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Research

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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.

KEYWORDS: 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

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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 CAG dynamic was perceived by different stakeholders, and study retention among patients in conventional care and CAG members in HC Nazereth.

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.

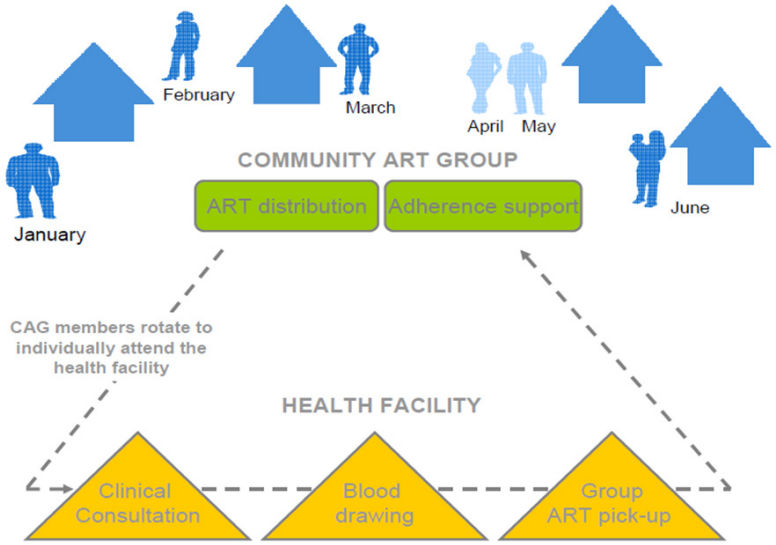
Description of the CAG Model

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 (Figure 1).

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 be-



ART: Antiretroviral treatment; CAG: Community ART group

Figure 1: Dynamic of the members enlisted in community ART groups.

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ing an adult with a CD4 above 350 cells/µl, 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). 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 2).

	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 maleCAG members Each FGD was composed by members from different CAGs.
Cliniciansdealing 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
Table 1: Key informants.

	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/µl, median (IQR)	183 (102-273)
CD4, last value, cells/µl, 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
Table 2: Characteristics and outcomes of the 2007-2010 ART cohort of HC Nazareth.

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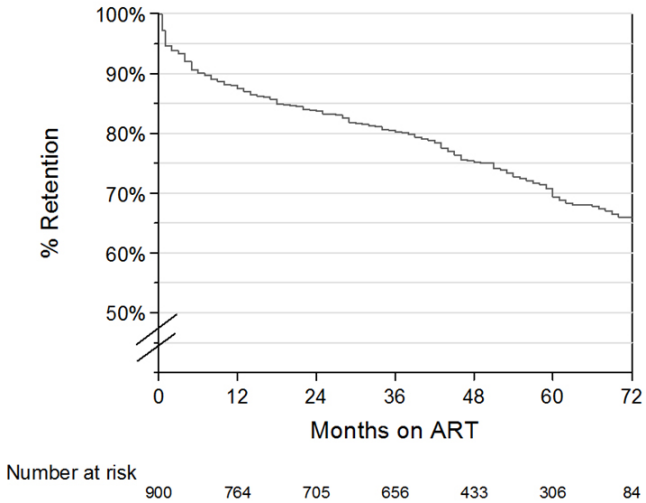
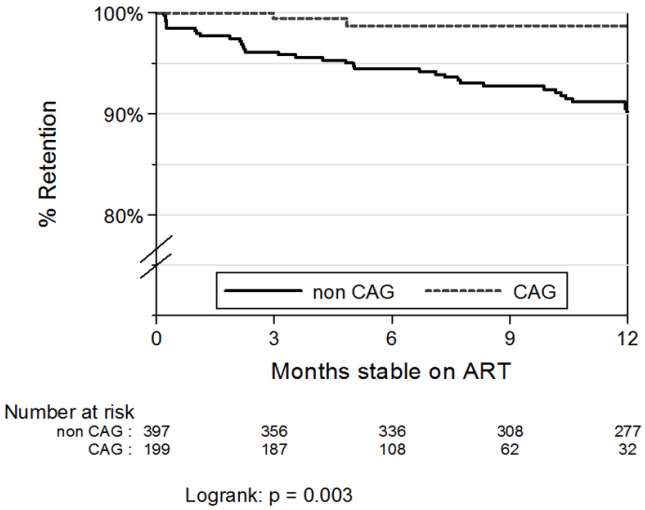


ART: Anti-retroviral therapy

Figure 2: Retention on ART among the 2007-2010 ART cohort of HC Nazareth.



ART: Antiretroviral therapy; CAG: Community ART Group

Figure 3: One year retention on ART among stable patients in CAG and in conventional care (not in CAG) h.

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/µl, 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 3).

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 con-

	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/µl), 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/µl, median (IQR)	202 (139-291)	209 (129-287)
CD4, first above 350, cells/µl, median (IQR)	485 (400-580)	496 (412-620)
CD4, last value, median (IQR), cells/µl	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

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

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sequence, *"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*

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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 areas, 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's 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 identity 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 experi-

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ences 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.

CONFLICTS OF INTEREST: None.

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