

Impact of Support Groups for People Living With HIV on Clinical Outcomes: A Systematic Review of the Literature

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Background: Support groups for people living with HIV are integrated into HIV care and treatment programs as a modality for increasing patient literacy and as an intervention to address the psychosocial needs of patients. However, the impact of support groups on key health outcomes has not been fully determined.

Methods: We searched electronic databases from January 1995 through May 2014 and reviewed relevant literature on the impact of support groups on mortality, morbidity, retention in HIV care, quality of life (QOL), and ongoing HIV transmission, as well as their cost-effectiveness.

Results: Of 1809 citations identified, 20 met the inclusion criteria. One reported on mortality, 7 on morbidity, 5 on retention in care, 7 on QOL, and 7 on ongoing HIV transmission. Eighteen (90%) of the articles reported largely positive results on the impact of support group interventions on key outcomes. Support groups were associated with reduced mortality and morbidity, increased retention in care, and improved QOL. Because of study limitations, the overall quality of evidence was rated as fair for mortality, morbidity, retention in care, and QOL, and poor for HIV transmission.

Conclusions: Implementing support groups as an intervention is expected to have a high impact on morbidity and retention in care

and a moderate impact on mortality and QOL of people living with HIV. Support groups improve disclosure with potential prevention benefits but the impact on ongoing transmission is uncertain. It is unclear whether this intervention is cost-effective given the paucity of studies in this area.

Key Words: support groups, clinical outcomes, resource-limited settings, PLHIV

(*J Acquir Immune Defic Syndr* 2015;68:S368–S374)

INTRODUCTION

HIV programs use support groups as an opportunity for health care workers to provide information to people living with HIV (PLHIV). HIV posttest clubs were among the first support groups to be used to provide support to clients who tested positive for HIV.¹ The World Health Organization (WHO) proposes support groups as an intervention to address retention and adherence among PLHIV receiving antiretroviral therapy (ART).²

Both WHO and the US President's Emergency Plan for AIDS Relief (PEPFAR) promote peer support groups facilitated by trained PLHIV to address the special needs of fellow PLHIV and their partners.^{3,4} Such groups serve the purpose of sharing experiences, encouraging disclosure, reducing stigma and discrimination, improving self-esteem, enhancing patients' coping skills and psychosocial functioning, and supporting medication adherence and improved retention in HIV care.^{5–7} These benefits can be maximized further if the support groups are formed around specific populations such as men who have sex with men, pregnant women, adolescents, or couples in discordant relationships. Support groups are also considered an intervention in the management of mental health issues, including alcohol and other substance abuse disorders.² Support groups are generally initiated and supported by nongovernmental organizations, civil society, or community-based organizations and may convene in a health facility or in the community.

Disclosure of HIV-positive status, one of the potential benefits of support groups, has broad prevention implications and is emphasized by both the WHO and the Centers for Disease Control and Prevention (CDC) in all HIV testing protocols.^{8,9} The Mentor Mother support group model—using mothers living with HIV—is a key strategy in the United Nations Global Plan for elimination of pediatric AIDS by 2015 and for keeping mothers alive.¹⁰ The Mentor

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Supported by the US President's Emergency Plan for AIDS Relief (PEPFAR) through the Centers for Disease Control and Prevention (CDC) and the United States Agency for International Development (USAID).

The authors have no conflicts of interest to disclose.

The findings and conclusions in this article are those of the authors and should not be construed to represent the positions of the US Department of State's Office of the US Global AIDS Coordinator and Health Diplomacy, the US Centers for Disease Control and Prevention, or the United States Agency for International Development or the US Federal Government.

Supplemental digital content is available for this article. Direct URL citations appear in the printed text and are provided in the HTML and PDF versions of this article on the journal's Web site (www.jaids.com).

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Mothers is considered an effective intervention to improve maternal and infant well-being among women living with HIV. They work alongside health care workers in the clinic and at community meetings to provide health education, to promote adherence to ART, and to promote disclosure of HIV status among other services.¹¹

Although the WHO and PEPFAR promote the role of support groups,^{2,4} evidence of their impact on key health outcomes has not been assessed. This article presents the results of a systematic review of studies examining the evidence of impact of support groups on mortality, morbidity, retention in care, quality of life (QOL), and HIV transmission, and determining whether they are cost-effective.

METHODS

This review was conducted as part of an assessment of 13 care and support interventions funded by PEPFAR.¹² Details about the interventions and methods for the review including the general search strategy are described fully in the introductory article of this supplement.¹³

The review team conducted a systematic search of the literature using: Medline (through PubMed), EMBASE, Global Health, CINAHL (Cumulative Index to Nursing and Allied Health Literature), SOCA (Sociological Abstracts), and AIM (African Index Medicus) from January 1995 through May 2014 using the following Medical Subject Headings (MeSH) terms: HIV, community support, social support group, informal group, PLHIV network, PLHIV group, volunteer group, support group, self-help group, self-help, peer support and peer support group. These were used in addition to the general search terms described in the introductory article.¹³

The authors reviewed the citations and abstracts independently and identified studies that seemed to address support group interventions and at least 1 of the outcomes of interest. For these “eligible” studies, full-text articles were obtained and evaluated independently by 2 authors. Studies that met the following criteria were “included” in the review: (1) evaluated the impact of HIV support groups, (2) were conducted in resource-limited settings, and (3) addressed 1 or more of the outcomes of interest—mortality, morbidity, retention in HIV care, QOL, or prevention of ongoing HIV transmission. Costing and cost-effectiveness outcomes were also considered.

The following data were abstracted from each study that fulfilled the inclusion criteria: study characteristics (citation, design, study year and year of publication), key findings (the magnitude of effect of the intervention, presented as hazard ratios, odds ratios, or relative risk and 95% confidence intervals), and the quality of evidence. For the latter, we assessed the internal and external validity and other factors and rated the quality of evidence of each study as *strong*, *medium*, or *weak*. Qualitative studies were rated on a scale of I–IV based on methods adapted from Daly et al.¹⁴ The methods for rating study quality are described in detail in the introductory article in this supplement.¹³

Variability in the intervention, study design, and study population precluded combining study results or meta-analysis. Instead, the review team summarised results from all studies

that reported on each outcome. We rated the overall quality of evidence for each outcome as *good*, *fair*, or *poor* based on the criteria developed a priori. We then rated the expected impact—based on the magnitude of effect reported in individual studies, the quality of the body of evidence (all studies addressing each outcome), and consistency of results across the studies—of the intervention on each outcome as *high*, *moderate*, *low*, or *uncertain* (further details regarding rating of quality of evidence for individual studies and quality of evidence and expected impact for each outcome can be found in the introductory article in this supplement).¹³

RESULTS

We screened 1809 abstracts and deemed 137 of the studies to be eligible (Fig. 1). Full-text articles of these 137 studies were reviewed; 20 met the “inclusion” criteria. Studies that were not “included” either did not address support groups as an intervention or did not report on any of the outcomes of interest. Characteristics of the 20 included studies are presented in Table S1 (see Supplemental Digital Content, <http://links.lww.com/QAI/A645>). Six articles reported on multiple outcomes, whereas 14 addressed 1 outcome of interest (see Table S1, Supplemental Digital Content, <http://links.lww.com/QAI/A645>). The majority of studies were conducted in sub-Saharan Africa: South Africa ($n = 7$)^{16,18,22,31,32,35,37}; Kenya ($n = 2$)^{17,29}; Mozambique ($n = 2$)^{15,23}; and one each from Nigeria,²¹ Rwanda,¹⁹ Tanzania,²⁰ Uganda,³⁰ and Zimbabwe.²⁵ Two studies were conducted in Vietnam^{33,34}; the remaining 2 reported multi-country results.^{28,36}

Most studies (18) were observational—using either a cross-sectional or cohort design (11), a qualitative (5), or a mixed methods study design (2); and 2 were experimental studies—an unblinded randomized controlled study²⁰ and a study using a quasi-experimental design.³² Sample sizes ranged from 21 in a qualitative study to over 300,000 in a multicountry observational cohort. Three studies targeted only women; 1 recruited only men; the remaining studies ($n = 16$) included both men and women. In addition to being enrolled in support groups, PLHIV often received other interventions, such as being seen by community health workers or being assigned treatment buddies. Table S1 (see Supplemental Digital Content, <http://links.lww.com/QAI/A645>) presents further details on the characteristics and findings from the 20 individual studies.

Outcomes, Quality of the Evidence and Expected Impact

Mortality

One study examined the effect of support groups on mortality. Decroo et al, reporting on a Mozambique cohort, found a mortality rate among 5729 individuals enrolled in Community Adherence Groups (CAGs) of only 2.1 per 100 person-years and a loss to follow-up (LTFU) rate of 0.1 per 100 person-years. Only 208 (3.6%) were reported as dead after a median follow-up time of 19 months (interquartile range: 10–29).¹⁵ The authors also reported an overall attrition of 3.9% mostly from mortality (3.7%) and the rest from LTFU (0.2%).

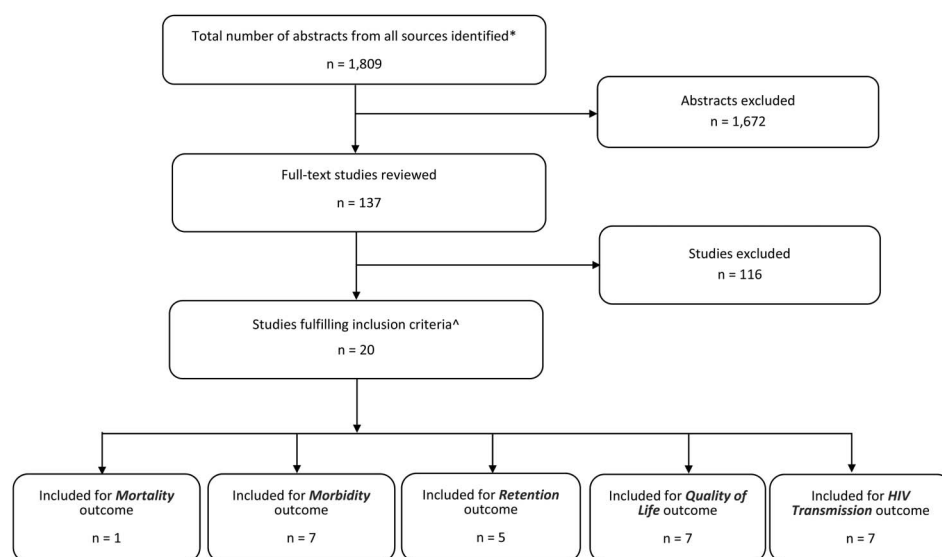


FIGURE 1. Total number of studies identified, screened, eligible, and included in the systematic review of support groups for PLHIV January 1990–May 2014.

* Duplicate citations removed.

^ Numbers below in outcome section add up to more than 20 as some studies addressed more than one outcome.

Factors associated with attrition (both mortality and LTFU) were presented at individual and group level. At the individual level, attrition in CAGs was associated with a low CD4 count at the time of enrollment in CAG [aHR 2.28, 95% confidence interval (CI): 1.60 to 3.24] and being male (aHR 1.93, 95% CI: 1.48 to 2.51). At the group (CAG) level, lack of rotational representation by each of the different group members at the clinic (aHR 1.72, 95% CI: 1.27 to 2.33), lack of regular CD4 count ascertainment among members of the same group (aHR 1.88, 95% CI: 1.18 to 3.00), and attending a rural (aHR 2.59, 95% CI: 1.81 to 3.70) or district clinic (aHR 1.57, 95% CI: 1.14 to 2.16) were associated with higher attrition. There was no comparison group.

Reviewers rated the “overall” quality of evidence for the outcome of mortality as fair. However, the expected impact on mortality was rated as moderate based on the low mortality rate among those who participated in the support groups in this study (Table 1).

Morbidity

Seven studies^{16–22} reported on the impact of support group interventions on a range of morbidity outcomes (see Table S1, Supplemental Digital Content, <http://links.lww.com/QAI/A645>). Support groups were associated with reduced frequency of HIV-related symptoms—somatic symptoms, anxiety and insomnia,¹⁸ and depression.^{20–22} Other benefits included improved access to ART, adherence to ART and treatment success,^{16,17,19,25} measured as time to treatment failure and reduced risk of detectable viremia or change in the CD4 cell count. For example, Achieng et al¹⁷ reported that time to treatment failure was longer in patients participating in support groups (448 days vs. 337 days, $P = 0.001$). Results from a South African cohort of 268 PLHIV enrolled in the public sector HIV treatment program reported participation in a support group as a predictor of treatment success (ie, viral load < 400 copies/mL, CD4 > 200 cells/mL),

during the first 6, 12, and 24 months of ART.¹⁶ Support group participants were significantly more likely to have an undetectable viral load ($P < 0.001$) and a CD4 cell count > 200 cells per milliliter at 12 months ($P < 0.01$) than those who did not participate in a support group. Viral load suppression was maintained beyond 24 months after enrollment in a support group ($P < 0.01$). In the Muchedzi study, women tested for HIV in a prevention of mother-to-child transmission (PMTCT) program and enrolled in a support group were twice as likely to access care and treatment (OR = 2.34, 95% CI: 1.13 to 4.88) although their treatment outcomes were not reported.²⁵ Outcomes from the remaining 5 studies are presented in Table S1 (see Supplemental Digital Content, <http://links.lww.com/QAI/A645>).

Although findings from the 7 studies consistently reported morbidity benefits, reviewers rated the overall quality of evidence as fair based on limitations of the included studies. Almost all were cross-sectional, qualitative, or had small sample sizes. In addition, different morbidity-related outcomes were reported. Nevertheless, the expected impact of support groups on reducing morbidity in PLHIV was rated as high based on significant associations between support group participation and decrease in morbidity from studies from 6 different countries.

Retention in Care

Five studies^{15,16,23,25,28}—2 from the same Mozambique cohort^{16,23}—reported low LTFU for patients on ART participating in support groups. Decroo et al²³ reported high retention with approximately 97.5% patients remaining in care for a median follow-up period of 12.9 months (range, 8.5–14 months) and 91.8% at 4 years.¹⁵ Overall, the authors reported that attrition in the cohort was lower than the national 12-month average for Mozambique (15%)³⁸ and even lower than rates reported in the literature for sub-

TABLE 1. Summary of Evidence From All Studies by Outcome

Outcomes	Overall Quality of Evidence		Impact of the Intervention	Evidence From Economic Evaluation		Comments
	Number of Studies	Overall Quality of the Body of Evidence (Good, Fair, Poor)	*Expected Impact (High, Moderate, Low)	Number of Studies	Quality of Evidence From Economic Evaluation	
Mortality	1 ¹⁵	Fair	Moderate	None	NA	Some support group characteristics described in the South Africa settings do provide some important lessons
Morbidity	7 ^{16–22}	Fair	High	None	NA	Almost all studies were cross-sectional or qualitative and only demonstrate associations. Different outcomes for morbidity were used in the different studies
Retention in care	5 ^{15,16,23,25,28}	Fair	High	None	NA	Results from several large cohorts demonstrate sustained retention especially in ART patients
QOL	7 ^{18,29–34}	Poor	Moderate	None	NA	As reported, the studies all used different measures of QOL. All reported outcomes would have an impact on QOL for PLHIV directly or indirectly
HIV transmission	7 ^{20,27,29,30,35–37}	Poor	Uncertain	None	NA	Three of the 4 studies were conducted in South Africa, with mixed results. One study conducted elsewhere had mixed results and involved nonrepresentative sample of participants from each country

Assessment of the expected impact of the intervention was based on published evidence. Additional considerations that would inform implementation decisions would have to take into account the cost-effectiveness information and country specific contextual considerations.

*The expected impact of the intervention was rated as: high, intervention expected to have a high impact on the outcome; moderate, likely to have a moderate impact on the outcome; low, intervention expected to have a low impact on the outcome; and uncertain, available information is not adequate to assess estimated impact on the outcome.

Saharan Africa (1.2%–26%).²⁴ A large study with more than 300,000 participants aged 10–24 years from 4 sub-Saharan countries showed that youth participating in support groups provided by clinics experienced slightly lower attrition after ART initiation (AHR = 0.73, 95% CI: 0.52 to 1.0); in the pre-ART period, the authors reported no significant associations between attrition and participation in support groups or other adolescent friendly services—availability of adolescent peer educators, or education on high-risk substance abusing behaviour.²⁸ Higher retention among support group participants was also reported among patients on ART in South Africa¹⁶ and among women enrolled in the PMTCT program in Zimbabwe²⁵ (see Table S1, Supplemental Digital Content, <http://links.lww.com/QAI/A645>).

Reviewers categorized the quality of evidence for this outcome as fair. All 5 studies were observational. Sample sizes were small for 2 of the studies^{16,25} and the findings from the larger study²⁸ are not generalizable beyond the 10- to 24-year age group. Lack of a comparison group in 2 studies^{15,23} and other methodological limitations affected the quality of evidence for this outcome. The expected impact of support groups on retention was rated as high for patients on ART but uncertain for pre-ART patients (Table 1).

Quality of Life

Seven studies—5 qualitative,^{29–31,33,34} 1 quasi-experimental,³² and the other using mixed methods¹⁸—reported associations between membership and/or attendance at support groups

and several measures of QOL (see Table S1, Supplemental Digital Content, <http://links.lww.com/QAI/A645>). Measures varied by study and included reported improvement in symptoms, improved confidence and self-esteem, better coping skills, and perceived reduction in stigma. The authors reported that support group participation enabled patients to seek care³⁰ and start ARVs.³⁴ Other benefits reported by Kim et al³⁰ were spill-over effects to the community in which HIV-infected persons who were not in support groups were encouraged to seek care. Although the benefits were mostly positive, Mfecane³¹ reported that a cohort of men who attended support groups felt that participation imposed pressure to conform in a way that negatively affected their perception of masculinity. Dageid and Duckert¹⁸ reported negative effects such as inadvertent disclosure of HIV-positive status and gossip and stigmatization from other support group members and/or the community.

Reviewers categorized the quality of evidence for this outcome as poor. Four of the studies were qualitative^{29,30,33,34} and most had small sample sizes. One reported only on men,³¹ and 3 only on women,^{29,32,33} limiting the generalizability of the findings. Despite the limitations in some of the studies, the expected impact on QOL was rated as moderate (Table 1) based on consistently positive results on QOL across studies.

HIV Transmission

Seven studies^{20,27,29,30,35–37} reported on outcomes, which may directly or indirectly impact HIV transmission,

such as risky sexual behavior and disclosure of HIV-positive status to sex partners. Three of the 7 studies were conducted in South Africa^{16,35,37} (see Table S1, Supplemental Digital Content, <http://links.lww.com/QAI/A645>). Gaede et al³⁵ reported positive associations between attendance at support groups and health behaviors and condom use. Four studies^{20,27,36,37} reported mixed results regarding the association between support group participation and disclosure of HIV status; Skogmar found no significant difference in disclosure rates between those who attended only pretest/posttest counseling (standard of care) and those who received either professional counseling or participated in support groups.³⁷ Wouters reported that assistance of community health workers and support group participation resulted in disclosure of HIV status to non-family members only in the second year of implementation of the program; however, the impact of support groups alone was not reported.²⁷ Hardon et al,³⁶ in a mixed methods study involving participants from 4 African countries (Burkina Faso, Kenya, Malawi, and Uganda), showed that membership in a support group was associated with not disclosing to partners for fear of stigma—the experience of prejudice and discrimination as the consequence of being HIV positive. Additionally, although an unblinded randomized control study conducted in Tanzania reported a 20% increase in disclosure for support group participants compared with controls, the difference was not statistically significant (RR = 1.2, 95% CI: 0.91 to 1.6, $P = 0.19$) and 12% of those who gave feedback about the disclosure reported negative reactions such as anger, blame, and being told to leave the household.²⁰ Two articles reported an association between support group attendance and increased disclosure to spouses and other family members.^{29,30}

Reviewers categorized the quality of evidence from the 7 studies as poor and the expected impact on HIV transmission as uncertain.

DISCUSSION

We identified 20 studies from low- and middle-income countries, which evaluated the impact of support groups on mortality, morbidity, retention in care, QOL, or HIV transmission. No studies reported costing or cost-effectiveness data. The studies were primarily from sub-Saharan Africa and varied in study design, target population, and sample size.

The review found largely positive results. Although limited by the quality of the included studies, the data suggest potential benefit of support groups on key health outcomes. We rated the expected impact of support groups as an intervention in PLHIV as high in terms of reducing morbidity and improving retention in care. Support groups also have the potential to influence mortality, QOL, and prevention of ongoing HIV transmission. Specific positive benefits associated with support group membership include enhancing treatment success and improving the QOL through equipping PLHIV with coping skills.

With the development of community-based care models in some settings, support groups could provide an opportunity for PLHIV to share experiences and become more engaged in their care. Given the severe human resource challenges in sub-Saharan Africa, specifically the shortage of trained health

care providers,²⁶ support groups can play an increasingly larger role in care models, particularly regarding retaining HIV-infected persons in care. Based on success of the pilot program developed by Médecins Sans Frontières (MSF) and provincial health officials in Mozambique reported in this review,^{15,23} the Mozambique Ministry of Health is scaling up CAGs nationally.

We did not specifically search for adherence as an outcome in this review. However, 5 studies reported increased adherence to ART^{16,17,19,31} associated with support group participation. In the study by Wouters et al, 89.9% of support group members reported that support group meetings helped create a forum for sharing knowledge and experiences, some of which related to taking medications. In Mozambique, PLHIV enrolled in support groups reported increased adherence.²³

Two studies described negative outcomes. In a South Africa study, male participants in support groups felt under pressure to conform to a lifestyle that was not consistent with established gender roles,³¹ whereas a large mixed methods study with participants from Burkina Faso, Kenya, Malawi, and Uganda showed that membership in a support group was associated with nondisclosure to partners.²⁸ These issues will need to be addressed to maximize the potential of support groups as an intervention.

Limitations

Conclusions of this review should be interpreted with caution given the methodological limitations and relatively small number of studies. The majority of the studies were observational, 8 used qualitative methods, 3 studies enrolled less than 70 participants each,^{15,24,31} 1 study included only men,³¹ and 3 recruited only women.^{25,29,32} Therefore, the findings may not be generalizable to the broader community and to other patient populations. Additionally, PLHIV participating in support groups often received other interventions. The impact of the other interventions or their combination may have influenced the results reported in this review. Evidence from this review may not be adequate to inform major policy changes regarding the role of support groups.

Research Gaps

Although this review has provided useful information regarding support groups, there are information gaps. Which patients are most in need of support group participation? What venues are optimal, and how do these depend on the populations participating? Who should lead the support groups? What specific considerations should be given to newly diagnosed patients, men, women, key population groups, and those starting ART?

Cost-effectiveness of the intervention is an outstanding issue. None of the studies included costing data; nor were they designed to test effectiveness for the outcomes under review. The Mozambique CAG pilot was successful in part because more than a quarter (28%) of the members shared the cost of transport. It is unclear whether other types of support groups would be feasible and sustainable in their respective settings. Programs already underway such as the national

rollout of CAGs in Mozambique should be rigorously evaluated. Data from these evaluations could be useful for national governments and donor funding decisions.

Programmatic Considerations for Implementation

It is apparent from this review that support groups have the potential to play an important role in HIV care and treatment programs, in terms of having impact on key health outcomes, and in retaining HIV-infected persons in care. They may also provide an alternative care model toward attaining universal access to ART in settings where long distances to health facilities, shortage of human resources, and waiting times remain barriers to HIV care. Implementation issues and challenges were beyond the scope of this review; however, several merit discussion: membership and access; resources and sustainability; monitoring and evaluation; and models of implementation.

Regarding membership, not all patients need or want to participate in support groups, and health care facilities may not be able to accommodate all patients who might benefit from a support group intervention. Therefore, it is important to target support group resources to those who might benefit the most. For example, support groups targeting key populations could be useful in settings with high levels of stigma and discrimination directed toward PLHIV. In this review, most support groups were formed to support patients on ART. Programs for pre-ART patients should be developed to determine whether these patients might benefit from support group participation. Implementers should identify motivators for attendance and also, perhaps, criteria to determine when participation might no longer be necessary. The needs for patients in urban vs. rural HIV care programs may differ significantly.

Second, resources are needed to start and maintain support groups—both human and infrastructural. Support group programs require physical meeting space away from crowded health facilities; they may require phone credit, transportation support, and refreshments during meetings, among other needs. Training in facilitation skills and capacity building are especially important to foster free expression and to encourage full participation. The actual costs associated with running support groups are difficult to estimate in part due to lack of accurate data on the number of PLHIV who currently access services. The comparative evaluation of different models would enrich our knowledge of which support group models to scale up. Programs should understand how best to make support groups self-sustaining and less dependent on donor funding. Early lessons from Mozambique suggest that the CASG support group model is self-sustaining and could potentially be replicated in other settings.

Third, for donors and ministries of health that fund support groups, monitoring and evaluation metrics are important to assess the value of support group interventions. Community-level HIV indicators, including those that measure linkage between facilities and the community and retention in support group programs will be important to develop to monitor success and to ensure accountability.

Last, support groups are yet to be formalized as standard practice in HIV care and treatment programs; inadequate data as evident in this literature review are one of the challenges. Models for such programming need to be explored. For example, a model that links community-based support groups to an assigned health facility in a hub-and-spoke fashion with a formalized system for bidirectional referral would be useful to explore.

CONCLUSIONS

Implementing support groups in PLHIV is likely to have an impact on morbidity and retention in care and has the potential to improve QOL and mortality. Additional research and operational lessons are needed to maximize the benefits of support groups as an integral component of HIV care and treatment.

ACKNOWLEDGMENTS

The authors acknowledge the following individuals who participated in the evidence review: Gail Bang and Emily Weyant from the CDC Library, who conducted the literature searches; and Ratanang Balisi from USAID (Botswana) and Peter Vranken from CDC (South Africa) who helped screen citations.

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