



# Patients and Healthcare Workers Views on Patients Retention Outcomes of Community Adherence Group (CAGs) Model for HIV/AIDS Treatment in Zambia: A Qualitative Study

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## Abstract

In 2015, the Zambian Ministry of Health through Center for Infectious Disease Research in Zambia (CIDRZ) piloted a Community Adherence Group (CAG) model to help improve ART patient's retention in to care. The models were piloted in two facilities of eastern province, one facility in Lusaka province and two facilities in Southern province. This was to overcome patient barriers to accessing antiretroviral therapy ART treatment, and to improve patient retention. Six stable ART patients would agree to self-form a group which operates by patients taking turns to collect ART refills. One of the six group members go to the health facility to collect drugs and share when they reach the community. A qualitative study was conducted to evaluate from patients and Health Care Workers (HCW) what led to two facilities having huge differences in patient's retention in care under CAG models. Data were collected from purposively selected participants in two sites which had highest and lowest retention rates respectively. The study had two study samples which are People Living with HIV (PLWH) and HCW. The PLWH were selected from CAG group and HCW were selected from those who were working with CAG model. A total of eight Focus Group Discussions (FGD) and six In-Depth Interviews (IDIs) were conducted with a total of 64 participants. All the participants were purposively selected. Narratives were audio-recorded, transcribed and translated to English and data was analyzed thematically. What triggered high retention rates at one site which had high retention rate included a reduced frequency of clinic visits, resulting in reduced transportation costs, peer to peer support through sharing challenges, experience and knowledge. However, conflict of CAG interventions activities and livelihood activities triggered low patient retention rate at the site which had low retention rate. CAGs were perceived as practical models of improving ART patient retention because of reduced frequenting the health facility, freed up time, peer to peer HIV knowledge sharing. Despite CAG addressing practical barriers of improve ART patients' retention, some participants at another site saw it as not compatible to their situation because accessing ART using CAG was in conflict with people's livelihood activities. Therefore, it can be said that CAGs are practical models of improving ART patient retention though there is no "one size fit all" in interventions meant to improve patients' retention.

**Keywords:** CAG; Retention; Mechanisms; Context

## Introduction

The proposed 90-90-90 by United Nation AIDS (UNAIDS) goal to end the AIDS pandemic by the year 2030 program has brought in different strategies in AIDS management. The focus is to improve viral suppression which can be achieved through high level ART adherence. In Southern Africa, several models of differentiated care have been introduced for stable HIV patients on ART to ensure that care is efficient, patient-centered and improve patient retention in care. Statistics from the avert study in 2017 indicated that about 1.2 million people were living with HIV in Zambia and about 671,066 PLWH were initiated on ART by the end of 2014. Many studies have shown that the percentage of ART patients remaining on care after initiation is low and retention in care remains a public health in many countries. To reduce the challenge of low retention in care, the Zambian government through Center for Infectious Disease Research in Zambia (CIDRZ) piloted CAG models following the successful implementation of the CAG models

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Received Date: 02 Sep 2020

Accepted Date: 12 Oct 2020

Published Date: 20 Oct 2020

### Citation:

Jere L, Chiti B, Zulu J. Patients and Healthcare Workers Views on Patients Retention Outcomes of Community Adherence Group (CAGs) Model for HIV/AIDS Treatment in Zambia: A Qualitative Study. *Open J Public Health.* 2020; 2(2): 1016.

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in Tete Mozambique by Medecin Sans Frontieres and the Thyolo in Malawi [1]. The CAGs models were piloted in five health facilities of Eastern, Lusaka and southern provinces of Zambia in Nsadzu clinic, Nyimba urban clinic, Luangwa Boma Clinic, Magoye Clinic and Kalomo Districts Hospital of Zambia in 2016. The mostly noted barriers to improving retention in Zambia include long distance to the health facilities for ART patients, long waiting hour at the clinic when patients go to access ART services, low staffing at the clinics and health care worker work overload [2]. The retention outcomes from the implementation of Community Adherence Group model indicated that a huge retention difference between two sites of Nyimba urban clinic and Luangwa Boma clinic. A systematic review of the implementation CAGs by the CIDRZ focused on quantitative assessment of the sites where the interventions were implemented. The focus of this report is to present the findings of a qualitative study on the mechanisms which influenced high retention at one site and low at another site where the interventions were implemented from patients and HCWs perspective. A systematic review of qualitative evidence of interventions for improving ART retention can help to better understand mechanisms that hindered or facilitated patient's retention under CAG models of care. Therefore, the purpose of this review was to synthesize qualitative evidence on mechanisms of interventions for improving ART retention among CAG members and to inform patient-centered policymaking.

## Methods

### Study site

The qualitative study was conducted in 2016 and this study is a nested within a larger quantitative study evaluating the feasibility, effectiveness, and efficiency of decentralized and streamlined antiretroviral therapy care models. It aimed to understand perspectives from ART patients and health care workers on acceptability, appropriateness, and feasibility of four models of differentiated care for HIV in Zambia. This qualitative study was conducted in two health facilities in two provinces of Eastern and Lusaka in Zambia.

### Site selection

The selection of the health facilities were purposively done based on the fact that the facilities were implementing Community Adherence Group Models (CAGs) supported by CIDRZ. We considered health facilities that had highest patient retention of 96% and other one with lowest retention rate of 45% after implementing CAG models. Nyimba clinic is located in Nyimba district of Eastern province of Zambia. According to the Census of Population and Housing of 2010, the district has an estimated population of 99,159 people (CSO, 2012). Economic activities are mainly informal, though a few people are formally employed while others do small business, they own small shops, sell second-hand clothes or sell vegetables at the market. Most people employed perform low-income jobs like taxi driving, bus drivers and conductors, shop keeping and general workers. Luangwa Boma Clinic is located in Luangwa district of Lusaka province of Zambia. According to the Census of Population and Housing of 2010, the district has an estimated population of 18,948 people (CSO, 2012). The predominant economic activities of the district is fishing and fish business which involve going to neighboring Mozambique to catch fish and sale fish in Lusaka province of Zambia.

### CAG intervention

The CAG model of differentiated ART delivery was piloted in Nyimba and Luangwa district through CIDRZ. CAG officers were trained to worker under the model and to monitor and evaluation how

the CAG intervention was working. To deliver ART through CAGs, the Community Liaison Officer (CLO) with the help of LHCW started by doing pulling CAG members ART files from storage location at least one day prior to the monthly visit of a CAG member and give them to the triage nurse on the day of the CAG member visit. The triage nurse would work on the file and submit them to the pharmacy technologist who would prepare drugs for each CAG member. After the pharmacy technologist has prepared a one-month drug supply for each one of the CAG members, the CLO would package the drugs prepared by the pharmacy technologist into an opaque plastic bags. On the day of drug collection for the group, one CAG member who is due for labs and is due to collect drugs for the group would go to the clinic, do the labs and later collects drugs from the CLO's office on behalf of the other five who are in the community. After collecting drugs, CAG members would meet in the community as a group on the same day that drugs have been collected to at the place agreed. In the community, the CAG chairperson would then facilitate on the meeting as they share with group on the importance of adherence and positive living. The group members could also give life experience as an HIV positive person. Moreover, the group members would then talk amongst themselves and offer adherence support to each other. Once the group has discussed everything that was on agenda for that day, the group chairperson led in the sharing of drugs each one according to the drugs that they are on.

### Study design

We used an exploratory qualitative study design to properly capture social and contextual mechanisms shaping high and low retention rates of CAG models. The study conducted discussions with two categories of participants from both facilities; health care workers and ART patients to explore what led to high/low patient's retention under CAG models of care. We conducted the study between the months of September 2017 to December 2017. A purposeful sampling method was used to select all the participants in the study. It is a qualitative sampling strategy aimed at in-depth understanding of a topic of investigation, rather than generalizing to larger populations. HWCs involved in the implementation of CAG models and patients who participated in CAG models were assessed by means of eight FGDs and six IDIs. The two different qualitative data collection methods were used to gain broader understanding of perspectives and allow cross validation of data.

### Study participants

This study had two samples populations. The first sample was PLWH from the two clinics who were accessing care through CAG models. The second sample was that of HWCs who were directly involved working with CAG models. Therefore, purposive sampling was used as it helped the researcher to identify information-rich cases to examine meanings, interpretations, and processes shown in Table 1.

### Data collection

Interviews and focus group discussions asked questions about what made the patients remain in care under the model and what helped healthcare worker and patient satisfaction with the models, and any challenges faced. The tools also asked both patients and health care workers what should be done to improve patient's retention under CAG. Interviews were conducted in English and focus group discussions with patients were conducted in local languages (Nyanja) where as those with health care workers was conducted in English. Written informed consent was obtained for all participants.

**Table 1:** Stakeholder groups interviewed in the focus group discussions and in-depth interviews.

Sites	Site 1		Site 2		Total Participants
<b>FGD</b>					
Gender	Men	Women	Men	Women	
PLWH	8	14	5	15	42
Gender	Men	Women	Men	Women	
HCW	3	4	3	6	16
<b>IDI</b>					
Gender	Men	Women	Men	Women	
HCW	1	2	1	2	6

### In-depth interviews

Participants for in-depth interviews were recruited by issuing an open invitation to lay health care workers who were working under CAG, facility in-charges and community liaison officers who were directly working under CAG. Interview guide for in-charges and community liaison officers were English but the participants were allowed to use local language during the interview. Interview guides for lay health care workers were in Nyanja but participants were allowed to use English during the interview. Open ended questions were used in both interview guides. It started with questions on participants' experiences in providing ART services at the facility using CAG models and ended with questions about participant's suggestions on how CAG can be sustained.

### Focus group discussions

We had two categories of participants for focus group discussions namely; ART patients and health care workers. The categories of ART patients were recruited during the community adherence group meetings with the help of lay health care workers who were engaged as counselors for the CAG groups and would introduce the study to CAG participants during the meeting. The CLOs would ask participants if they would be willing to take part in the focus group discussion. The willing participants were recruited to form a group of eight focus group discussion participants. The groups discussions were formed in such a way that males were in their own groups and females in their own group to avoid cultural barriers. The FGD questionnaire guide was designed in English and translated into Nyanja the common local language in both facilities. Interview questions were all open-ended to enable probing for causal mechanisms influencing patient continue accessing ART services in CAG model. Summarized field notes that were taken on any non-verbal expressions we observed. The categories of health care workers were recruited by issuing an open invitation to HCWs who were involved in CAG service delivery at the facility to attend one FGD sessions. Enrolment of participants was on a first come first served basis. The questions were open-ended to enable the facilitator to probe emerging themes, and field notes containing contextual details and non-verbal observations were taken. The main language used in the FGDs for professional HCWs was English, though we allowed participants to express themselves in the language of their choice during discussions. All the FGDs were conducted at the health facilities. All interactions were documented through field notes and audio recordings. Achievement of theoretical saturation was assessed through going through what has been recorded at the end of the day for each individual interaction to check what was coming out and areas lacking in clarity. Theoretical saturation for each of the two sites was specifically assessed in terms

of whether any new concepts were continuing to appear or required further development, and responses unique to site. Additionally, transcription of audio files and initial analyses were carried out in parallel with the data collection, allowing researcher to focus on areas which lacked clarity. The study had plans to potentially expand data collection if theoretical saturation was not reached by end of planned data collection in the two sites.

### Design and participants

We conducted a total of six IDIs with ART in-charges, community liaison officers and lay health care workers from two study sites. Out of the six IDIs conducted, two were conducted with the ART In-charge (n=2) and were done in English, two were conducted with Community Liaison Officer (n=2) and were conducted in English and the last two were with Lay health workers (n=2) in Nyanja. Moreover, we conducted a total of eight (n=8) discussions all together in both facilities. Six (n=6) were with PLWH and they all were done in Nyanja. Two (n=2) were conducted with HCW and they all were done in English.

### Data analysis

Audio recordings from the interviews and focus groups were transcribed. All the transcribed scripts were then imported into Nvivo 11 QSR™ and open coded to inductively identify possible codes. A final codebook was then developed from codes which emerged from the data. After the coding was completed, all codes with the same label were grouped together in a family, which represents a theme. The researcher then focused on facilitating the development of the concepts, categories and themes, as well as going further with the narrative and discourse pertaining to the study.

### Ethical issues

The study received ethical clearance from the University of Zambia Biomedical Research Ethics Committee UNZABREC [IRB00001131 of IORG0000774, reference number 040-08-18]. An explanation about what the study involves and objectives of the study were given to the study participants to make an informed decision. Potential risks were also highlighted to participants and they were informed that they are free to withdraw from the study at any time if they feel like. Confidentiality of study participants during and after the study was also emphasized to the study participants. Thereafter, a written consent was obtained from focus group discussion and in-depth interview participants to participate in the study.

### Results

The results of this study are presented in line with ecological model. A total of 64 participants participated in the study of which 22 (34.6%) were health care workers who were involved in the day to day operations of the CAG models and 42 (65.6%) were patients comprised of both males and females though females who have been receiving HIV services using CAG models.

### Individual factors

From the finding, it was identified that what practically drove patients on ART to join, remain in a CAG and influenced retention in to care behavior were issues to do with freed up time in CAG, and convenience when it comes to their work schedule, knowledge enhancement among CAG members and social support among CAG members. Additionally, conflict with livelihood activities and fear of unintended disclosure were identified as negative influences on patient retention in care.



**Freed up time:** Long waiting times due to congestion at the clinic made access to ART challenging for many PLWH. However, the introduction of the GAGs and the rotation of clients when collecting drugs on behalf of the other group members reduced the frequency of going to the clinic and created freed up time for PLWH to do other livelihood activities as well as staff members to concentrate on patients with serious conditions at the clinic. Both the healthcare workers and the patients agreed that they both benefit from CAG through freed up time. “CAG is good for me as a farmer, it has been much easy for me to continue being in care because we have been rotating going to the clinic to collect drugs, I even have time, like five months to work at my farm and sale the farm produce to the market when it is not my turn to collect drugs for the group” (PLWH, FGD site 1). “... for me as a health care worker, the introduction of CAG has reduced the workload that I used to have. Instead of attending to twelve ART patients for example, I only handle two patients through CAG. So, because of this I shift my focus with the time that has been created as a result of service provision using CAG, I concentrate on patient with very serious conditions” (HCW, FGD, site 1).

**Convenience:** As stated above that rotation in drug collection among CAG members provided not only freed up time, it's also a drive for CAG members to remain in care because they could easily access to drug and a relief of not frequenting the facility hence having easy access to ART treatment. Most of the participants indicated that before they joined CAG, they used to face challenge with frequenting the ART facility to collect their drugs. For example, before the joining the CAGs, participants said they used to go to the clinic to collect drugs every month making access to ART like a punishment as one participant reflected; “... before we joined CAG, we used to go to the clinic to collect drugs every month as if it was a punishment, but now when we joined CAG, we are free, you just go and get your drugs to the clinic twice every year unlike going to the clinic every month” (PLWH, FGD site 1).

### Interpersonal factors

**Knowledge enhancement among CAG members:** It was highlighted by some CAG members during the FGD that whenever they meet for CAG meetings, they learn one or two things because the topics that were discussed in CAG meetings were educative. They even mentioned that CAG meetings were conducted orderly as the CAG chairperson facilitated the discussion and allowed members to discuss on a topic and members gave life experiences. It is during the time of adherence support that they even share experiences of living a positive and how they have been overcoming challenges through positive living as one member reflected. “To tell you the truth, I didn't have much knowledge about HIV, adherence and even the time of taking my medication I didn't have specific time but when I joined CAG I learnt that it is important to follow the directives given when taking drugs. The CAG chairperson controls our discussion whenever we meet, so all our discussion were very fruitful and when we had challenges we could call the Lay health worker to come and help us explain more at the meeting” (PLWH, FGD site 1).

**Social support among CAG members:** The peer to peer support offered through CAG meetings is one thing that made members cling together. It was reported by participants that CAG meetings helped to provide peer to peer support. Members of the group found that it offered them a good opportunity to discuss and offer encouragements to each like members of one family. Because of this, the patients realize that they were not the only ones living with HIV and were

on treatment. This created a very strong bond and network between the members. CAG members also felt comfortable with each other because CAG members feel they have a group they can call theirs. “The major important thing with CAG is the encouragement that we give each other at CAG meetings because there are situations sometimes when you feel like you can stop taking drugs, so when you meeting you will find that your friends will explain their experience on the thing which was troubling you” (PLWH, FGD site 1).

**Organizational and community:** Whilst local contextual factors were important in the implementation of the CAG models of care, it was discovered that in communities where livelihood activities cause people living with HIV leaving the community or facilities where they collect drugs from for an extended period of time are not suitable for the formation of CAG. One of the factors that were reported by PLWH hampering ART patient retention was facility-based stigma especially in clinics that offer non-integrated ART services. They cited that the moment the patients are seen around the ART section, they were labeled that they were on ART. However, it was reported that accessing ART services under CAG has helped reduce ART patients being seen by people who are not on ART at the clinic. Participants said that this has facilitated reduced facility related stigma because CAG members do not frequent the facility. As one CAG member narrated; “From the time I joined CAG I feel much free because people who are not on ART won't be seeing me at the ART clinic especially our non-integrated clinic because they already know that whoever goes to ART section is on drugs. They are no issues now talking in the community that I am HIV positive because they have found me at the ART clinic. This CAG has removed that shame from us now” (PLWH, CAG, site 1).

**Public policy:** Participants suggested some process by which government can implement CAGs in different setting to deliver desired changes in improving patient's retention in care as prospects for integration, scale up and sustainability. For the model of CAG to be maintained, participants highlighted that patients should be inviting their friends whom they know that they could keep confidentiality. They said that maintaining CAGs could only be possible if patients themselves are the ones to select who they should form the group with for each respective group. They said that this was so because, participants would choose people they were comfortable with as members of the CAG group. “we know each other in our group and our group is working very well, so I have seen that it is very important to form CAG with the people you know that they can uphold your confidentiality because this has worked for us” (PLWH, FGD site 1).

**Barriers to improved patient retention:** The research also found that patient's retention through CAGs had barriers such as conflict with livelihood activities and fear of unintended disclosure of one's HIV status. Some participants said that what triggered some members of CAG not to continue accessing care using CAG model was because of conflict with livelihood activities. It was said that in communities where livelihood activities cause people living with HIV leaving the community or facilities where they collect drugs from for an extended period of time like fishing areas were said to be not suitable for the formation of CAG.

**Conflict with livelihood activities:** It was also noted that in communities where people's livelihood activities give patients time to be in the communities where they are collecting drugs from, such context were seen to be good grounds to set up CAGs. One participant in an FGD reflected about suitable context for establishment of CAGs;

“...most of our CAG members are usually busy either catching fish or selling fish out of our community for more than two months, and couldn't manage to collect drugs for other, so CAG is not suitable for them” (PLWH, FGD, site 2).

**Fear of unintended disclosure:** HIV related stigma was reported as one of the reasons why some CAG patients discontinued ARV treatment. Some patients do not want to disclose their HIV status either to their marital partners or other social network members for fear of being known that they are on drugs and rejection by the community. They indicated that this was because community members could see them when they meet for CAG meetings and conclude that they were HIV positive. “...some patients didn't want to join CAGs and others were withdrawing from CAGs because they feared that they can be seen or known by other people when they meet with other CAG members in groups during CAG group meetings, this made some of them stop accessing ART services in CAG model or even withdraw from being a member of CAG” (HCW, FGD, site 1).

**What triggered improved retention?** It was realized that most CAG participants in Nyimba being a predominant farming area found CAGs model supportive to them because of accessing ART in CAG was not in conflict with farming, doing business, or work because the participants would do all these and collect drugs without challenges. “...yes, we are resting, because when we collect now by the time the other person will go to collect then at least we have rested. Yeah, we are not troubled like the way we used to do previously when every month you have to come, ah we used to suffer” (PLWH, FGD, site 1). Additionally, CAG participants felt they have people who are also in the same status they could share their challenges with. “Because of CAG, I know that here is a group that I know will be there for me, even when I get sick, they come and encourage me, because of this everyone in our group make sure that he/she do what is required” (PLWH, FGD site 2). Because of the above listed CAG supportive activities, it led to Nyimba clinic having high ART patient retention rate. However, it was not everyone who joined CAG in Nyimba who was comfortable with CAG model; some few members withdrew from CAG groups sitting fear of being seen in the group as the group meet in the community to share drugs. They said that they would prefer going to the facility to collect drugs in a routine way which would help them maintain their privacy. “It is true some people were scared to join CAG others even withdraw because, they were saying that it is a like a secret when I go alone to collect drugs, but now being on the group of sharing drugs with other people there is no secret” (PLWH, FGD, site 2).

### Sustainability

**Self-forming of CAG groups:** For the model of CAG to be maintained, participants highlighted that patients should be inviting their friends whom they know that they could keep confidentiality. They said that maintaining CAGs could only be possible if patients themselves are the ones to select who they should form the group with for each respective group. They said that this was so because, participants would choose people they were comfortable with as members of the CAG group. “We know each other in our group and our group is working very well, so I have seen that it is very important to form CAG with the people you know that they can uphold your confidentiality because this has worked for us” (PLWH, FGD site 1).

**Sensitization:** From the findings of the research, it was discovered that apart from the group being self-form, some CAG members

suggested that there is need for sensitization so that the would-be participants will have enough information about what they are all about to get in to. One CAG member narrated in an FGD. “For the model to be sustainable, people who are on ART should be sensitized so that whoever want to join the group can have clear information and they can make an informed decision even when join the group” (PLWH, FGD, site 2).

## Discussion

This study sought to explore facilitators and hindrances to patient's retention in care under community adherence group models from the selected health facilities. According to the studies done by Ma et al. [3], Barnighausen et al. [4] and Miller et al. [5] respectively, they reported that PLWH who access ART services using clinic based service are inconvenienced with service because they spend long waiting hours at health facilities due to high patient loads which affected patient access. However, the study found freed up time to be one of the drivers that influenced patient retention in care using CAG model. A study conducted by Tuller et al. [6] reported that lack of knowledge and poor knowledge about ART and the HIV/AIDS can also lead to an inadequate understanding about the effectiveness of medications resulting to reduced retention to care. However, accessing ART services allowed CAG members to share their experiences and challenges. Through shared individual HIV experiences, CAG participants developed their Knowledge and understanding of HIV. This led to enhanced HIV knowledge and improved retention among CAG members on HIV enhanced combine and develop their knowledge. Mobility due to patients' livelihood in many sub-Saharan African settings has been cited as an access barrier to community and clinic based HIV services [7-10]. Our study found that access to ART in CAGs was a solution to the mentioned challenges though few indicated that mobility due to livelihood was a barrier accessing ART with some CAG members who were finding it difficult to meet during CAG meetings. It was therefore noted that flexibility in the design of the CAG model would positively influencing the increase in patient retention rate even in areas where people's livelihood are conflicting with time of accessing ART services through CAG. For instance, providing a three months drugs supply to people who are accessing ART through would be suitable unlike one month supply of drugs as per practice.

## Conclusion

The findings of this study suggest that low retention rates are an indicator of major weaknesses in the support system around the patient. The findings highlight the need for a flexible approach of community-based ART delivery models adapted to the local context, resources and needs. Further future modifications will likely be required to adapt to the changing needs and context, to motivate patients and to avoid participation fatigue. Therefore, the introduction with CAG may be need to address the underlying factors of non-retention in care of patients on ART program taking into account that, every single patient who is retained in care and on ART is a life saved and potentially a source of tremendous benefit to the family, community and the nation at large.

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