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Feasibility, Acceptability and Preliminary Efficacy of Tikambisane ('Let's Talk to Each Other'): A Pilot Support Group Intervention for Adolescent Girls Living With HIV in Zambia

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Abstract

Background: In Zambia, 84,959 adolescent girls and young women (AGYW) aged 15-24 are currently living with HIV. We explored the feasibility and acceptability of a 6-session, curriculum-based support group intervention designed to address key concerns of AGYW living with HIV. **Setting:** Urban Zambia **Methods:** Surveys and in-depth interviews were collected pre- and post-intervention from participants enrolled from 2 health facilities. Eight participant observations of sessions were conducted. Descriptive statistics at baseline were reported only for AGYW who participated in the intervention (N = 21), while analyses comparing baseline and endline outcome measures were restricted to participants who had data at both time points (N = 14). **Results:** Support groups were feasible to conduct and acceptable to participants. Co-facilitation by an adult counselor and peers living with HIV raised confidence about session content. Sessions on antiretroviral therapy (ART), disclosure and stigma, and grief and loss were most in demand. We did not observe significant differences in key outcome measures between baseline and follow-up. However, qualitative data supported the positive impact of the intervention on ART adherence and hope for the future following the intervention among our participants. **Conclusion:** A short-term, structured support group series holds promise for helping AGYW living with HIV safely navigate a complex time in their lives.

Keywords

adolescent girls, young women, HIV, support groups, Zambia, stigma, adherence

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Q: What Do We Already Know about This Topic?

A: We know that there is an unmet need for emotional and informational support for adolescent girls and young women living with HIV to support both their mental and physical health, particularly in sub-Saharan Africa.

Q: How Does Your Research Contribute to the Field?

A: The 6-session Tikambisane support group series was feasible to implement, acceptable to participants, and has the potential to support healthy transitions to adulthood by reducing stigma, increasing hope for the future and improving ART adherence among AGYW living with HIV.

Q: What Are Your Research's Implications towards Theory, Practice or Policy?

A: Our research provides an evidence-based, community-developed curriculum that can be integrated into national HIV response plans and implemented alongside care and treatment for AGYW living with HIV.

Background

HIV disproportionately affects adolescent girls and young women (AGYW) in sub-Saharan Africa due to a range of social and structural factors.[1,2] Previous research has identified several challenges facing AGYW living with HIV, including ART adherence, stigma, lack of emotional support and harmful gender norms, which may impact their medical and psychosocial outcomes.[3-6] In Zambia, an estimated 84,959 AGYW aged 15-24 were living with HIV in 2020,[7] yet interventions to support their healthy transition to adulthood are limited, and tend to focus specifically on ART adherence, in the form of adherence support clubs,[8] peer support within health facilities,[9,10] or on parents and caregivers.[11]

In 2015, we carried out formative research with a group of 24 AGYW living with HIV in urban Zambia to identify challenges they were facing and ways that a healthy transition to adulthood could be supported. Unmet needs for emotional and informational support emerged from the research as critical gaps. In addition, the participants had few opportunities to engage with other AGYW living with HIV, and the desire for an effective support group outside of the health facility environment was raised.[12,13]

Developing interventions to support a healthy transition from adolescence to adulthood for girls living with HIV is important, as this population accounts for nearly 30% of incident cases.[14] Support groups among peers living with HIV can be beneficial for reducing internalized stigma, which in turn can facilitate greater engagement with care and treatment,[15,16] and have been shown to reduce morbidity and mortality and increase quality of life in previous research with adults living with HIV.[15] Further, support groups can provide necessary emotional support and serve as a platform for knowledge and skill sharing, all of which can empower young people living with HIV to take control of and manage their health.[17-20] To this end, we sought to assess the feasibility, acceptability and preliminary efficacy of a 6-session support group intervention designed to facilitate healthy transitions to adulthood among AGYW aged 15-19 living with HIV in Lusaka, Zambia.

Methods

Intervention

The Tikambisane curriculum was designed collaboratively with AGYW living with HIV, participatory educators with expertise in HIV stigma-reduction, healthcare providers, HIV counselors, program implementers, and research staff to address the key needs and concerns identified in our formative research.[12,13] The final curriculum contains 6 sessions addressing the following topics: getting to know you, disclosure and stigma, antiretroviral therapy (ART), relationships, grief and loss, and planning for the future. The sessions were 2-3 hours in length and were held every other Saturday over a 3-month period. Facilitators used a variety of participatory techniques and methodologies, such as buzz groups, card storms, small group work and role plays, to convey the session content. The curriculum is publicly available online.[21] A trained team, consisting of an adult HIV counselor and participatory educator and 2 peers living with HIV facilitated each session. The peer co-facilitators had previously participated in the pilot study,[12] were involved in the development of the support group curriculum, and participated in a 2-day training workshop that covered listening and facilitation skills and the content of the support group curriculum.

'Tikambisane' means 'Let's talk to each other' in Nyanga, one of the primary languages spoken in Lusaka. Our research team chose this name because it reflects the essence of the support group approach, in providing a safe space for AGYW to talk with, share stories with and support each other.

Study Design and Population

This study utilized a pre-post, mixed methods design to assess the feasibility and acceptability of a curriculum-based support group. The intervention was implemented in private spaces (i.e. a community sports center and a classroom at an orphanage) in the 2 intervention communities, Chipata and Kanyama, near the 2 selected public health facilities in Lusaka, Zambia. Eligible participants included AGYW aged 15-19 years living with HIV in Lusaka who were currently in HIV care. Those who did not meet these criteria, were mentally unable, were at high risk of further or increased abuse as a result of participation, had a parent/guardian who was unaware of the young woman's HIV positive status, or had ever participated in a formal support group for youth living with HIV were excluded.

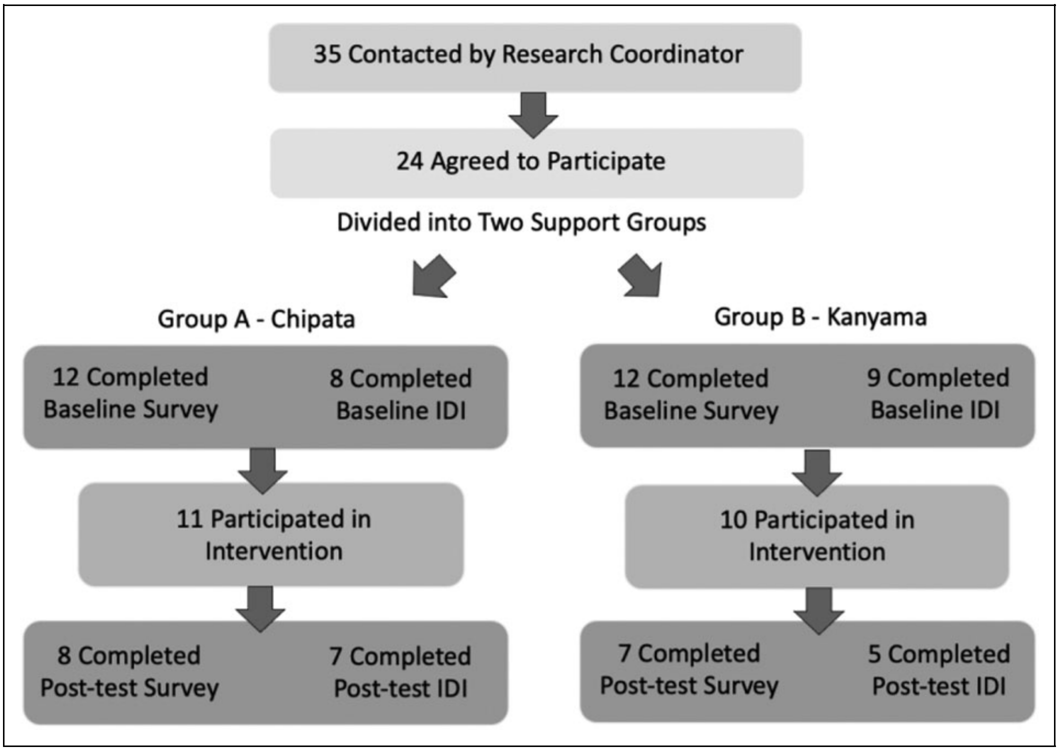

Figure 1. Study flow chart.

The research participants were recruited from 2 public health facilities in Lusaka that provided primary health care services and were in the process of being upgraded to first level hospitals during the period of this research. Recruitment took place during adolescent clinic hours. The research coordinator (MM) worked with the adolescent coordinators at the health facilities to identify adolescent girls who fit the selection criteria. The research coordinator then spoke to each adolescent about the project and asked if she was interested in participating. Potential participants under the age of 18 years of age received an information letter to be taken home to parents/ guardians explaining the study. Information sheets, as well as the surveys and in-depth interview (IDI) guides, were available in 2 vernacular languages (Bemba and Nyanja), as well as in English. Baseline data collection took place at the Zambart study office in September 2017. The support groups ran from October to December. Endline data collection was planned for January 2018, however, shortly after beginning, a cholera outbreak in Lusaka delayed data collection by several weeks. Thus, most interviews took place between February and March 2018, either at Zambart or at the home of the participant, based on their preference. Participants received 50 Kwacha ($5 USD) to cover their transport to and from support group sessions, and to and from baseline and endline assessments. Thirty-five AGYW living with HIV were approached over a 6-week period and 24 eligible AGYW agreed to participate and completed the baseline survey. Seventeen purposively selected participants completed an IDI. Twenty-one girls participated in the intervention, 15 completed the endline survey and 12 completed IDIs (Figure 1). Surveys and in-depth interviews were conducted in either Bemba, Nyanja or English, based on the preference of the participants. IDIs were recorded, transcribed and translated into English. In-depth interviews took about 60 minutes, while surveys took about 45 minutes to complete.

Quantitative Outcome Measures

Outcome measures assessed included stigma, measured using the 14-item Stigma Scale for Chronic Illness,[22] hope for the future, measured using the 12-item Hope Scale,[23] and ART adherence, measured using the CASE Adherence Index.[24] The Stigma Scale for Chronic Illness was validated among African American women living with HIV in the US. The 14-items measure internalized and enacted stigma. All items used “lately” as the recall period and each item had 5 response options ranging from “never” to “always.” In our study, we modified the scale items to reference HIV rather than an unspecified illness. The sum of these items is taken; a higher total equates with greater experience of internalized and enacted stigma. We report both the full scale and the internalized stigma sub-scale. Mean imputation was used to estimate the value of 2 scale items for 1 participant.[22]

The Hope Scale was developed and validated for use among young women in South Africa living in high HIV prevalence areas. The 12-item scale has a 4-point response format ranging from “1 = Total Disagreement” to “4 = Total Agreement”. The average of these items is taken; a higher score reflects more hope.[23]

Table 1. Participant Characteristics at Baseline.

	N = 21 n (%)
Age (years)	
15	7 (33.3)
16	2 (9.5)
17	2 (9.5)
18	7 (33.3)
19	3 (14.3)
Highest Grade Completed	
8 or Lower	18 (85.7)
9 or Higher	3 (14.3)
Both Parents Living*	
Yes	4 (20.0)
No	5 (25.0)
Mother Only	8 (40.0)
Father Only	3 (15.0)
Currently Taking ARV Drugs	
Yes	20 (95.2)
No	1 (4.8)
Lives with Person Living with HIV	
Yes	20 (95.2)
No	1 (4.8)
Ever had sex	
Yes	7 (33.3)
No	14 (66.7)

*N = 20 for this characteristic due to a missing response.

Self-reported ART adherence was assessed using the validated 3-item, CASE Adherence Index. The index assesses 3 related aspects of adherence, including: difficulty taking medications on time (contributing 1 to 4 points), average number of days per week missed at least 1 dose (contributing 1 to 6 points), and last time missed at least 1 dose (contributing 1 to 6 points). Scores greater than 10 on the 3- to 16-point scale are highly correlated with better adherence, and thus the additive scale is dichotomized around 10 for analysis purposes.[24]

Qualitative Approach

Topics explored in the IDIs pre- and post- intervention included existing sources of support, challenges experienced due to living with HIV, and the impact of both HIV and ART on the AGYW's body, life aspirations and hope for the future. These topics were informed by the formative research and the literature. At baseline, participants were asked to reflect on their expectations of the group-based support intervention. The perceived quality of and benefits derived from the support groups were explored following the intervention, as well as participants' satisfaction with the sessions.

Data Analysis

Interview transcripts and observation notes were coded in Nvivo 11.0 and analyzed using a content analysis approach. Deductive coding and analysis were employed to assess feasibility, acceptability and preliminary efficacy of the intervention. Survey data were analyzed in Stata 14. Descriptive statistics at baseline were reported only for AGYW who participated in the intervention (N = 21), while analyses comparing baseline and endline outcome measures were restricted to only those participants who had data at both time points (N = 14). Unpaired t-tests were used for continuous variables and the Chi-square test for independence was used for dichotomous variables. A p-value of 0.10 was considered for statistical significance due to the small sample size. The findings from these 2 approaches were jointly assessed to enhance the robustness of the analysis and interpretation of these results. Qualitative findings provided a deeper understanding of how participants perceived the support groups and how the support group content shaped their understanding and experiences.

Ethical Approval and Informed Consent

Written, informed consent for participation in the research was sought from a parent or legal guardian for participants under the age of 18, and if granted, assent was then sought from the participant under 18 prior to enrolment. Participants 18 years of age and older provided written, informed consent prior to enrolment. All participants were provided with a referral list of organizations from which they could seek support as needed for any physical, social or psychological issues they might face. Ethical clearance was obtained from review boards at the International Center for Research on Women in Washington, D.C. [Approval ID: 16-0007], the London School of Hygiene and Tropical Medicine in London, U.K. [Approval ID: 14074], the University of Zambia Humanities and Social Science Research Ethics Committee, Lusaka, Zambia [No reference ID provided] and the National Health Research Authority of Zambia [Approval ID: MH/101/23/10/1]. The findings from the study and the curriculum were disseminated to the participants and other interest groups in the 2 health facilities first, and then nationally. Care was taken to not identify participants at the disseminations to uphold confidentiality.

Results

Participant Characteristics

The participant characteristics at baseline are described in Table 1. Participant ages ranged from 15 to 19 years, with the most common ages being 18 (9 participants) and 15 (7 participants). Most participants had completed grade 8 or lower (87.5%). Eighteen participants had lost either 1 (n = 13) or both parents (n = 5). With the exception of 1 participant, all reported that they were currently taking ARVs (95.8%) and resided with at least 1 person living with HIV (95.8%). Nine participants (37.5%) reported ever having sexual intercourse (Table 1).

Feasibility

The research team was able to achieve full enrollment within a 6-week period and all participants completed their baseline assessments. Most of the AGYW went on to participate in the intervention and participation was very high, with all AGYW attending a minimum of 5 sessions and 7 attending all 6 sessions. The length of the sessions was sufficient to cover all of the session content; however, the participants expressed a desire to stay longer to continue discussions and extend the time they were able to be with other "girls like them". Holding sessions on Saturdays enabled participation for the mostly school-going and church-going participants, and financial reimbursement for travel was noted as important to facilitate regular participation in support groups. While the sessions were initially clinic-based, the locations were shifted to safe spaces near the public health facilities, a community sports center and a classroom at an orphanage, in order to provide a more private atmosphere in which to engage in the participatory activities and discussions.

Acceptability

Participants appreciated all of the sessions and the content covered in each, and they especially valued the facilitation style. Several participants noted that co-facilitation by a trained team consisting of an adult counselor and peers living with HIV raised confidence about both the organization of sessions and the quality of information provided. Participants relayed that having peers co-facilitating put them at ease and made them more comfortable to openly discuss their experiences. They expounded on this by stating that the peer facilitators treated them kindly, made them feel accepted and fostered a sense of unity.

> "We [participants and peer facilitators] used to be together [at support group sessions] and we used to make jokes, laughing together. [The peer facilitators living with HIV] never treated us like we were from elsewhere." (18 years old, Chipata)

The AGYW shared similar positive sentiments about the adult counselors who co-facilitated the support group sessions. Most of the respondents reported their satisfaction with the facilitation and appreciated that they were treated nicely and with patience. The respondents asserted that they did not think that the facilitation should have been done differently, thus did not offer any suggestions for improvement. Overall, the main recommendation from participants was that they would have liked to have more than 6 sessions. Although both clinics had support groups for adolescents living with HIV, these groups were not funded at the time, the group facilitators were struggling to run sessions regularly and attendance was reportedly poor. One clinic facilitator at the dissemination said that many adolescents required transport funds to reach the support group venue. When we referred the participants to these support groups, they were not keen to attend.

Preliminary Efficacy

The intervention appears to have met the expectations expressed by the participants. Specifically, they were eager to gain more knowledge about HIV and ART, the implications of living with HIV on their lives in the future, maintaining good health and coping strategies. Accordingly, the most popular sessions were those on ART, disclosure and stigma, and grief and loss.

> "On disclosure we learnt how we can tell someone about your status... [and on stigma] you do not need to feel that since I have... this condition, I cannot do certain things, no, you need to be like... everyone else is. That even me, I can do this work, or even at work, some refuse people who are HIV positive. But you can do that work, do not have a feeling that since I am [living with HIV] I cannot do it." (19 years old, Kanyama)
>
> "[The grief and loss session] helped me because I shared with my friends, because from the time [my father] died, I have never shared with anyone." (18 years old, Chipata)

The respondents discussed their intentions to share the information they obtained from the support group with others in their community to educate and spread awareness.

Establishing connections and friendships with other AGYW living with HIV was another key outcome mentioned by several of the participants. As most participants had never before interacted with another youth living with HIV, these connections were particularly important for facilitating coping by expanding the AGYW's peer support networks.

> "We became more like friends with people we found there." (18 years old, Chipata)
>
> "Support groups... are different. When I am in the support group and with friends, I just have fun, hanging out with my friends. And then at home, I don't do much. When I come to the support group, I even forget many things." (18 years old, Chipata)

All participants wanted the support groups to continue for longer and many exchanged contact information in order to stay in touch with the other participants after the intervention. Some girls expressed concerns about where they would access future emotional and informational support, due to a range of challenges with the support groups offered in their communities. Participants valued the stability of the Tikambisane support group. Some made comparisons to other available programs, noting how much more reliable and informative they found Tikambisane.

While not significant, mean scores on the hope for the future scale increased slightly following the intervention, from a mean score of 3.0 to 3.2 ($p = 0.261$) (Table 2). This hopefulness was also reflected in the stories shared by participants in the endline IDIs.

> "I see that I can have a different life, from where I have been... because last year, in fact last year I was living a life where I was not happy at all times, being alone most times. Now I think my friends will be more and I will have a lot of things to do." (19 years old, Kanyama)
>
> "My hopes and dreams, [HIV] cannot even stop me [from achieving them]. I know where I am going now, and I can still take my medication." (15 years old, Chipata)

Table 2. Comparison of Outcomes Pre- and Post-Intervention for Participants with Data at Both Time Points (N = 14).

	Baseline		Endline		
Outcome variables	n/N	Mean (SD)	n/N	Mean (SD)	*p*-value@
Enacted and internalized stigma*	14/21	27.4 (7.7)	14/14	28.0 (8.3)	0.834
Internalized stigma^	14/21	18.8 (4.6)	14/14	18.9 (6.4)	0.973
Hope for the future#	12/21	3.0 (0.4)	13/14	3.2 (0.4)	0.261
Case Adherence Index&	n/N	%	n/N	%	
≥ 10	14/20	85.7	13/14	84.6	0.140

*Higher scores on the Stigma Scale for Chronic Illness Scale (SSCI) reflect more stigma reported; ^Limited to the 7 items measuring internalized stigma in the SSCI; #Higher scores on the Hope Scale reflect more hope for the future; &Scores greater than or equal to 10 on the CASE Adherence Index reflect better adherence; @*p*-values were calculated using unpaired t-tests for means and the Chi-square test of independence for dichotomous variables.

Table 3. Mean Agreement With Items Included in the Stigma Scale for Chronic Illness.

SSCI Items*	Baseline (N = 21) Mean* (SD)
Because I am living with HIV, some people have seemed uncomfortable with me	1.33 (1.06)
Because I am living with HIV, people were unkind to me.	0.95 (0.22)
Because I am living with HIV, some people have avoided me.	1.29 (0.96)
Because I am living with HIV, I was treated unfairly by others.	1.38 (1.20)
Because I am living with HIV, people tended to ignore my good points	1.00 (0.00)
Because I am living with HIV, I worried that I was a burden to others.	1.86 (1.35)
Some people acted as though having HIV was my fault	1.29 (0.96)
Because I am living with HIV, I felt emotionally distant from other people.	2.19 (1.12)
Because I am living with HIV, I felt left out of things	2.10 (1.22)
I felt embarrassed about living with HIV	1.48 (0.87)
Because I am living with HIV, I felt different from others	2.29 (1.35)
I avoided making new friends.	2.19 (1.44)
I was careful who I told about my HIV status.	4.62 (1.20)
I worried that people would tell others about my HIV status.	4.62 (0.97)

*Higher means on the Stigma Scale for Chronic Illness Scale (SSCI) items reflect more stigma reported; items shaded in light grey capture internalized stigma.

The means of the combined stigma scale and the internalized stigma sub-scale were similar at baseline (combined mean: 27.4; internalized mean:18.8) and endline (combined mean:28.0; internalized mean: 18.9), indicating that reported stigma did not change ($p = 0.834$). It should be noted that agreement with the stigma measures was fairly low at baseline, but slightly higher for the internalized stigma items (Tables 2 & 3). Similarly, we did not find a significant increase in ART adherence following the intervention (Table 2). Only 2 participants self-reported poor adherence at baseline, one of which reported good adherence at endline. For that participant, she noted that the detailed knowledge she gained about what ARVs are and how they work led to her improved adherence.

> "Like people in the support group, I can go and teach others . . . like what are ARVs. So now I explain . . . that these are medicines that . . . suppress the virus. And then CD4, you see how well you are doing. Also, the name of your medication, you need to know it. It happens that maybe you go somewhere else, or you shift from where you were staying, if you know the name of your medicine, you can just see people from adherence at the pharmacy, you talk to them, and they can give you the medicine."(19 years old, Kanyama)

Another participant reported that she sometimes did not take her ART because she felt badly that she was the only girl living with HIV among her friends. Overall, participants indicated that the session on ARVs enhanced their understanding of the benefits of adherence, which consequently had a positive effect on their self-efficacy as well as acceptance to take the medication as prescribed.

> " . . . they told us that when you stop taking meds the virus multiplies and the virus reproduces every day, any time and all the time . . . [during the session, I learned] to take care of myself and not to miss at all. To drink meds all the time, even though the due time passes, just take the meds. I used to stop taking my meds when I missed my due time, but now I have changed, even when my due time has passed, I still drink". (18 years old, Chipata)

Discussion

Our findings suggest that a relatively short-term, structured support group series holds promise for helping AGYW living with HIV safely navigate a complex time in their lives. The intervention filled critical support gaps for participants that were not being met with the current services available where they resided in Lusaka, including in-depth knowledge on HIV and ART, support to cope with grief, loss and stigma, and strategies to support disclosure and medication adherence. The Tikambisane intervention warrants further testing in a larger trial.

Similar to previous research in Zimbabwe,[25,26] the support groups provided an opportunity for AGYW living with HIV to meet other AGYW 'like them' in a safe environment and build social connections important for coping. As suggested by

Skovdal and Ogutu, the ability to mobilize and participate in "friendship groups which are characterized by sharing and reciprocity of support" enables children affected by HIV to draw on peer social capital and foster resilience.[27] While children may form such groups in schools, young people living with HIV may require opportunities outside of the school setting, given concerns around unwanted disclosure.[12] Structured support groups addressing a range of topics important to AGYW living with HIV provide an opportunity to tap into peer social support, which has been linked with better ART adherence and virologic suppression in previous research in the U.S.[28] and globally,[15,26] expand their understanding of HIV and ART, and enhance their coping skills.

The qualitative findings indicate that the information learned from the session, 'Everything you need to know about ART' reinforced the importance of taking ARVs regularly and on time for several participants. In particular, understanding how ARVs work and the effects of poor adherence motivated participants to take their medications as prescribed, suggesting that adolescents living with HIV would benefit from detailed information on the science of HIV and ART adherence.

Similar to previous research on support interventions for adolescents living with HIV, removing logistical barriers to attendance by providing transport reimbursement, and holding sessions at a safe, convenient space on the weekend facilitated participation.[29] Previous research in Zambia has demonstrated the importance of peer education in HIV prevention efforts in school settings.[17] While having a peer facilitator was equally important for our study participants, we found that co-facilitation by an adult counselor and peers living with HIV was preferred. The adult counselors brought a level of seriousness to the sessions that instilled credibility, while the peer co-facilitators provided someone their age to relate to. This combination of facilitators made the participants feel confident about the session content and more at ease to express themselves. A systematic review of peer education for HIV prevention found a significant influence on key prevention outcomes, such as HIV knowledge and condom use.[30] Our study suggests that involving peers as co-facilitators in support groups for AGYW living with HIV may be equally beneficial.

Similar to other intervention studies with AGYW living with HIV in the US,[31] reaching the participants following the intervention was a challenge. While the AGYW actively participated in the baseline assessment and intervention sessions, we were unable to reach 9 of the participants at endline, despite repeated attempts to contact the participants and offers to meet the participants at their homes or on the weekend. It may be that AGYW place more value on the intervention, as it provides tangible and direct benefits, and less value on the research aspects of the study. In future studies with this population, accommodations should be made to minimize the impact of loss to follow-up after the intervention on the evaluation, including oversampling during recruitment and/or using different methodologies for capturing the data (e.g. through provision of study phones with survey data collection programs).[32,33] With the extensive shift towards remote/virtual networking in 2020 due to COVID-19, this will be seen as more feasible in the future.

A few limitations must be noted. The findings around preliminary efficacy must be interpreted with consideration of the fact that the sample size was small, there was loss-to-follow-up and there was no control group given the nature of the pilot study, which was designed to assess the feasibility and acceptability of the Tikambisane intervention. However, we observed changes that suggest the intervention might help to increase hope for the future. A larger trial powered to assess efficacy and that accounts for potential loss-to-follow-up is needed. Further, our support group intervention only addressed one area of need that emerged from the formative research. Structural interventions to address the logistical challenges that greatly lengthen the time AGYW need to access ART and HIV services in health clinics and harmful norms that facilitate stigma and gender inequality are also needed,[12,34] as well as interventions to enhance inter-personal relationships, support and communication with family members.[3,35] Future research testing a multi-level intervention to support a healthy transition to adulthood for AGYW living with HIV is needed.

The Tikambisane curriculum, designed collaboratively with AGYW living with HIV, was both feasible to implement and acceptable to participants. The support group sessions addressed the key concerns identified by AGYW living with HIV during the formative research and have the potential to support a healthy transition to adulthood by increasing peer social support, reducing stigma, increasing hope for the future and improving ART adherence.

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