Out of the 41 volunteers 39 remained active over the entire study period.²⁰⁻²³ 185 patients

on ART were enrolled in the CBART cohort, and 200 patients in the facility-based cohort. Treatment outcomes and response of the CBART cohort were comparable with the results of the facility-based cohort at 24 months of treatment, with 30% attrition in both arms, and respectively 7% and 13% viral suppression in the CBART and facility-based arm.²³ The mean physical and mental health among patients in CBART improved significantly after one year CBART.²¹

1.c. Home-based ART delivery by peer CHW

In Kenya, CHW were recruited among PLWHA, and named community care coordinators (CCC).^{24,25} CCCs received a 7-day didactic training, followed by two months practicum. Each CCC is responsible for up to 20 clinically stable HIV positive adults and deliver ART, monitor adherence and refer patients if clinical problems arise. CCCs used personal digital assistants (PDAs), pre-programmed electronic devices that assist them in identifying and managing common problems and complaints. Routine clinic visits were scheduled every three months. Outcomes obtained were similar in both arms. At 12 months, of the 96 patients randomly assigned to community-based arm, 5 (5%) were lost to follow up, 1(1%) had died, and among those retained 89% had an undetectable viral load. Among the 112 patients in the health facility-based arm, 5 (5%) were LTFU, none had died and the viral load was undetectable for 86% among the retained.²⁵ The total number of health facility visits, including 3-monthly routine visits and unplanned visits, were reduced by 50% for the intervention arm.²⁵ CCCs were able to add their experience of living day-to-day with HIV to their professional skills which resulted in unexpected insights and practical solutions for adherence barriers and psychosocial problems.^{24,25} Occasional reports on stigma-related events decreased after 16 months of implementation. Nevertheless, patients preferred to receive the peer CHW in their homes than at public venues, to prevent stigma.²⁴

2. Patient-led community ART dispensing

In Mozambique, in Tete province, Médecins Sans Frontières (MSF) and the district Ministry of Health proposed a series practical solutions based on the concepts of peer support and self-management to improve retention in this highly resource-constrained environment. Driven by their own desire to improve their health, PLWHA agreed to self-form peer groups, named Community ART Groups (CAG). PLWHA could join a CAG when more than six months on ART, clinically stable, and having a CD4 more than 200 cells/ μ l. CAGs had maximum 6 members, who participated in standardized care tasks such as ART distribution, adherence monitoring, outcome reporting, and referral of sick members to the health facility, and supported each other socially. CAG members elected monthly a representative to fetch a drug refill at the clinic. When back in the community, the medication was delivered to the fellow members of the CAG.²⁶

Joint decision making, regular dialogue, and opportunities to give feedback were essential steps in the process of implementation of CAG. Early results showed an excellent retention of 97.5% (attrition 2.5%) among 1301 stable patients on ART (median follow-up time 13 months).²⁶ These early results have been sustained over time, with 95,7% of 5727 members still in care by December 2012, with a median follow-up time of 21 months (program data). Moreover CAG members are encouraged to bring children (below 15 years old) for counselling and testing and to start ART when eligible. Retention among 265 children of CAG members was 94,0% after a median of 13 months.²⁷ As CAG members send one representative to represent a maximum of six members, health facility visits were reduced, and the pressure on the medical workforce decreased. CAG members were perceived as partners in care, and as such the patient-provider relationship changed considerably. PLWHA who were part of community groups felt empowered to voice their concerns and were able to have a more active role in the management of their HIV.

TABLE 3: Attrition on ART in CBART and FBART

CBART model and type lay ART provider	Study	Attrition (dead or LTFU) on ART				
		At 6 m	At 12 m	At 24 m	At 36 m	Per 100py
Home-based ART delivery by CHW	Weidle et al, 2006 ¹⁰	NA	CBART: 7%	NA	NA	NA
	Mermin et al, 2008 ¹²	NA	CBART: 7 %	CBART: 9%	NA	CBART: 5/100py (*)
	Moore et al, 2011 ¹⁴					
	Mermin et al, 2011 ¹⁵					
	Amuron et al, 2007 ¹⁶	NA	CBART: 12%	NA	CBART: 14%	CBART: 6.3 /100py
Jaffar et al, 2009 ¹⁷ Amuron et al, 2011 ¹⁸		FBART: 13%		FBART: 13%	FBART: 6.5/100py (**)	
Home-based ART delivery by volunteers	Kipp et al, 2010, 2011, 2012 ^{20,22,23}	CBART: 25% FBART: 17%	NA	CBART: 30% FBART: 30%	NA	NA
Home-based ART delivery by peer CHW	Selke et al, 2010 ²⁵	NA	CBART: 6% FBART: 5%	NA	NA	NA
Patient led community ART dispensing in peer groups	Decroo et al, 2011 ²⁶	NA	NA	NA	NA	CBART: 2.3 /100py (***)
Meta-analyses attrition in sub-Saharan Africa	Fox & Rosen ⁴	14%	20%	30%	35%	NA

CBART = community-based ART; FBART = facility-based ART; LTFU = lost to follow up; py = person year

NA = not available

(*) Mortality was 5/100py during an average follow-up time of almost 2 years since ART initiation. During first 16 weeks on ART mortality was 14 /100py, afterwards 3/100py

(**) Mortality during an average follow-up period of 2 years since ART initiation.

(***) Mortality and LTFU among patients clinically stable on ART, and more than 6 months on ART.

TABLE 4: Virological outcomes among patients in CBART and FBART

CBART model and type lay ART provider	Study	Virologic rebound on ART				
		At 6 m	At 12 m	At 24 m	At 36 m	
Home-based ART delivery by CHW	Weidle et al, 2006 ¹⁰ ###	CBART: 2%	CBART: 4%	NA	NA	
	Mermin et al, 2008, 2011 ^{12,15} ##	CBART:4%	CBART: 4%		6%	
	Jaffar et al, 2009 ¹⁷ ##	NA	CBART: 16% FBART: 17%	NA	NA	
Home-based ART delivery by volunteers	Kipp et al, 2010, 2011, 2012 ^{20,22,23} #	CBART: 10% FBART: 11%	NA	CBART: 7% FBART: 13%	NA	
Home-based ART delivery by peer CHW	Selke et al, 2010 ²⁵ #	NA	CBART: 10.5% FBART: 13.5%	NA	NA	
Patient led community ART dispensing in peer groups	Decroo et al, 2011 ²⁶	NA	NA	NA	NA	

Cut-off points used to define virological rebound: # : VL > 400 copies/ ml; ##: VL > 500 copies/ ml; ###: VL > 1000 copies/ml
 NA = not available; CBART = community-based ART; FBART = facility-based ART; py = person year; - = not available; VL =viral load; ml = milliliter

TABLE 5: Cost of CBART and FBART for the provider and the patients

CBART model and type lay ART provider	Study	Health-service costs		Patient costs	
		CBART	FBART	CBART	FBART
Home-based ART delivery by CHW	Marseille et al, 2009 ¹³	Per patient-year: \$ 695	NA	NA	NA
	Jaffar et al, 2009 ¹⁷	Per patient-year: \$ 793	Per patient-year: \$ 838	First patient-year on ART: \$ 29 Per patient-year after 1 st year: \$ 18 (75% less clinic visits, with a median cost of \$ 2.3 per clinic visit)	First patient-year on ART: \$ 60 Per patient-year after 1st year: \$ 54
Home-based ART delivery by volunteers	Kipp et al, 2011 ²²	Program costs per patient-year: approximately \$ 100	Program costs per patient-year: approximately \$ 100	Average of 2 clinic visits per patient per year	Average of 12 clinic visits per patient per year
Home-based ART delivery by peer CHW	Selke et al, 2010 ²⁵	NA	NA	Average of 6.2 clinic visits per patient per year (50% less clinic visits)	Average of 12.4 clinic visits per patient per year
Patient led community ART dispensing in peer groups	NA	NA	NA	NA	NA

NA = not available; \$ = US dollar; CBART = community-based ART; FBART = facility-based ART

TABLE 6: Social outcomes of CBART

CBART model and type lay ART provider	Study	Data on positive social outcomes	Data on negative social outcomes
Home-based ART delivery by CHW	Apondi et al, 2007 ¹¹	.Positive social outcomes (including family or community support and relationship strengthening) were significant <i>improved</i> 3 months after joining CBART	. Negative social outcomes (break-up marriage, discrimination, alienation by family) were <i>not</i> associated significantly with participation in CBART
Home-based ART delivery by volunteers	Alibhai et al, 2010 ²¹	. The mean physical and mental health improved significantly after one year CBART .The largest increases were in physical, social, and role functioning. . The perceived physical and mental health after one year CBART was similar to HIV negative woman observed in another study living in a similar context . Overall a strong sense of appreciation of the support received from the volunteers.	. 15% (15/130) of patients in CBART experienced a decline in their overall wellbeing, which was not associated with clinical findings or lack of viral suppression. . This decline could be caused by stress associated with poverty, concerns about uncertainty of drug supply in the future, and stigma.
Home-based ART delivery by peer CHW	Wools-Kaloustian et al, 2009 ²⁴	."Peer effect": The peer CHW were able to gain the trust of their clients, obtain unexpected insights into patient adherence, and identify and address psychosocial issues such as disclosure. .The peer CHW linked the community with the clinic, and were perceived by the PLWHA as their advocates. . Peer CHW addressed other than HIV related problems, such as domestic discord or alcohol abuse, and there was a willingness to address reproductive health issues.	. Peer CHW presented themselves as health counselors, to avoid the AIDS label and prevent stigma. Patients preferred to receive the peer CHW in their homes than at public venues, to prevent stigma. Reports on stigma related events decreased after 16 months of implementation . Expectations in the community were not only ART related. Some clients had unrealistic expectations such as provision of food or even money.
Patient led community ART dispensing in peer groups	NA (*)	NA	NA

CBART = Community-based ART; CHW = community health worker

(*) Qualitative study ongoing

Discussion

This review identified 18 records documenting a variety of models for CBART (Table 1 & 2). In all studies the responsibilities of the lay ART provider included ART delivery in the community, provision of adherence support, and referral of sick people to the clinic. In most programs lay ART providers were remunerated CHW or peer CHW who deliver ART at the homes of PLWHA. However, two CBART programs engaged non-remunerated lay ART providers. One program in Uganda used community volunteers for ART home-delivery.²⁰⁻²³ In Mozambique community ART delivery was part of a peer group dynamic.^{26,27}

There were substantial differences in patient populations and resources available across different studies. Nevertheless, all outcomes provided positive evidence in support of CBART. In all comparative studies, patients in CBART had similar outcomes than patients in facility-based care.^{17-20,22,23,25} Attrition rates from observational cohort studies that reported only data on the CBART cohort compared favorably with those reported in a recent meta-analysis (Table 3).^{4,10,12,14,15,26,27}

The few studies reporting data on cost found that provider costs were similar for facility-based ART and CBART,^{17,22} and one study found that CBART was more cost-effective than estimates for facility-based ART.¹³ Moreover, CBART was much cheaper for patients (Table 5).^{17,25} Community interventions which are visibly associated with HIV care potentially impact on stigma. Only three studies reported data on the acceptability or social outcomes of CBART, and concluded that CBART is associated with more positive than negative social outcomes (Table 6).^{11,21,24}

Potential of community participation in ART delivery

CBART aims to overcome two major challenges related to ART initiation and retention: how to decongest health services, and how to sustain adherence for patients

over the long-term. To increase the capacity of the health services and offer ART to increasing caseloads, strategies such as decentralization and task shifting have shared the workload over a larger number of health facilities and different levels of the medical workforce, including professionals without formal clinical training.^{5,6,28} However, caseloads will increase progressively, and the growing queues at the health facilities will likely lead to inequities in which the most persistent and motivated patients receive care first. Without further adaptations in the model of care delivery, inclusion rates on ART risk to remain limited and attrition is expected to become even more problematic.^{3,7,29}

To overcome these structural bottlenecks, CBART models aim to deliver a package of essential ART care functions beyond the clinic and in the community such as ART refills, monitoring of treatment adherence and outcomes, and detection of sick patients and rapid referral to care. This in turn frees up capacity within the clinic-based medical workforce to be able to focus on complicated tasks such as clinical care for sick patients, training and supervision of lower cadres, and management of health care services.^{7,17,25} Moreover, CBART can serve communities beyond the reach of the formal health system.^{7,12,17,20,26}

Provision of HIV care in the communities will also impact on the dynamic and quality of relationships between providers and patients, and can catalyze the social networking between peers. The intensified link between provider and beneficiary will make information more readily available for PLWHA, and will improve the understanding of the practical problems faced by PLWHA. In this way, care delivery can be expected to become more holistic and result in a relationship built on trust between the provider and the PLWHA. Delivery of HIV care in the social and living environment of PLWHA can activate social and peer support.³⁰

Role for PLWHA in CBART care

It will be important to pilot new studies, in different contexts, to compare the cost, acceptability, effectiveness and sustainability of the different models. To date, most CBART models function as clinical outreach programs, with professionals delivering services in the community. Few examples of voluntary engagement of PLWHA in the medical management of their condition have been described to date. In Mozambique, PLWHA self-formed a social network of peer groups, and became engaged in provision of ART.²⁶ In Thailand, PLWHA groups as the Thai Network for People Living with HIV/AIDS became engaged in planning of HIV care and provision of ART. PLWHA groups advocated for expanded access to treatment and promoted social normalization of HIV, a process which reduced social discrimination. When by early 2006 ART became widespread available in Thailand, PLWHA assisted the health workers at the clinic as part of multidisciplinary teams, to provide psychosocial support and counseling, monitor CD4, and provide ART. Also, PLWHA volunteers were involved in defaulter tracing. The engagement of PLWHA was one of the factors that made the HIV program of Thailand widely recognized as successful.^{31,32}

The involvement of PLWHA in care functions is compatible with lessons learnt from chronic disease management. To sustain long-term adherence to daily treatment, patients need to be self-reliant within their living environment.^{33,34} The level of self-reliance of each patient can be increased through acquirement of knowledge, sharing of treatment experiences among peers, and practice of self-management skills.^{33,35} Moreover, motivation to adhere to ART can be increased through social support.⁸ Once informed and motivated, PLWHA can overcome barriers to daily adherence, and become experts in the daily management of their condition.^{7,30,33}

Implications of CBART for Health systems

Community participation holds the potential of enabling countries to build sustainable, cost effective and equitable HIV care for

populations in countries with a scarce health workforce. However, to achieve success some major challenges need to be overcome. First, community participation requires an approach which is contradictory to the dominant provider-driven development of health services, according to needs defined by health managers. Sustainable community participation is only possible when community programs are driven, owned by, and embedded in the communities. Indicators that can measure the process of community participation are related to the quality of the partnership between community members and service providers and the level of ownership of the community program by the community members.³⁶ Community participation also requires an understanding and consideration of cultural factors such as gender inequalities, and traditional beliefs about health. Moreover, formal communication loops between representatives of the community and the providers need to be installed to assure mutual understanding.

Second, an enabling environment and supportive regulatory framework are needed to ensure that task shifting to lay staff and PLWHA is effective and quality services are provided. At country level health policies which embrace the concepts of task shifting and community participation need to be designed, defining the distribution of responsibilities and task packages among existent cadres, new cadres and actors in the communities. All relevant stakeholders need to participate in a process of collaborative planning. Standardized training, supportive supervision, supply of equipment and functional referral systems are essential, and as such task shifting needs to be coupled with growth of the workforce, and investment in training, supervision and equipment.^{7,37,38}

Finally, to achieve the above described redefinition of the landscape within the health workforce, a long term vision and commitment from national governments and international donors is required.^{37,38} The global financial crisis threatens the

achievements made and in times that HIV exceptionalism and vertical HIV funding are being questioned, efficiency of new interventions becomes more and more important. It is important to look for sustainable solutions, and “to do more with the same”, and increase coverage of ART at population level to decrease morbidity, mortality and new infections. From this perspective community-based strategies for HIV care can play an important role. However, they need to complement, rather than replace, functional health systems, and as such sustained investments in health service improvements will be needed for some time to come.³⁹

Concerns with CBART models

Two potential concerns related to CBART are related to stigma and quality of care. First, the impact of the visibility of HIV related activities on stigma in the community needs further investigation.²⁴ However, studies have reported that only 3% of patients refused to participate in the community ART program due to stigma,¹⁷ and it has even been suggested that involvement of CHW in HIV care reduced stigma.¹¹ Being part of peer groups has been found to decrease the perception of social stigma.⁸ Second, task shifting and community engagement may come at the cost of lower quality of care. Task shifting to CHW and PLWHA is limited by the level of knowledge and skills required to exert defined medical tasks. However, the results of community-based models of care that bring care to populations that would not otherwise have had access should not be compared with results from conventional care.⁶ Survival is the most important indicator for quality of care for patients with advanced AIDS, and provision of ART will always compare favorably with no treatment, as ultimately this is the only effective clinical intervention for reduction of mortality among PLWHA.⁴⁰ This was demonstrated in Uganda where a CBART program without scheduled routine clinic visits led to a reduction of mortality with 95% among PLWHA, and a 81% reduction of mortality among their depended HIV uninfected children, in a population that

otherwise would have had difficulties to access HIV care.¹²

Limitations of this review

Limitations of this review are related to the diversity of the set-up of the CBART models, and the observational design of most studies. The latter could have resulted in observation bias, and confounding bias when a comparison with a facility-based cohort was made. Moreover, in Mozambique the patients were able to choose between CBART and facility-based ART, which could have resulted in a selective enrolment of the fittest in CBART.²⁶⁻²⁷ Another important bias is publication bias, as positive results tend to be more likely to be submitted and accepted for publication. Finally the limited number of rigorous studies means that more studies are needed to confirm if the results of CBART can be sustained in different settings, including settings that are not supported by external agencies.

Conclusions

The seeming insurmountable challenge of bringing ART current global targets to provide 15 million people with ART by 2015 forces policy makers to consider redesigning the current model for HIV care to overcome structural bottlenecks, particularly in the resource-constrained context of SSA. The results of this review suggest that community models serve to help overcome two major challenges. First, they can decongest health services to find space for new people and scale up ART. Second, they can support adherence and sustain retention of patients on ART over the long-term.

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Chapter five: Spill over effect of participation in ART delivery on utilization of other health services

Patients in CAG were motivated and empowered to participate in ART delivery. Two studies assess if participation in one component of health care resulted in a better utilization of other health services. In *“Utilization of and barriers to HIV and MCH services among Community ART Group members and their families in Tete, Mozambique”* the utilization of mother and child health services by CAG members and their family aggregates is studied. The barriers they perceived and experienced are explored. In *“Journey towards universal Viral Load monitoring in Maputo, Mozambique: Many gaps, but encouraging signs”* the association between different delivery platforms, including CAG, and uptake of routine viral load monitoring is studied.

Key messages

- Empowering PLHIV in using HIV care doesn't imply a spill over effect on the utilization of other health care services, such as mother and child health care. Mother and child health services were not well used by the CAG members and their family aggregates.
- In contrast, there was a higher uptake of routine viral load monitoring among CAG members, when compared with patients attending conventional care. Moreover, CAG members were more likely to have virological suppression.
- How to motivate communities to use available health services? How to engage them in the delivery of selected medical activities? Different factors are at play, including patient, social, and health system factors, and the characteristics of the intervention.
- If community engagement in selected medical activities is desirable, targeted approaches towards both providers and patients are needed to capacitate and empower patients as co-providers.

Utilization of and barriers to HIV and MCH services among Community ART Group members and their families in Tete, Mozambique

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Abstract

Mozambique continues to face many challenges in HIV and maternal and child health care (MCH). Community-based antiretroviral treatment groups (CAG) retention to care among members, but whether such benefits extend to their families and to MCH, remains unclear. In 2011 we studied utilization of HIV and MCH services among CAG members and their family aggregates in Changara, Mozambique, through a mixed-method assessment. We systematically revised all patient-held health cards from CAG members and their non-CAG family aggregate members, and conducted semi-structured group discussions on MCH topics. Quantitative data were analysed in EPI-Info. Qualitative data were manually thematically analysed.

Information was retrieved from 1 624 persons, of which 420 were CAG members (26%). Good compliance with HIV treatment among CAG members was shared with non-CAG HIV-positive family members on treatment, but many family aggregate members remained without testing, and when HIV-positive, without HIV treatment. No positive effects from the CAG model were found for MCH service utilization. Barriers for utilization mentioned centred on insufficient knowledge, limited community-health facility collaboration and structural health system limitations. CAG members were open to include MCH in their groups, offering the possibility to extend patient involvement to other health needs. We recommend that lessons learnt from HIV-based activism, patient involvement and community participation are applied to broader SRH services, including MCH care.

Introduction

A decade after its large-scale introduction, countries in poor resourced sub-Saharan Africa (SSA), including Mozambique, continue to face challenges to scale-up antiretroviral therapy (ART). It is estimated that ART coverage is still only around 50%, while HIV-related mortality remains high, not only because of low treatment coverage, but also due to poor retention of patients initiated on treatment [1, 2, 3]. Prevention of mother-to-child transmission (PMTCT) fares little better in SSA, as the uptake of PMTCT and Early Infant Diagnosis continue to be unsatisfactory [1, 4]. As such, there is an urgent need for innovative strategies to offer ART to more people, including to HIV-positive pregnant

women, as well as to retain them in care [5]. Simultaneously, Mozambique and other SSA countries face difficulties in the field of maternal and child health (MCH) and are struggling to achieve their MDG 4 and 5 commitments [6, 7, 8]. The integration of HIV with other components of reproductive health, including MCH, is increasingly being recommended, aiming at a holistic approach towards sexual and reproductive health (SRH) through family-centred care [4]. Moreover, the HIV care model needs to adapt to lessons learnt from chronic disease care, and attribute a more central role to patients [9, 10, 11].

In order to improve retention of patients receiving ART, Mozambique recently introduced innovative community-based

groups for antiretroviral treatment (Community ART Groups, CAG). The methodology and results of this patient-driven care model have been described elsewhere and include good retention in care among CAG members (97.5% at 12-months follow-up) [12]. Self-forming groups of a maximum of six patients perform four key tasks: monthly distribution of antiretroviral medication among group members in the community, provision of adherence and social support, monitoring and reporting of treatment outcomes, and ensuring 6-monthly clinical consultations for each group member. The model uses social support networks to enhance social capital as a resource built on trust, cooperation, reciprocity and sociability [13]. In particular for HIV care supportive peer relationships have the capacity to decrease stigma and improve adherence [14, 15, 16]. Moreover, when chronic disease care is provided by and integrated in the community, social outcomes may be improved [17]. It is, however, not yet clear whether these benefits for HIV care are extended to the families of CAG members, and to other aspects of SRH, such as MCH. We therefore studied the utilization of HIV and MCH services and outcomes among family aggregates of CAG members in rural Mozambique.

Methods

A quantitative and qualitative assessment was implemented between April and June 2011 in the rural district of Changara, Tete Province, in Central Mozambique, where the CAG model has been introduced since 2008. A district-wide mobilization of members from all 105 CAG registered in the district at the time, was realized through the established communication channels within the groups, inviting members to participate in one of 12 meetings in seven different localities throughout the district. During these gatherings, a systematic revision of a variety of patient-held health cards related to MCH from the CAG members and the non-CAG members of their family aggregates was carried out by one of the principal investigators (medical doctor). We

distinguished two types of CAG members: formal members, who are HIV-positive and receive antiretroviral treatment within a CAG, and social members, who are also HIV-positive, but who do not receive antiretroviral treatment and participate in the CAG for the social dynamics, while receiving individual follow-up for the prevention of opportunistic infections. For the purpose of this study, the family aggregate was defined as comprising all persons who habitually eat and sleep in the same household as the CAG member. Variables collected through questioning of CAG members and observation of their health cards included:

- For all participants: utilization of HIV counselling & testing and test results, follow-up and treatment for HIV (if HIV-positive)
 - For women of reproductive age (15-49 years): utilization of health care in pregnancy and childbirth, modern contraceptive use, and tetanus immunization status
 - For children under the age of 5 years: attendance of under-five child care, including immunization and growth monitoring, as well as follow-up of HIV-exposed infants and children with low weight-for-age.
- The quantitative data were digitalised, verified, and analysed in EPI-Info, version 3.5.1.

In addition, a group discussion of two to three hours duration based on a semi-structured questionnaire was conducted by one of two experienced facilitators, debating knowledge and perceptions on a series of reproductive health care topics, with an emphasis on pregnancy and childbirth, contraception and child health and nutrition. Both facilitators have longstanding experience interacting with the CAG and their members in Changara, and received additional information and guidance on MCH matters from one of the principal investigators (medical doctor) before and during the period over which the group meetings were held. The discussions were conducted in the local language, and transcribed into Portuguese by two scribes, who afterwards digitalised the information in Microsoft Office Word. The transcriptions were double-checked and, when necessary,

corrected by the facilitators and principal investigators. These qualitative data were thematically organised in Microsoft Excel, and manually analysed by the study team, based upon general consensus. On-going analysis was carried out during the period of data collection, resulting in punctual adaptations of the discussion guides in order to enrich the obtained information and understanding of all study topics, and data collection was continued till saturation was reached.

The study adhered to international ethical principles for health research. It was designed and implemented by the District Health Authorities within their routine health program management practices. CAG is a dynamic recommended by the Ministry of Health in Mozambique to increase patient participation to overcome barriers to adherence to and retention in care. Formal ethical approval was not looked for as meetings, debates, and interactions between health care providers, facilitators and CAG members form part of the normal activities of the CAG. Participation in CAG and in meetings among CAG members in the community is

voluntary. Participants in the group meetings for this study were explained orally the methods and purpose of our research, and gave their verbal consent before the start of every debate and the review of their health cards. No information regarding personal identification was collected. When significant health problems were identified, the CAG member concerned was informed and advised to seek care. In serious cases, clinical attendance was immediately arranged through the local health facility.

Results

A) Quantitative results

In the group meetings participated 367 formal and social CAG members affiliated with 92 CAG (88% of all CAG in the district). These informants provided information on 330 family aggregates. The 330 family aggregates consisted of a total of 1 624 persons, including 420 CAG members. Of the 420 CAG members, 358 were formal members (76% of all persons registered as a member of a CAG in Changara) and 62 social members. Demographic details of these participants are presented in table 1.

Table 1. Demographic characteristics of the participants

	Formal and social CAG	Non-CAG
Number of family aggregate members reached	420 (26%)	1 204 (76%)
Range of members per family aggregate	1 to 5	0 to 13
Sex distribution	302 female (72%) 118 male (28%)	570 female (47%) 634 male (53%)
Number of women of reproductive age (15-49 years)	255 (61%)	160 (13%)
Number of children under five years of age	4 (1% of all CAG members)	204 (17%)

HIV care utilisation among CAG members and their family aggregates

Table 2 details our findings on utilization of HIV services. As expected, all CAG members were HIV-positive and receiving either preventive care for opportunistic infections or ART, to which they showed excellent retention, all having taken their turn for clinical care and collection of medication for themselves and the members of their CAG within the previous 6 months.

Among the non-CAG members of their family aggregates, 32% of men and 41% of women had received counselling and testing for HIV, with a positivity rate of 19% and 16% respectively. Many of the non-CAG HIV-positive adult family members (men 79%; women 69%) reportedly did attend health care services to receive preventive care for opportunistic infections or ART, and they had the same good retention in care as the CAG

members. The non-CAG children aged 6-14 years and under-fives had been tested in respectively 44% and 50%, in both groups with a positivity rate of 5%. All non-CAG HIV-positive children aged 6 to 14 years and 75% of HIV-positive under-fives were reportedly receiving treatment (preventive care for

opportunistic infections or ART) with good adherence to care. Among infants from HIV-positive mothers, 79% of whom were registered in the follow-up programme for HIV-exposed infants, 67% had been tested, while none had been found to be HIV-positive.

Table 2. Utilization of HIV services

	Formal and social CAG members (N=420)	Non-CAG members (1 204 persons; 1 199 with known age)				HIV-exposed infants aged 0-18 months (N=34)
		Men aged 15 years or more (N=252)	Women aged 15 years or more (N=200)	Children aged 6-14 years (N=544)	Children aged 0-5 years (N=203)	
Counselling and testing for HIV	420/420(100%)	77/243 (32%)	81/195 (41%)	158/357(44%)	89/179 (50%)	16 / 24 (67%)
Tested HIV-positive	420/420(100%)	14/75 (19%)	13 / 79 (16%)	8 / 149 (5%)	4 / 84 (5%)	0 /14 (0%)
HIV treatment and care:						
. ART care	358/420 (85%)	10/14 (71%)	3 / 13 (23%)	4 / 8 (50%)	1 / 4 (25%)	-
. OI care	62/420 (15%)	1 /14 (7%)	6 / 13 (46%)	4 / 8 (50%)	2 / 4 (50%)	
. None	0/420 (0%)	3 / 14 (21%)	4 / 13 (31%)	0 / 8 (0%)	1 / 4 (25%)	
Retention in HIV care (consultation in last 6 months)	420/420 (100%) within previous 6 months	8 / 8 (100%) within previous 6 months	8 / 8 (100%) within previous 6 months	8 / 8 (100%) within previous 6 months	3 / 3 (100%) within previous 6 months	27 / 34 (79%) registered in follow-up programme

OI: Opportunistic infections; ART: Antiretroviral therapy

NB. Denominators vary as information was not available for all variables and all participants.

MCH service utilisation among woman of reproductive age

Table 3 presents the study findings regarding care for pregnancy and childbirth, contraception and tetanus immunization among women of reproductive age. Many women had experienced childbirth at least once, CAG members (89%) more often than non-CAG members (55%), probably related to their older age (mean age 33,4 years and 22,3 years, respectively). Their most recent childbirth occurred frequently with skilled attendance (78% and 83% of CAG and non-CAG members, respectively). At the time of data collection 7% of CAG members and 5% of non-CAG members reported to be pregnant (including early, non-confirmed pregnancies); 61% of pregnant CAG members and 86% of pregnant non-CAG members had started antenatal care in their current pregnancy. Of

the pregnant CAG members 89% were receiving antiretroviral therapy, started already before their current pregnancy, protecting them also against HIV transmission to their child, but neither of the two HIV-positive pregnant non-CAG members were receiving any medication for the prevention of mother-to-child transmission. Use of modern contraceptive methods was limited in all women of reproductive age (16% and 19% of CAG and non-CAG members, respectively), usually injectable or oral contraceptives. Condom use as a contraceptive method was reported just three times (one CAG member and two non-CAG members). Less than half of the participants brought documentation regarding tetanus immunization in women of reproductive age, which was up-to-date in 41% of CAG members and 38% of non-CAG members.

Table 3. Healthcare for women of reproductive age

	Women of reproductive age (Formal and social CAG members; 255 women)	Women of reproductive age (Non-CAG members; 160 women)
Pregnancy	18 / 247 (7%) report a current pregnancy 11 / 18 (61%) started antenatal care 18 / 18 (100%) are HIV-positive pregnant women 16 / 18 (89%) receive PMTCT	7 / 153 (5%) report a current pregnancy 6 / 7 (86%) started antenatal care 2 / 7 (29%) are HIV-positive pregnant women 0 / 2 (0%) receive PMTCT
Childbirth	227 / 255 (89%) report at least one childbirth 176 / 227 (78%) report skilled attendance	88 / 160 (55%) report at least one childbirth 73 / 88 (83%) report skilled attendance
Contraceptive use	37 / 226 (16%) report current use of a modern method	24 / 126 (19%) report current use of a modern method
Tetanus immunization	45 / 109 (41%) with up-to date immunization	14 / 37 (38%) with up-to date immunization

NB. Denominators vary as information was not available for all variables and all participants.

MCH service utilisation among children under five years of age

Results regarding immunization, growth monitoring, and nutrition in the under-fives included in our study population are presented in table 4. Only four under-five were reportedly social CAG-members, and as such these results are not disaggregated for CAG and non-CAG members. Of the children under the age of one year 72% had received all immunizations recommended for their age according to the national vaccination calendar. Children aged 12-59 months were fully immunized in 95%. Babies under 6 months of age were exclusively breastfed in 70%. Growth monitoring had been performed

within the previous month in 79% of children under the age of one year, and within the previous 3 months in 52% of children aged 12-59 months. A low weight-for-age at the most recent visit had been documented on the health cards of 15% of children under the age of one year and of 49% of children aged 12-59 months. The health cards of these children with low weight-for-age indicated in 75% and 23%, respectively, referral to the at-risk child clinic for further follow-up. Those same health cards showed that Vitamin A supplementation and de-worming were up-to-date according to the national guidelines at the time of the study in respectively 62% and 61% of children of eligible age.

Table 4. Healthcare for children under five years of age (including 4 CAG and 204 non-CAG members)

	Children aged 0-11 months (41 children)	Children aged 12-59 months (167 children)
Fully immunized for age	21 / 29 (72%)	81 / 85 (95%)
Growth monitoring	23 / 29 (79%) within the previous month	43 / 85 (52%) within the previous 3 months
Low weight-for-age in the last consultation	4 / 29 (15%); of whom 3 (75%) were referred for further evaluation and care	43 / 87 (49%); of whom 10 (23%) were referred for further evaluation and care
Exclusive breastfeeding (age < 6 months)	14 / 20 (70%)	-
Vitamin A supplementation (age 6-59 months)	-	61 / 98 (62%) up-to-date
De-worming (age 12-59 months)	-	52 / 85 (61%) up-to-date

NB. Denominators vary as information was not available for all variables and all participants.

B) Qualitative results

The 367 CAG members participating in the quantitative assessment also participated in the qualitative data collection. During the discussions in the group meetings, the three main MCH areas were addressed: pregnancy and childbirth; contraception and tetanus immunization for women of reproductive age; and health and nutrition for young children. Three main themes emerged: 1) knowledge and perceptions in the community; 2) interface between community and health services; and 3) performance of the health services.

Knowledge and perceptions in the community

Many participants appeared well informed regarding care during pregnancy and childbirth as recommended by the health services, and they recognized the importance of those health services for pregnant women and women in childbirth. Nonetheless, they also mentioned that some others in the community were less convinced of the benefit of such health services, and that therefore not everybody showed interest in using the health services for care during pregnancy and childbirth.

“Nowadays there are many diseases, and attending in the hospital is good, because there they provide a health check and care to guarantee a healthy development of the baby and a safe childbirth. In case of disease, when we comply with the antenatal care visits, it is unlikely that this disease transmits from the mother to the baby. [Attending the hospital] is also important because sometimes a blood transfusion is required during or after childbirth, and this prevents death.”

Participant in Marara-Centro, 25th May, 2011.

Modern contraceptive methods formed another topic on which participants were quite knowledgeable, reciting extensively on the range of available methods and their advantages. However, at the same time, many expressed serious doubts and concerns regarding the actual use of contraceptives, related to side effects such as irregular or

persistent vaginal blood loss, but also due to fears that such use might adversely affect their fertility in the future. *“Contraceptives damage the uterus”* was a frequently heard remark. In addition, contraceptive use arose as a potential source of discord between couples, as the participants claimed that husbands do not always agree with their wives' wishes for contraception, fearing a loss of control over their sexual activities. It was suggested that many women have to practice family planning in secret. Therefore, the participants were not very confident that contraception would actually be a good option for them.

[Why is it that some women do not practice family planning?] *“Because they are afraid that they will not be able to conceive again, and others because the husbands forbid it, they allege that if a woman uses family planning, she will prostitute herself with other men, because she knows she will not be able to get pregnant.”* Participant in Luenha, 15th June, 2011.

Much less knowledge was displayed regarding tetanus immunization for women of reproductive health. Though the participants knew about tetanus immunization in pregnant women, they were not clear about its purpose, and apparently neither had they any idea about the recommended immunization calendar for tetanus in women of reproductive age.

The need for extra care for young children, such as immunization and growth monitoring, was well known and accepted by the participants in the group meetings. However, it appeared that the participants considered this particular care for young children only necessary till they were quite grown already, that is, until the age of two years or so, while the health services recommend such care from birth till the age of five years. Moreover, a young child for our participants appeared to be only the youngest child: when a mother has several under-fives, she often would take only the youngest to the health facility for growth monitoring and check-up, and any

older children would be taken to attend the health services only in case of illness. Despite this, the participants generally showed great interest and felt the need to learn more about care for young children, in particular about ways to improve their children's care which would be feasible in their environment and within their means, and especially in the field of child nutrition.

[Why do people no longer bring their children for weighing when they reach the age of two or three years?] *"Many people do no longer take them for weighing because they see that the child is already quite big, and is looking good, and then they think there is no need anymore to take them for weighing when the child is not sick..."* Participant in Changara-Sede, 17th June, 2011.

Interface between community and health services

The long travelling distances to and from health facilities and the lack of means for transportation, especially in emergencies, were highlighted on several occasions as major barriers for the use of health services, in particular during pregnancy and childbirth. Moreover, many participants considered that the great efforts required to reach a health facility for care were not always sufficiently compensated by the quality of care received there, in pregnancy and childbirth, but also in childcare.

"A lack of transport, here it is not possible to hire a car, and [women in childbirth] therefore stay a long time at home, where they end up giving birth. The few cars that sometimes are available charge a lot of money, which we do not have. In the health centre there is no place for pregnant women to wait for their childbirth, and the nurses sometimes are not present in the health centre, so that does not compensate the efforts we make in traveling from home to the health facility, when upon arrival there we do not encounter the nurse." Participant in Dzunga, 6th June 2011.

The participants thought it might be useful to try to bring health care closer to the people

requiring it. It was suggested to look at the option of widening the range of activities in the CAG for this purpose, and to engage CAG members in growth monitoring and prophylaxis for opportunistic infections in HIV-exposed infants and HIV-positive family members. In the case of contraception, though they considered that contraceptive use might be a delicate secret, an analogue was found with the secret of being HIV-positive, which was overcome within the social group dynamics:

[What support could the group provide for those people who need family planning?] *"We could organize the groups so that one person could collect the family planning for the others, as we do with the antiretroviral medication. Family planning is often a secret in the family, similar as HIV/AIDS. In the beginning it was also a secret to take antiretroviral drugs. Nowadays we are organized in groups, and we manage to help ourselves, so we should proceed in a similar manner for family planning."* Participant in Cacheembe, 20th May 2011.

Performance of the health services

During all group discussions it became apparent that the CAG members experience and are disappointed by the lack of qualified human resources, of commodities including drugs, of equipment and means of transport such as ambulances, prevailing in their health services. Complaints about the unavailability of prescribed medications and other commodities, such as HIV tests, insecticide-impregnated nets, and products for nutritional supplementation and treatment, appeared during practically all debates, especially when referring to the more peripheral health facilities.

"Sometimes in the health centre there is a stock rupture of medications, family planning, or the nurse is absent. There should be immunizations always, HIV tests, because here they do not test anymore for HIV when mothers go to start antenatal care, and the number of nurses is not sufficient." Participant in Missawa, 8th June, 2011.

In addition, the difficulties encountered during visits to health facilities, where large crowds and long queues are common, contribute to the feeling that such visits are not always worthwhile. The participants also remarked repeatedly that they consider that some health care providers, particularly certain staff in the MCH department and pharmacy at the district hospital, do not attend them with adequate manners and respect, which leads them to avoid seeking care.

[What are barriers to antenatal care visits?]
“Many do not go to the hospital, because the midwives beat them, and get angry with them, and that way they intimidate the people who attend the hospital.” [All participants concurred with this remark] Participant in Changara-Sede, 13th June, 2011.

“Many mothers are afraid to talk, because it appears they are just complaining, but it is true that this is happening, that bad attendance occurs in the hospital. Not everywhere, but it does occur in the MCH sector and in the Pharmacy. Many people turn around when they are on the way, when they hear that a certain person is on duty there.”
Participant in Changara-Sede, 17th June, 2011.

Discussion

Our study confirms that the CAG model as implemented in Changara, one of the districts which pioneered this patient-centred care model, is associated with very good compliance to HIV care and treatment among the group members, as has been reported before [12]. The study findings also suggest that this habit of good compliance to HIV care and treatment is shared with HIV-positive persons receiving individual treatment among the family aggregates of the CAG members, as all known HIV positive persons on treatment in our study population reportedly complied with the required regular clinical consultations and medication collection. However, many

non-CAG family members remained without counselling and testing, and a considerable number of HIV-positive family members remained without HIV treatment and care. Men had the lowest utilization of counselling and testing (32%), while those who were tested resulted often HIV-positive (19%) and eligible for ART (71%). This probably reflects the known reluctance of men in Mozambique and similar areas in accessing health services unless they are really ill, as reported by other studies [18, 19]. Yet even women, who use health services more regularly for themselves or their children, were only counselled and tested in 41%, with a high positivity rate of 16%. A considerable proportion of these non-CAG HIV-positive adult family members did not access HIV treatment, despite their respective CAG members' knowledge of the positive HIV test. It appears that the positive effects of the CAG support are centred in the compliance to ART care, rather than also addressing utilization of testing services and initiation of HIV treatment. It might be possible to strengthen the CAG dynamics towards the inclusion of counselling and testing through community-based VCT services, as well as towards increased utilization of HIV care and treatment for those tested HIV-positive through improved interpersonal communication and support among the adults within family aggregates and the wider community.

In our study population, utilization of counselling and testing increased with younger age of the family members, and in parallel their HIV-positivity rate reduced. Despite this, a considerable number of children, even when known HIV-exposed, had not been tested. In view of the need to accelerate access to paediatric HIV treatment, which in Mozambique till date has a much lower coverage than adult HIV treatment [2], it would be important to actively promote among the CAG members the use of Early Infant Diagnosis and HIV testing for their children at all possible entry points in health facilities, and to ensure universal access to treatment for those children testing HIV-positive. Regarding the prevention of

paediatric HIV infection, it appears that the CAG model does make a positive contribution, as 89% of pregnant CAG members received medication effective for PMTCT, although this might rather be an unintentional benefit from the large proportion of women of reproductive age on ART within the CAG. As such, encouraging counselling, testing, and access to HIV treatment for all women of reproductive age might expand this PMTCT effect to the family aggregates and the wider community.

Our data regarding utilization and outcomes of MCH services among the CAG members and their family aggregates appear to largely resemble those for the general population as reported routinely by the district and provincial health system. Only the proportions of skilled attendance at birth and of exclusive breastfeeding of babies under 6 months of age seem relatively high in our study population. However, these might relate to certain general characteristics of the study population, such as the very high HIV prevalence and a general motivation to use formal health services, rather than to particular positive effects from the CAG model. However, the CAG members in our study made it clear that they were interested in and open to an expansion of the health topics dealt with within their groups. This patient driven care model offers the possibility to extend the activated level of patient involvement to other needs than HIV care and treatment among people living with HIV/AIDS. Lessons learnt from HIV-based activism, patient involvement and community participation might be applied to broader SRH services, including MCH care. Community and patient participation increases the sharing of knowledge, treatment experiences, and acquired self-management skills among peers and their family aggregates in the community [5, 10]. Moreover, the social interactions may induce the necessary motivation to adhere to health services and to initiate care. More informed and more motivated people are more likely to acquire health promoting skills and practice health seeking behaviour [20]. There is a need for honest and open

information at an appropriately simplified but not unsophisticated level within the CAG about wider SRH, including MCH topics. For example, in the case of family planning, the need exists for a honest and open dialogue on its pro's and con's, including on ways to safeguard fertility for the future, and on what to do in case of infertility.

Our participants related the lack of MCH service utilization to cultural perspectives leading to lack of trust, and to a lack of appropriate information in the community, but also to structural barriers such as a lack of transport, unavailability of MCH personnel, stock-outs of drugs and equipment and the fragmented delivery of MCH services. For obvious ethical reasons such structural health system limitations need to be addressed in order to respond appropriately to any created demand for services. General health system strengthening is essential in Mozambique and many other countries in SSA, for health systems to be able to offer services of a quality which is worthy of people's trust and which generates confidence in its use among the population.

Despite the wide participation in our study among the CAG members in Changara, we did not manage to collect information on all family aggregate members, as not all health cards were available for review. Hence, the denominators of many of the variables presented in the tables are smaller than the total number of CAG and aggregate members, sometimes leading to very small numbers in certain subgroups. It is possible that this has caused a distortion of our results, probably in a positive direction, as CAG members with knowledge and cards on the health status of their family aggregate members likely represented families with more motivation for health care utilization than those without. In addition, we do not present a statistical comparison between the various groups in our study population, as its interpretation would be difficult due to the obvious interdependence between the CAG members and their non-CAG family aggregates.

As such, our quantitative results should be interpreted with caution, in view of these inherent difficulties in their generalizability. It is also possible that our participants provided socially acceptable answers, particularly regarding the adherence to consultations among CAG members, and that their retention to care is actually somewhat less ideal than at first appearance. Regarding their information on barriers to care, however, socially acceptable answers were much less obvious, and in addition, saturation of information was reached rather early in the series of debates, while subsequent discussions repeated confirmed the earlier findings. Despite these drawbacks, we therefore feel that our findings, both quantitative and qualitative, provide a reasonably accurate picture of the utilization of and barriers to utilization of HIV and MCH care amongst the CAG members and their family aggregates in Changara, and possibly suggest similar tendencies among comparable populations elsewhere.

Community participation as a bottom-up strategy, binding people on the basis of their common needs, engaging people in their lifelong care, and increasing awareness of the needs of their fellow community members, has a potential in Sub-Saharan contexts, where social capital is a means to survive in its harsh economic environments. People support each other knowing that roles can change over time, and that the supporting may become the supported [21, 22]. These traditional ways to overcome barriers can become the foundations on which health interventions can be built. It is important to engage the real decision makers (both male and female) within the communities, such as traditional chiefs, church leaders, and other people with a credibility which is widely recognised. Some of the participating CAG members are well known in their community, as they use their service utilization experiences to guide others who suffer disease or face other health needs. We therefore stress the importance of linking HIV care, including in the very successful and innovative models such as the CAG, with

broader SRH, including MCH, activities and services, leading to the promotion of comprehensive family-centred care.

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Journey towards universal Viral Load monitoring in Maputo, Mozambique: Many gaps, but encouraging signs

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Abstract

Introduction: Viral load (VL) monitoring for people on antiretroviral therapy (ART) is extremely challenging in resource-limited settings. We assessed the VL scale-up in six Médecins Sans Frontières supported health centers in Maputo, Mozambique, during 2014-15.

Methods: In a retrospective cohort study, routine programme data was used to describe VL uptake and results, multi-variate logistical regression to estimate predictors of VL uptake and suppression.

Results: Uptake of a first VL was 40% (17,236/43,579). Uptake of a follow-up VL for patients with a high first VL was 35% (1095/3100). Factors associated with a higher uptake included: age below 15 years, longer time on ART and attending tailored service delivery platforms. Virological suppression was higher in pregnant/breastfeeding women and in Community ART Group members. Patients with a high first VL (18%; 3100/17,236) were mostly younger, longer on ART or had tuberculosis. Out of 1095 with a follow-up VL, 678 (62%) had virological failure. Of those fewer than one third started second line ART.

Conclusion: This was the first study describing the uptake and results of VL scale-up in Mozambique. Identified gaps show patient and programmatic challenges. Where service delivery was customized to patient's needs, VL monitoring was more successful.

Key words: Antiretroviral Therapy, Highly Active; HIV; Mozambique; Operational Research; Sub-Saharan Africa; Viral Load Monitoring

Introduction

To control the HIV epidemic by 2020, the 90-90-90 targets were set by UNAIDS in 2014. These targets require that 90% of the population know their HIV status, 90% of all people with diagnosed HIV infection are receiving sustained antiretroviral therapy (ART), and 90% of all people on ART are virological suppressed. This implies that every person on ART should have access to viral load (VL) testing.¹ From 2013, the World Health Organization (WHO) has

recommended yearly routine VL monitoring for all patients more than six months on ART. In most high and middle-resourced settings VL measurement every three to six months has been the standard of care for over a decade.² In resource-limited settings the combination of financial, logistical and human resource related constraints make the widespread of VL implementation extremely challenging.³

Médecins sans Frontières (MSF) has initiated and run various VL programmes funded by

UNITAID in seven sub-Saharan African (SSA) countries with high HIV prevalence and large ART cohorts, including Mozambique.⁴ Routine VL in Mozambique has been rolled-out in MSF-supported health programmes in Maputo, the capital city, since October 2013.

Most studies on VL monitoring in SSA countries have assessed determinants of virological outcomes and initiation of second-line therapy.^{5,6} However, the feasibility of large-scale implementation of VL monitoring in high prevalence, resource-limited settings has not been extensively studied. A study from Malawi demonstrated that good quality VL monitoring is feasible and affordable in their setting.⁷ Another study from Swaziland showed the same, but stressed the needs for close monitoring of gaps in the “VL cascade”. The VL monitoring cascade is a management process for VL testing: if a first VL is high, enhanced adherence counselling (EAC) is offered and then, if a follow-up VL remains high, the patient should be considered for second line ART.⁸ At all steps of this cascade, from initial VL testing to switching to second line ART, patients are “lost”.

We know that implementation of VL monitoring in resource-limited settings is challenging in many ways, but there are no studies that examine which patient and programme level factors associated with uptake of first and follow-up VL testing. Identification of such factors is important if successful implementation of the WHO and UNAIDS’ recommendation of universal VL testing is to be achieved.

In this Mozambican study we describe the VL cascade in six MSF-supported health centers (HCs) in Maputo city, including the uptake of first and follow-up VL testing and VL results. In addition, we study the patient and programme factors influencing the uptake of VL testing and VL results, with an emphasis on the performance of different service delivery platforms.

Methods

Design

A retrospective cohort study using routine programme data.

General setting

Mozambique is a large country situated in South-East Africa, with a population of over 26 million. Despite its’ economic growth, Mozambique is still one of the poorest countries in the world. Mozambique scores among the lowest in the world when it comes to trained human resources for health capacity, with only 0.04 physicians and 0,412 nurses/midwives per 1000 people, reported in 2012.⁹ However, numbers and densities of health workers are improving, showing the impact of the human resources development strategy in the country.¹⁰

The country has a high HIV prevalence, with about 1.5 million people living with HIV/AIDS (PLWH). Approximately 10,5% of the population in between 15 and 49 years is HIV positive. The country ranks third in the world for new paediatric infections and almost 110,000 teenagers are living with HIV.¹¹ Maputo, the capital, has a population of 1.2 million, and an HIV prevalence of 16,8%. Although over 300,000 PLWH take first line ART in Maputo, only counts a few hundred people are on second line ART.¹²

VL roll-out in Mozambique

In the Mozambican National Strategic Plan for the HIV/AIDS response from 2010-2014 (NSP III), a phased roll-out of VL testing was foreseen. Initially, VL was to be implemented for early infant diagnosis and as well as targeted VL, when therapeutic failure was suspected (clinically or immunologically).¹³ The next NSP aims to further scale-up routine VL for all children between two and five years of age and pregnant/breastfeeding women on ART, with a goal to reach routine VL for all by 2017.¹¹

The guidelines for routine VL monitoring in Mozambique at the time of the study were as follows: a patient was eligible to do a first VL if

more than six months on ART or at three months if pregnant/breastfeeding. In case of a high VL (more or equal than 3000 copies/ml) the VL should be repeated six months later, after one or more sessions of EAC. All patients with repeated high VLs (two times more or equal than 3000 copies/ml, minimum two months apart) had to be presented and approved by the ART Committee, responsible for deciding if they should switch to second line ART. The actual start and follow-up of people on second line ART was performed at the referral hospital.

Implementation of routine VL in MSF-supported health centers in Maputo

MSF and the Direction of Health in Maputo City have collaborated since 2001 in supporting HIV/AIDS activities in the health areas of Chamanculo and Mavalane. The seven HCs scaling-up routine VL monitoring at the time of the study were Chamanculo, Xipamanine, Alto-Mae, Maxaquene, and Porto in the area of Chamanculo, and Primeiro de Maio and Albasine in the area of Mavalane. HIV care, including VL testing, is integrated into primary health care delivery.

In October 2013 a VL machine (type bioMérieux, NucliSENS EasyQ® HIV-1 V2.0) was fully installed at the laboratory in Jose Macamo Hospital and became functional. Henceforth the MSF-supported HCs started sending DBS VL samples for routine testing.¹⁴

Medical staff included VL monitoring in their daily work, including; prescribing and explaining the test, taking the venous blood samples, preparing the DBS samples for transport, receiving and classifying the VL results in the patient files, informing the patients about their results during the next consultation and making clinical decisions accordingly.¹⁵

Study site, period and population.

The study included patients from six MSF-supported HCs who did roll-out routine VL monitoring in Maputo city, Mozambique: Chamanculo, Xipamanine, Alto Maé, Maxaquene, Porto and Primeiro de Maio. All

patients more than six months on first line ART (eligible for routine VL testing) with at least one consultation between 2014 and 2015 were included. Patients who started ART after March 2015, were excluded. VLs were retrieved if sampled in the study period. Each HC offered a mix of different service delivery platforms (Box 1).

Source of Data.

Study variables were extracted from the database used by MSF at all six studied HCs for HIV programme monitoring, called Three Information Register Net Worked (Tier.net) and from the MSF second line referral and switch register.

Variables included sociodemographic patient characteristics, service delivery platforms (conventional, conventional with iDART¹⁶, CAG¹⁷, SAAJ, ANC/PNC, TB; see Box1), year of ART initiation, VL results and dates, treatment outcomes (active in treatment, transferred out, dead, lost to follow-up) and dates, ART Committee referral and approval dates, second line starting date.

Data analyses

Proportions were calculated for categorical variables, median and interquartile ranges (IQR) for numeric variables to report on demographic and clinical characteristics of patients, service delivery platforms (Box 1), uptake of first and follow-up VL testing, virological outcomes, second line referral and switch to second line ART. Patients were attributed to a specific service delivery platform if they had attended at least four consultations during the study period in the specific platform.

Lost to follow-up was defined as being more than three months late for the last appointment. VL results were categorized as: first VL, virological rebound, follow-up VL, virological failure and low follow-up VL (Box 2).

We employed univariate and multivariate logistic regression to estimate the association between patient and programme level factors

and coverage and results of first and follow-up VL. P-values of <0.05 were considered as significant. Analyses were performed with Excel and Stata (version 11.2).

Review Board-approved criteria for analysis of routinely-collected programme data. Since the data were anonymised and routinely-collected, patient consent was not required.

Ethics approval

The study was approved by the Maputo City Health Directorate and met the MSFs' Ethics

Box 1. Service delivery platforms in six MSF supported health facilities in Maputo city, Mozambique, between 2014 and 2015

Conventional Care:

- Care provided to all patients not attending the below mentioned services.
- Provided in all six HCs.

Conventional Care with iDART (intelligent dispensing of ART)¹⁶:

- Care at Primeiro de Maio HC, with a specific pharmacy software in place, called iDART. It was not only used as a tool to ease the ART stock control and the dispensing of drugs, but also helped to monitor patients on ART. This by a mobile phone recall system for late presenters to ART refill and by flagging patients with a high VL for referral by the pharmacy to enhanced adherence counselling.

- All patients in conventional care at Primeiro de Maio HC.

Urban Community ART Groups (CAG)¹⁷:

- A community model for ART delivery in urban settings, in which stable patients on ART were organized in groups of maximum six people, taking turns to pick-up ART refill at the health facility, attending their 6 monthly medical appointment.
- Available in all six HCs.

One-Stop models: service delivery platforms where all aspects of HIV care, including testing, ART and counseling, are provided in an integrated way.

Service for adolescent care (SAAJ=Serviços de Amigos dos Adolescentes e Jovens):

- Patients between 10 to 24 years old on ART received adapted clinical and psycho-social care, including counseling and peer support.
- Available at Primeiro de Maio HC.

Ante Natal Care (ANC) and Post Natal Care (PNC):

- Pregnant and breastfeeding women up to two years after delivery received adapted clinical and psycho-social care, including counseling and peer support.
- Available at all six HCs.

TB service

- Patients with tuberculosis on ART received intensified clinical care.
- Available at all six HCs.

ART: Antiretroviral therapy; HC: Health Centre

Box 2. Definition of VL variables

First VL = A first VL taken from a patient more than six months on first line ART, between 2014-15.

Low first VL = A first VL <3000 copies/ml.

Virological rebound, or high first VL = A first VL ≥3000 copies/ml.

Follow-up VL = A VL taken from a patient with a first VL ≥3000 copies/ml, more than 60 days after the first VL, between 2014-15.

Virological failure, or high follow-up VL = A follow-up VL ≥3000 copies/ml.

Low follow-up VL = A follow-up VL <3000 copies/ml.

VL: viral load; ART: Antiretroviral therapy

Results

Baseline characteristics of study population (Table 1)

During the study period, 43,579 patients were eligible to do a first VL test, of whom 98%

never had a previous VL. Table 1 shows the baseline characteristics of eligible patients. Two thirds were women, and older than 35 years, only four percent were younger than 15

years. We can see the majority of patients were attended in conventional care, with or without iDART, while other service delivery platforms were attended as shown in Table 1. Patients had a median of 42 (IQR: 21- 71) months on ART.

Serious gaps were observed throughout the VL cascade. We saw low levels of uptake of first (40%) and follow-up (35%) VL. Only one in three patients identified with virological failure was switched to second line ART (Figure).

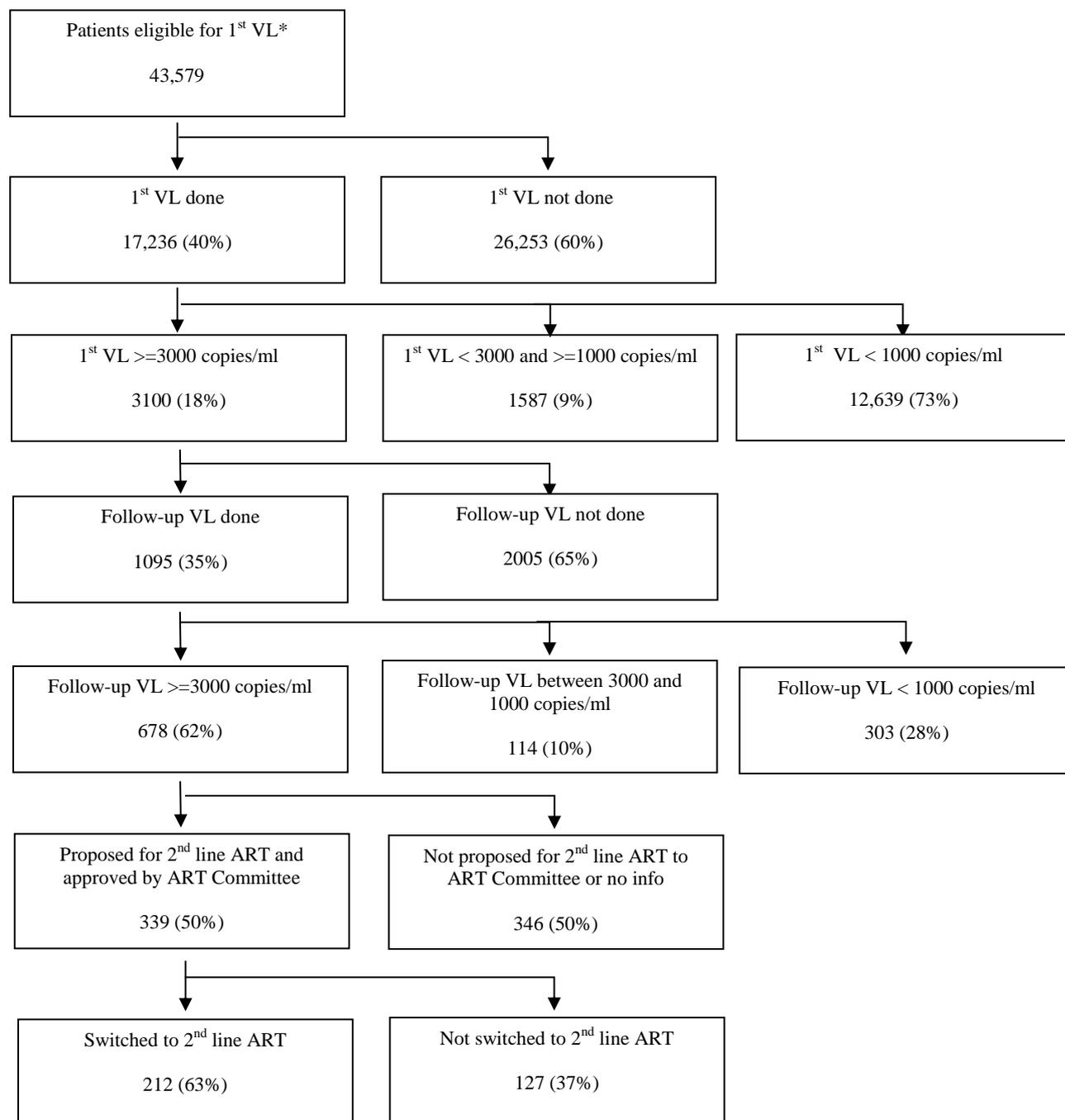
Table 1. Characteristics of patients eligible for first viral load testing in six MSF-supported health centres in Maputo, Mozambique, between 2014 and 2015

Characteristics	Number of eligible patients*	
	N	(%)
Total	43,579	(100)
Sex, female	29,657	(68)
Age category (years)		
< 5	488	(1)
5-- 15	1510	(3)
15-- 25yrs	2,220	(5)
25-- 35yrs	12,117	(28)
>= 35yrs	27,244	(63)
Year ART start		
< 2010	11,241	(26)
2010-2013	21,989	(50)
2014-2015	10,349	(24)
Facility		
Primeiro de Maio	8691	(20)
Alto Mae	10,211	(23)
Chamanculo	10,079	(23)
Maxaquene	2,946	(7)
Porto	4,382	(10)
Xipamanine	7,270	(17)
Service delivery		
Conventional [§]	30,989	(71)
Conventional [§] with iDART	6,687	(15)
CAG	1,202	(3)
SAAJ	451	(1)
ANC/PNC	3,723	(9)
TB	527	(1)

*eligible for first VL testing included all patients more than six months on first line ART

[§] conventional care is the care provided to all patients not attending the other mentioned service delivery platforms
 ART: Antiretroviral therapy; CAG: Community ART Groups; SAAJ: Servicio Apoio Amigos Jovens (Adolescent Friendly service); iDART: intelligent Dispensing of ART - pharmacy software to dispense and monitor ART

Figure. Viral load cascade of eligible patients in MSF-supported health centres in Maputo, Mozambique, between 2014 and 2015



ART: Antiretroviral therapy; VL: Viral Load

*eligible for first VL testing included all patients more than six months on first line ART

Uptake and results of first VL testing (Table 2)

Among eligible patients, 40% (17,236) had a first VL test during the two-year study period, with a higher uptake in men, children younger than 15 years and patients longer on ART, all

statistically significant. Certain service delivery platforms performed significantly better than conventional care. Uptake of first VL test was highest in the more heavily MSF-supported services (SAAJ, CAG, TB). In SAAJ, uptake was the highest. Among patients who never had a

first VL, 8006 (31%) were LTFU, 164 (0.6%) were reported dead and 895 (3.4%) were transferred out.

First VL results were significantly higher across all age categories below 35 years old. The

younger the patients were, and the longer on ART, the higher was the probability of virological rebound. Patients in CAG and pregnant/breastfeeding women were more likely to have a low first VL.

Table 2. Patient and programmatic factors influencing first VL uptake and result in six MSF-supported health centres in Maputo, Mozambique, between 2014 and 2015

	First viral load uptake						First viral load result					
	Eligible first VL*	With first VL	(%)	aOR	(95% CI)	P value	With first VL	First VL >=3000	(%)	aOR	(95% CI)	P value
Total	43,579	17,326	(40)	-	-	-	17,326	3,100	(18)	-	-	-
Gender						0.001						0.37
Female	29,657	11,501	(39)	1	-		11,501	1,978	(17)	1	-	
Male	13,922	5,825	(42)	1.08	(1.03-1.13)		5,825	1,122	(19)	1.04	(0.95-1.13)	
Age category (years)						< 0.001						< 0.001
< 5	488	254	(52)	2.40	(1.99-2.91)		254	102	(40)	3.71	(2.87-4.82)	
5-<15	1510	1066	(71)	3.10	(2.75-3.49)		1,066	347	(33)	2.52	(2.19-2.91)	
15-<25	2220	757	(34)	0.75	(0.67-0.83)		757	203	(27)	2.13	(1.76-2.58)	
25-<35	12,117	3,893	(32)	0.75	(0.71-0.79)		3,893	687	(18)	1.31	(1.18-1.45)	
>35	27,244	11,356	(42)	1	-		11,356	1,761	(16)	1	-	
Year ART start						< 0.001						0.025
< 2010	11,241	5,658	(50)	4.14	(3.87-4.42)		5,658	1,009	(18)	1.21	(1.05-1.40)	
2010-2013	21,989	9,568	(44)	3.23	(3.05-3.43)		9,568	1,751	(18)	1.18	(1.04-1.35)	
2014-2015	10,349	2,100	(20)	1	-		2,100	340	(16)	1	-	
Service delivery						< 0.001						< 0.001
Conventional [§]	30,989	10,845	(35)	1	-		10,845	1,930	(18)	1	-	
Conventional [§] & iDART	6,687	3,486	(52)	2.07	(1.96-2.19)		3,486	705	(20)	1.23	(1.12-1.36)	
CAG	1,202	761	(63)	2.60	(2.30-2.93)		761	95	(12)	0.75	(0.60-0.94)	
SAAJ	451	372	(82)	9.61	(7.32-12.61)		372	120	(32)	1.18	(0.92-1.52)	
ANC / PNC	3,723	1,604	(43)	2.44	(2.26-2.64)		1,604	192	(12)	0.63	(0.53-0.74)	
TB	527	258	(50)	3.58	(2.98-4.30)		258	58	(22)	1.43	(1.06-1.94)	

*eligible for first VL testing included all patients more than six months on first line ART

[§] conventional care is the care provided to all patients not attending the other mentioned service delivery platforms

VL: viral load; ART: Antiretroviral therapy; CAG: Community ART Groups; SAAJ: Servicio Apoyo Amigos Jovens (Adolescent Friendly service); iDART: intelligent Dispensing of ART - pharmacy software to dispense and monitor ART; aOR: adjusted Odds Ratio

Uptake and results of follow-up VL testing (Table 3)

The median time between first and follow-up VL was 214 days (IQR: 152-323). Of patients with virological rebound, 35% (1095) had a follow-up VL test, with a higher uptake in women, children between five and 15 years old and patients longer on ART, all statistically significant. Adults between 25 and 35 years old had the lowest uptake. Specific service

delivery platforms performed significantly better than conventional care. Follow-up VL uptake was higher in conventional care with iDART in place. Among patients that never had a follow-up VL, 351 (18%) were LTFU, 25 (1%) were reported dead and 124 (6%) were transferred out. Patients in CAG and pregnant/breastfeeding women were more likely to have a low follow-up VL, indicating effective viral suppression.

Table 3. Patient and programmatic factors influencing second VL uptake and result in six MSF-supported health centres in Maputo, Mozambique, between 2014 and 2015

	Follow-up viral load uptake					P value	Second VL result					P value
	Eligible follow-up VL*	With follow-up VL	(%)	aOR	(95% CI)		With follow-up VL	Follow-up VL >= 3000	(%)	aOR	(95% CI)	
Total	3,100	1,095	(35)	-	-	-	1095	678	(62)	-	-	-
Gender						0.016						0.30
Female	1,978	709	(36)	1	-		709	428	(60)	1	-	
Male	1,122	386	(34)	0.82	(0.70-0.96)		386	250	(65)	1.15	(0.88-1.51)	
Age category (years)						< 0.001						0.25
< 5	102	32	(31)	1.06	(0.68-1.65)		32	17	(53)	0.62	(0.30-1.29)	
5-<15	347	160	(46)	1.46	(1.14-1.87)		160	103	(64)	0.95	(0.64-1.39)	
15-<25	203	85	(42)	1.11	(0.78-1.59)		85	59	(70)	1.13	(0.63-2.00)	
25-<35	687	183	(27)	0.70	(0.57-0.86)		183	119	(65)	1.38	(0.95-1.98)	
>35	1,761	635	(36)	1	-		635	380	(60)	1	-	
Year ART start						< 0.001						0.72
< 2010	1,009	406	(40)	3.84	(2.71-5.42)		406	247	(61)	1.13	(0.60-2.11)	
2010-2013	1,751	641	(37)	3.59	(2.57-5.00)		641	403	(63)	1.22	(0.66-2.25)	
2014-2015	340	48	(14)	1	-		48	28	(58)	1	-	
Service delivery						< 0.001						<0.001
Conventional [§]	1,930	622	(32)	1	-		622	398	(64)	1	-	
Conventional [§] & iDART	705	271	(38)	1.32	(1.10-1.59)		271	169	(62)	0.92	(0.68-1.24)	
CAG	95	54	(57)	2.67	(1.75-4.07)		54	19	(35)	0.30	(0.17-0.55)	
SAAJ	120	71	(59)	2.66	(1.71-4.13)		71	54	(76)	1.74	(0.90-3.34)	
ANC/PNC	192	52	(27)	1.05	(0.73-1.50)		52	25	(48)	0.46	(0.25-0.84)	
TB	58	25	(43)	2.67	(1.50-4.73)		25	13	(52)	0.59	(0.26-1.34)	

* eligible for a follow-up VL testing included all patients on ART with a first VL above 3000 copies/ml, and who had done their first VL more than 2 months ago

[§] conventional care is the care provided to all patients not attending the other mentioned service delivery platforms

VL: viral load; ART: Antiretroviral therapy; CAG: Community ART Groups; SAAJ: Servicio Apoyo Amigos Jovens (Adolescent Friendly service); iDART: intelligent Dispensing of ART, - pharmacy software to dispense and monitor ART; aOR: adjusted Odds Ratio

Discussion

This is the first study describing the uptake of VL testing during the scale-up of routine VL monitoring in Maputo, Mozambique. Serious gaps were observed throughout the VL cascade with low levels of first and follow-up VL uptake. Understanding the cascade and the reason for patients dropping out is an essential step to breaching those gaps. Patient and programme factors contributed to these findings. The benefits of routine VL monitoring in this programme were seriously undermined. Few patients who required second line ART gained access to it. These findings are important as they point to areas of care that need to be strengthened if the goal of universal VL monitoring is to be reached.^{1,2} A recent study reported outcomes of national scale-up of routine VL monitoring in seven SSA countries (Côte d'Ivoire, Kenya, Malawi, Namibia, South Africa, Tanzania, and Uganda) and showed big differences in uptake of first VL test, ranging from 3% to 95%.¹⁸ A study from a heavily MSF-supported VL programme in Swaziland reported better VL uptakes, with 73 % of 16,349 eligible patients who did a first VL. Of patients with a high first VL, 60% had a follow-up VL done within six months.⁶

We found that the proportion of patients with virological rebound was 18%, similar to what was reported by other studies. The Swaziland study showed 16% high first VLs.⁶ The study from seven SSA countries showed that virological rebound ranged between 6% in Uganda and 22% in South Africa.¹⁸ Another study also described a heterogeneity of virological outcomes in patients on ART in SSA and Asia.¹⁹ In Mozambique, thresholds for virological rebound recently changed from 3000 copies/ml to 1000 copies/ml in October 2015. This will lead to increased second line ART needs. Applying this new threshold to our data, an additional 9% of patients would have had virological rebound in Maputo (Figure).

Our findings supported the WHO recommendation that a patient with virological rebound should be addressed by

EAC, as well as repeat VL measurement before considering ART switch.²

Patient and programme factors influencing VL monitoring

Patient factors associated with VL uptake included time on ART and age. The longer patients were on ART, the higher the uptake of first and follow-up VL. This finding is important, especially in programmes with aging ART cohorts, since the risk of virological failure increases with time on ART, mainly due to drug resistance.²⁰ Another reason why early VL testing should be systematized, is the bigger potential yield of EAC for failing patients when introduced early.²¹

Uptake of first VL was high among children of different age categories, reflecting the priority given to this vulnerable subgroup in the scale-up of routine VL in the Maputo HCs. The younger the children, the more likely they were to have a high first VL. This finding confirms what is published elsewhere and requires programmatic responses to prevent and address high VLs in children.²²

Adolescents had a lower uptake of first VL testing if they attended conventional care, as opposed to those who attended SAAJ, a specialized adolescent service, where uptake was excellent. Overall, adolescents were seen to have statistical significant higher levels of virological rebound, when compared to adults. This is in line with previous research, describing worse suppression rates in adolescents.²³ Internationally, there is a consensus that adolescents living with HIV need to be addressed in a specific way and innovative ideas are needed to further improve retention in care and treatment adherence.²⁴ SAAJ can be one of such innovations, which experience can guide similar roll-outs elsewhere.

Not only SAAJ, but also the service delivery platforms ANC/PNC and TB, showed an improved uptake of first and follow-up VL testing in vulnerable groups, when compared to conventional care. The benefits of these One-Stop models of HIV care were already

highlighted in other studies,^{24,25} and were recognized by the Mozambican government.^{25,26}

ANC/PNC services were prioritized in the scale-up of VL monitoring by the Ministry of Health in Mozambique, which opted for the option B+ approach since 2013.¹³ Although some studies show worrisome retention in care and adherence levels among pregnant/breastfeeding women,²⁷ our results show better first VL uptake and outcomes when compared to conventional care. Given the importance of having a low VL at delivery and during breastfeeding extra support to these services is needed to reach the goal of elimination of mother to child transmission.

When addressing the community models of care in previous studies on CAG an excellent retention in care of patients on ART was shown; however, VL uptake and virological outcomes were not studied.¹⁷ Our results show that both VL uptake and virological suppression was better in CAG members when compared to conventional care.

The pharmacy software programme iDART was piloted in one MSF-supported HC in Maputo at the time of the study.¹⁶ It was not only useful to dispense ART, but also to recall patients for EAC, which positively influenced uptake of follow-up VL. However, the influence of iDART alone was difficult to measure, since also other task forces were organized at pharmacy level in that HC, to improve follow-up VL uptake. Future studies will have to show the effect of monitoring and communication technology on adherence.

Feasibility of routine VL monitoring

In well-resourced settings, HIV care, including the choice of ART regimen and VL monitoring, is tailored to the individual patient. However, the reality is different in low-resource high HIV prevalence settings, such as Mozambique. VL monitoring is complex and resource intensive and includes many tasks; venous blood sampling, preparation and transport of samples, archiving of VL results inside the medical files of patients, and clinical decision

making based on the virological outcomes. In Maputo, the bulk of this additional workload is currently dependent of scarce clinicians. Even though supported by an NGO, which activities were integrated into the framework of the Mozambican Ministry of Health, the implementation of routine VL monitoring remained a big challenge at all levels in Maputo's HCs.

How to maximize access to routine VL? *First*, awareness about the importance of VL testing has to be raised, in patients as well as providers. *Second*, in a context of scarce resources, policy makers have to make hard choices. For example; VL monitoring could replace CD4 monitoring.²⁸ In addition, national surveillance systems of resistance patterns should further orient the periodic revision of the first line ART regimen. *Third*, decentralization of HIV care is a must.^{2,29} Not only first line ART delivery and care, but also the decision-making about when to switch to second line ART as well as the follow-up of patients on second line ART should be integrated in primary health care services. Community ART delivery and spaced clinical appointments for stable patients may decompress already overburdened HCs and ease the medical follow-up of people living with a chronic lifelong condition.¹⁷ *Fourth*, new tools and procedures for VL collection and analysis, such as: DBS, finger prick sampling, pooled blood sampling and new VL platforms, including point-of-care technology¹⁴, may bring VL testing closer to the people. *Finally*, besides a simplification of VL monitoring, further task shifting holds a great potential.³⁰ Lay counsellors are key to the well-functioning of HIV care.³¹ Drawing on the literature of chronic disease care, also PLWH can be trained and made partially responsible in the follow-up of their own health status, once appropriate tools are available.³²

In the meantime, HIV programmes scaling-up routine VL monitoring should continue to prioritize the most vulnerable patients; sick patients (including co-infected TB patients),

children and adolescents,
pregnant/breastfeeding women.

There are a number of strengths in our study. The size of the sample cohort was large, permitting evaluation of patient and programme factors. Relying on routinely-collected patient-level program data also permitted these findings to reflect the reality of the ART programme in Maputo city. Additionally, data handling was carefully managed: they were retrieved from the program database from different HCs with well-established and supervised data cleaning procedures. Data from the VL laboratory were double encoded during most of the study period. Hence, we believe the results are based on robust data.

However, our study has some important limitations. Since data on adherence counselling was not systematically encoded during the whole study period, this important step of the VL cascade was not reported in this study. Moreover, high patient attrition and programmatic gaps throughout the VL cascade hampered an accurate estimation of the real need for second line ART. Moreover, additional unmeasured factors related to the organisation of care may have contributed to our findings.

Conclusion

This study of two years' outcomes of routine VL monitoring in Maputo city showed many gaps throughout the VL cascade, which reflect the challenges linked to large VL monitoring scale-up. One-Stop services for vulnerable patients, Community ART Groups, and patient recall systems at the pharmacy, showed additional benefits in uptake of VL testing. Continuous efforts to further simplify and decentralise VL monitoring are needed. This study has pointed the way forward to achieve universal VL testing in Mozambique. The mantra of 90% virological suppressed patients on ART, as the ultimate objective of the VL cascade, is even a step further away.

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Authors' contributions

SS, TD and TR conceived the study and designed the study protocol. SS, TD, AWT, WM collected, analysed and interpreted the data. SS wrote the first draft of the paper. All co-authors contributed to the subsequent draft and approved the final version.

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5. General discussion and conclusion

Facility-based ART delivery: insufficient to cover ART needs

The absorptive capacity of the ART services increases when more health facilities and providers become involved in the ART programme. Several studies confirm that decentralized ART provision in primary health care facilities increases the overall cohort on ART without compromising treatment outcomes (1,2). Similarly, when ART was decentralized maximally, involving all the available health facilities in ART delivery, the cohort on ART increased in Tete city (3).

However, it seems unlikely that facility-based ART will suffice to achieve a coverage of ART needs. Tete city counts a population of approximately 200,000, including 20,000 PLHIV (4). In 2003, the ART programme was introduced in the hospital. In 2006, all four primary health care facilities were providing ART. In 2009, about 2600 patients were enrolled on ART (3). Even though ART coverage was low, the health system was saturated. The health care workers in the primary health care facilities were not coping with the workload. The infrastructure was inadequate. Supply of ART was not secured. To access ART PLHIV has to queue many hours. Moreover, relationships between providers and PLHIV worsened (3). Across Mozambique, similar challenges were reported. To cope with these challenges guidelines were simplified and standardized, tasks were shifted to nurses and lay staff (5). Where ART cohorts were larger, attrition was higher (6).

Moreover, decentralization to rural health facilities requires an important investment in terms of human resources, training, and logistics. But the incremental increase of the ART cohort per additional health facility providing ART is smaller in rural areas (7). In rural contexts the catchment population per health facility is smaller, and the HIV prevalence is often lower (4). In addition, ART decentralization to rural health facilities benefits mainly those living in the vicinity of the health facility. A South African study showed that individuals living at five kilometre of a health facility with ART were 50% less likely to be on ART than those living nearby the health facility (Figure 1) (8).

Figure 1: Effect of distance between communities and health facilities on access to ART

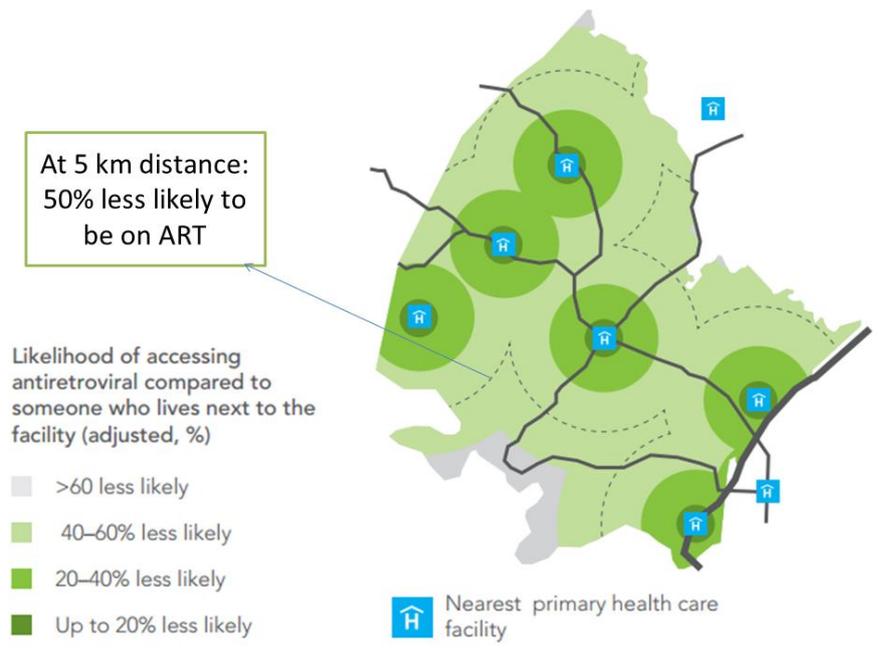


Figure legend: PLHIV living 5 km from the nearest clinic are half as likely to be on ART when compared with an individual living in the vicinity of a clinic.

Decentralization of ART delivery to all available health facilities may close some but not all the gaps.

Figure adapted from Cooke et al, 2010 (8).

Km: kilometre; ART: antiretroviral therapy

Moreover, ART provision in rural primary health care facilities leads to additional health system challenges. In rural contexts qualified clinical staff are more scarce. Distances between rural health facilities and referral facilities hamper supply, supervision, and the referral of patients with severe conditions. Moreover, rural communities are dispersed. In Mozambique, more than half of population lives more than 10 kilometre distant from a health facility (9). Many PLHIV depend of public transport to access ART. They have to sell goods or livestock, or borrow money, to pay the monthly transport fees. Once resources are exhausted they have no other option than to abandon treatment (10). In Mozambique, more of the same will not suffice to reach the 90-90-90 UNAIDS targets (11).

Peer-led ART delivery in Tete: high retention on ART

In 2008, in the central province of Tete, a CBART model was piloted to overcome barriers to ART.

Patients stable on ART formed peer groups, named CAG, to distribute ART in the community. In CAG, ART refill was separated from clinical care. Stable patients accessed ART without interrupting daily life. When sick, patients in CAG, as any other person, visited a health facility to have a clinical consultation (12).

By 2012, about half of the ART cohort was enrolled in a CAG (13). One-year retention in CAG and individual care was 99.1% and 89.5%, respectively (13). High retention in CAG was sustained over time. Four year retention in CAG was 91.8 % (14). Moreover, retention in CAG was higher than what is reported by other ART programmes in Africa (15). Children of CAG members benefitted as well. When a CAG member represented a CAG to pick up ART at the health facility, children of fellow group members accompanied that representative. One year retention in children dependent of CAG members was 94% (16).

Qualitative data confirmed that the CAG dynamic was effective in overcoming barriers to ART. CAG members reported a reduction of direct and indirect treatment costs, and felt relieved by the secured supply of ART. In CAG, peers shared their knowledge, experiences of living with HIV, and adherence practices. They supported each other when social problems occurred (17-19). The better the peer group functioned, the higher the retention on ART (14). CAG members became a source of information for health related problems in their communities. This positive social role reduced discrimination and enabled peers to cope with stigma (17-19) (figure 2). As CAG send a representative to collect a refill for the whole group the burden on scarce health care providers reduced. Queues were less long, especially in health facilities where a substantial proportion of ART patients were enrolled in a CAG (17). Moreover, the relationship between CAG members and providers improved. CAG members felt recognized and less unanimous. Health care workers perceived CAG members as co-providers (19).

Figure 2: Effect of CAG at CAG, health facility, and community level

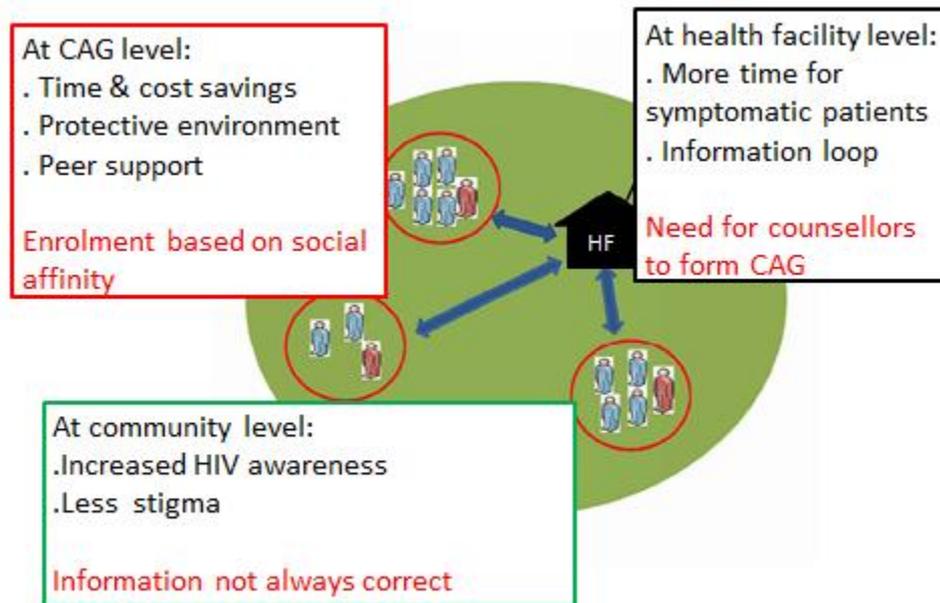


Figure legend: CAG members reported time and cost savings when accessing ART, peer support, and information sharing. Their positive role reduced stigma. Moreover, clinicians had more time for unstable patients, and were able to pass messages to the community through the CAG network.

The CAG dynamic was counsellor dependent. Social affinity determined access to the CAG dynamic. Information shared in the CAG network was not always correct.

Figure adapted from Rasschaert et al, 2014 (17).

CAG: Community ART Group; HF: health facility

However, there were some drawbacks as well (figure 2). Because CAG were formed based on social affinity and trust relationships, those patients who were isolated or perceived as untrustworthy experienced difficulties in joining a CAG (17). Moreover, to join a CAG patients had to be more than six months on ART, clinically stable, and have a CD4 count higher than 200 cells/ μ l. Hence, CAG didn't reduce barriers to care for those who started treatment. Moreover patients with a poor adherence, who could have benefitted most from the peer support, could not join as long as they had a low CD4 count (12,17). Some of these patients were introduced to the peer network and became a social members of CAG. They participated during the peer group meetings, but had to come to the health facility on a monthly basis to see the nurse and get an ART refill.

Health related messages were not always transmitted correctly within the CAG network. Especially the concomitant use of antiretroviral and antituberculous drugs was not well understood by HIV and TB co-infected patients (17,19). Another caveat was the dependence of the CAG dynamic on counsellors remunerated by MSF. Counsellors were key for the formation of CAG and the monitoring

of outcomes in CAG. On the long term a solution for the dependency of counsellors will need to be sought (17). On the other hand, the CAG model was also effective outside Tete, in facilities with and without NGO support (20).

Peer-led ART delivery: transferable to other settings

The experience with CAG was transferred from Tete province in Mozambique to other settings. The CAG model was implemented and adapted to the local context in other provinces in Mozambique, and in Lesotho, Zimbabwe, Malawi, South Africa, and Haiti (21,22). In 2011, in Mozambique, the CAG model was piloted nationwide in purposively selected health facilities. Some facilities were urban, others were rural, some were high-volume, others were low-volume (23). Two mobile teams, each with one clinician, one counsellor, and one CAG member, visited the health facilities piloting CAG. They complemented the information presented in a national CAG protocol. Moreover, they ensured that all stakeholders, including the patients themselves, were consulted and involved during the implementation process (23).

Initially the national CAG pilot aimed at comparing cohort outcomes of health facilities “with CAG” with cohort outcomes of health facilities “without CAG”. However, when patients attending health facilities “without CAG” heard about CAG implementation in neighbouring communities, they showed their interest in forming CAGs as well. Hence the national CAG pilot implementation was less strictly regulated, and remained patient-driven. A study of the national pilot included data from 68 health facilities, where patients had the option between CAG and conventional individual care. In most of these health facilities CAG were run by nurses, and were not supported by counsellors. In 2015, in Mozambique, 37,000 patients were reported in CAG, and 844 facilities had CAGs or were being prepared for implementing CAGs. One year retention in stable patients in CAG and individual care was 91.4% and 82.9%, respectively (20).

Similarly, in rural Lesotho, high retention on ART was achieved in CAG. Here community health care workers played an important role by activating a peer network, and subsequently proposing CAG participation within this network. Reported patient and provider benefits were similar to those reported in Tete (24). In Malawi, programme data showed similar high retention rates (25).

In Haiti, stakeholders met to adapt the CAG dynamic to their context, views and experiences.

Stakeholders included patients on ART, community health workers, nurses, and physicians. They named the peer-led ART delivery model “group of 6”. As in Lesotho, community health workers were instrumental in assessing interest and catalysing the implementation of the “group of 6” model.

However, recruitment was hindered by distances between the homes of PLHIV interested in joining a “group of 6”. Another barrier to forming groups was the fear of stigma. Nevertheless, outcomes of patients enrolled in the “group of 6” model convinced programme managers of the benefits of offering the “group of 6” as an option. None of the first 80 patients enrolled in the “group of 6” model was LTFU or died. Group representatives travelled up to 78 km to reach the clinic. Moreover, patients reported that the “group of 6” made them more confident in managing their HIV. Health care workers reported that the dynamic reduced their workload (22).

These examples show that lessons learnt from a CBART model can be transferred to programmes in other contexts. Moreover, these pilot experiences show the importance of consulting all the stakeholders and involving them in the planning and implementation of the peer-led ART delivery model. As such, the proposed participative approach to community ART delivery is adapted to local barriers and enablers of health service utilization (22,26).

Box 1: NGO's and governments: is a collaborative approach towards better delivery of HIV care feasible?

When compared with the response of Governments, NGO often have 1) more experience in working with communities, enhancing mobilization of local resources and participation in care, 2) better access to vulnerable groups, 3) a faster response, especially to controversial issues, and 4) an operational approach which rewards innovation more. On the other hand, coordination and collaboration with other partners and the Government is sometimes poor. Moreover, planning may be hampered when funding is limited in time, or when the NGO's priorities change. Hence, the question "how to sustain NGO-led activities" is never far away (27,28).

The CAG roll out is fine example which shows that collaboration between an NGO and Government instances can be fruitful (although not easy). In 2008, in Tete, the CAG pilot was supported by lay counsellors, remunerated by MSF. Once recognized as a successful strategy, other actors became involved. In 2011 the central MOH took the lead and recommended CAG implementation as a national policy. Partners working with and through the government provided technical and financial support. CAG was rolled out countrywide. MOH doctors, MSF counsellors and CAG members visited implementing facilities across the country to provide support (23). By the end of 2015, more than 37,000 patients were enrolled in CAG (20).

During this process, during periodic national MOH meetings, Tete province was recognized by the central MOH level as an example for other provinces. In 2012, MSF received the mandate to pilot more innovative approaches in a selected district in Tete province. The need for Innovative approaches was emphasized in a new memorandum of understanding between MSF and the provincial MOH. This was an important milestone, considering the vertical approach of MSF's HIV project between 2001-2006 (MSF-led HIV clinics), and the unstable relationship between 2007-2011 (integration of HIV care in MOH-led health facilities). After supporting CAG roll out, MSF handed over most of the support to CAG implementation to the MOH and partners. First, the number of counsellors was rationalized. Then tasks that were previously done by "MSF counsellors" were shifted to CAG members (for example: support drug dispensing, fill in registers, report outcomes), counsellors employed by the partner (HIV testing, CAG formation, and monthly reporting), and nurses (oversee the CAG dynamic, CAG formation). A formal evaluation of this process would have been very informative.

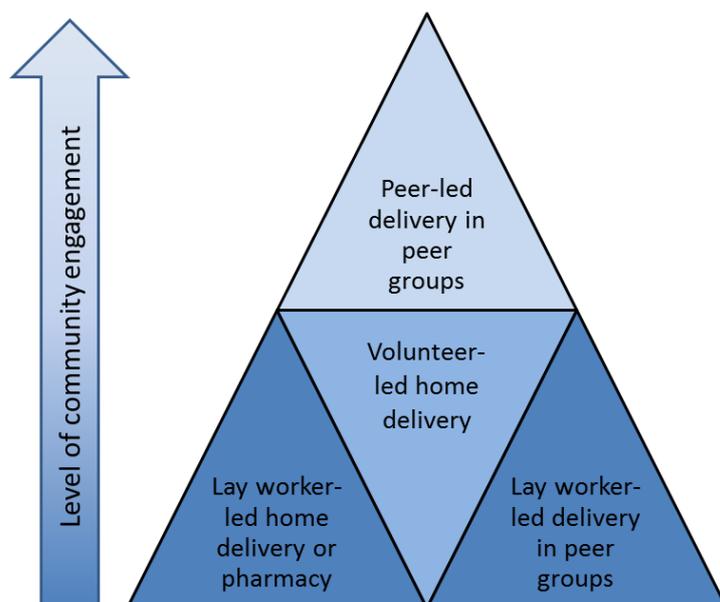
As evidence emerged, results were published and presented at conferences. WHO and USAID recommended the CAG dynamic(25, 29-32). In Tete, regularly visits were organized for MOH officials from other provinces in Mozambique, and for MOH representatives from neighbouring countries such as Zimbabwe, Malawi, Lesotho, and South Africa. Pilot projects emerged in Lesotho, South Africa, Malawi, and Zimbabwe. Depending of the local setting, CAG pilots were supported by lay counsellors, community health care workers, and/or nurses.

Community-based ART: a key component of differentiated care

A systematic review included in this thesis confirmed that community-based-ART (CBART) is effective in retaining patients on ART in SSA (33). Other reviews had similar conclusions (34-36). Moreover, CBART increases access to ART, increases the absorptive capacity of ART programmes, and is likely cost-effective (36,37). However, the effect of CBART on community virological suppression and HIV transmission remains unclear (35).

CBART programmes employed lay health workers in Uganda, Rwanda, Kenya, the DRC, and South Africa. In Kenya and the DRC lay health workers were recruited among PLHIV (38,39). In Uganda, Rwanda and Kenya lay health workers delivered ART at the patient's home (38, 40-43). In the DRC peer lay health workers managed a community pharmacy (25,44). In South Africa peer groups were formed and met periodically in the community to meet with a lay health-worker, received a counselling session, and an envelope with pre-packed ART (45-46). In these CBART models lay health workers were remunerated, and were perceived as being part of the regular health workforce (45). Activities were designed and managed by policy makers and programme managers.

Figure 3: level of ownership for different community-based ART delivery models



Different community-based ART delivery models were piloted. Most models were led by remunerated lay health workers. Lay health workers were responsible for ART delivery at home, in a community pharmacy, or in a peer group in the community (Uganda, Kenya, Rwanda, DRC, South Africa; 38-46).

Few models primarily build on a voluntarily engagement of community actors. One model relied on volunteers (47). In Mozambique, PLHIV joined CAG's, peer groups responsible for ART delivery.

Very few CBART models are grounded on the voluntary engagement of community actors (Figure 3). Kipp et al documented a CBART model in which non-remunerated volunteers were responsible for community ART delivery to impoverished PLHIV in their community. They were motivated by the recognition received from fellow community members (47). In CAG, non-remunerated PLHIV joined peer groups and were responsible for community ART delivery. They were united by their common health need (17,19). Moreover, the model was flexible. Community distribution dynamics were largely defined by the CAG members (18). The level of ownership and participation is higher when the care model engages community stakeholders during the designing, planning and implementation, and takes into account pre-existing social dynamics (18,19,24,26,48,49).

However, the CAG model doesn't fit every patient's needs. Some patients were not eligible for CAG, others were not able to join a peer group due to geographical or social barriers, others preferred individual care because they gave a lot of importance to the monthly consultation, or preferred not to share their sero-status with peers. Patients with a high social status had often a facilitated access to ART. For them the CAG model was not perceived as beneficial (17). This shows how different type of patients have different needs and expectations. Hence, patients should be able to choose the ART delivery model that fits them best, either in the facility or the community (Figure 4). Both community- and facility-based ART are needed.

ART delivery platforms at the health facility may include a) clinical consultations, especially for those who started ART recently or are in need of clinical care, b) fast track, directing those who present without symptoms or clinical signs to the pharmacy (without a stopover at the consultation) (50), c) spacing of ART pick-ups (for example 3-monthly ART pick-up; 50), and d) ART pick-up during a facility club (a peer group meeting organized by health facility staff in the health facility (51)).

ART delivery platforms within the community may include a) mobile outreach teams, b) community pharmacies (50), c) community clubs (a peer group meeting organized by health facility staff in the community (46)), and d) CAGs (peer group led by the peers themselves; (12)). Delivery platforms

could even be combined. For example, a CAG could send a representative to a facility or community club to pick up treatment for three months (combination of CAG, club, and spacing).

Figure 4: Community and facility-based ART delivery platforms

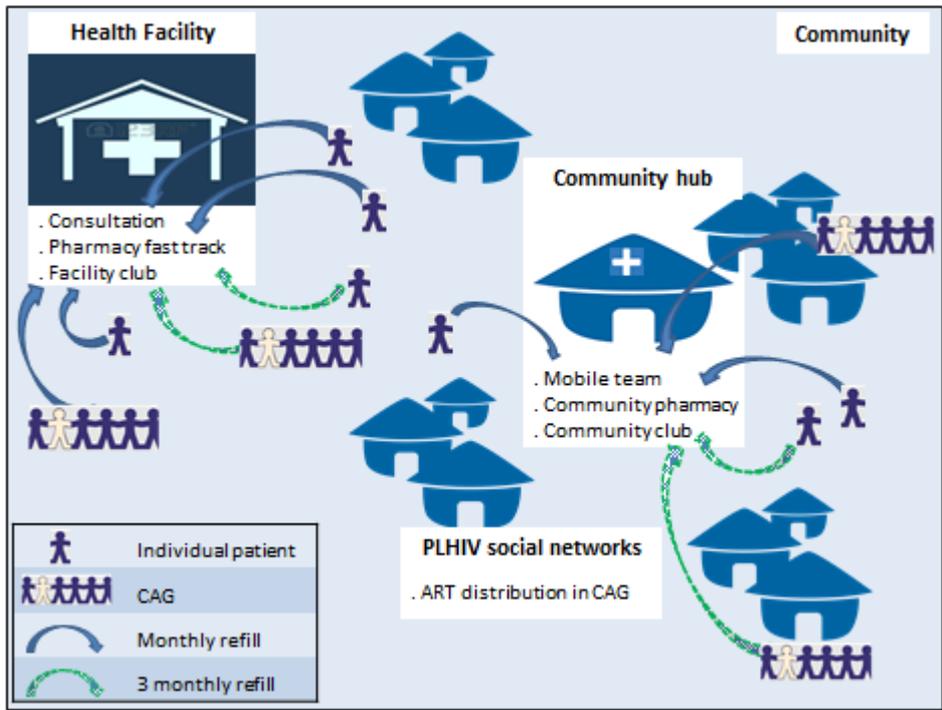


Figure legend: At the health facility sick patients and patients less than 6 months on ART are prescribed ART during a clinical consultation. When stable on ART patients can receive up to three months of ART directly at the pharmacy (fast track), or during a peer group meeting (club). In the community ART can be provided by a mobile outreach team on scheduled days, at the community pharmacy, or during a peer group meeting in a community hub or a patient's house. Individual patients or CAG representatives can fetch an ART refill in the health facility or in the community.

CAG and other forms of CBART have been recommended by WHO and UNAIDS (25,29-32): WHO amended its 2013 treatment guidelines and recommended *“Community-based models of ART delivery can benefit people living with HIV and decongest facilities in settings with a high burden of HIV infection”* (32). However, so far no programme has tested the effectiveness of offering simultaneously a large diversity of ART delivery platforms.

Peer-led ART delivery: uptake of other health services remains low

Policy makers repeatedly asked whether the CAG dynamic could serve the uptake and utilization of other health services. Although retention on ART was high among CAG members, other health services remained underused. Surprisingly less than half of the family aggregate was tested for HIV. Moreover, mother and child health services were not well used by the CAG members and their family aggregates (49). On the other hand, a study of the early results of large-scale implementation of routine viral load monitoring in Maputo showed that uptake of VL monitoring was higher when service delivery was customized to the patient's needs. For example, the uptake of a first viral load and a follow-up viral load (for those with a first high viral load) was more than two-fold higher in CAG than in individual care (52).

Why were CAG members motivated to engage in ART distribution, outcome monitoring, reporting, and use viral load monitoring? Why were they less motivated to use other health services?

Community ART delivery was perceived as beneficial in several settings (17-19,22,24). In CAG, members became knowledgeable about standardized and repetitive interventions. Group members shared information within their network. Higher levels of understanding and self-efficacy induced a feeling of relief and comfort (17-19,22,24). In Maputo, CAG members likely shared information on the importance of having a viral load and the practicalities related to blood sampling (52). How peer groups interact in a metropole like Maputo requires further study, and probably differs from the dynamic which was documented in rural Tete.

In Tete, several mother and child health activities were not well understood, or not perceived as beneficial. For example, the benefit of tetanus vaccination in woman of reproductive age was not well understood. Contraceptive methods were perceived as harmful. Individuals believed intrauterine devices could irreversibly reduce fertility. Male participants were afraid that birth-control would enable woman to have sexual relationships with other men. Moreover, the infrastructure and the referral system were perceived as inadequate. Mother and child health care

nurses were perceived as disrespectful (49). This contrasted with the trust relationship between community members and traditional birth attendants (53).

Figure 5: Enablers of community engagement in medical care



Successful engagement of communities in medical care implies a comprehensive approach, taking into account individual factors, societal factors, provider factors and the characteristics of the medical intervention.

These examples illustrate some enablers at different levels which may motivate PLHIV to use a medical intervention, or even engage in medical care. Enablers at the individual level include a) be knowledgeable about the intervention, b) be confident that the intervention will result in a health benefit, and c) give importance to this health benefit (48). Enablers at the societal level include a) peer and social support (55-58), b) social and economic capital (10,59), and c) leadership that emphasizes the importance of participating in health related activities. The medical intervention should be a) simple and standardized, b) repetitive, and c) beneficial to a large group (60). Finally, at the provider level enablers include a) recognition of the community actors as co-providers (17,19), b) willingness and flexibility to adapt the intervention to the needs voiced by community actors (26,19,22), c) a functional supply and patient referral system (61) (figure 5).

Strengths & limitations of the methodological approach

Out of 9 studies included in this thesis, 8 study programme data retrospectively. The use of programme data for operational research has some important strengths (Table 2). Whereas experimental trials are conducted in a controlled study setting for a selected study population, operational research is conducted in a programme setting, and aims at answering questions generated during programme implementation. The study population is the population attending the programme. Hence, the findings of the operational research studies included in this thesis reflect the reality of the programme (62). In addition, a cycle was installed, whereby operational research findings from studies informed programme implementation and generated new research questions:

- Constraints encountered during ART decentralization were studied (3). The results of this study boosted policy makers to “think out of the box”.
- To respond to constraints faced during ART decentralization an innovative peer-led ART delivery model, CAG, was proposed, implemented and evaluated (12).
- Early results were confirmed by a study of long term outcomes in CAG (12,14).
- Findings from Tete were confirmed by findings in Lesotho (24).
- Qualitative data collected from multiple stakeholders provided a deeper understanding of the CAG dynamic and the findings obtained from quantitative studies (24-49).
- The literature was reviewed systematically on the involvement of lay providers in CBART in SSA (33).

The findings of these different studies confirmed that peer-led ART delivery complemented facility based-ART delivery, without compromising treatment outcomes. Informed by these findings, disseminated through WHO and UNAIDS reports (25,29-32), implementers and policy makers working in similar high prevalence settings piloted community-based ART delivery and new research

initiatives. Through this cycle findings from the presented studies were tested by other actors, in other settings, using similar or different methods (20,22,25,44,46,50).

However, the use of observational designs has also some inherent limitations (Table 2). First, selection bias may have affected the generalizability of our findings. CAG eligibility criteria required patients to be clinically stable and to be on ART for six months. Patients who didn't recover immunologically could not join CAG in most health facilities. Moreover, social characteristics of patients stable on ART in CAG may have been different from patients stable on ART in individual care. CAG formation depended on the social affinity and trust between interested patients on ART living in the same or nearby community. Individuals who were perceived as less reliable, such as those known for recurrent alcohol abuse, were less likely to find a CAG. Other patients were satisfied with individual care, especially if their social status or network facilitated access to treatment. Hence, outcomes of patients in CAG may not be generalizable to other PLHIV stable on ART. Moreover, some of the differences between CAG members and patients in individual care may explain the higher retention in CAG. Nevertheless, the low rate of defaulting and mortality in CAG suggests that CAG has a clear potential in supporting long-term ART in stable patients. A recent systematic review showed that long term attrition on ART exceeds the attrition in CAG. Attrition in ART programmes in African countries was 18%, 24%, and 31% after six months, one year, and two years of ART, respectively (15).

Second, the retrospective design may have resulted in measurement bias. To ensure that the programme data were reliable the following measures were taken. The CAG databases used in the studies were managed by a trained data team, and prospectively updated. Data from the databases were periodically compared with data from the patient files and ART registers. Encoding errors were cleaned, discrepancies were discussed with the clinicians. Data on patient's whereabouts and health status were relatively easily collected through the network of CAG's. Moreover, reports of treatment interruption or non-adherence in CAG were discussed and verified during community meetings.

Solutions for challenges were sought, involving maximally the peer network. Still, for patients in individual care less data sources were available. For them data were collected from patient files and ART registers. Some patients on ART in individual care who were reported as LTFU may have been dead, active on ART in another facility, or have abandoned treatment. Sometimes the CAG network was used for the tracing of patients in individual care who were reported as LTFU.

Table 2: Main strengths and limitations of studies included in the thesis

Limitations	Strengths
Observational study design for most studies included in the thesis.	Study population = real population, hence findings account for patients found in the routine practice of ART programmes
Selection bias may have threatened the generalizability of findings. Patients joined CAG voluntarily. Hence, results from patients in CAG may not apply to patients stable on ART.	<p>The aim of the different studies was not to identify the single best ART delivery platform. The studies showed that benefits outweighed harm among those who opted to join a CAG:</p> <ul style="list-style-type: none"> • Both quantitative and qualitative data showed that peer-led ART delivery in CAG was effective. Stakeholders confirmed that benefits outweighed harm. • The systematic review showed that confirmed that lay provider-led community ART delivery results in outcomes that are not inferior to outcomes of facility-based ART <p>The same topic, effect of participation in CAG on outcomes, was studied using different approaches</p> <ul style="list-style-type: none"> • Early findings were confirmed by long term outcomes (12,14) • Findings from Tete were confirmed in another setting (Lesotho; (24)) • Quantitative data were complemented with qualitative findings (mixed methods approach in 2 studies;(24,49)) <p>A systematic review of the literature added insights into the characteristics and outcomes of lay provider-led CBART in SSA (33)</p>
Retrospective analysis of data may have resulted in measurement bias.	Programme data on CAG were collected prospectively and cleaned periodically (comparison with data in patient files).

ART: antiretroviral therapy; CAG: community ART group; CBART: community-based ART; SSA: sub-Saharan Africa

Third, virological suppression, the most reliable marker of adherence, was not reported in most studies. Routine viral load monitoring was not available in Tete and Lesotho during the study periods covered by the studies. Although retention-in-care was high among CAG members, it doesn't imply high levels of adherence. Recent reports from Tete have shown a high proportion of patients with a

viral load above 1000 copies per microliter in patients in CAG and patients in individual care. A mixed methods study is planned to study the prevalence of virological failure, the presence of resistance in patients with virological failure, and the views and experiences of patients with virological failure, in CAG and in individual care. Moreover, one study included in this thesis reports on the uptake and outcomes of viral load monitoring in Maputo. Here, members of CAG were more likely to have a viral load, and more likely to be virologically suppressed, when compared with patients in individual care.

Communities and HIV care: the way forward

Community engagement is key to achieve 90-90-90

So far we discussed how community-based ART delivery increased access to ART maximally. Will this suffice? Can the 90-90-90 targets be achieved by removing geographical and cost barriers? Results from the recently conducted TASP trial in Kwazulu Natal in South Africa illustrated well that optimal accessibility of HIV testing and ART doesn't suffice. Here HIV testing was provided in the client's home, and ART initiation and dispensing was provided in small community-based clinics. The walking time between homesteads and the ART clinics was maximal 45 minutes. Although home-testing identified more than 90% of PLHIV, linkage to care and ART initiation was poor. Less than half sought treatment at the clinics. Population virological suppression was 42.2% and 40.2% in the intervention and control arm, respectively. Hence, the proportion of PLHIV that were virologically suppressed was much lower than the combined UNAIDS target (73% of all PLHIV are virologically suppressed). HIV transmission was not lower in intervention arm. The adjusted risk ratio for acquiring HIV was 0.95 (95% CI 0.79-1.14) in the intervention arm (63).

Utilization of services is more likely when access enhancing strategies are combined with community participation (26). This was demonstrated by the SEARCH trial, conducted in Uganda and Kenya. Here, 320,000 people living in 32 communities were enrolled. Interventions were designed taking into account the proposals voiced by community stakeholders. Community leaders were involved in mobilizing their communities, planning, and organizing two-weekly community health campaigns. These campaigns were the cornerstone of the intervention, and generated a platform where stakeholders met and discussed. During the health campaigns HIV testing was offered together with malaria testing and screening for diabetes mellitus and hypertension. Soccer games, boat races, and music and theatre shows were organized on the same day. Home-based testing was offered to those who didn't attend the fair. Same-day ART initiation during the first clinic visit, three-monthly ART refills and flexible opening hours facilitated access to treatment. After two years population

virological suppression increased from 48% to 82%. Hence, the combined UNAIDS target (73% of all PLHIV are virologically suppressed) was met (64). Similarly, qualitative data suggest that high uptake of HIV testing and high ART coverage can be achieved when communities are engaged (65).

Community-based comprehensive HIV care: a proposal

A growing body of evidence illustrates the potential of involving community actors and PLHIV along the continuum of HIV care.

Figure 6: Proposal for a comprehensive HIV care model

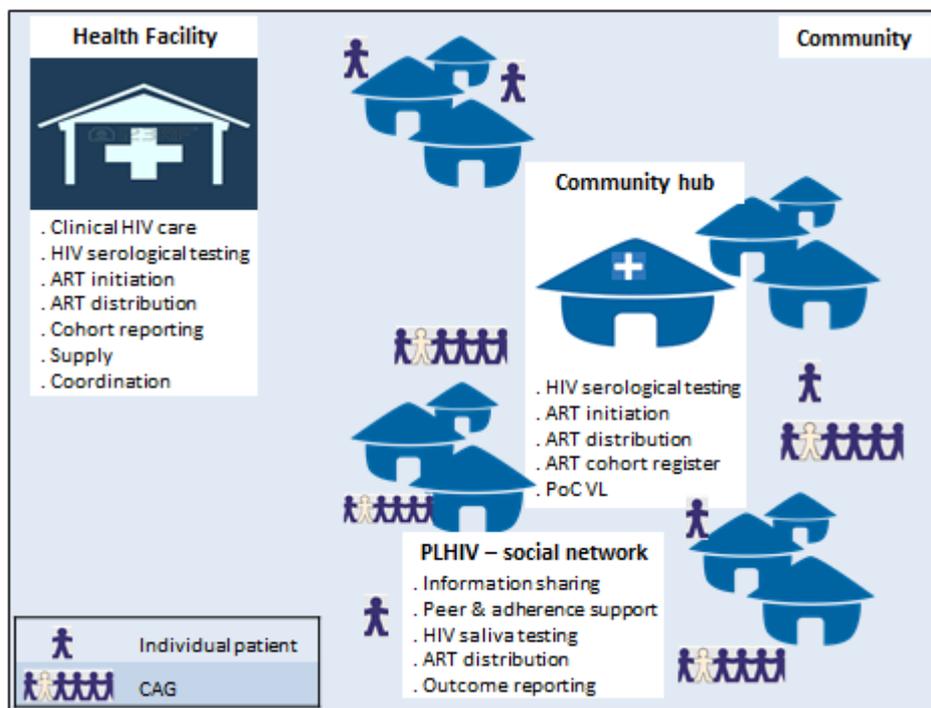


Figure legend: PLHIV share information and provide support to peers and social contacts. Saliva test could be used for index testing of family and contacts. Confirmatory HIV testing using serological tests could be provided by a lay health worker in a community hub or in a health facility. Those who are stable and don't present alarm signs could start ART in a community hub. ART could be fetched at the hub, or in CAG in a patient's home. Outcomes would be reported by the social networks of PLHIV, registered by lay health workers, and reported centrally. Patients who are ill would be referred to the health facility. A functional referral systems between platforms would be key.

First, home- and community-based HIV testing strategies can increase uptake of HIV testing and thus the proportion of PLHIV who are aware of their sero-status. A systematic review showed that home-testing consistently resulted in higher uptake, a larger proportion of first-time testers, and a higher population coverage, when compared with facility-based testing (66,67). Moreover, currently underserved subgroups, such as men, young adults and high-risk key populations, are more likely to be reached when testing is provided in their daily environment (66,67). In addition, the use of saliva-

tests favours self-testing and patient-led index testing, a testing strategy whereby PLHIV offer a self-test to their family members and sexual partners. Interestingly, index testing yielded a higher proportion of clients with a positive test results (67).

Second, social support and follow-up visits by community members can increase the proportion starting ART, among those who tested positive (68). Especially home-based ART initiation needs to be explored further. A recent Malawi study compared a package of home-based HIV testing and home-based ART initiation with conventional facility-based care. Volunteers distributed self-tests. Those who tested positive received a visit from a nurse to do a serological confirmatory HIV test. When positive, patients could opt for home-based ART initiation. The proportion starting ART was higher when patients were offered the option of home-based ART initiation (69). Another trial will study the effect of same-day home-initiation on linkage to care and virological suppression in Lesotho (70).

It's not clear how much treatment initiation algorithms can be simplified. If effective, simplification would favour task shifting and community-based ART initiation (71). Community-based ART initiation by community health workers or trained expert patients has been proposed a decade ago, but has not yet been evaluated (71,72). Meanwhile, ART initiation has become less complex. Since the 2015 WHO guidelines recommend ART initiation for all PLHIV (73), CD4 testing is not an absolute must, and should not delay ART initiation (74). Although the identification of active opportunistic infections remains a challenge, more and more patients start ART earlier and require less clinical care for opportunistic infections. Moreover, tuberculosis, the most important opportunistic infection, can be ruled out (negative predictive value higher than 95%) when TB symptoms are absent (75,76). A Malawian study showed how trained lay health workers assessed the presence of symptoms as good as nurses (77). Furthermore, current first line ART regimens are less toxic, easier to prescribe and adhere to (one tablet a day), and require less laboratory monitoring. In addition, injectable ART regimens (cabotegravir with rilpivirine) are currently being investigated. Early results

showed that such regimens could be more robust, very well supported, and result in a high proportion of patients with virological suppression (78).

Finally, as shown by the studies presented in this thesis, community-based ART delivery resulted in high levels of retention, and can be tailored to the preferences and needs of patients in a given setting (33). Especially in high prevalence countries, with important workforce gaps and many communities out of reach of the health system, it seems obvious that community actors will need to participate in designing, planning, and delivering HIV care services along the continuum of HIV care (60). Comprehensive community-based HIV care would likely reach currently underserved subgroups and facilitate treatment adherence for many currently on ART. However, a comprehensive community-based HIV care model, with community engagement at every stage of the continuum of HIV care, has yet not been evaluated (79, 80). Moreover, future point-of-care technologies, such as point-of-care viral load test, may create new opportunities for community engagement (81).

There are some caveats which concern the proposed comprehensive community-based HIV care model. First, one size doesn't fit all. Hence, community-based ART care should not replace facility-based ART. Moreover, referral systems between communities, primary health care facilities and health facilities providing referral care should be functional (61). Second, communities should not be considered as a cheap solution when health systems fail or when funding sources are less secure (26). Instead, patient engagement in ART delivery should be considered as a good practice which enhances utilization of available HIV services and motivation to adhere to lifelong ART. Third, unintended disclosure of the sero-status may cause discrimination and stigma. Discrimination and stigma interfere with coping mechanisms and social support, and consequently reduce adherence to ART (58,82). Finally, achieving the 90-90-90 targets will not suffice to stop transmission and end the HIV epidemic (83,84). A Botswana survey showed that 70.2% of all PLHIV had an undetectable viral load (85). The combined UNAIDS target (73% of all PLHIV are virologically suppressed) was almost met. However, the HIV incidence in the general population remained high (1.35% in 2015 compared

with 1.45% in 2008) (85,86). To control HIV transmission, high ART coverage will need to be combined with a range of prevention approaches including high uptake of male circumcision, condom use, and pre-exposure prophylaxis for those most at risk of acquiring HIV (83).

Conclusion

Investments in decentralization of ART to peripheral health facilities are essential to increase the absorptive capacity of resource constrained health systems in sub-Saharan Africa. However, facility-based ART will not suffice to achieve ART coverage. The absorptive capacity of health systems has a limit and distances between remote communities and peripheral primary health care facilities are insurmountable for an important proportion of PLHIV. Moreover, staggering attrition rates illustrate that it takes more than removing health system and geographical barriers to achieve ART coverage. Studies included in this thesis show that CAG, a peer-led ART delivery model, is effective in retaining patients on ART. CAG members and health care workers reported that CAG increased social and peer support within the community, reduced direct and indirect treatment costs, and reduced the workload in health facilities. Moreover, members showed interest in becoming more involved in other components of HIV care. Future approaches may consider community engagement along the continuum of HIV care, to maximally increase both the accessibility of HIV services and the motivation of PLHIV to use these services. On the other hand, community engagement in HIV care is not be a magic bullet. Different patients require different care models. Hence, a comprehensive community-based HIV care programme may complement, but not replace facility-based HIV care. Moreover, community engagement in medical care is a process which is determined by multiple patient, societal, and health system factors, and the characteristics of the medical intervention. While CAG is being piloted or scaled-up in different countries, more research - "learning while doing"- will be needed to fully understand how communities can be engaged along the whole continuum of HIV prevention and care.

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