

# 'LET'S TALK TO EACH OTHER' (TIKAMBISANE):

THE DEVELOPMENT, FEASIBILITY AND ACCEPTABILITY OF A SUPPORT GROUP INTERVENTION FOR ADOLESCENT GIRLS LIVING WITH HIV IN ZAMBIA.

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HIV disproportionately affects adolescent girls in sub-Saharan Africa due to a range of social and structural factors.<sup>1,2</sup> Previous research has identified several challenges facing adolescent girls living with HIV, including antiretroviral therapy (ART) adherence, stigma, lack of emotional support

and harmful gender norms, which may impact their medical and psychosocial outcomes.<sup>3</sup> In Zambia, nearly 6 percent of adolescent girls aged 15-19 are living with HIV, yet interventions to support their healthy transition to adulthood are limited.<sup>4</sup>

The International Center for Research on Women (ICRW), Zambart, 3C Regional Consultants and the London School of Hygiene and Tropical Medicine conducted a pilot study between September 2017 and March 2018 to assess the feasibility, acceptability and preliminary efficacy of a six-session support group intervention designed to facilitate healthy transitions to adulthood among adolescent girls aged 15-19 living with HIV in Lusaka, Zambia.

## METHODOLOGY

We used a mixed-methods study design to explore the feasibility, acceptability and preliminary efficacy of the Tikambisane intervention. Twenty-four girls were enrolled in the study from the ART clinics in two urban health facilities and 21 participated in the support groups. Their socio-demographic characteristics are shown in Table 1. Quantitative surveys and in-depth interviews were collected pre- and post-intervention (see Figure 1). Eight participant observations of support groups were conducted.

### BOX 1 THE TIKAMBISANE INTERVENTION

'Tikambisane' means 'Let's talk to each other' in Nyanga, a local Zambian language. Our local research team chose this name because it reflects the essence of the support group approach, in providing a safe space for adolescent girls to talk with, share stories and support each other.

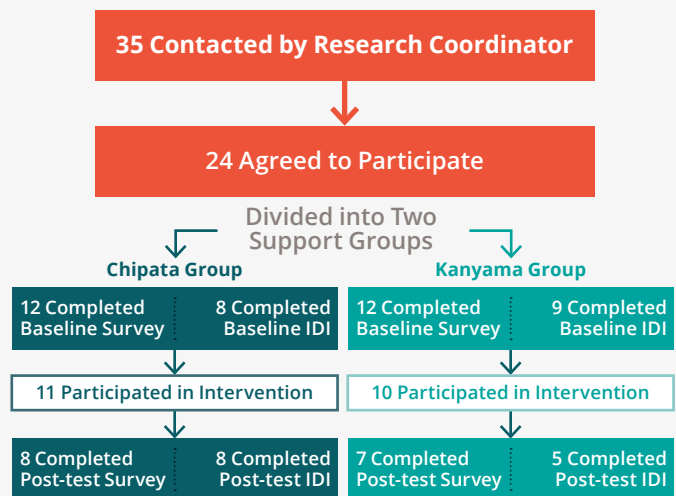
The Tikambisane curriculum was designed collaboratively with adolescent girls living with HIV, healthcare providers, HIV counselors, program implementers and research staff to address the key needs and concerns identified in our formative research.<sup>3,5</sup>

The curriculum contains six sessions addressing the following topics: getting to know you, disclosure and stigma, ART, relationships, loss and grief and planning for the future.

Sessions were 2-3 hours in length and were held every other Saturday over a three-month period.

Participation was very high. Among the 21 girls who participated, 14 (67 percent) attended all six sessions and 7 (33 percent) attended five of the six sessions.

Figure 1. Study Flow Chart



Outcome measures assessed included internalized stigma, measured using the 14-item Stigma Scale for Chronic Illness;<sup>6</sup> hope for the future, measured using the 12-item Hope Scale;<sup>7</sup> and ART adherence, measured using the CASE Adherence Index.<sup>8</sup>

**TABLE 1: PARTICIPANT CHARACTERISTICS AT BASELINE**

|   | N*=24<br>n (%) |
|---|----------------|
| <b>Age (years)</b>                        |                |
| 15  | 7 (29.2)       |
| 16  | 2 (8.3)        |
| 17  | 2 (8.3)        |
| 18  | 9 (37.5)       |
| 19  | 4 (16.7)       |
| <b>Highest Grade Completed</b>            |                |
| 8 or Lower                                | 21 (87.5)      |
| 9 or Higher                               | 3 (12.5)       |
| <b>Both Parents Living</b>                |                |
| Yes                                       | 5 (21.7)       |
| No  | 5 (21.7)       |
| Mother Only                               | 9 (39.1)       |
| Father Only                               | 4 (17.4)       |
| <b>Currently Taking ARV Drugs</b>         |                |
| Yes                                       | 23 (95.8)      |
| No  | 1 (4.2)        |
| <b>Living with Person Living with HIV</b> |                |
| Yes                                       | 23 (95.8)      |
| No  | 1 (4.2)        |
| <b>Ever had sex</b>                       |                |
| Yes                                       | 9 (37.5)       |
| No  | 15 (62.5)      |

\*N does not always equal 24 due to missing data for a few characteristics.

Interview transcripts and observation notes were coded using Nvivo 11.0 and analyzed thematically. Survey data were analyzed in Stata 14. Analyses were conducted on the entire sample. 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. Ethical clearance was obtained from review boards in Washington, D.C., London, U.K. and Lusaka, Zambia.

## KEY FINDINGS

Overall, we found the Tikambisane intervention to be both feasible to conduct and acceptable to participants. In this brief, we draw from both the qualitative and quantitative data collected in the pilot study to examine how the intervention was experienced by the 21 adolescent girls (88 percent) who participated, how it influenced their lives and what recommendations they had for improvement. The complete findings will be presented in a forthcoming publication and the curriculum will be made available online.

## Feasibility

The research team achieved full enrollment within a six-week period and all participants completed their baseline assessments. Most of the girls went on to participate in the intervention and participation was very high, with all girls attending a minimum of five sessions and seven of the girls attending all six sessions. Holding sessions on a Saturday enabled participation for the mostly school-going and church-going participants and financial reimbursement for travel helped to facilitate regular participation in the support groups.

The main challenge was reaching the participants following the intervention to collect endline data. In some instances, the phone numbers provided were no longer in service. In other cases, girls cited schoolwork or having moved away to stay with other relatives as reasons for not being able to attend their endline assessments.

## Acceptability

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

*“They were just okay because even them, we never used to know them, but they used to behave like we had known them for a long time and they used to treat us like we are sisters without considering where we came from, we used to be together and we used to make jokes, laughing together. They never treated us like we were from elsewhere.”* (18 years old, Chipata)

The adolescent girls shared similar sentiments about the adult counselors who co-facilitated the support group sessions. The participants asserted that they did not think that the facilitation should have been done differently. Overall, the main recommendation from participants was that they would have liked to have had more than six sessions.

## Preliminary efficacy

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

*"[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)*

Interestingly, the participants 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 girls living with HIV was another key outcome mentioned by several of the participants. As most participants had never before interacted with another adolescent girl living with HIV, these connections were particularly important for facilitating coping through the expansion of the girls' peer support networks. Participants expressed relief at realizing that they are not the only girls living with HIV in their communities.

*"We became more like friends with people we found there."*  
(18 years old, Chipata)

*"Support groups, let's see, they 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 so that they could stay in touch with the other participants after the intervention. The girls were encouraged to attend the support groups being run at the nearby health facility but seemed reticent about doing so and would rather the pilot support groups continue.

We found a significant increase in the hope for the future scale following the intervention (Table 2), indicating that the knowledge and support gained improved the girls' outlook in terms of future accomplishments. This hopefulness was also reflected in the stories shared by participants in the endline in-depth interviews (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)

The mean internalized stigma score decreased at endline, although the change was not statistically significant. It should be noted that agreement with the internalized stigma items was fairly low at baseline. Similarly, we did not find a significant increase in adherence to ART following the intervention (Table 2). Only two participants reported poor adherence at baseline, one of whom reported good adherence at endline. From this participant's endline IDI, it was clear that the detailed knowledge she gained regarding antiretroviral drugs (ARVs) led to her improved adherence.

**TABLE 2: COMPARISON OF OUTCOMES PRE- AND POST-INTERVENTION**

| Outcome variables                           | Baseline (N= 24) |         | Endline (N= 15) |         | p-value <sup>^</sup> |
|---|------------------|---------|-----------------|---------|----------------------|
|   | Mean (SD)        |         | Mean (SD)       |         |                      |
| Internalized stigma*                        | 19.8 (4.2)       |         | 18.6 (6.2)      |         | 0.479                |
| Hope for the future <sup>#</sup>            | 2.92 (0.5)       |         | 3.2 (0.4)       |         | 0.070                |
| <b>Case Adherence Index<sup>&amp;</sup></b> | n/N              | percent | n/N             | percent |                      |
| ≥ 10  | 21/23            | 91.3    | 12/14           | 85.7    | 0.140                |

\*Higher scores on the Stigma Scale for Chronic Illness Scale (SSCI) reflect more internalized stigma reported; #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.



Photo Credit: Robyn Hayes



## RECOMMENDATIONS

Our findings suggest that a brief, structured support group series holds promise for helping adolescent girls living with HIV to 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 in Lusaka, including in-depth knowledge on HIV and ART, support to cope with grief and loss and strategies to support disclosure and medication adherence. Recommendations for future research and program implementation are summarized below:

### Research

- ♦ The Tikambisane intervention was found to be feasible and acceptable and warrants further testing in a larger, controlled study.
- ♦ Accommodations should be made to minimize the impact of loss to follow-up after the intervention, including oversampling during recruitment, increased incentives for completing the endline assessment and/or different methodologies for capturing the data.

### Program implementation

- ♦ Support groups provided an opportunity for adolescent girls living with HIV to meet other girls 'like them' in a safe environment and build social connections important for coping.

- ♦ Co-facilitation by an adult counselor and a peer living with HIV was important for ensuring credibility and making the girls feel at ease.
- ♦ The Tikambisane curriculum, designed collaboratively with adolescent girls living with HIV, addressed their key concerns and is recommended for use with this population to support a healthy transition to adulthood.
- ♦ Provision of in-depth knowledge on HIV and ART and practical advice on strategies to support adherence, coping with grief and loss and issues around disclosure and stigma was critical to address the key concerns of adolescent girls living with HIV in this context.
- ♦ Participatory methodologies and high quality facilitation fostered engagement in the session content, encouraged openness and sharing among the girls and ensured strong participation throughout the intervention.
- ♦ Transport reimbursement facilitated good session attendance.

## ACKNOWLEDGEMENTS

We wish to thank the adolescents who participated in the study and the clinic staff at the health facilities in Chipata and Kanyama where the participants were recruited. This work was made possible by the generous support of the M•A•C AIDS Fund and with the permissions of the Zambian Ministries of Health.

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