Improving Patient Antiretroviral Therapy Retention through Community Adherence Groups in Zambia

COUNTRY: Zambia

IMPLEMENTING PARTNER: Centers for Infectious Disease Research in Zambia (CIDRZ)

Differentiated Models of Care (DMOC) reduce patient costs to continue on antiretroviral therapy (ART), provide tailored ART support, reduce congestion in ART facilities, and provide the foundation for patient-centered chronic disease wellness systems. The PEPFAR-supported Centers for Infectious Disease Research in Zambia (CIDRZ) has developed, and is implementing, Community-based Adherence Groups (CAGs). CAGs provide routine ART management to patients and through community-level distribution decongest high-volume facilities and reduce patients’ difficulties in accessing ART from centralized distribution sites. Currently, CIDRZ is implementing 856 CAGs across 5 Districts in 3 provinces (Lusaka, Eastern and Southern Provinces) in Zambia and in 21 facilities.

WHAT WAS THE PROBLEM?

Antiretroviral therapy (ART) is frequently distributed via health facilities and their pharmacies. An increased volume of medically-stable patients at facilities reduces the time clinicians can spend with those who require acute care and also discourages patients from attaining care, due to long wait times. For medically-stable patients, going to a health facility for monthly refill pickup reduces the likelihood of retention on treatment for a variety of factors, including the transportation costs and financial losses of time missed at work incurred by a trip to the health facility. Importantly, retention on ART is vital to the health of HIV-positive individuals, but also to the well-being of the communities in which they live. Achieving higher rates of retention among HIV-positive patients, then, is crucial.

WHAT IS THE SOLUTION?

CIDRZ developed and is implementing Community-based Adherence Groups (CAGs) in some of the high-volume ART sites in Zambia. To participate, stable patients must have been retained on ART for at least 6 months. They should not have any active opportunistic infections (OIs) and should have a CD4 count of >200 and viral load (VL) <1000. To engage in CAGs, patients should be ≥ 15 years.

Self-forming groups were created by asking patients identify other potential group members. Patients who are unable to connect with other members are grouped with patients from same catchment by volunteers. Health education is provided to all patients as they wait to see clinicians during their routine visits. Those interested in joining a community-based adherence group (CAG) request to be screened for eligibility during their visit with the clinician. Clinicians then refer those who meet the eligibility criteria to lay volunteers, who explain the CAG model in detail and assist patients with identifying other group potential. Once a group has been formed, it is assigned a community health worker (CHW), who contacts all group members to plan the first meeting at the facility (at a time convenient for all 6
members). During this first CAG meeting, the CHW and members create group norms, review the Code of Conduct, sign consent forms, and share contact information.

CIDRZ provides multi-month drug dispensing (3 months’ supply of ART) for each of the patients participating in the CAGs. Each CAG has 6 patients, who take turns visiting the ART clinic for clinical consultation and antiretroviral (ARV) drug collection. Upon return from the clinic, the other CAG members collect their ART supply at a designated collection point. Since groups consist of six patients, each patient rotates to the facility to see a clinician and to complete a routine clinical visit. Annually, each patient has two clinical visits and will return to the clinic for their clinical follow-up appointment, even if it is not their turn to collect medications.

Each CAG is assigned a community health worker (CHW) who provides basic psycho-social and clinical support to the CAG members. CHWs interact with patients during routine clinical visits and during each CAG meeting, as patients dispense the ART medications with each other in a community-based setting. If a CAG member is unwell and needs clinical attention, they self-refer or are referred back to the clinic by the CHW. The CAG members also provide peer-support to each other. Due to the psycho-social and peer-support, satisfaction with this ART distribution approach has been very high.

Index testing through family and partner notification has also been implemented through the CAGs.

WHAT WAS THE IMPACT?

856 CAGs have been formed, with 4,876 patients across 5 districts participating in these groups. In fiscal year 2016 (FY16), CAGs were used as an entry point for index testing. 4,375 people were tested for HIV through index testing and of those, 540 tested positive representing a 12 % yield, with 100% of clients linked to treatment. CIDRZ will recommence implementing index tracing and partner notification through CAGs in FY18. CIDRZ aims to link at least 90% of all clients who test positive, as this method will be implemented on a larger scale at multiple sites. Linkage to care and treatment is easier through CAGs, since clients already have established relationships with volunteers and it is easier for HIV-positive clients to receive follow-up care.
The following ART outcomes have also been observed:

- ART retention is 97%, compared to 76% retention in patients at the health-facility level;
- High linkage to treatment for those testing positive through index testing methods;
- High patient satisfaction, as ARVs are collected in the community at a time convenient to patients;
- Decongestion and reduced waiting times at ART clinics;
- Providers perceived a decrease in the burden of care and are advocating for scale-up of differentiated models of care.

**HOW DOES IT WORK?**

**INDIVIDUAL LEVEL**

CAGs aim to provide routine ART management to patients, decongest high-volume facilities, and minimize barriers to accessing ART sites. The Ministry of Health is engaged in site selection and is actively involved in the roll out plan for scale-up of CAGs. CAG participants meet routinely in the community to discuss adherence challenges and to offer each other psychosocial support.

Groups are self-forming, and patients are able to join the groups with which they are comfortable. With the CHWs as liaisons, the groups develop and maintain a feedback system with the facility for monitoring purposes. Patients also have to adhere to an agreed-upon Code of Conduct while participating in the groups. CAGs are also formed with special population groups such as adolescents, couples or amongst other demographics, as determined by the patients. Those who fail to identify other group members are grouped with patients from the same catchment area by CHWs.
At the health facility, health education is provided to all patients as they wait to see clinicians during routine visits and those willing to join a CAG request to be screened for eligibility when they see clinicians. Clinicians refer those who meet criteria to CHWs, who explain the model in detail and assist patients in identifying other group members who also have to be screened for eligibility.

When a group is first formed, group members will receive one month’s supply of ARVs. This is to monitor the group and to ensure that each member collects the drugs when required, and that there are no conflicts or issues between members that will affect member participation in the CAG. Once the group is stable, they graduate to multi-month dispensing, with 3-month supply of ARVs.

In addition to ARV drug dispensing and adherence and psychosocial support, CAGs are also used as an entry point for index testing. Through index testing of group members’ children, spouses and other sexual partners and through partner notification, more people are tested for HIV and linked to treatment.

At one of the original pilot sites, Chilenje First Level Hospital in Lusaka, there has been further modification to the CAGs to include unstable clients in some groups. The objective of this is for the stable clients in the CAGs to provide psychosocial support to the unstable clients, with the intended result of improved adherence. In addition to the psychosocial support within the CAGs, the unstable clients receive support from a dedicated multidisciplinary clinical team at the facility, trained in management of patients with complicated diseases. Unstable clients also receive additional viral load testing (every 3 months) to determine improvement in viral load suppression.

Below are some quotes from health workers and patients on the impact of CAGs:

“Reducing the burden on already saturated health systems is an ever-increasing challenge in resource limited settings. Stable patients, will need limited interaction with their health facilities if these are to continue with new ART initiations. So, monitoring and adherence support in the community is critical and CAGs have helped in achieving this.” Sister Mwelwa Kanyinda, Chilenje First Level Hospital ART In-Charge

“This is a fantastic and innovative model! It should be duplicated among many similar facilities. For people facing long journeys and long waiting times to get ART this could make a huge difference.” Lwiimba lay- counselor

“Being a CAG member has helped me not to miss school and build relationships with the staff at the clinic. It also reinforces positive adherence behaviors amongst us members.” Mathews Nkhoma, Chilenje First Level Hospital, adolescent CAG member

“The lay counsellors’ teachings on sexual reproductive health programs in the CAGs ensures us the young people living with HIV to have the knowledge, skills and confidence to make good decisions and we are linked to care including STI and family planning services. I want to learn life
skills and how to improve my health. I am going to be a leader.” Sangwani Zimba Chilenje First Level Hospital, adolescent CAG member

SYSTEMS AND SERVICES LEVEL

The groups have assisted in minimizing barriers to accessing treatment, decongesting facilities, and thereby enabling healthcare workers to spend more time on complicated cases. These groups have led to improved adherence among patients, as well as retention on treatment. Furthermore, CAGs have provided an avenue for index testing and partner notification, with a higher yield of HIV positivity. The groups also act as an avenue for minimizing loss to follow up, as patients in CAGs are in touch with each other, and therefore patients who do not attend drug pick-ups or clinic appointments can be easily traced.

PEPFAR above site investments have included:

- Capacity building of health care workers and lay community providers
- Advocacy for differentiated service delivery (DSD) policy development with the Ministry of Health

PEPFAR OPERATING MODEL

Following successful initial implementation in four sites (2 rural and 2 urban), the Ministry of Health granted authorization to scale up implementation of this model at other sites. CIDRZ worked closely with facility staff at the implementation sites to help ensure that there was ownership of the program as far as implementation was concerned. The implementing partner provided technical assistance and mentorship in implementation at participating sites.

LOCAL ENVIRONMENT

CAGs have enabled patients to be more involved in the management of their health through active participation in accessing ART treatment. In rural areas, the initiative has been supported by the traditional leadership. Through the Senior Community Advisors, meetings have been held with chiefs and headmen who have provided their support for the initiative, thereby ensuring that members of the community buy-in to the intervention and participate fully. In some rural areas, villages can be up to 60 kilometers from health facilities. CAGs have lessened the frequency with which participants have to travel to health facilities, thereby improving patients’ satisfaction and adherence to treatment. CAGs also reduce patients’ travel costs to access treatment. In urban areas, advocacy from Neighborhood Health Committees, which still have considerable influence in peri-urban communities, and advocacy and support by facility staff and volunteers, helped to drive the intervention at the facility-level and encourage participation.

Key advocates (local, national, community):

- In rural communities: Traditional leaders, such as chiefs and headmen
- In urban areas: Neighborhood Health Committees
At facility level: Facility staff and volunteers
At national level: This requires buy-in from the Ministry of Health. A focal point person focusing on differentiated service delivery is now in place at the Ministry of Health and the 2018 National Guidelines have been revised to include DSD interventions.

NATIONAL ENVIRONMENT

In the 2018 Zambia Ministry of Health Consolidated ART Guidelines, differentiated models of care (DMOCs) have been included as an approach to service delivery. Successful pilot implementation of DSD has enabled stakeholders to advocate for scale-up in other facilities, focusing especially on high-volume sites. The CAG model is seen as an avenue for reaching out to untested people living with HIV by involving patients in the groups as indexes and role models.

Currently, there is a DSD Task Force, led by the Ministry of Health through a DSD Focal Point Person. This Task Force develops policy, as well as guidelines, on DSD and provides oversight for implementation at the Ministry of Health level.

SCALE UP

The pilot phase of the model commenced in April 2016 and approval to implement at scale was granted by the Ministry of Health in March 2017. CIDRZ is scaling up the model in all Lusaka high-volume sites in quarter 1 of FY 2018, (October to December 2017), and to high-volume sites in Western, Southern and Eastern Provinces in quarter 2 of FY 2018 (January to March 2018).

Involvement of the facility staff and patients during implementation has been an important factor in the success of the innovation. Sensitizing stakeholders about the potential benefits of the CAGs, to both patients and facility staff, has helped to ensure the success of the innovation. Key players in the model are facility-based lay volunteers (CHWs), clinicians, and nurses who screen patients for eligibility and provide patient care at the community and facility level, pharmacy staff who pre-pack drugs for pick up by the CAG participants and data associates who ensure that patient records are updated electronically in SmartCare. Patients themselves are also vital to the success of implementation, based on the model’s use of patient rotation for drug pick up from the facility and through the psycho-social support offered to each other within the group.

While the original pilot began in April 2016, a delay to scale-up of the model occurred due to the Ministry of Health’s approval process. Other challenges include inadequate drug quantities, or drug stock outs, at the health facilities, which can hinder adequate dispensation of a 3-month supply of drugs to the groups. Delayed lab results, particularly viral load results, also limit the eligibility screening for potential CAGs patients.

PEPFAR TEAM INVOLVEMENT

The PEPFAR team has worked closely with the Ministry of Health and implementing partners in the development and implementation of DSD and the CAG model, in particular. The involvement has
PEPFAR SOLUTIONS
PLATFORM (BETA)

included regular monitoring of progress through technical oversight in DSD implementation and review of monthly reports. PEPFAR Zambia also participates in the Technical Working Group (TWG) on DSD and has advocated to Ministry of Health for the adoption of DSD models and inclusion of this approach for service delivery in the National ART Guidelines.

IMPLEMENTING PARTNER

The implementing partner worked closely with the Ministry of Health to help ensure that the innovation’s concepts were understood prior to implementation and scale-up. The implementing partner then targeted the high-volume sites and oriented facility staff on how to implement the model. Ongoing mentorship and support is offered to implementing facilities to ensure the continued success of the innovation. The DSD model ought to be seen as a Ministry of Health initiative that will result in better retention among clients and decongestion of health facilities leading to improved quality of care.

MONITORING

Routine monitoring and support in the implementing facilities by the Ministry of Health, PEPFAR and the implementing partner has helped identify gaps and solutions. The implementing partner works with the staff at health facilities to implement the solutions. Solutions are then shared with other implementing facilities to improve CAG service delivery across facilities.

Outside of the Health Management Information System (HMIS), the indicators collected include:

- Proportion of stable patients enrolled in CAGs
- Number of CAGs formed and operating
- Proportion of CAG members attending CAG meetings – (90% attendance target)
- Proportion of CAG members retained in care – (90% retention target)
- Proportion of clients who leave CAGs (due to pregnancy, transfer out, death, loss to follow up)
- Proportion of clients referred to the facility for clinical follow-ups (clients who present with any symptoms)
- Number of people tested for HIV through CAGs as indexes
- Positivity yield of index clients tested through CAG
- Proportion of positive clients from index testing linked to treatment – (90% linkage target)

IMPLEMENTING MECHANISM MANAGEMENT

Implementation of DSD was included under care and treatment initiatives of the CIDRZ program. There were no PEPFAR or agency-specific challenges that affected program implementation.

COMMUNICATIONS

Monthly reporting is done from each facility to CIDRZ Head Office on the progress of the model and comparisons are done with previous months to identify any arising challenges. Individual CAGs also
communicate specific challenges that they cannot resolve to the facility through the group leader (CHW). Facility leadership then works with the group to resolve the issue.

**COST**

Costs include the orientation/training for new implementing facilities. Orientation/trainings are done during lunchtime and the healthcare workers and facility-based volunteers receive a lunch allowance for the trainings. Other costs include the purchase of items such as bags to help with transporting of drugs from the facility to the community and stationery to document the group activities. Depending on the distance to the communities, facility-based volunteers may require transport refunds. To overcome transport challenges, CIDRZ is considering the purchase of bicycles to be used by volunteers (CHWs) to monitor and provide support to the groups.

*Training - $3,225*

Once a site is selected for the implementation of CAGs, it is essential to train Ministry of Health staff from the District and Province and program staff on this model. Based on our implementation experience and the Community ART for Retention Study, funded by the Bill and Melinda Gates Foundation, CIDRZ created a training manual for CAG implementation. The manual covers eligibility criteria, recruitment and enrollment procedures, and the various forms used as part of the model. On average, the training takes no more than 5 days. Training costs consisted of $600 for venue hire, $2,250 for a conference package for 5 days for 30 participants and $375 transport allowance for 15 Ministry of Health staff.

*Orientation for Facility Staff - $100*

Staff members at implementing facilities need to be trained on the model. This is an on-site orientation, to enable facility staff and volunteers to participate. Ministry of Health staff members (nurses, clinicians, pharmacy staff, etc.) are paid a lunch allowance at $8.50 and volunteers are paid the CIDRZ rate of $4. The total depends on the size of the facility, which will dictate how many people participate in the training.

*Support/Supervisory Visits*

CIDRZ DSD activities are overseen by the Community Coordinator for Treatment and the Head of Community Programs. At Chilenje First Level Hospital, they conduct monthly supervisory visits to ensure implementation is done in accordance with the program’s Standard Operating Procedures. If the facility is more than 25 kilometers away and staff members spend 6 or more hours out of their work station, they receive a lunch allowance of $7.50. If the facility is in another province, requiring an overnight trip, staff receives a travel per diem of $80 a night for each night spent out of station.
Stationery - $100

Stationery consists of printing costs for the various forms used to implement the CAG model. These include the CAG Paper Register, the CAG Clinical Care Form and the CAG Event Form. Other costs include the printing of infographic posters, which are placed in busy areas of the health facility.

Computer Tablets - $2,800

As the number of CAGs increases at a facility, the use of paper forms becomes cumbersome. CIDRZ is currently in the process of digitizing the above-mentioned forms to make the collection of data easier. CIDRZ is also implementing SmartCare Lite, which has modules on community ART distribution and community testing. It is recommended that each facility be allocated 4 tablets, at a unit cost of $700.

Backpacks - $700

The CAG model consists of one patient collecting ARVs on behalf of the other group members. When the group is stable and graduates to the quarterly collection of drugs, this indicates that the patient collecting the ARVs may need to carry up to 18 boxes of medication to their fellow group members. Backpacks are procured to make the transportation of drugs easier. Once the drugs are distributed in the community, the backpack is returned to the facility. A facility of the size of Chilenje First Level Hospital with more than 200 CAGs will require no less than 20 backpacks at $35 per bag.

Filing Cabinets - $150

The implementation model requires that the files of CAG members are kept separately from other ART files. This ensures that the files of these patients are readily accessible. This also enables for the fast-tracking of clients who are defaulting. Filing cabinets also ensure the secure storage of computer tablets. It is recommended that each facility be allocated a minimum of 2 filing cabinets, at a unit cost of $75.

Mobile Phones - $60

Regular communication between groups and the volunteers supervising the CAGs is essential. Phones are also used to follow-up with clients who miss drug collections or CAG meetings in the community. Basic smartphones can be purchased at a unit cost of $30.

Airtime - $180

Each facility is allocated airtime, which is loaded on the above-mentioned phones to call clients. The use of this airtime is tracked with a call-log, which must be submitted each month before a new allocation of airtime is made.

Treatment Supporter (CAG Supervisor) Stipends - $3,840

At facility level, the CAG model is implemented by treatment supporters. These ‘CAG Supervisors’ conduct health talks on the CAG model, recruit and enroll clients, and monitor CAG meetings and
activities in the community. This cadre of volunteers receives a monthly stipend of $80 from CIDRZ. At Chilenje 1st Level Hospital, there are four treatment supporters assisting with CAG activities.

*Transport Refunds - $3,200*

A transport refund of $4 is given to each treatment supporter to supervise CAG meetings in the community. A total of $3,200 is required for 4 treatment supporters to supervise 200 CAGs in Chilenje, which meet 4 times in a year.

**EFFICIENCY MEASURES**

Discussions are underway with Ministry of Health for adoption of the model as a standard of care. It is hoped that this innovation will be treated as one of the models of care nationally, with financial allocation from the Ministry of Health to support implementation.

Community ART clubs not only reduce the burden placed on clinics, but also result in improved retention (with 97% of patients in CAGs adhering to treatment, compared to 76% of patients in care but not in CAGs), medication adherence, and reduced drug resistance, as patients are better able to fit the management of HIV around their home and work lives. The HIV-related stigma and discrimination can be reduced with CAGs, as people living with HIV are no longer only considered as ill patients.

The CAG model reduces the workload of the health staff, freeing up more time to attend to complicated cases. CAGs also decongest the clinic as more clients are accessing treatment outside of the facility. The model also provides better access to patients’ information regarding treatment adherence, wellbeing and treatment outcomes through a direct feedback loop between group members and healthcare workers.