

Published in final edited form as:

AIDS Behav. 2019 September; 23(9): 2477–2485. doi:10.1007/s10461-019-02419-6.

Mozambique's Community Antiretroviral Therapy Support Group Program: The Role of Social Relationships in Facilitating HIV/ AIDS Treatment Retention

Karen E. Kun¹, Aleny Couto², Kebba Jobarteh³, Rose Zulliger⁴, Elpidia Pedro⁵, Inacio Malimane⁶, Andrew Auld⁷, Marisa Meldonian⁸

¹Division of Global HIV and TB, Center for Global Health, US Centers for Disease Control and Prevention, 1600 Clifton Road NE, Mailstop E30, Atlanta, GA 30333, USA

²HIV Program, Mozambique Ministry of Health, Maputo, Mozambique

³ThinkWell, Maputo, Mozambique

⁴Division of Parasitic Diseases and Malaria, Center for Global Health, US Centers for Disease Control and Prevention, Maputo, Mozambique

⁵Jhpiego, Maputo, Mozambique

⁶Division of Global HIV and TB, Center for Global Health, US Centers for Disease Control and Prevention, Maputo, Mozambique

⁷Division of Global HIV and TB, Center for Global Health, US Centers for Disease Control and Prevention, Lilongwe, Malawi

8The Lewis Family Foundation, Boston, MA, USA

Abstract

The Community Antiretroviral (ARV) Therapy Support Group (CASG) program aims to address low retention rates in Mozambique's HIV treatment program and the absorptive capacity of the country's health facilities. CASG provides patients with the opportunity to form groups, whose members provide peer support and collect ARV medications on a rotating basis for one another. Based on the promising results in one province, a multi-site level evaluation followed. We report on qualitative findings from this evaluation from the patient perspective on the role of social relationships (as facilitated through CASG) in conferring time, financial, educational and psychosocial benefits that contribute to improved patient retention. These findings may be helpful

Karen E. Kun, icn3@cdc.gov.

Author Contribution Conceptualization and design: KJ, AC, AA, KEK. Acquisition of data: EP, IM. Analysis and interpretation of data: EP, RZ, IM, MM, KEK, AA, KJ, AC. Drafting manuscript: KEK. Revision of the manuscript: RZ, IM, KJ, AC, AA, MM, EP. Study supervision: KJ and AC.

Compliance with Ethical Standards

Ethical Approval Ethical approval for the study was obtained from CDC's Institutional Review Board and Mozambique's National Bioethics Committee. A 2-day training for all those engaged in the evaluation was conducted to review the study protocol and procedures (including those related to ethical considerations and informed consent).

Informed Consent All participants provided written informed consent.

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

in informing what aspects of social relationships are critical to foster as CASG is implemented within a greater number of Mozambican health facilities, and as other countries design and implement related models of care and treatment with a support group component.

Keywords

HIV; ART; Retention; Support groups; Resource-limited settings; Mozambique; Southern Africa

Background

The Community Antiretroviral (ART) Support Group (CASG) Program

Mozambique experiences relatively low antiretroviral therapy (ART) retention rates in its HIV treatment program [1]. While some patients are moving to receiving 3-month prescriptions for antiretroviral (ARV) medications under pilot programs, many patients in Mozambique must still visit every month to collect their ARVs. Such frequent visits are challenging for patients to sustain, likely contributing to Mozambique's low retention rates since key reasons for attrition include: time spent getting to health facilities; wait time at over-burdened health facilities; and transportation costs [2–5]. National health systems must consequently devise strategies that address these root causes of ART-related attrition if their treatment goals, including those at the global level [6], are to be met.

In response, the Ministry of Health (MoH) in Mozambique has pioneered a model of care and treatment, the CASG program, aimed at addressing low retention rates and its health facilities' absorptive capacity. Adult patients stable on ART for more than 6 months with a CD4 count > 200 cells/ μ L, are not pregnant, and who do not have any active World Health Organization stage III or IV conditions are eligible to participate. The CASG program provides patients with the opportunity to form groups, typically comprising four to six patients living in close proximity, who collect ARVs for one another on a rotating basis and provide peer support.

Every month a different CASG member visits the health facility, after having collected information on the health status of the other group members. The CASG member receives clinical follow-up, shares information with the clinician on the health status of the other group members, collects a monthly supply of ARVs, and subsequently meets with the other group members to distribute their medications and share information from the health facility.

Medecins Sans Frontieres initially piloted the CASG program in one Mozambican province (i.e., Tete Province). Based on its promising results in improving retention, decreasing loss to follow up, decreasing mortality, and decreasing health facility burden [7–12], the Mozambican MoH subsequently expanded the program beyond Tete to 69 sites (at the time of our study).

Support Groups for Individuals Living with HIV/AIDS

While prior studies in resource limited settings demonstrate that support group participation can contribute to improved treatment adherence and retention [7, 11–16], less is known

about the mechanisms through which support groups do so. A body of literature is emerging, and relevant themes are reflected below regarding how support groups can facilitate adherence and retention.

Time and Financial Related Benefits—The CASG pilot in Tete Province demonstrated that participation conferred time and cost savings in only having to visit the health facility once every 6 months (rather than monthly). Program participation also provided access to financial support as those participating in CASG may choose to pool funds to support group members when needing assistance with food, transportation or health care costs [8–10, 12]. A study in Zimbabwe similarly found that support groups facilitated access to financial assistance from other group members [17]. A study in Rwanda involving HIV positive women demonstrated that other financial benefits could additionally accrue from support group involvement, as women reported being able to return to work because of improved mental and physical health resulting from their participation [18].

Educating About Treatment Adherence—The CASG pilot in Tete further demonstrated that program participation facilitated information sharing amongst group members about disease progression and the importance of daily drug intake [8–10]. Support group members in the Rwandan study of HIV positive women reported similar findings [18]. The study in Zimbabwe additionally detailed how HIV positive support group participants encouraged each other to continue attending clinical appointments [17], and a South African study found that the dynamics in a patient's social environment could serve to encourage a healthy lifestyle and promote HIV treatment adherence [19]. Support group participation may thus facilitate greater awareness and understanding of the importance of treatment adherence and/or actively promote it.

Contributing to Acceptance, Belonging, and Diminished Shame and Stigma-

The CASG pilot in Tete demonstrated that participating in the program decreased feelings of isolation in living with HIV, and conferred a sense of belonging, like to a family or a church [8, 9]. Support group participation in Zimbabwe also enabled individuals to speak openly with others in the same situation, facilitating an improved sense of self and greater acceptance of one's HIV status [17]. Researchers likewise found improved peace of mind and diminished shame and stigma with support group participation in Tanzania [20]. Rwandan support group participants relayed feeling a sense of connectedness, becoming free of shame and having a sense of "rebirth" [18]. A study in Uganda also demonstrated the importance of connectedness and of belonging to a wider community of those living with HIV in facilitating treatment adherence [21].

Preserving Social Capital—A study in three resource-limited countries (Nigeria, Tanzania and Uganda) revealed that adherence and retention can ensue as a means of preserving social capital. That is, those living with HIV adhere to treatment to promote good will on the part of those they consider to be helpers (i.e., support group members, family members, and friends). This ensures that these helpers will be committed to assisting them in the future, when the need arises [4].

Purpose of this Paper

The Mozambican MoH supported a multi-site level evaluation of the CASG program based on promising results in Tete Province. This paper describes the evaluation's qualitative findings from the patient perspective on the role of social relationships, as facilitated through CASG, in improving treatment retention. As an increased number of Mozambican health facilities potentially implement CASG, these findings may be helpful in informing the facilities, staff members charged with directing CASG, and patient group leaders about what aspects of social relationships are important to foster within the groups. These findings may likewise serve to improve existing CASG programs within Mozambique by contributing to potential modifications to group facilitation and discussion. Lastly, the paper seeks to contribute to the qualitative body of literature emerging from resource-limited settings on how participating in support groups contributes to improved retention and adherence. The paper's qualitative findings may thus be helpful to policymakers, health facility staff, and patients as they consider potential strategies to improve HIV treatment adherence and retention within their programs.

Methods

Qualitative Methods

We conducted focus groups to learn from patients about the CASG program's perceived utility and their thoughts on if (and how) the program facilitated improved retention for themselves and others. We selected focus groups because they are appropriate for learning more about perceptions about programs and services, given they encourage the exploration and clarification of shared experiences. Focus groups can therefore contribute to an environment in which stories can be shared, and in which participants bound by common experience can expound upon the thoughts of others [22–25]. We therefore deemed focus groups to be the most appropriate method, as we aimed to gauge not only an individual patient's own perceptions about the CASG program, but their reactions to what other patients thought as well. In addition, each CASG has a patient leader who serves as its facilitator and point of contact with the health facility. As CASG leaders routinely meet with one another at their health facilities, using a focus group methodology additionally enabled us to logistically tie into their existing meetings.

Site Selection

We conducted focus groups during November–December 2014 with CASG leaders at 10 health facilities in Mozambique. We randomly selected the 10 sites from the 69 health facilities in Mozambique with existing CASG programs at the time of data collection. The sites were located in the provinces of Maputo City, Cabo Delgado, Maputo, Inhambane, Nampula, and Zambezia. For each site (n = 10), we conducted one focus group.

Participant Selection and Recruitment

We used key informant sampling to learn from highly knowledgeable patients (i.e., the CASG leaders) [24, 25]. We worked with health facility staff, who then approached their CASG leaders approximately 1 month in advance of the focus groups, describing the

purpose, the general topics for discussion, and that participation was voluntary. Those agreeing to participate received a reminder 1 week beforehand, followed by a SMS and phone call the day before the focus group. Focus groups comprised 6 to 10 CASG leaders per site, a number supported by the literature [22, 23].

Data Collection

Our data collection lead managed a team of nine individuals experienced in qualitative methods in piloting the semi-structured focus group instrument and collecting data at the sites. We designed the instrument to learn more from patient leaders about why they and others might join a CASG and any changes they observed in themselves or others as a result of participation. For all focus groups, one data collection team member served as the moderator, leading it in Portuguese, while another acted as note-taker and digital recorder. Not all focus group participants were fluent in Portuguese at four sites. A facility staff member joined these focus groups, translating questions from the moderator into the local language, and participants' answers in the local language into Portuguese. Other focus group participants (fluent in both the local language and Portuguese) served as back translators, enhancing the reliability of the notes and digital recordings.

Data Management and Analysis

Members of the data collection team met daily to debrief, review notes for completeness, discuss common themes, and monitor for data saturation. They subsequently developed focus group transcripts in Portuguese from the digital recordings (adding annotations from their written notes), and uploaded them into QSR International's NVivo version 10 for analytic purposes [26].

The data collection team then inductively drafted a codebook based on the transcripts. The co-authors reviewed the draft, provided feedback, and revised the codebook in collaboration with the data collection team. The codebook defined each code and coding guidelines, including example quotations. Two data collection team members then independently coded each of the 10 transcripts and used NVivo's reliability tool to assess intra and inter-coder reliability [26]. Whenever two data collection team members found discordance, they discussed and resolved it in the presence of a third data collection team member who served as a moderator, ensuring 100% concurrence in the coding process. The data collection team additionally translated summaries of the coded information into English. The co-authors then synthesized the codes into themes, using the applied thematic analysis approach as a framework [27].

Results

Eighty-seven participants, 58 females (67%) and 29 males (33%), participated in the focus groups at the 10 health facilities. Most participants were 35 to 49 years old (64%), and had primary school education (70%). Some were living with a partner (41%).

Three major themes (and related sub-themes) emerged from the qualitative analysis concerning the means through which CASG participation can contribute to improved treatment adherence and retention: (1) time and financial benefits, (2) health educational

benefits, and (3) psychosocial benefits. Tables 1, 2 and 3 provide more information on these themes and sub-themes, accompanied by example quotations to assist in illuminating the findings.

Table 1 demonstrates the time and financial benefits that can accrue through CASG participation. It highlights the ways in which focus group participants reported that CASG saves them and other group members money, for example through decreased transportation costs and time away from work (with the potential for lost wages), given there is no longer a need to visit the health facility each month. Table 1 additionally highlights how CASG can result in time-savings for members by decreasing wait time at the health facility because of the priority status that members receive in line and/or because of CASG's overall contribution to decreased patient volume. The table also depicts another financial benefit of CASG participation, access to mutual savings funds (or xitique, in Portuguese). Focus group participants described that money can be collectively pooled through CASGs to support members with their transportation costs when going to pick up medications, or aid those who might be ill or in general need of funds.

Table 2 depicts what we learned from focus group participants regarding the ability of CASG members to accrue health-educational benefits as a result of their CASG participation. This could take the form of knowledge sharing about the benefits of retention and adherence (including the importance of properly taking medications and receiving clinical follow-up) and the overall benefits of pursuing a healthy lifestyle.

Table 3 demonstrates the psycho-social benefits that can accrue through CASG participation. It highlights the ways in which focus group participants reported that being in CASG benefitted them psycho-socially, but also how it aided others, including members of their families and communities living with HIV. Focus group participants reported that CASG contributed to their greater acceptance of living with HIV and facilitated a sense of belonging within themselves. CASG members also reported psycho-socially aiding other group members by motivating them not to give up (i.e. in living with HIV), encouraging them to take their medications, visiting them when sick, and by providing food and other support. Focus group participants additionally shared how CASG enabled them to create a supportive extended family in which mutual understanding ensued because of their common HIV status, and in which certain cases could serve as a proxy for their own families. Some focus group participants also reported that their membership in CASG facilitated spiritual healing and/or spiritual connections.

Discussion

Time and Financial Benefits

We found from our focus group participants that CASG confers time and financial benefits to its members through: decreased transportation costs; decreased work absences, decreased patient volume and wait time at health facilities, and by facilitating access to mutual savings funds. Our findings corroborate findings from the CASG pilot on the time and cost savings that CASG participation can confer [8–10, 12]. Our findings additionally converge with

findings from the CASG pilot and a study in Zimbabwe on how support groups can facilitate access to mutual savings and financial assistance from other group members [17].

We found, as did a study in Rwanda [18], that support group participation could result in less time away from one's workplace and source of income. Of note is that our study contributes to the qualitative literature in revealing that less time away from work could confer not only a financial benefit (i.e. less lost wages), but could also decrease concern about unintended disclosure, given that bosses and co-workers were reported to be less likely to wonder and inquire about an individual's health (given fewer work absences). Future studies could benefit from exploring the potential of support group participation to decrease the fear of unintended disclosure and stigma, given improved health in general, and fewer absences from work in particular.

Health Educational Benefits

We learned from focus group participants that they accrued health-educational benefits from CASG participation in the form of knowledge sharing about the benefits of retention and adherence, the importance of properly taking medications and visiting the health facility, etc. Our study thus augments existing literature on how support group participation can facilitate information sharing about disease progression and the importance of daily drug intake [8–10, 18], and the importance of attending clinical appointments [17].

We additionally found that CASG participation more generally encouraged a healthy lifestyle beyond just taking medication (e.g., using condoms and limiting the number of sexual partners, appropriate nutrition, and decreasing one's smoking and alcohol consumption). While a study in South Africa found that the dynamics in a patient's social environment could serve to encourage a healthy lifestyle and promote HIV treatment adherence [19], the ability of support groups in resource-constrained countries to more generally encourage a healthy lifestyle remains relatively unexplored in the literature. Additional studies to explore theoretical constructs pertaining to health promotion and behavior change such as socio-ecological theory [28, 29], could assist in illuminating the influences and dynamics through which individuals decide to pursue healthier behaviors, and what particular components of support group functioning are contributing factors.

Psycho-social Benefits

Our focus group participants reported that being in CASG not only benefitted them directly, but also aided others, including members of their families and communities living with HIV. They shared that the opportunity to help others was an important benefit of their support group participation, potentially boosting their own psychosocial health. Such support of others could entail encouraging other group members to take their medication, visiting them while ill, or facilitating family and community members' access to life-saving treatment by bringing them into a CASG. The "Helper" Therapy Principle initially postulated that the act of supporting others could potentially assist in healing the helper [30]. More study is needed of this particular dynamic and understanding of how individuals are motivated to potentially join and/or remain in a support group because of the ability to help others and what direct impact serving as a "helper" has on mental and physical health outcomes of interest.

Our focus group participants also reported that CASG contributed to their greater acceptance of living with HIV and facilitated a sense of belonging. A salient point that additionally emerged was of CASG members motivating other group members not to give up (i.e. in living with HIV) by encouraging them to take their medications and by providing nutritious food and other support. Focus group participants also shared how CASG enabled them to create an extended family, a supportive one in which common understanding ensued because of their common HIV status. Like the CASG pilot in Tete and studies in Zimbabwe, Rwanda, Tanzania, and Uganda, we similarly found that participating in a support group could decrease feelings of isolation in living with HIV, enhance feelings of connectedness, improve peace of mind, and confer a sense of belonging, like to a family [8, 9, 17, 18, 20, 21]. Of note is that the emergent body of qualitative literature in resource-constrained settings that demonstrates that support groups can have a beneficial impact upon retention and adherence all involve support groups comprising those living with HIV. This may be of interest to policy makers, clinicians, and communities considering how to structure social support to best boost retention and adherence, as it may be beneficial to thoroughly consider whether social support provided by non-HIV positive individuals (e.g., community workers, families or friends) would be equally as effective.

Of additional note is that a study conducted in Nigeria, Tanzania and Uganda revealed that adherence and retention can ensue as a means of preserving social capital (i.e., those living with HIV adhere to treatment to ensure that those they consider to be helpers such as support group members, family, and friends remain committed to assisting them in the future) [4]. This may suggest much more of a quid-pro-quo situation in which individuals living with HIV do what is expected or conform to normative behavior (i.e., adherence) to build up social capital to support themselves through future illnesses, financial difficulties, etc. This raises that the nature of relationships may be more symbiotic, rather than altruistic in nature. Such a notion of social relationships merits additional inquiry as well.

Lastly, some of our focus group participants shared that a benefit of CASG was spiritual healing and/or spiritual connections facilitated through group membership. These findings corroborate findings from the CASG pilot in Tete [8, 9], and we additionally illuminated that a CASG may get formed by those known to one another at church. The role of spirituality and of faith communities potentially serving as entities through which support group members can be recruited should not be underestimated as potentially important variables when considering support group composition, functioning and effectiveness.

Implications for the CASG Program in Mozambique and Emerging Models of HIV Care and Treatment

Our findings may be helpful in informing what elements of social relationships are critical to foster within CASGs as the Mozambican MoH further considers scaling up the program and other retention strategies. It is additionally important that the CASG program not only continues to foster these critical elements of social relationships, but is complemented with an enabling health system (e.g., shorter wait times for CASG members), to support continued programmatic effectiveness.

This inquiry provides important information to the national HIV program in Mozambique on how CASG participants perceive the benefits of the program, and builds on existing evidence of CASG effectiveness in reducing attrition and lost to follow-up regardless of CD4 count [1, 31]. It demonstrates the importance of the social relationships among patients enrolled in CASG in helping members become and remain adherent. Documenting and learning from the patient perspective remains important in the era of test-and-start, and as some patients are moving to receiving 3-month prescriptions for ARVs under pilot programs in Mozambique.

While there is still much to learn about how social relationships affect adherence and retention in resource-constrained settings, we learned about the salient benefits that social relationships conferred through the CASG program in Mozambique. It is important to be cognizant of the types of financial, time, educational and psycho-social benefits that we found to be important in CASG, and to potentially consider if conferring similar benefits would be advantageous within other emerging models of social support for those living with HIV. Our findings further demonstrated that being part of and supported by a group of peers living with HIV was an important component of the CASG program. This may have implications for models where social support is provided through non-peer groups (e.g., families, community-based NGOs, and/or health care providers).

Limitations

We employed a key informant sampling strategy, enabling patients with the richest and most information about the CASG program (i.e. CASG leaders) to participate. Our focus group participants may therefore have been more inclined to emphasize program benefits and underestimate shortcomings, given their leadership roles. The generalizability of our findings to represent the perceptions of all CASG participants, may therefore be limited, and our use of purposive sampling (i.e. a non-random approach) may limit the generalizability of our findings overall. A majority of our focus group participants were 35–49 years old. There is a possibility that younger or older patients may have had different perspectives on the CASG program than those in this age range. CASGs also vary in their composition. Although we did not attempt to understand how group composition impacts adherence and retention, this is an important question for future inquiries. In addition, while our focus group participants reported improved adherence, we did not directly link their self-reports with viral load testing results as a quantifiable measure of adherence. We also did not explore why CASG members are more likely to be women, and why some patients elect not to join a group. These are important issues to elucidate in the future to potentially address the low uptake of CASG amongst men [1]. Health facilities with CASGs also vary in their levels of support for the program, which may influence the extent to which their CASGs facilitate adherence and retention. Access to HIV treatment services also geographically varies across Mozambique. Patients may therefore be more inclined to join and benefit from a CASG where there are shortages of health facilities, and/or where transportation costs would be higher, and time spent away from home (and/or work) longer. Future inquiries would benefit from considering such geographic variability in CASG and the benefits it confers to patients. We also conducted the focus groups in 2014. Although there is no evidence from this analysis or prior publications of patient perspectives on CASG

participation changing over time, a follow-up study could be helpful in confirming. Lastly, this paper does not explore how the CASG program could be improved nor the program's impact on health systems. This area of inquiry could also benefit from additional consideration.

Conclusions

This paper describes findings from a multi-site evaluation of the CASG program in Mozambique, specifically in exploring the role of social relationships in improving patient adherence and retention. These findings may be helpful in informing what elements of social relationships are critical to foster within CASGs as the Mozambican MoH expands the program nationally.

This paper additionally contributes to the emerging qualitative literature on how support group participation contributes to improved HIV treatment outcomes in resource-limited settings, and to more generally inform others in such settings about salient aspects of social relationships to potentially consider within emerging models of social support for those living with HIV.

Acknowledgements

This work has been supported by the President's Emergency Plan for AIDS Relief (PEPFAR) through CDC under the terms of COAG# PS001542 and COAG# GH001186. The findings and conclusions in this paper are those of the author(s) and do not necessarily represent the official position of the funding agencies.

References

- Auld AF, Shiraishi RW, Couto A, et al. A decade of ART scale-up in Mozambique: evaluation of outcome trends and new models of service delivery among > 300,000 patients enrolled during 2004–2013. J Acquir Immune Defic Syndr 2016;73:e11–22. [PubMed: 27454248]
- 2. Kagee A, Remien RH, Berkman A, Hoffman S, Campos L, Swartz L. Structural barriers to ART adherence in Southern Africa: challenges and potential ways forward. Glob Public Health 2011;6(1):83–97. [PubMed: 20509066]
- 3. Miller C, Kelhapile M, Rybasack-Smith H, Rosen R. Why are antiretroviral treatment patients lost to follow-up? A qualitative study from South Africa. Trop Med Int Health 2010;15(Suppl 1):48–54. [PubMed: 20586960]
- 4. Ware NC, Idoko J, Kaaya S, et al. Explaining adherence success in sub-Saharan Africa: an ethnographic study. PLoS Med 2009;6(1):e11. [PubMed: 19175285]
- 5. Scanlon ML, Vreeman RC. Current strategies for improving access and adherence to antiretroviral therapies in resource-limited settings. HIV/AIDS (Auckl) 2013;5:1–17.
- UNAIDS. 90–90-90: an ambitious treatment target to help end the AIDS epidemic. Geneva: UNAIDS; 2014.
- Decroo T, Koole O, Remartinez D, et al. 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. [PubMed: 24898272]
- 8. Rasschaert F, Telfer B, Lessitala F, et al. A qualitative assessment of a community antiretroviral therapy group model in Tete, Mozambique. PLoS ONE 2014;9(3):e91544. [PubMed: 24651523]
- 9. Rasschaert F, Decroo T, Remartinez D, et al. Adapting a community-based ART delivery model to the patients' needs: a mixed methods research in Tete, Mozambique. BMC Public Health 2014;14:364. [PubMed: 24735550]

 Rasschaert F, Decroo T, Remartinez D, et al. Sustainability of a community-based ART care delivery model—a qualitative research study in Tete, Mozambique. J Int AIDS Soc 2014;17:18910. [PubMed: 25292158]

- 11. Decroo T, Rasschaert F, Telfer B, Remartinez D, Laga M, Ford N. Community-based antiretroviral therapy programs can overcome barriers to retention of patients and decongest health services in sub-Saharan Africa; a systematic review. Int Health 2013;5:169–79. [PubMed: 24030268]
- Decroo T, Telfer B, Biot M, et al. Distribution of antiretroviral treatment through self-forming groups of patients in Tete Province, Mozambique. J Acquir Immune Defic Syndr 2011;56(2):39– 44
- Dewing S, Matthews C, Fatti G, Grimwood A, Boulle A. Antiretroviral adherence interventions in Southern Africa: implications for using HIV treatment for prevention. Curr HIV/AIDS Rep 2014;11:63–71. [PubMed: 24390683]
- 14. Luque-Fernandez MA, Van Cutsem G, Goemaere E, et al. Effectiveness of patient adherence groups as a model of care for stable patients on antiretroviral therapy in Khayelitsha, Cape Town, South Africa. PLoS ONE 2013;8:e56088. [PubMed: 23418518]
- Kamau TM, Olsen VG, Zipp GP, Clark M. The effectiveness of social resource intervention to promote adherence to HIV medication in a multidisciplinary care setting in Kenya. Int J STD AIDS 2012;23:843–8. [PubMed: 23258821]
- 16. Achieng L, Musangi H, Ong'uti S, et al. An observational cohort comparison of facilitators of retention in care and adherence to anti-retroviral therapy at an HIV treatment center in Kenya. PLoS ONE 2012;7(3):e32727. [PubMed: 22427869]
- 17. Scott K, Campbell C, Madanhire C, et al. In what ways do communities support optimal antiretroviral treatment in Zimbabwe. Health Promot Int 2013;29(4):645–54. [PubMed: 23503291]
- 18. Walstrom P, Operario D, Zlotnick C, Mutimura E, Benekigeri C, Cohen MH. "I think my future will be better than my past": examining support group influence on the mental health of HIV-infected Rwandan women. Glob Public Health 2013;8(1):90–105. [PubMed: 22812728]
- Masquillier C, Wouters E, Mortelmans D, van Wyk B, Hausler H, Van Damme W. HIV/AIDS competent households: interaction between a health-enabling environment and community-based treatment adherence support for people living with HIV/AIDs in South Africa. PLoS ONE 2016;11(3):e0151379. [PubMed: 26963257]
- Layer EH, Kennedy CE, Beckham SW, et al. Multi-level factors affecting entry into and engagement in the HIV continuum of care in Iringa, Tanzania. PLoS ONE 2014;9(8):e104961.
 [PubMed: 25119665]
- Russell S, Martin F, Zalwango F, et al. Finding meaning: HIV self-management and wellbeing among people taking antiretroviral therapy in Uganda. PLoS ONE 2016;11(1):e0147896.
 [PubMed: 26807932]
- 22. Krueger R, Casey MA. Focus groups: a practical guide for applied research 2nd ed. Thousand Oaks: Sage; 2009.
- 23. Morgan DL, Krueger RA. The focus group kit Thousand Oaks: Sage; 1998.
- 24. Patton MQ. Qualitative research and evaluation methods 3rd ed. Thousand Oaks: Sage; 2001.
- 25. Patton MQ. Qualitative research and evaluation methods: integrating theory and practice Thousand Oaks: Sage; 2015.
- 26. NVivo qualitative data analysis software. Version 10 Melbourne: QSR International Pty Ltd.; 2012.
- 27. Guest G, Macqueen KM, Namey E. Applied thematic analysis Thousand Oaks: Sage; 2012.
- 28. Golden SD, Earp JAL. Social ecological approaches to individuals and their contexts twenty years of health education and behavior health promotion interventions. Health Educ Behav 2012;39(3): 364–72. [PubMed: 22267868]
- 29. Richard L, Gauvin L, Raine K. Ecological models revisited: their uses and evolution in health promotion over two decades. Annu Rev Public Health 2011;32:307–26. [PubMed: 21219155]
- 30. Riessman F The, "helper" therapy principle. Soc Work 1965;10(2):27-32.
- 31. Jobarteh K, Shiraishi RW, Malimane I, et al. Community ART support groups in Mozambique: the potential of patients as partners in care. PLoS ONE 2016;11(12):e0166444. [PubMed: 27907084]

Author Manuscript

Author Manuscript

Table 1

Theme—time and financial benefits accruing from CASG participation

| Sub-themes | Example quotations |
|-------------------------|---|
| Time savings | A focus group participant observed: |
| | "When she arrives at the facility, they make a note, and if she's from CASG, he tells her not to get in the line just to enter." |
| | Another participant offered this reflection on CASG's ability to reduce patient volume (and correspondingly, wait-time): |
| | "We join together to avoid always coming here together to the Doctor in order to avoid the fill up [of patients] here in the hospital." |
| Decreased work absences | Decreased work A focus group participant explained how CASG participation could result in fewer work absences: absences |
| | "I got in mainly to know this will reduce the requests for excuses at work in the work we always have problems, because the bosses they ask you every time you go to the hospital, actually what do you have? I knew that [CASG] could reduce the problem of always having excuses" |
| | While another focus group participant offered: |
| | " before entering the [CASG] group, sometimes I had problems in coming for consults because I always had to come each month, with fear that they [your employers] still haven't discovered I'm in this situation [have HIV]. |
| Cost savings | A focus group participant shared how participating in CASG can help save money on transportation: |
| | " we have to catch a bus and cross the bridge to here to catch one bus and another, sometimes you don't have money or sometimes you work, and you don't have time to go to the hospital every month." |
| Pooling savings | A focus group participant offered how CASG participation can help in pooling savings: |
| | "CASG helps. It has benefits. For example, if my son were to be sick, my group manages to help me. It could be that I don't have money in order to come to the hospital." |

Page 12

Table 2

Theme—health educational benefits accruing from CASG participation

| Sub-themes | Example quotations |
|---------------------|---|
| Treatment adherence | One focus group participant offered: |
| | "It helped me in moving forward in managing my health. You're doing a lot of things by the fact you're managing yourself. The biggest thing is taking the medication that the doctors give younot taking the medication is what makes your days short" |
| | Another focus group participant highlighted changes in a group member: |
| | "Before he entered CASG, he wasn't adherent. He didn't want to always take his medication, so there were always illnesses. To cut his grass, he was left really weak. But now when he entered the group he is taking his medicationAnd just like that, he's there cutting his grass and does everything." |
| A healthy lifestyle | One focus group participant explained that |
| | being healthy goes beyond taking medication: |
| | "In my group, they teach us to take the medication on time and that even if she [a group member] has a boyfriend, she has to always use the condom she has to know how to reduce the number of these boyfriends the medicine can't make any effect if she takes it, and then does nothing [about risky behaviors]." |
| | Another described how the CASG tried to counsel one of its group members about the negative impact of her smoking and alcohol consumption before she died: |
| | "She was drinking a lot and smoking cigarettes. My group we tried to advise her we talked with her at least three times, of wanting to put her in line, but we lost her, she's just not with us." |

Author Manuscript

Author Manuscript

Author Manuscript

Table 3

Theme—psycho-social benefits accruing from CASG participation

| Sub-themes | Example quotations |
|-----------------------|--|
| Helping others | One focus group participant offered: |
| | "We are able to help our neighbors our friends." |
| | Another shared: |
| | " when a member is sick, and they come to visit Now I see that is what is most important." |
| Sense of belonging | A focus group participant reflected on a reason to participate in CASG: |
| | to have love, we don't feel lost, we have this disease, but we are people just as those who don't have the disease." |
| | One focus group participant shared how effectively living with HIV could motivate others: |
| | " I had courage to encourage my brothers saying, "you, having this (HIV/AIDS) is not the dead. It's not the end of the world I am here. I walk by my feet. Go you too to make treatment to cure yourself." |
| | Another shared how CASG members support one another as a community: |
| | "If a [member] says he doesn't have food at home then other [CASG members] say, come to take [these] peanuts home or come, take [these] beans home." |
| Extended family | A focus group participant described how CASG could serve as a supportive extended family: |
| | "My extended family is CASG. If my family were to be far away, if I were to have problems my friends [other CASG members] would come before my family arrives." |
| | Another shared how the CASG can serve as a proxy for one's own family when encountering stigma and rejection: |
| | to join, to be a family because sometimes at home there are families which when you are sick, they start to reject" |
| | While another reported: |
| | "When we join together as a group, we entertain ourselves, we laugh much it seems like a family." |
| Spiritual connections | A focus group participant described the creed-like nature of CASG as being similar to religious belief: |
| | "Because [CASG membership] is a belief, a creed, like an agreement that you have at church. You accept it with all of your heart" But if your heart is not there, you are not going it, nor are you going to be healed." |
| | Another focus group participant reported how spiritual connections led to CASG formation. |
| | " My colleague is my spiritual sister in the church. We pray together, and we are from the same zone and we met and I started to get sick and as always we tell each other our secrets and she said she has a husband who is there in the hospital. That is when we said let is form a group." |