

Feasibility, Acceptability, and Effectiveness of a Peer Youth Leader Model to Deliver a
HIV Curriculum in Routine HIV Adolescent Clinic and Impact on Youth Leader
Resilience: a Mixed-Methods Study

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Thesis submitted in partial fulfillment of
the requirements for the degree of
Master of Science in the Duke Global Health Institute
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ABSTRACT

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Abstract

Background: Youth living with HIV have worse health outcomes compared to adults or children. Few interventions have been developed engaging youth in their care to promote resilience. Peer-led education is one potential way to boost confidence and bolster resilience while also improving HIV knowledge of youth living with HIV (YLHIV). Peer youth leaders (PYL) can be effective educators because they are seen as trustworthy and relatable to their peers. PYL themselves may also benefit from increased resilience and empowerment after taking on leadership position at their monthly adolescent HIV clinic. This study evaluated the acceptability, feasibility, and effectiveness of using PYL to teach an HIV education. **Methods:** Seven HIV-infected youth were recruited based on their previous enrollment in a mental health intervention for HIV-infected youth. Those who demonstrated confidence, excellent adherence, and upstanding behavior were chosen to become PYL. PYLs were trained by a doctor, social worker, and previously trained group leaders of a mental health intervention to teach an HIV education curriculum adapted from the Baylor International Pediatric AIDS Initiative. Trainings occurred once a week for two to three hours in preparation for teaching at the monthly adolescent HIV clinic. Two PYLs taught one-hour lessons to youth during the monthly adolescent HIV clinic. Approximately 25 clinic attendees were asked to volunteer to complete pre/post knowledge assessments and provided feedback on the PYL model. Acceptability and feasibility of using PYL to deliver an HIV curriculum to YLHIV was evaluated through attendance records, fidelity checklists and feedback notes that were documented by trained group leaders who supervised PYL curriculum delivery. In depth interviews were

conducted to evaluate change in fears, motivations, and resilience among PYL before and after assuming the leadership role. PYL resilience was measured using the Connor-Davidson Scale at baseline (prior to starting the teaching role) and 6 months after initiating training. **Results:** A PYL model of delivering an HIV curriculum was both feasible and acceptable as reported by youth attending monthly adolescent HIV clinic and PYL. Qualitative findings showed peer education created safe discussion spaces, reduced stress of participants, and enhanced beliefs of importance in maintaining good adherence. HIV knowledge was improved as measured by self-report, and improvement did not meet statistical significant ($p = 0.057$). PYL leaders demonstrated trends toward improved resilience as measured by Connor-Davidson Resilience Scale and increased confidence, feelings of self-worth, sense of purpose, social support, and optimism and decreased internal stigma based on in-depth interviews. **Conclusions:** Results demonstrated the PYL model of teaching an HIV curriculum was feasible and acceptable. PYL had improved resilience as a result of taking on a leadership role at their monthly adolescent HIV clinic. Future evaluation of YLHIV retention in care and health outcomes as a result of participation in the PYL education should be explored.

Dedication

I would like to dedicate this thesis to my wonderful family who are everything to me.

Thank you for your endless love and support.

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1 Introduction

1.1 Significance and Burden of HIV in Youth

Globally, 3.9 million youth (aged 15-24) are living with HIV and the majority of these youth living with HIV (YLHIV) reside in sub-Saharan Africa (UNAIDS 2018; UNICEF, 2016). Half of the adolescents (aged 15-19) living with HIV live in only five countries, one of which is Tanzania (UNICEF, 2016). In 2013, 120,000 adolescents died of AIDS-related illnesses (UNAIDS, 2016). AIDS-related deaths among the adolescent population have risen by 50% from 2005-2012 despite treatment becoming more readily available. A study conducted in nine southern African countries found adolescents were 50% less likely to maintain perfect adherence and 70-75% less likely to be virologically suppressed when compared to adults (Nachege et al., 2009). In the Kilimanjaro region of Tanzania only 45 of 183 HIV-infected adolescents (24.6%) demonstrated adherence of > 95% (Nsheha, Dow, Kapanda, Hamel, & Msuya, 2014) and more recently 41% had virologic failure (Dow, Shayo, Cunningham, & Mmbaga, 2019).

Improved treatment and clinic care have increased the number of HIV-infected children aging into adolescence. With adolescence comes challenges of social development and navigating self-identity and relationships. YLHIV face additional and more burdensome challenges characterized by their chronic illness compared to their uninfected peers. Within this transitional period of emotional, mental, and physical changes, YLHIV must also face added psychosocial issues, maintain proper adherence to treatment, and learn to negotiate sexual relationships (Lowenthal et al., 2014). YLHIVs' childhoods are often frequented by hospital visits leading to poor school attendance, experience delayed puberty, skin disfiguration, and intellectual impairment (Ferrand et

al., 2007; Mavhu et al., 2013). Fear of disclosure, discrimination, stigma, and their uncertain future lead to higher rates of emotional and behavioral problems among YLHIV in both high and low-resource settings (Bhana et al., 2016; Bomba et al., 2010; Mellins & Malee, 2013; Mellins et al., 2011; Nachega et al., 2009). Poor coping mechanisms have led to lower levels of medication adherence, higher rates of drug resistance, increased risk of negative health outcomes, and HIV transmission in adolescents compared to both children and adults (Lowenthal et al., 2014; Van Dyke et al., 2016). WHO guidelines for the care of adolescents living with HIV/AIDS calls for them to be actively engaged in the delivery of mental health services, but clear methods for youth engagement enhancement have not been well explored (Kidia, Ndhlovu, Jombo, Abas, & Makadzange, 2015).

1.2 Peer Education Interventions

In sub-Saharan Africa only 26% of adolescent girls (15-19 years old) and 33% of adolescent boys had comprehensive knowledge about HIV (UNICEF, 2016). In Tanzania, only 46% of adolescent girls and 41% of adolescent boys had comprehensive knowledge about HIV/AIDS (Population Council, 2015.). Patients who demonstrate higher HIV knowledge and treatment literacy are significantly more likely to achieve 80% adherence than those with lower health literacy (Kalichman et al., 2008). Peer education interventions are widely used to promote prevention, but not much is known about effectiveness of using education interventions for youth already living with HIV.

Peer education interventions follow a behavioral change strategy that has shown evidence of being effective in vulnerable populations. Peer education interventions typically involve members of a given group being used to effect change among other

members of the same group. Peer education can effect change at the individual level by attempting to modify a person's knowledge, attitudes, beliefs, or behaviors. Use of peer education can also effect change at a group or societal level by modifying norms and stimulating collective action that leads to changes in programs and policies (Luna & Rotheram-Borus, 1999; UNAIDS Peer Education and HIV/AIDS, 1999.) Peer education interventions are also more cost-effective than incorporating highly trained professionals (C. R. Kim & Free, 2008).

Peer group interventions are based on Bandura's social-cognitive learning theory (1982) that behavioral changes can be a result of increasing self-efficacy and/or self-confidence. Effective peer group interventions make use of skill building, role modeling, and rehearsal tasks to improve self-confidence of group members while also reducing self-stigma. Interventions making use of peer support also aim to provide members with effective methods to combat external stigma they might face from their communities (Mburu et al., 2013). Interventions that rely on support group methods help to spread secondary prevention messages, ultimately increasing understanding importance of proper medication adherence (Hardon et al., 2013).

Peer group interventions not only work to benefit the participants in attendance but the peer youth leaders (PYL) themselves. Trained leaders report satisfaction and personal benefits as a result of their work with a population they know and with whom they identify (Campbell & Mzaidume, 2001; Strange, Forrest, Oakley, 2002; Population Council, 2015). Use of PYL in Malawi showed becoming a leader led to psychological empowerment. PYL changed their personal knowledge, attitudes, and behaviors about

HIV, interacted with members of their family and community regarding prevention, and became agents for change (McCreary, Kaponda, Davis, Kalengamaliro, & Norr, 2013).

Selection of peer leaders is critical for success and acceptability of youth to the education they will be receiving. Guidelines for selection of peer educators emphasize the need for “true peers” that are acceptable to the target audience and must have personalities that are conducive to training (UNAIDS, 1999; Svenson, 1998).

1.3 Resilience

Resilience can be defined as an individual’s ability to adapt, recover from or remain strong when confronted with challenges (Ungar et al., 2007). Resilience of HIV-infected youth is found to be an outcome of their agency and interactions with the environment in which they reside (Skovdal, 2012). High resilience can factor into an adolescent’s ability to cope with stressful events and maintain supportive familial and social relationships (Bhana et al., 2016). In the field of HIV, research tends to focus on the negative aspects of living with HIV/AIDS. Little research has been done to highlight protective factors that help to mediate the negative impact of HIV/AIDS on YLHIV. The risks and vulnerabilities of HIV/AIDS are important but understanding strategies to help individuals living with HIV to face adversity and future challenges is important in improving health outcomes of a vulnerable population.

One major challenge affecting YLHIV is stigma, both external and internal. The Tanzania Stigma Index 2013 Report by the National Council of People Living with HIV demonstrated evidence of clear infringements on the rights of PLHIV in health, work and school settings. PLHIV must therefore practice self-censorship for fear of disclosure and have increased feelings of guilt that can affect quality of life. Forty-four percent of those

surveyed for the Stigma Index had low self-esteem, and 30% felt ashamed (NACOPHA, 2013).

Existing literature identifies elements of contextual, social, and self-regulation factors that have been found to be protective in YLHIV and therefore may improve resilience. Contextual factors have a significant influence on YLHIV resilience including caregiver factors (education and depressive symptoms), access to quality schools and health services, living in safe neighborhoods, and financial security (Benzies & Mychasiuk, 2009; Bhana et al., 2016). Youth-reported supervision, parental warmth, and parental communication are social regulation factors associated with promoting resilience in YLHIV (Bhana et al., 2016; Fergus & Zimmerman, 2005). Self-regulatory methods (actively seeking support from others, low internal stigma), development of healthy sense of self (self-concept), coping, self-efficacy and acceptance of one's diagnosis are closely related to achieving healthy cognitive behavioral emotional and mental health functioning which can in turn be important in promoting resilience in YLHIV (Bhana et al., 2016; Fergus & Zimmerman, 2005; Zolkoski & Bullock, 2012). This is consistent with the Social Action Theory which explains self-change to be influenced by self-regulatory processes and social interactions (Ewart, 1991).

A systematic review found twenty-nine studies pertaining directly to mental health and resilience of families affected by HIV/AIDS and HIV-infected youth. It identified individual, family, and community/cultural factors believed to strengthen resilience in HIV-infected youth. Individual factors attributed to higher resilience included effective coping mechanisms, higher self-esteem, and hope for the future (Betancourt, Meyers-Ohki, Charrow, & Hansen, 2013). In Tanzania, a study looking at

caregiving children of HIV infected parents found supportive networks (school, social, relationships) to be important protective factors (Evans, 2005). Parental monitoring and attachment, positive family functioning, and coping in response to parental impairment demonstrated important factors found to be associated with higher resilience (Betancourt et al., 2013). This was demonstrated by a South African Study conducted with 25 HIV-positive adolescents and 15 caregivers of HIV-positive adolescents where goal-setting was identified as an important factor that contributed to coping with an HIV diagnosis (Petersen et al., 2010). Access to educational resources and social support are important community and cultural factors that impacted resilience (Betancourt et al., 2013)

1.4 Peer Education Interventions and Role in Resilience

There is a strong lack of interventions aimed at improving psychosocial well-being of youth affected by HIV/AIDS. Current practices are not informed by evidence-based interventions. Rather, they rely on recommendations and anecdotal knowledge based on “lessons learned” from researchers (King, De Silva, Stein, & Patel, 2009).

Very few interventions aimed at improving resilience of YLHIV exist in the literature, with even less of these interventions conducted in sub-Saharan Africa (SSA) despite the higher prevalence of HIV in this region (Betancourt et al., 2013). This could be attributed to higher exposure of individuals in this setting to simultaneous interventions by various organizations and governments which makes it difficult to determine effects of a specific intervention (King et al., 2009). Two studies in SSA focused on peer-support programs to improve mental health outcomes and resilience in HIV-affected youth (Betancourt et al., 2013). In Uganda a peer support intervention involving sharing of fears/worries, problem solving activities, and action planning

exercises was administered in schools to 326 children orphaned by AIDS. The intention of this intervention was to improve coping mechanisms through social support and researchers found significant improvements in depression, anxiety, and anger in the group receiving the intervention (Kumakech, Cantor-Graae, Maling, & Bajunirwe, 2009). A group therapy intervention found improvements in preoccupations about illness and fears about medication and reduced viral load in YLHIV after attending a 90-minute session once every 6 weeks for 26 months (Funck-Brentano et al., 2005). Interventions that make use of narratives in group settings can help promote resilience of YLHIV. A mental health intervention conducted in Tanzania targeted 3 domains to improve resilience of YLHIV (ability to identify and cope with stressful events; foster strong familial and social relationships; cultivate a safe and healthy living environment). Trained group leaders were successful at improving peer and caregiver relationships, reducing stigma, and improving confidence through peer group, individual, and joint youth/caregiver sessions (Dow, Mmbaga, et al., 2019).

To address the evidence gap in effective interventions to improve resilience and overall HIV knowledge in YLHIV, we piloted a peer education intervention in which youth were trained to become leaders at their monthly adolescent HIV clinic (Teen Club) and deliver an HIV curriculum to their peers. A formative evaluation approach was taken to monitor challenges to implementation, fidelity to the intervention, and adapt the intervention in real time based on weekly session feedback.

1.5 Study Aim and Objectives

The principal aim of this study was to evaluate if an intervention to train peer youth leaders to deliver a HIV curriculum to their fellow peers at monthly adolescent HIV

clinic (Teen Club) was feasible, acceptable, and effective. The objectives of this study were threefold. First, to determine the acceptability and feasibility of delivering a monthly HIV curriculum using peer youth leaders as educators. Second, to understand the impact leadership had on youth who became peer youth leaders. Finally, to measure change in knowledge of youth who attend the HIV teaching sessions embedded in the routine monthly adolescent HIV clinic.

2 Methods

2.1 Overview

This study was conducted to evaluate if using PYLs to deliver an HIV-education curriculum to YLHIV is acceptable, feasible, and effective. PYL were chosen based on excellent attendance to the youth HIV clinic, prior participation in a mental health intervention (Sauti ya Vijana or SYV), and who the group leaders of SYV noted during the intervention to have excellent HIV knowledge and leadership potential. Though not an official criterion, all PYL had fully suppressed HIV (<40 copies/mL) during initial PYL training.

Acceptability and feasibility of using PYL to deliver an HIV curriculum to YLHIV was evaluated through attendance records, fidelity checklists and feedback notes documented by SYV group leaders who supervised PYL curriculum delivery. In addition, youth attending the HIV curriculum sessions during clinic were asked to provide anonymous feedback about how much they felt they learned, their preferences regarding being taught by a PYL versus an adult clinic staff member, and any open-ended feedback about the session.

The study utilized a mixed-methods design to evaluate change in fears, motivations, and resilience among PYL before and after assuming the leadership role. Outcomes included change in resilience in PYL pre-training to 6 months into the project and was measured using the Connor-Davidson Scale. Two in-depth interviews with PYL, first prior to starting the teaching role and after 6 months of ongoing teacher training allowed PYL to describe their motivations and fears as well as successes and challenges after becoming a PYL.

Knowledge gained by youth in attendance of PYL delivery of the HIV curriculum was measured using a comparison of pre/post knowledge assessments. Each session had a unique set of five multiple choice questions to assess changes in HIV knowledge and treatment literacy among YLHIV. Participants attending clinic volunteered to take pre/post knowledge assessments on de-identified forms. No personal identification was associated with completion of the pre/post assessments.

2.2 Setting

This study took place in the Kilimanjaro region of Tanzania at Kilimanjaro Christian Medical Center (KCMC) and Mawenzi Regional Hospital. KCMC and Mawenzi are referral hospitals that host a routine youth HIV clinic, known as “Teen Club”, once per month for YLHIV who reside in surrounding areas. Teen Clubs have been established in KCMC since 2007 and Mawenzi since 2014. At KCMC Teen Club youth are separated into two age categories, with youth aged 12-17 years on one side with pediatric nurses and physicians, and youth aged 18-24 years on the other side with adult nurses and physicians. Both groups attend clinic on the same day. During the course of this study, Mawenzi Teen Club split into two separate Teen Clubs catering to younger youth the first Saturday of the month and older youth the third Saturday of the month. Traditionally, Teen Club provides both clinic care as well as an educational lesson taught by nurses and/or social workers to YLHIV; however, in practice educational lessons occurred infrequently due to overburdened clinic staff and did not follow a curriculum or schedule prior to this intervention.

2.3 Participants

2.3.1 Sauti ya Vijana Leaders

Sauti ya Vijana (SYV), or “Voice of Youth”, was an intervention aimed at improving the mental health of YLHIV in the Kilimanjaro region (Dow et al., 2019). SYV group leaders were lay counselors of various backgrounds (half HIV-infected; half with prior mental health research experience) and education levels (secondary school to some graduate education in social work) who were trained to be group leaders of the SYV intervention by a pediatric infectious disease specialist and a clinical psychologist. Six SYV leaders (three male and three female) recruited and trained YLHIV who had participated in SYV to become peer youth leaders. Following a “train-the-trainer-model,” the SYV group leaders supervised training of the PYL to teach the newly designed 12-session HIV curriculum to be delivered in routine adolescent HIV clinic.

2.3.2 Peer Youth Leaders

This study enrolled YLHIV from KCMC and Mawenzi Hospital Teen Clubs who participated in the SYV program.

Inclusion criteria: PYL had to be 18 years or older, have participated in the SYV mental health intervention and attended Teen Club at either KCMC and/or Mawenzi for ≥ 2 years, recommended by SYV leaders with confirmation of good adherence and behavior from a nurse and or social worker, willing to attend trainings every Friday for 12 months, attend and lead monthly Teen Club education sessions for 12 months.

Exclusion criteria: Below the age of 18 and therefore not able to consent for themselves, poor adherence to ART, demonstrate inappropriate behavior, inability to actively participate in consent process, in-depth interviews, or participation in the weekly trainings and/or monthly teachings.

PYL were required to come to training each Friday to practice delivering the HIV curriculum. On Teen Club days at their respective sites PYL taught the curriculum in pairs (two youth) to each Teen Club peer audience. For their time and effort, PYL were reimbursed transport to the Friday training and bites were provided. They were compensated 15,000tsh (\$6.5) for their time in preparing and teaching the lesson each month.

2.3.3 Teen Club Youth

Twenty-five youth were asked to volunteer to complete pre/post assessments before and following the presentation of the lesson at each monthly Teen Club session. No identifying information was taken about the youth who completed assessments.

2.4 Procedures

2.4.1 Training

A “train-the-trainer” model was used to train PYL. SYV leaders held two to three-hour weekly training sessions on Fridays in preparation for the monthly Teen Club lesson. Trainings were conducted by SYV leaders and supervised by a Duke graduate student and a pediatric infectious disease specialist. The HIV curriculum was adapted from the Baylor International Pediatric AIDS Initiative and consisted of 12 lessons (Table 1).

Table 1: HIV Curriculum

Lesson	KEY OBJECTIVES
Epidemiology and Pathophysiology of HIV	<ol style="list-style-type: none"> 1. Gain a basic understanding of immune system 2. Understand how HIV Infection leads to AIDS
Clinical Manifestations of HIV	<ol style="list-style-type: none"> 1. Understand the phases of HIV Infection

HIV Therapy	<ul style="list-style-type: none"> 2. Identify common opportunistic infections and why they occur in people living with HIV 1. Basic understanding of HIV treatment mechanism 2. Know the possible side effects of ART 3. Benefits of treatment for people living with HIV
Monitoring HIV Infection: CD4 Vs. Viral Load	<ul style="list-style-type: none"> 1. Understand the difference between a CD4 count and viral load 2. Basic skills to interpret a CD4 count and viral load result
Careers and Career Planning¹	<ul style="list-style-type: none"> 1. Learn about career options and what it takes to reach a career goal
HIV Transmission and Prevention	<ul style="list-style-type: none"> 1. Explain the ways in which HIV can and cannot be spread 2. List the 4 bodily fluids that can transmit HIV 3. Know how to prevent HIV infection
Food and Water Safety, Nutrition and Permaculture	<ul style="list-style-type: none"> 1. Components that make up a balanced diet 2. Importance of good nutrition for people living with HIV 3. Basics of permaculture 4. How to safely prepare, handle, and consume food
Stigma and Discrimination	<ul style="list-style-type: none"> 1. Identify what stigma and discrimination are 2. Identify causes of stigma most often faced by HIV-positive adolescents 3. Methods of coping with stigma and discrimination
Antiretroviral Therapy Adherence	<ul style="list-style-type: none"> 1. Understand what adherence means 2. Explain why good adherence is important 3. Understand the concept of an 'adherence scale' that we move along 4. Identify ways of overcoming challenges to good adherence
Alcohol and Drugs	<ul style="list-style-type: none"> 1. Describe some of the effects of alcohol on the brain and body 2. Identify effective alternatives to using alcohol
Sexual Reproductive Health and Gender²	<ul style="list-style-type: none"> 1. Understand the risks associated with unprotected sex 2. Identify various methods of family planning 3. Assess the advantages and disadvantages of each method 4. Know the difference between sex and gender

Disclosure of HIV Status

1. Understand that disclosure is a process
2. Learn recommendations for disclosing status
3. Know when and whom to disclose to and how to prevent accidental disclosure

¹Delivered by guest speakers

²Delivered by trained clinic staff

Training sessions consisted of SYV leaders outlining the lesson, allowing PYL to ask questions. Then the PYL would lead the session to ensure they were able to deliver the material and answer questions posed by their fellow PYL and the SYV trainers. SYV leaders provided clinical notes following each training session to summarize discussions that occurred, relay any concerns/questions, and provide observations of PYL.

PYL rotated teaching at their respective clinics and were evaluated at Teen Club both by their peers (YLHIV attending clinic) through questionnaires and by SYV group leaders using fidelity checklists. Fidelity checklists were specific to each lesson of the curriculum. Each checklist outlined the lesson and was used to assess coverage of key components of the curriculum. Following teaching at Teen Club, PYL participated in debrief sessions to discuss their experience teaching and any concerns that arose. SYV leaders provided feedback on their performance based on observations and fidelity checklist notes.

Weekly meetings took place with SYV leaders, the graduate student, a pediatric infectious disease specialist, and local investigator, to review the training notes and the fidelity checklists from the weekly training session and curriculum delivery during Teen Club. A formative evaluation approach was taken to use continuous monitoring and reflective feedback to make adjustment to training and intervention implementation as

challenges arose. Adaptations were made periodically throughout the intervention to address concerns and barriers based on PYL and SYV group leader feedback.

2.4.2 In-depth Interviews

PYL were interviewed prior to and 6-months after taking on an educator role at Teen Club. In-depth interviews (IDI) were conducted by trained, local qualitative interviewers and followed a semi-structured in-depth interview guide. Initial baseline interviews addressed relationships, coping habits, motivations and fears related to becoming a PYL. Interview guides were created based on literature reviews evaluating effective methods of measuring resilience in adolescents. Interview guides were reviewed by SYV leaders and translated and back-translated to validate for cultural and language accuracy. Interviews were recorded and conducted in Swahili then simultaneously transcribed and translated by the interviewers for interviews conducted prior to training commencement. Interviews ranged from 45 minutes to 1 hour.

The second part of PYL interview was conducted 6-months following PYL beginning training to take on a teaching role at Teen Club. Interviewers followed a semi-structured interview guide that addressed PYL experience teaching at Teen Club and topics regarding resilience. IDI were transcribed into Swahili and then translated into English by the SYV team. Edits to English transcripts were made to correct grammar, but context of the text was not altered. Study participants received compensation for transportation and lunch after completion of each interview.

2.5 Measures

2.5.1 Pre/Post Assessment

Youth participants received two knowledge questionnaires with an identifying number at the top (1-25) of both pre and post forms. They were asked to complete and hand in the pre-test before the lesson began. After all pre-test forms were collected, the PYL taught the lesson. Youth were asked not to complete the post-test until after PYL had finished teaching. Answers were entered into REDCap database. Incomplete or assessments were omitted from analysis and not inputted into REDCap. Changes in score were evaluated using Wilcoxon rank-sum test and t-tests for paired data. Pre/Post assessments were collected over five consecutive months (August 2018 – December 2018) at each Teen Club.

2.5.2 Connor-Davidson Resilience Scale

The Connor-Davidson resilience scale (CD-RISC) was used to measure changes in PYL resilience. The scale was integrated as part of the in-depth interview with PYL. Resilience was defined as “the ability to thrive in the face of adversity” by the creators of the scale. The CD-RISC consisted of 25 statements with responses measured on a 0 to 4 Likert scale: not true at all (0), rarely true (1), sometimes true (2), often true (3), and true nearly all of the time (4). Scores were tallied to give a value from 0-100 with higher scores indicative of higher resilience. A Swahili version obtained from the tool developers was back-translated and assessed for language validity at the site. No major changes were required to the original Swahili version.

2.6 Analysis

2.6.1 Qualitative Analysis

All English language transcripts were reviewed by the research team for feedback and sent back to the interviewers if any clarifications needed to be made. Thematic

analysis was conducted following Attride-Sterling's (2001) four analytic steps 1) coding the material; 2) identifying themes; 3) constructing the network; 4) describing and exploring the thematic network.

Prior to the commencement of the coding process, each transcript was read through several times to identify relevant themes relating to the research question. A codebook was created by reading through PYL part 1 interviews to identify emerging themes. Structural themes were identified through the creation of memos for each of the 7 participants. By comparing memos for each participant, seven broad themes were generated, which were defined in the codebook. These themes were disclosure, relationships, coping mechanisms, previous leadership experiences, history attending Teen Club, fears, and motivation for teaching at Teen Club. Code specific memos were created to highlight important thematic summaries, describe data, and identify important quotes related to the theme. Themes were analyzed using NVivo 12 for comparison of common constructs that emerged throughout the in-depth interviews. One other coder used the generated master codebook to begin coding two transcripts to ensure the generated codebook was comprehensive. Changes were made based on a discussion between both coders and the final master codebook was then used to code all seven baseline PYL interviews.

The final codebook created from baseline interviews was used to code part 2 IDI to evaluate any changes since PYL took on a leadership role. Interviews were translated and became available for analysis on a rolling basis. Memos were created for each PYL and overlapping themes were used to create new codes. New codes were identified based on responses from PYL about initiating training and their experiences teaching at Teen

Club. Creation of memos for each new overlapping theme that emerged was used to finalize the codebook.

2.6.2 Quantitative Analysis

The results of pre-post assessments and resilience scores were exported from REDCap into an Excel spreadsheet and analyzed using R Studio statistical software. From pre-test and post-test scores a learning gain score was obtained. A neutral learning gain score (0) indicated no difference, a negative score indicated a lower post-test score, and a positive learning gain score indicated a higher post-test score compared to pre-test score. Descriptive statistics including means and frequencies were generated for all quantitative variables. Differences in post-test score compared to pre-test-scores were assessed using non-parametric statistical methods. Paired Wilcoxon rank sum test was used to measure if there was a significant difference in participant test-scores. The significance level for the Wilcoxon rank sum test was $p < 0.05$. A Kruskal Wallis test was used to determine if the average difference in pre and post-test score (learning gain score) differed among the 2 clinic sites.

2.7 Ethical Considerations

Peer youth leaders provided written consent to undergo two in-depth interviews. Youth in clinic were waived from consent due to no identifying data being collected. All study procedures were approved by the ethical board of Duke University and Kilimanjaro Christian Medical Center. Ethical approval was submitted as part of an amendment to Duke University Medical School board and Kilimanjaro Christian Medical Center Ethical Board. The study protocol was also submitted and approved by Tanzanian National Institute Medical Review.

3 Results

3.1 Feasibility and Acceptability of the PYL Model

3.1.1 Feasibility

Practice attendance logs demonstrated excellent attendance of PYL to training sessions. No PYL missed practice training sessions before teaching at their respective Teen Club sessions. On rare occasions, some PYL missed training sessions due to illness or family problems. The training schedule accounted for possible absences and allowed PYL to review each lesson several times before teaching at Teen Club.

Fidelity checklists demonstrated that PYL maintained fidelity to the HIV curriculum and session notes demonstrated that PYL understood the material quite well. On rare occasion, misinformation did occur. For example, during session 2 (Clinical Manifestations of HIV) at KCMC, PYL misrepresented malaria as being an example of an opportunistic infection. This was noted on the fidelity checklist reviewed during supervision meeting, and the information was corrected during the following Teen Club as well as a debrief session held with PYL to ensure proper understanding of opportunistic diseases.

Based on notes from training sessions and fidelity checklists during HIV curriculum delivery, a few adaptations were implemented during the study. One PYL was late to multiple training sessions as he was still in school. Training sessions were rescheduled to start one hour later to allow time for transportation to the training site. A female PYL from Mawenzi Teen Club moved to Mwanza and had to drop out of the

intervention before 6 months had surpassed. The remaining PYL from Mawenzi Teen Club were able to continue to deliver the monthly HIV curriculum.

Modifications to the curriculum were continuously made to improve clarity. For example, after malaria was misrepresented as an opportunistic infection during session 2 at KCMC, adjustments were made to the curriculum to better explain what opportunistic diseases are and are not more broadly. Another example was clarifying a visual analog scale to measure adherence used in lesson 9. The graph was interpreted that “good” adherence was more than 50%, but the figure redrawn to show adherence less than 90% is “not good” and the goal is for > 95% adherence. Weekly supervisor meetings were very important in reviewing PYL training progress and clarifying any misunderstandings of the curriculum content.

3.1.2 Acceptability

3.1.2.1 Acceptability Reported by Youth

Youth responded to specific questions about teaching preferences and their own impression of knowledge gained at the end of pre/post knowledge assessments. Although over a third (38%) had no real preference, the majority of youth preferred being taught by PYL (44%) compared to a nurse or social worker (18%). Though some responses were missing, nearly 90% of youth reported that they learned new information based on delivery of the HIV curriculum by PYL (Table 4).

Table 2: Preference and Reported Knowledge Gained by Youth Attending KCMC and Mawenzi Teen Clubs

	Mawenzi Teen Club (N=105)	KCMC Teen Club (N=95)	Total (N=200)

Youth ¹ Educator Preference	Prefer being taught by an elder (nurse/social worker)	23 (22 %)	12 (13%)	35 (18%)
	Prefer being taught by a peer youth leader	48 (46 %)	39 (41%)	87 (44%)
	No preference	32 (31%)	43 (45%)	75 (38%)
	Don't want to be taught by anyone	1 (1%)	1 (1%)	2 (1%)
Information Learned ²	Didn't learn new information because of PYL	5 (5 %)	5 (5%)	10 (5%)
	Learned new information because of PYL	91 (93%)	77 (85%)	168 (89%)
	Already knew the information	2 (2%)	9 (10%)	11 (6%)

¹1 missing response at Mawenzi; ²Missing 7 responses at Mawenzi and 4 responses at KCMC

Youth also provided written comments at the end of each session. The majority of feedback from Teen Club participants was positive. Below are some examples of the feedback youth provided. After the first lesson at Mawenzi and KCMC Teen Clubs' youth were very excited to have PYL lead the HIV curriculum as part of Teen Club. One youth participant commended PYL as educators writing, they learned “more than any other day [they] have been taught”. Another participant described their ability to understand the material being a direct result of having PYL as educators.

Youth reported feeling more confident and comfortable engaging in discussion as a result of having PYL teach lessons.

“Yes, I love to be taught by PYL because they are good and I am more confident answering questions. My comment is that we ask to continue to be taught by peer youth leader”- Mawenzi Lesson 6

Receiving education was important to youth and having PYL consistently teach a lesson every month was appreciated. Youth enjoyed lessons and were eager to learn

more. After each session, several youth asked that PYL return to teach at the next Teen Club.

“I enjoy lessons which we are given every Saturday. PGL should continue teaching us every clinic”- KCMC Lesson 3

“My opinion is today's lesson was well understood and I would like to learn more and more to know more about the disease and to know about our health”- KCMC Lesson 3

Youth reported increased realizations of the importance of maintaining good adherence to medication. The youth attending Teen Club sessions were able to offer advice and brainstorm ideas on how to stay adherent and maintain disclosure when presented with scenarios that might make taking their medication difficult.

“We should continue to advise and educate different youth in order to know the importance of medicine so that they do not stop medicine.” - KCMC Lesson 1

“I would like this lesson to proceed because I learned a lot about HIV and opportunistic diseases and how to avoid them. We learned how to live with people who are not infected and don't have the same problems as us.”- KCMC Lesson 2

“Comments about this lesson is medical adherence is important, educating people especially youth about side effects of stopping medication and importance of right instructions for taking medicine.”- Mawenzi Lesson 3

Youth also reported feeling less stress about their HIV status after learning more about their condition. Several youth reported increased feelings of acceptance of their disease following PYL teachings.

“I learned many things and I understand my condition more. I'm happy to be able to participate in the session. It reduced my stress and cheered me up. I also see myself as more valuable. I love it and it brings me joy. Thank you all.” -Mawenzi Lesson 2

Education covered in the HIV curriculum was relevant and helped address misconceptions about HIV. One participant described being able to use the information presented to go back and educate their community.

“The lesson should continue because it provides us with education to make us strong. We are having fun and it also helps us provide knowledge to the society”- KCMC Lesson 4

3.1.2.2 Acceptability Reported by PYL

Six months after initiating training, PYL were interviewed to better understand implementation progress and their opinions on HIV curriculum delivery. PYL expressed their opinion that youth benefitted from having peers teach over previous methods using of being taught by clinic staff. PYL believed youth were more comfortable asking them questions about sensitive topics than they would a nurse or elder. PYL felt their ability to create open discussion spaces for youth made them better educators than clinic staff.

“Peer leader compared to nurses is so different because [youth in Teen Club] were not comfortable to ask nurses questions they ask me, so with peer leaders they are free to talk because we are the same age and we are youth like them. They can be free to ask questions.” - Female PYL, Mawenzi

“When you compare us with nurses...you find the youth are afraid of the nurses but they aren't afraid of us. You find when I teach, the youth feel free to ask, challenge me about anything in that lesson until they understand” – Male PYL, KCMC

“The difference between me and the nurses there is a big difference because you can find that I am speaking the youth language and we are understanding each other and the youth is free to talk about his things, you can find that nurses when they teach they teach very well but the youth is not free to talk about his things rather than when his fellow youth teach him he is free to tell his fellow youth so there is a difference in teaching and being free” - Male PYL, KCMC

PYL believed the HIV curriculum was relevant and had valuable information for YLHIV on how to maintain adherence as well as culturally relevant information about improving overall health and well-being.

“[What] I like [about the curriculum] is the lessons are relevant to the society as how people say for example lesson on food and water safety is something which is in our society and is relevant. For example, when you eat clean food, [you need] clean equipment, clean environment, and boiling water in the clean equipment, so this is relevant for everyone.” – Female PYL, KCMC

3.1.2.3 Acceptability Challenges and Adaptations

The most common challenge reported at KCMC Teen club were loud environments where teaching sessions took place. Youth were sometimes unable to hear the PYL due to clinic set-up. Teaching sessions took place in the waiting rooms while youth were being called in to see nurses/doctors. Controlling side conversations was also a challenge reported by PYL and Teen Club participants at both Mawenzi and KCMC sites. If lessons began later in the morning, PYL and SYV group leaders reported lower participant engagement in discussion as a result of distracted participants. Youth expressed need for PYL to put more energy into gaining attentions of the audience.

“They are good at teaching, but they should work hard to improve their confidence and deep understanding to teach us so we can gain something. Another thing is that people are disturbing when youth are teaching because you aren’t careful. You should put more effort/energy to get the attention of the youth- KCMC Lesson 4

Following lesson 4, incentives were used to increase participant engagement when PYL posed questions and tried to spark discussions among youth. Candy was offered to youth as an incentive to increase participation at both KCMC and Mawenzi Teen Club. Participant engagement increased as a result, reported by both SYV group leaders and noted in fidelity checklists. Participation was also hindered when youth were escorted to

clinic by their caregivers and sat together during teaching at KCMC. At Mawenzi Teen Club, SYV and PYL along with clinic staff had implemented a practice of asking caregivers to wait outside during session teaching so that youth would feel free to ask questions and participate in the discussion. This practice was then implemented at KCMC to improve youth freedom to participate.

Confidentiality and fear of disclosure were issues brought up by a PYL after youth recorded them teaching at KCMC Teen Club. Youth were then asked not to record or take pictures of PYL teaching in order to maintain confidentiality of the Teen Club teaching activities. No reported issues with disclosure or confidentiality were reported after this announcement was made.

Though the majority of youth preferred PYL, some youth participations felt the PYL's peer status limited their ability to comprehend and deliver the curriculum adequately. Two youth reported wanting "experts" to replace PYL as educators. Youth asked for more knowledgeable educators despite being told the PYL had undergone training and were quite knowledgeable.

"Good session but should be more expert people. When there is something to share it should be more professional people (medical) as it will help to get scientific and professional knowledge" - KCMC Lesson 1

PYL expressed need for supervision at Teen Club as a result of their peer status and expressed not being taken seriously like a nurse (or elder) would. One PYL who taught at KCMC believed that some youth did not take her seriously like they would a nurse or social worker due to her familiarity as a peer. She reported having to rely on SYV leaders to step in and command attention on some occasions.

“Sometimes they make jokes as we teach. They don’t like see our lessons as serious like nurse or doctors or they may ask hard questions, so we call our [SYV leader] to come and help us...they see us as a people to joke [around with]” -Female PYL, KCMC

PYL relayed complaints from youth about the repetitive nature of completing pre/post assessments. PYL also reported that some youth didn’t like how some of the activities about staying adherent were repetitive. Youth complaints about pre/post assessment testing being repetitive were addressed by emphasizing each lesson contains different questions and underscoring the importance of reviewing past activities for those youth who missed the previous session.

“We give the youth [assessments] to fill. When they read questions, they think that is the same as the last lesson and we see them bothered because they say it is the same questions, but we tell them is not the same and we convince them to fill it as it is...The last lesson we were asking questions about students in boarding school, about good adherence to medicine. We asked them to repeat (tips on adherence) because some of the youth where missing at the last lesson but they attended this lesson so this will help those who were missing to understand about last lesson.” -Female PYL, KCMC

3.2 Changes in PYL Before and After Initiating Training

3.2.1 Motivating Factors

3.2.1.1 Education

PYL reported education, being a good role model, creating a comfortable environment where youth could ask any question and the ability to instill confidence, hope and self-worth in their peers as well as improve their own confidence and leadership skills as being motivating factors to becoming a PYL. These motivating factors were similar before training and six months after PYL initiated training.

All seven PYL identified education as a tool to address common misconceptions and misinformation and a motivating reason to teach. PYL shared that feelings of mistreatment, isolation, and internal stigma were all themes that emerged as negative aspects of living with HIV and they desired to help their peers cope with these challenges through education. For example, one PYL reported being stigmatized by his caregiver as a result of his HIV status. After his caregiver learned more about HIV she no longer mistreated the PYL.

“She used to have some kind of stigmatization. She isolates all the utensils I use... When they cook they cook their food and I cook mine... When somebody comes they start to speak ill about me...She used to have stigmatization. She used to beat me.” -Male PYL, Mawenzi

Recruited PYL stressed the importance of their role in educating youth that their HIV status should not limit them. PYL were motivated to undergo training in order to accurately teach their fellow youth at clinic what they believed to be valuable information. PYL were also motivated to educate unaffected youth about HIV in order to increase testing for HIV.

“I can also convince those who have not yet receive the education about HIV, to understand that this is a small problem not big, and [convince] those who have not been tested to get tested.” -Female PYL, KCMC

Another important motivating factor brought up by PYL was the inconsistency in which they were being taught before the implementation of the PYL model. Clinics were understaffed and workers over-burdened and therefore several months could go by without youth receiving any sort of lesson. Other organizations and youth would sometime volunteer to teach but these teachings were sporadic and inconsistent. Recruited PYL believed this education model of implementing a consistent teaching schedule following a set curriculum to be a potential solution. A PYL reported teachings

had become rare and youth would simply come to clinic to pick up their medication and leave. She reported three months could pass without receiving any sort of formal lesson.

“There is a time where they don’t educate us about medicines. You just go there, pick up your medicine and leave. Some others take their medicines and they use them only when they are sick. I don’t like that.”-Female PYL, Mawenzi

Beyond educating their peers, PYL believed undergoing training was a way to prepare them to better educate others in the community about living with HIV and address common misconceptions surrounding HIV transmission. PYL believed stigma and discrimination stemmed from lack of HIV knowledge, and that education would help reduce both external and internal stigma. PYL would use knowledge received to inform others about transmission and address misconceptions in their community.

“You know education is little especially in village not like in town. The education has not reached in the village. I cannot say much about it here in town since people have mingled lot but in the village one may deny you to sit with their children once they discover that you are having that problem (HIV+).”- Female PYL, KCMC

“Because you may find there are other who don’t have the education. So, you find a person living with someone with HIV and still show the stigmatization because they don’t have that education...I like volunteering to educate them...To give him that education so as I can eliminate challenges for my fellows” -Female PYL, Mawenzi

3.2.1.2_Perceived Impact

PYL believed a major difference of using peers to teach lessons over clinic staff (nurses/social workers) was that it would allow youth to be more open and engage in discussion. Both PYL and youth attending Teen Club sessions reported not feeling comfortable asking questions when clinic staff (and elders in general) taught. PYL believed having a familiar peer teach would open up dialogue. This would allow youth in Teen Club to ask questions about concepts they didn’t understand, share experiences, and offer advice.

“Interviewer: How do you think it will be different for the peer group leader to teach different from the way it was in the past. I mean you told me you were being taught by the nurses, what will be the difference if the youth provides the knowledge?”

Male PYL (KCMC): There will be a difference since with the nurses it feels like school, people are, are, they are... What is it? They are scared, you may find one is even afraid of asking questions, but if fellow youth teaches them, they become freer, one may ask any question.”

When asked six months after taking on a leadership role, the same PYL reported youth felt more comfortable asking questions and challenging PYL than they would a nurse or elder.

“When you compare with nurses like I told you the youth are afraid of nurses, but they aren’t afraid us. You find when I teach the youth [feel] free to ask, challenge me on anything about that lesson until they understand.” – Male PYL, KCMC

PYL also reported youth felt more comfortable with the PYL since they consistently taught at the same location and became recognizable to the youth attending Teen Club.

“For how we were taught compared to now I see is also good. I see the structure now is very okay, because every day the nurses changed, but [the youth] see me every day.”- Male PYL, Mawenzi

PYL felt youth who attended clinic would benefit from seeing a YLHIV teach and would be able to see PYL’s as role models who live healthy and fulfilling lives while also living with HIV. This was a common theme brought up by several PYL as a motivator for taking on a leadership role at their own clinic.

“It will help me since, there are youth who live by looking on how one lives like, may be for example the soccer players, you may find the soccer player want to play and be like a certain person for them to be recognized. So, I will, the way I will teach will attract other person and they will also make a follow up of what I do for them to be like me.” – Male PYL, KCMC

Wanting to instill confidence in YLHIV emerged as a common motivating factor in PYL as well as a need to give them hope and increase their overall self-worth.

“My motivation is when I see the youth who are living with HIV not stigmatizing themselves...It is because, there are times youth do not accept their own self. You may find a youth does not accept that they are infected (HIV infected), you find, ‘I one saying I cannot stand in front of people, I can’t lead anything’. So, I would like to motivate youth who are living with HIV... they are capable, if they decide, they are capable of leading something” - Male PYL, Mawenzi

3.2.1.3_Skill Building

All PYL reported wanting to improve public speaking skills, gain overall confidence, and become an advisee counselor to their fellow peers as motivating factors for undergoing training. PYL reported wanting to build their own confidence as well as their peers’.

“It will build my confidence and the courage to speak up without being scared of people knowing (my status). It will also help me in skills and academics. Somebody may say he saw me as a peer leader somewhere so when he gets a problem, he may come to you for help... I want to build confidence both in myself and in them so when I teach them, they will understand. I need to get rid of (both of our) anxiousness.” – Female PYL, Mawenzi

3.2.1.4 Career and Future Goals

When asked what motivated youth to become leaders at clinic, many participants mentioned using their participation as an opportunity to gain experience in leadership. Three PYLs were interested in careers as HIV educators.

*“Interviewer: As a peer group leader, how do you think this position will be helpful in future?
Female PYL (KCMC): It will help me may be to gain income, to educate the society and go to different institution and tell them I have gone through something and they may give you a letter which may help to earn income too.”*

One PYL was specifically interested in using this leadership opportunity as a stepping stone in her career.

“This position will help me, since as I continue living in the society or family or nation, I will be a big leader like a minister, or member of the parliament, it will not be very difficult for me to know what I am expected to do since I will be repeating, and I will already understand what I am required to do” – Female PYL, KCMC

3.2.2 Fears

Understanding what worried youth about teaching in front of their peers was important in addressing barriers to the PYL model. Most PYL reported fears of taking on a leadership role in front of their fellow peers. The most common reported sources of worry and fear for teaching at Teen Club were not being respected, being mocked and/or gossiped about, and fear of public speaking.

PYL reported being wary of how youth would act when taught by someone familiar to them and worried youth might not listen when asked to quiet down or pay attention. Youth attending Teen Club were used to being taught by nurses (or elders in general). Four of the PYL reported being afraid their fellow youth would only see them as a peer and therefore not pay attention during Teen Club leading to overall disruption.

“Some will be surprised that you are going to teach since you are the same as them (HIV+). Some will ignore me, and they may not listen to me” –Female PYL, Mawenzi

“If it happens where someone does not respect me, this is what makes me worried. I will despise it” –Male PYL, KCMC

Some of the PYL reported worries involving gossip or being mocked by youth at Teen Club. PYL also reported fear of “being asked silly questions”. All PYL expressed worries regarding standing up in front of their peers and teaching. Anxiety about standing

in front of others and having everyone stare at them was a common theme throughout all 7 interviews.

When asked about their fears 6 months after beginning training, PYL reported experiencing what had worried them initially but learned how to move past the fear. PYL reported some youth in Teen Club were noisy, distracting to others, and asked funny questions. PYL reported being fearing this type of behavior in the beginning, but not at the point of interview when they had taught 5 lessons.

3.2.3 Changes in Resilience

Table 3: Changes in Peer Youth Leader Resilience 6 Months After Initiating Training

Teen Club Clinic Site	Peer Youth Leaders	CD-RISC Before Training (0-100)	CD-RISC 6-Months After Training (0-100)	% Change in CD-RISC	P-value
Mawenzi ¹	PYL 03	64	74	15.6	0.054
KCMC	PYL 053	68	75	15.4	
	PYL 04	49	59	20.4	
	PYL 027	66	67	1.5	
	PYL 018	47	56	19.1	

¹2 missing responses: PYL05 (Male, Mawenzi) due to loss of the interview and PYL02 (female, Mawenzi) due to move to Mwanza

Change in PYL’s resilience before and 6-months after taking on a leadership role at Teen Club training was significant (p-value<0.05). All PYL had increased resilience scores after taking on a leadership role.

Five of the seven PYL reported a 0 (none of the time) or 1 (a few times) to “I can make unpopular or difficult decisions that affect other people if it is

necessary” before initiating training. After training, all PYL reported inability to make unpopular or difficult decisions if necessary. PYL responded with greater capability of being able to deal with challenges, failures, and unpleasant feelings after taking on a leadership role.

Promotion in resilience seen in increased self-esteem, confidence, social-support, and sense of purpose, as well as reduced internal stigma were reported by PYL after six months of training to become educators at Teen Club.

PYL reported greater confidence in themselves as leaders and self-esteem as a result of training and reported being able to handle challenges as a result. Their peer status helped to create an open environment for discussion and also helped PYL feel more adept to talk about issues related to living with HIV. They themselves were aware of challenges related to living with HIV and therefore PYL reported feeling comfortable in addressing issues YLHIV frequently face.

“The first time when I was [teaching] in front I was scared, I was worried I would forget something I should teach, but I have taught and put that worry far and I have much confidence... Us as peer leaders you see that we have experienced those same problems (as YLHIV), and you see instance of a youth who has the same problem as you, so you will have freedom to talk about the reality and more deeply [about those problems].” - Female PYL, KCMC

“Friends show up and are there (at Teen Club). They are happy that we are still teaching especially because we are also youth. We feel very happy being peer leaders, so that friends who need more advice or are afraid to ask questions they can follow beside us... They are comfortable to ask me the question because I am peer leader and we grow together.” - Male PYL, Mawenzi

“Training of being group leader helping me much, because they give me education about HIV infections, they give me education about stigma, so education which I get help me, to be confidence, to stand and share with people, and to get freedom let I learn how to disclose, and being

confidential so it made me on the freedom that is not necessary to everybody to know your status, so it made me on that power and I understand many things about that education” -Male PYL, KCMC

PYL reported reduced feelings of internal stigma as they learned more about living with HIV. Education was an important component identified by PYL to combat internal resilience. Education they received as part of training helped PYL understand they could live healthy lives even though they are living with HIV.

“Internal stigma about me it reduced a little, because I have education, if you have enough education and you understand your status that situation of stigmatizing yourself is gone.”-Male PYL, KCMC

Increased confidence helped PYL feel more comfortable within their communities as well. One PYL believed her role as a PYL has helped her confidence and self-image within her community saying, “since I have become a peer leader, the community thinks that I've moved on [to do good things]” (PYL053). PYL also reported feeling more confident in trying to address stigma by educating individuals within their community.

“[Another change] is my confidence also, because you may meet some person on the road or persons who tell bad stories about someone who is living with HIV, but I gained confidence of saying and educating. I got confident here, so I educate” -Male PYL, Mawenzi

“Let’s say the skills, which I have gained is I have more confidence to stand in front of people, even if it’s to teach elder people. It (my confidence) gives me the ability to do many things, and to teach elders and not only youth... I feel free because I like having that knowledge because in my society, they treat persons who has infections different, or a person who can’t do hard work in the society. So, I would like so much to be a teacher. — Male PYL, KCMC

The recruited youth reported their support network expanding to include their fellow leaders throughout the training process. PYL acknowledged the importance of the support they received from one another during Teen Club and training sessions. PYL from KCMC clinic would frequently travel to Mawenzi to support their fellow leaders at Teen Club. SYV group leaders supported this finding during supervision meetings saying PYLs would often come to training sessions early to talk to another and offer advice.

“My relationship with Peer Leaders is that we have become more familiar with each other. (Before training) I was not used to them as I am now. Also, we have become closer, support, caring and encourage each other.”-Female PYL, KCMC

“We share different thoughts so if one person cannot do something they will share with the other (PYL) so there are changes and we have the willpower to help our fellow youth”- Male PYL, Mawenzi

PYL reported relying on their fellow leaders during Teen Club sessions when youth were disruptive and did not engage properly.

“An example that happened there's a friend I say he's joking with, so it happened that he answered badly so I got angry and my fellow leader calmed me and told me to be gentle, so I listened to him.” - Male PYL, Mawenzi

Changes in coping mechanisms for HIV-related stress was also expressed by PYL as a result of undergoing training to become leaders. One PYL reported feeling suicidal thoughts before undergoing training. The HIV knowledge learned in training helped this PYL learn how to cope with stress and increase feelings of self-worth.

“I think if I did not begin teaching there is possibility of me to make more bad decisions, but because of the [curriculum] it made me understand and cope with stress. I am good, stress [isn't gone completely in me], but now I am good in total. I think I may hate myself, that I may kill myself before when I wasn't a peer leader. You find many thoughts in your mind and you stigmatize yourself, thinking... Start to hate yourself, and see you're not

*important and it is better to die, but for now I know what I can do.” -Male
 PYL, KCMC*

3.3 Knowledge Gained by Youth Attending Teen Club

3.3.1 Knowledge Assessment Scores

A total of 200 complete assessments were collected (Table 2). Learning gain scores from KCMC and Mawenzi Teen Clubs were overall normally distributed with scores from Mawenzi Teen Club skewed slightly to the right (Figure 1). Both KCMC and Mawenzi learning gain scores were centered around 0 with a larger distribution of positive scores at KCMC (Figure 1).

Table 2: Lesson Responses from KCMC and Mawenzi Teen Clubs

<i>Lesson*</i>	<i>Teen Club Clinic Site</i>		
	Mawenzi	KCMC	Total
<i>1-Epidemiology and Physiology of HIV</i>	17	18	35
<i>2-Clinical Manifestations of HIV</i>	23	14	37
<i>3-HIV Therapy</i>	15	19	34
<i>4-Monitoring HIV Infection</i>	24	27	51
<i>6-HIV Infection and Transmission</i>	26	17	43
<i>Total</i>	105	95	200

** Lesson 5 (Careers and Career Planning) not taught by PYL*

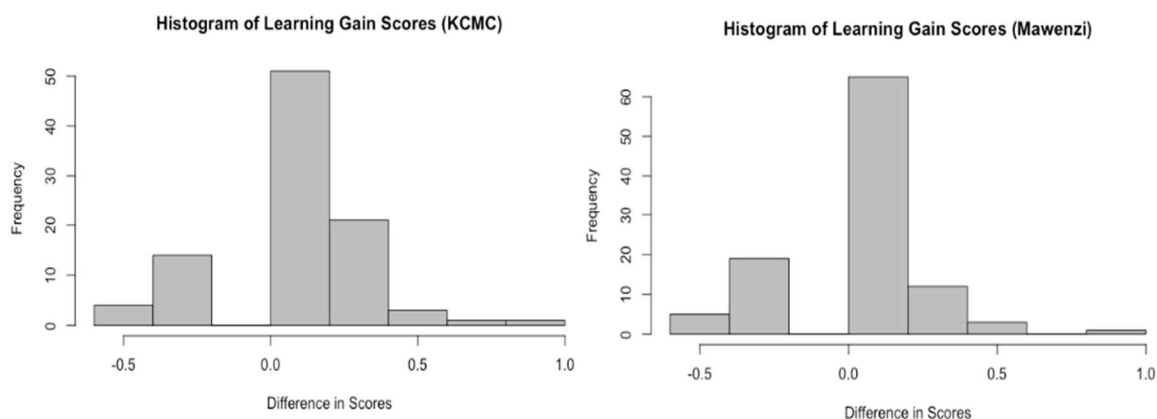


Figure 1: Distribution of Learning Gain Scores at KCMC and Mawenzi Teen Clubs

A statistically significant difference in assessment scores was found after youth received education from PYL (p-value=0.05). When stratified by clinic site, only KCMC had a statistically significant improvement (p-value=0.01). Participants attending Mawenzi Teen Club had higher average pre-test scores than participants attending KCMC Teen Club therefore the difference was not statistically significant. Mean difference in scores were 6.8% and 1.6% respectively at KCMC and Mawenzi, respectively (Table 3). Assessments consisted of 4 to 5 questions, and therefore these small changes in assessment score would not translate to answering an additional question correct on post-tests.

Table 4: Assessment Scores from Youth Attending KCMC and Mawenzi Teen Clubs

<i>Clinic Site</i>	<i>Mean Pre-test Score</i>	<i>Mean Post-test Score</i>	<i>Mean Difference in Assessment Score</i>	<i>p-value</i>

<i>Mawenzi</i>	67.1%	68.8%	1.6%	0.792
<i>KCMC</i>	61.8%	68.7%	6.8%	0.014
<i>Both</i>	64.6%	68.8%	4.1%	0.057

Youth attending Mawenzi Teen Club had higher distribution of perfect pre-test scores, but a higher post-test score median. IQR range of scores collected from KCMC Teen Club were similar when comparing pre and post-tests. Median of post-test scores collected at Mawenzi and KCMC Teen Clubs were higher than the mean. Higher median scores indicate the mean is skewed by low outlier scores. The mean pre-test score from youth attending Mawenzi Teen Club was higher than the median due to a higher distribution of perfect scores (Figure 2).

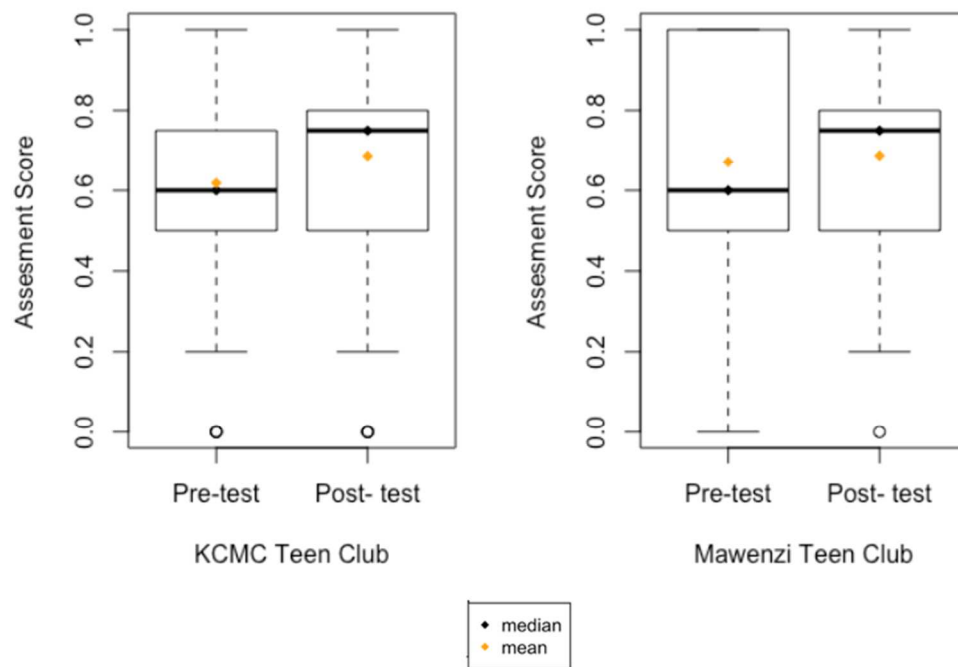


Figure 2: Boxplot Comparison of Pre and Post-Test Scores from KCMC and Mawenzi Teen Clubs

Learning gain scores varied per lesson at each Teen Club clinic site. Participants at Mawenzi performed worse on assessments following presentation of lesson 2 (Clinical Manifestations of HIV) and lesson 3 (HIV Therapy) but better after lesson 1 (Epidemiology and pathophysiology of HIV), lesson 4 (Monitoring HIV Infections), and lesson 6 (HIV Transmission and Prevention). Participants at KCMC performed better on assessments following presentation of lesson 1 (Epidemiology and pathophysiology of HIV), lesson 2 (Clinical Manifestations of HIV), lesson 3 (HIV Therapy), and lesson 6 (HIV Transmission and Prevention) but worse on lesson 4 (Monitoring HIV Infections). Positive learning gain scores were observed at Mawenzi and KCMC Teen Clubs after presentation of lessons 1 and 6. Youth who volunteered to take pre/post assessments at KCMC had a higher average learning gain score than Mawenzi after presentation of lesson 6 by PYL by approximately 7%. Mawenzi had average learning gain scores higher than KCMC for lesson 1 by approximately 4% (Figure 4).

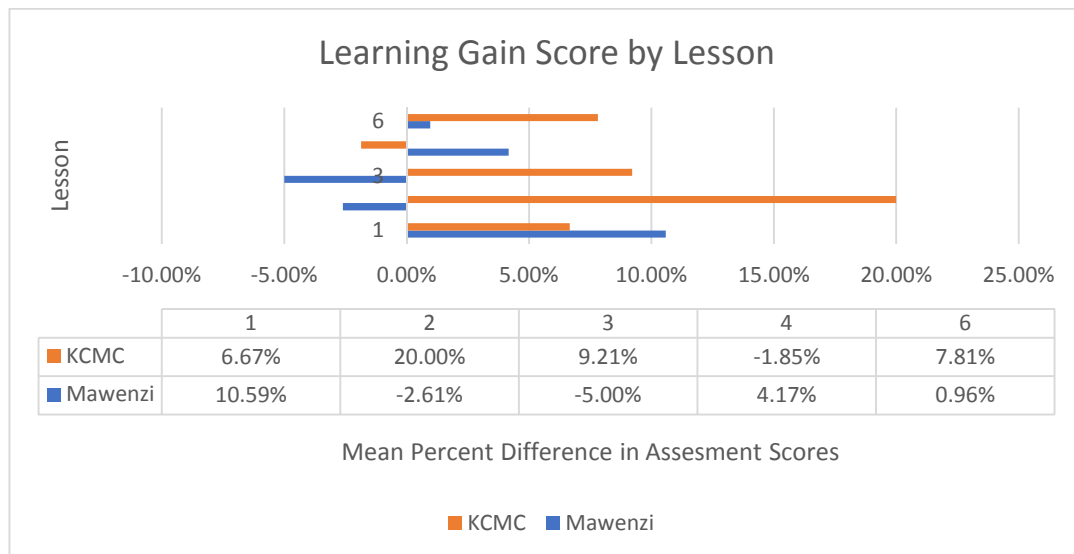


Figure 3: Learning Gain Scores by Lesson of Youth Attending KCMC and Mawenzi Teen Club

4 Discussion

4.1 Objective 1: Feasibility and Acceptability of Training and Using PYL

This education-based intervention of training and using PYL to teach an HIV curriculum to YLHIV was feasible to implement and highly acceptable among the YLHIV who participated. Through qualitative data, this study highlighted important information on specific barriers to implementation and ways to improve the PYL education model to enhance delivery and youth participation. A formative evaluation approach was used to make decisions on how to improve the intervention based on continuous feedback of outcomes and observations which lead to its overall success.

The majority of YLHIV in attendance of Teen Club lessons reported the HIV curriculum to be composed of relevant and new information. The PYLs were able to create comfortable environments for youth to engage in discussion about sensitive topics.

Most youth preferred PYL over clinic staff due to creation of these safe and open discussion spaces. Findings of this intervention are supported by the literature. Using peers as resources is a common and effective method in improving knowledge and promoting attitudinal and behavioral changes among adolescents (Adeomi et al., 2014; Brieger, Delano, Lane, Oladepo, & Oyediran, 2001). Youth prefer to receive education about sensitive topics, like sexual education, using active methods that allow for engagement and role-playing (Stephenson et al., 2008).

This study found peer education to have a positive impact on both youth attending Teen Club and PYL. Youth attending Teen Club reported reduced stress and feelings of joy after sitting through PYL teachings. This positive change in attitudes is an important predictor for changing behaviors (Ajuwon & Brieger, 2007). PYL knew the importance of taking medicine and believed lessons would remind them and their fellow peers to stay adherent to treatment. Common responses from YLHIV attending PYL teachings were desires to improve their own health and well-being and that of their peers as well as stressing the importance of adherence to treatment. Increased realizations of importance of adherence is critical as adherence is a good predictor of viral rebound, drug resistance, and adverse health outcomes associated with HIV (Haberer et al., 2010). Use of waiting rooms as a site for youth engagement was also important as waiting rooms of HIV clinics are areas that can influence YLHIV's experiences and perceptions of their illness and lead to better retention in care (Lee et al., 2016).

This study found training and implementation of PYL as educators to be feasible and acceptable; however, limitations of their teaching ability were observed. Some youth were not able to see past the peer status and would prefer having clinic staff teach the

HIV curriculum. This accounted for approximately 18% of our sample. PYL also needed supervision when teaching to ensure accurate information was relayed to youth attending Teen Club. Debrief meetings were necessary to review session notes and fidelity checklists following weekly supervised training and monthly Teen Club teachings. Supportive supervision is recommended when working with adolescents in educational programs (Edström & Khan, 2009; Luna & Rotheram-Borus, 1999). The use of formative evaluation to monitor implementation progress and initial study outcomes was helpful in creating adaptations to identified challenges as they arose.

4.2 Objective 2: Changes in PYL Before and After Initiating Training

Highly motivated YLHIV were recruited as PYL and were instrumental in the successes of this PYL education model. Peer leader selection is crucial to the efficacy of peer education interventions. Educators with strong leadership skills and sufficient confidence, compassion, technical competency, and communication skills are more likely to be accepted as leaders by their peers (Al-Iryani, Basaleem, Al-Sakkaf, Kok, & van den Borne, 2013; Borgia, Marinacci, Schifano, & Perucci, 2005; Shepherd et al., 2010). Peer leader themselves are the key factor directly related to the outcome of peer education (Qiu, Shen, & Lu, 2016).

All recruited and trained PYL expressed their desire to learn more about HIV to promote both their own and their peer's overall wellbeing. This was an important attribute as PYL had to commit to attending weekly training sessions and continually review all 12 lessons in the curriculum. Motivation in wanting to increase one's own HIV knowledge and motivation to undergo training to help with future career interests seemed to be linked. Two PYL were interested in becoming HIV counselors. All PYL believed

the education would help them learn valuable skills and reduce internalized stigma. Similar to other studies, interests in improving one's own education and future were important motivators to becoming peer leaders (Ochieng, 2003).

A common overlap in PYL testimonials of perceived impact of the PYL education model and written comments from youth attending Teen Club was observed. PYL believed their peer status would allow for more open and safe discussion spaces and sharing of stories from youth attending Teen Club. Feedback from youth attending Teen Club suggested PYL were successful at creating a comfortable environment for open discussion. Peer educators are more capable of understanding youths' concerns than adults and are seen as less patronizing (Baker, 1994; Luna & Rotheram-Borus, 1999). PYL believed youth would benefit from seeing youth living with HIV in a leadership position. Youth testimonials reflected their view of PYL as behavioral role models. Studies show peer educators can be effective as behavioral role models and play a role in changing behaviors of other adolescents (Luna & Rotheram-Borus, 1999).

Fears expressed by PYL before initiating training helped in foreshadowing barriers to the PYL model. PYL were afraid of not being respected or seen as leaders by their fellow peers. They also reported fear of not being able to command attention of the room, which was a reported challenge. Session notes and fidelity checklists reflected problems with engagement and attention to PYL teachings.

This study was important as resilience in YLHIV is not well understood and there is a growing need to evaluate the role of resilience in mental health outcomes (Betancourt et al., 2013). PYL did see a statistically significant increase in resilience (CD-RISC) scores after taking on a leadership role at Teen Club (p-value=0.05). Almost all PYL

resilience scores fell below the mean score (65) found in healthy adolescents in sub-Saharan Africa (Bruwer, Emsley, Kidd, Lochner, & Seedat, 2008; Jørgensen & Seedat, 2008). Resilience scores of PYL were similar to scores seen in patients diagnosed with generalized anxiety (62.4) (Dodding, Nasel, Murphy, & Howell, 2008). All PYL demonstrated lower resilience when compared to the US general population (Connor & Davidson, 2003). Age, ethnicity, and gender are all determining factors that can influence CD-RISC scores though this relationship depends on the population and environment (Böell, da Silva, & Hegadoren, 2016; Campbell & Mzaidume, 2001; Gillespie, Chaboyer, Wallis, & Grimbeek, 2007; Jørgensen & Seedat, 2008; E. E. Lee, Martin, Tu, Palmer, & Jeste, 2018; Marwitz et al., 2018; Rosenberg et al., 2014; Seib et al., 2018; Terrill et al., 2016).

Qualitative analysis also supported improved resilience of PYL through reported improved self-confidence, feelings of self-worth, and optimism as a result of participating in training and teaching at Teen Club. The education PYL received as part of training promoted resilience by teaching PYL how to cope with challenges related to living with HIV. Interventions which aim to normalize living with HIV are valuable in promoting youth resilience (Betancourt et al., 2013; Rotheram-Borus, Stein, & Lester, 2006). Training and becoming leaders at respective monthly HIV clinic led to increased confidence and reported feelings of self-worth in PYL. Development of a healthy self-image and acceptance of living with HIV is important in building resilience of YLHIV (Bhana et al., 2016; Ungar et al., 2007). PYL reported more optimism about their health and future which are important predictors of increased resilience (Rutter, 2013; Skovdal, 2012).

Peer youth leaders benefitted from social support when their roles were acknowledged in their communities as well as at Teen Club. Peer education programs which make use of social support systems are recommended to ensure efficacy of peer leadership approach (Bond, 1982; Ochieng, 2003). PYL also benefitted from support from their fellow leaders while undergoing training. Supportive peer networks are an important component to promoting resilience and can help YLHIV cope with hardships (Dow, Mmbaga, et al., 2019; Skovdal, 2012).

4.3 Objective 3: Knowledge Gained by Youth Attending Teen Club

Studies show education-based interventions can be especially effective in increasing knowledge in adolescents (Abdi & Simbar, 2013). This is important as improved HIV knowledge is strongly associated with improved medication adherence (Kalichman et al., 2008). Peers can be effective at improving knowledge of their fellow peers (Adeomi et al., 2014). Youth reported learning new information during PYL teachings. A statistical difference in assessment score was found but there was no practical difference. Youth at KCMC did show a statistically higher post-test score, but this percent difference (6.8%) was minimal. Higher post-assessments scores found at KCMC Teen Club could be explained by the division of youth by age groups. Unlike in Mawenzi where all youth gather in a large waiting room, youth in KCMC are held in separate waiting rooms based on by age groups (13-17 years and 18-24 years). This might have allowed youth receiving lessons at KCMC to take the curriculum more seriously and the less crowded waiting rooms might have provided less distractions.

The lack of evidence for a practical significant change in assessment scores post-teaching could be explained by characteristics of the YLHIV receiving the education. No

identifying information was taken and therefore literacy, education level, and adherence of youth could not be determined. Youth who attend Teen Club might already be doing well and understand their disease because they are motivated to attend clinic monthly. The target population of YLHIV who lack comprehensive HIV knowledge therefore might not be in attendance. Literacy levels could also explain insignificant changes in assessment scores. Low literacy could have prevented youth from being able to answer questions correctly. Only 5.4% of Tanzanian youth in early grades are able to read with comprehension and overall literacy rate of youth (85.76%) falls below rates seen in high and higher-middle income countries (98-99.9% youth) (UNICEF DATA, 2018.; USAID Tanzania Education Fact Sheet, 2018). Feedback from YLHIV attending Teen Club also showed annoyance with completing pre/post assessments every session and this might have led them to fill out answers without reading the questions properly.

4.4 Study limitations

Limitations of the study included, verification of accuracy of pre/post assessment results, possible desirability bias introduced in IDI's, and the question of sustainability of the PYL education model. Sustainability of this intervention is an issue as this project was funded as part of a graduate student's fieldwork project. PYL received payment for teaching at Teen Club and transportation reimbursement for attending training sessions and continuing funds and willingness of PYL to volunteer in the role are uncertain.

Accuracy of pre/post assessment results could have been compromised due to youth sharing answers with one another when completing assessments or completing pre and post assessments prior to lesson completion. Teachings at Teen Club took place in waiting rooms and this resulted in multiple incomplete forms at the end of Teen Club as

youth were called in to see the doctor and did not always return to the lesson. No identifying information was taken about the youth who volunteered to take the pre/post knowledge assessments, so it is also not possible to match results to HIV outcomes nor to know if youth attended the lesson the month. Two-month prescriptions were given to some patients and therefore some youth choose not to attend Teen Club every month.

Desirability bias could have been introduced in the study and affected results. One of the IDI interviewers was an SYV leader who was involved in training PYL. As a result, PYL may have reported socially desirable answers about successes of the PYL model to the interviewer. It is important to note the variation among PYL interviews as some participants were more willing to discuss sensitive issues and share stories than others. This may result from feeling more comfortable opening up with a known and respected interviewer. Desirability bias could have also been introduced in completion of session notes following training and fidelity checklists following Teen Club teachings. SYV leaders had a vested interest in this study and this could have impacted how they reported challenges and successes at weekly session meetings. Lastly, initial interviews with PYL prior to training were simultaneously translated and transcribed from the local language, Swahili, into English; therefore, some details and phrasing may have been lost in the process. Interviews with PYL conducted 6 months after initiating training were also not transcribed and translated by the interviewers due to limited capacity and timeframe. Therefore, details and context may have also been lost as research staff conducting transcription and translation were not present for the interviews themselves.

4.5 Implications for Practice

Studies have shown effectiveness of using peer leaders to educate youth. Using PYL to teach an HIV curriculum to youth at Teen Club in the Kilimanjaro region demonstrated feasibility and effectiveness based on feedback from youth and PYL and should continue. Both youth attending Teen Club and PYL benefitted from this PYL education model. There is a growing recognition of involving YLHIV in their care to improve health outcomes (Edström & Khan, 2009; UNAIDS, 2018).

In the Kilimanjaro region the HIV adolescent clinics, like many adolescent healthcare services in LMICs, are filled with vulnerable individuals at a very critical time in their lives. Some of these youth are very passionate about improving their own mental health and well-being and that of their peers. Bolstering support of eager individuals can help ease burden of clinic staff while providing youth in waiting rooms with important HIV knowledge (Lee et al., 2016).

Government mandate has called for restructuring of HIV clinics. Youth who are considered “unstable” (on 2nd line ART or have viral loads >1000 copies/ml) will soon be required to attend clinic every month while youth who are considered “stable” (on 1st line ART and are virally suppressed) will only need to attend clinic every 6 months. Monthly clinic visits for “unstable” patients will include education to enhance youth engagement. This will allow “unstable” patients to receive more focused care. Youth who participated in PYL teachings did report increased realizations of the importance of staying adherent. Therefore “unstable” patients might benefit from more specialized education.

4.6 Implications for Further Research

Research on retention in care and health outcomes of YLHIV in attendance of educational lessons should be conducted. PYL reported stress relief, less internal stigma,

and increased resilience. Youth attending Teen Club realized importance of staying adherent and feelings of empowerment after PYL teachings; however, conclusions about improvement in mental health and adherence to treatment among youth listening to the treatment sessions could not be made due to deidentified pre/post assessments.

Understanding how changes in resilience and HIV knowledge can affect YLHIV quality of life and overall health outcomes is important in understanding effective treatment strategies. Involvement of youth in the implementation of programs that affect their health, promoted by the UNAIDS three lens-approach, can lead to improved health outcomes (UNAIDS, 2018). Peer education is not well understood in context of youth already infected with HIV. In working to understand best practices for new and effective interventions for YLHIV, long-term health outcomes must be better understood (Lall, Lim, Khairuddin, & Kamarulzaman, 2015; L. Lee et al., 2016; UNAIDS, 2018). Future research should focus on gathering evidence on interventions aiming to promote resilience of YLHIV (Betancourt et al., 2013).

5 Conclusion

This study demonstrated a PYL model of delivering an HIV curriculum is feasible and acceptable among Tanzanian YLHIV and use of peers can also empower and promote resilience of YLHIV who take on a PYL role. Through rich qualitative data and a formative evaluation approach, this study addressed challenges to implementation of a PYL model of delivering an HIV curriculum. The data illustrated the positive impact of using PYL as educators in waiting rooms of youth HIV clinics to alleviate YLHIV's stress and feelings of internal stigma while also promoting importance of staying adherent and feelings of empowerment. PYL themselves were empowered through their leadership roles and showed increased resilience. Lastly, this study provides guidance on modifications to the PYL education model to enhance youth participation

Appendix A

IN DEPTH INTERVIEW PART 1

FOR INTERVIEWER ONLY: Please remember to power on the recorder (on the left side of the recorder), make sure you have at least 1 bar of battery (lower right side of the screen) and place the microphone of the recorder (at the top) facing the youth, not more than three feet away. Please also make sure your cell phone is off.

Thank you so much for joining us today for your first of two interviews. During today's interview and your interview in the future, we hope to talk about Teen Club and what you think you've learned during Teen Club lessons. Our conversation today will last between 45 minutes to an hour. In order to learn about your experience in Teen Club lessons we'll be talking about your peer educator and what you think about the different lessons that you've been taught so far. The information we gain from you will be helpful in understanding the importance of peer-led education in young people living with HIV.

I have a recorder here and I have turned it on. You don't need to pay any attention to it, it will stay here during the interview. The recorder will help me capture all that you share with me today. What we discuss will remain confidential and only the study team will listen to your recording. We ask that you try not to use names during the interview in order to protect your privacy and the privacy of others. Before we begin, is it okay with you if I record this interview?

ESTABLISHING RAPPORT/EXPLORING SELF PERCEPTIONS

Tell me a little about yourself.

PROBES:

What is important to you in your life?

Why is it important to you?

What is something that motivates you each day?

How do other people describe you?

How do you describe yourself?

LIVING SITUATION AND SOCIOECONOMIC STATUS

Now I'd like to hear about your living situation.

PROBES:

Where do you live?

Who do you live with?

Does your house have plumbing? Electricity?

Relationships

How is your relationship with your caregiver?

Probes: aware of your status, treat you differently than others in the households

How open are you with your caregiver? Do you feel comfortable talking about everything with them?

Tell me about your close friends.

Probes: aware of status

Describe your ideal secure and open friendship.

How supportive or unsupportive are your current friends?

How aware are your friends in your role as a peer group leader?

How often do you turn to your friends when you are feeling stressed or overwhelmed?

How capable are your friends at being able to reduce your stress?

Describe your current romantic relationship.

Probe: Is your boyfriend/girlfriend/partner aware of your HIV+ status, how long have you been together

What is your boyfriend/girlfriend/partner's HIV status?

Have you ever turned to your partner when you were stressed? Were they a good resource?

Describe your ideal supportive relationship.

How supportive or unsupportive is your current partner?

How open are you in your current relationship?

Probes: talk about your status, stress, negative events

Teen Club

Now I would like to talk about Teen Club.

When did you start attending Teen Club?

Probes: How many years has it been

What made you start coming to Teen Club?

What kind of education have you received during Teen Club?
Who taught the education?
What did you like about it?
What did you not like about it?
How different do you think it will be with peer leaders teaching as opposed to the previous structure?

Being a Peer Leader

What is your primary reason for becoming a peer group leader?
How do you feel about leading your first lesson?
Probes: nervous, anxious, excited
What do you think makes you a good leader?
How do you plan to make participants comfortable during the lessons?
Comfortable enough to ask questions and engage
How have you prepared to lead your first lesson?
Have you spent time outside of training?
How do you think being a peer group leader will help you in your future?
Probes: disclosure, explaining HIV transmission to someone, career opportunity or skill
What worries you about being a peer group leader?
What excites you about being a peer group leader?

Stress and Coping

How well do you cope in stressful situations?
How often do you feel overwhelmed by stress?
What do you try to do in order to reduce stress?
How often do you feel overwhelmed with your treatment or HIV status?
When something bad happens how do you cope with that negative event?

Disclosure and Stigma

Now I want to talk about living with HIV.
Who have you disclosed your status to?
Have you had any bad experiences telling anyone? Describe the situation.
How supportive is your immediate family?
caretakers, siblings, etc.
Why do you think you haven't disclosed your status to others?
Probes: why they haven't disclosed to (friends, other family)
How do you think people will treat you if they become aware of your status?
Describe a time you felt you were treated differently because of your status.
Do you think having HIV limits you?
Probes: career, relationships
Why do you think people treat those who have HIV differently?
Probes: lack of education, religious beliefs (divine justice), cultural beliefs
What would you like to tell them about HIV to get them to change their minds?
What do you think needs to happen to reduce the stigma around HIV in your community?

If one of the youth came to you asking for advice on how to disclose their status to someone, what would you tell them?

Resilience

Now we will begin with statements. Please rate each statement on a scale from 0-4 (Connor-Davidson Resilience Scale 25) with 0 being not true at all and 4 being very true nearly all the time. Please use this illustration to help rate each statement.

I am able to deal with change

I have at least one close and secure relationship that helps me when I am stressed.

When there are no clear solutions to my problems, sometimes fate or God can help.

I can deal with whatever comes my way

Past successes give me confidence in dealing with new challenges and difficulties

I try to see the humorous side of things when I am faced with problems

Having to cope with stress can make me stronger.

I tend to bounce back after being sick, injury, or other hardships

Good or bad, I believe that most things happen for a reason.

I give my best effort no matter what the outcome may be.

I believe I can achieve my goals, even if there are obstacles.

Even when things look hopeless, I don't give up.

During times of stress/crisis, I know where to turn for help.

Under pressure, I stay focused and think clearly.

I prefer to take the lead in solving problems rather than letting others make all the decisions.

I am not easily discouraged by failure

I think of myself as a strong person when dealing with life's challenges and difficulties

I can make unpopular or difficult decisions that affect other people, if it is necessary.

I am able to handle unpleasant or painful feelings like sadness, fear, and anger.

In dealing with life's problems, sometimes you have to act on a hunch without knowing why.

I have a strong sense of purpose in life.

I feel in control of my life

I like challenges

I work to attain my goals no matter what roadblocks I encounter along the way.

I take pride in my achievements.

CLOSING OF INTERVIEW

What else haven't I asked you that you think I should know?

I would like to thank you for sharing your experiences with me today. Is there anything else before we conclude the interview?

If I have any other questions would you be willing to discuss it with me?

Appendix B

IN DEPTH INTERVIEW PART 2

FOR INTERVIEWER ONLY: Please remember to power on the recorder (on the left side of the recorder), make sure you have at least 1 bar of battery (lower right side of the screen) and place the microphone of the recorder (at the top) facing the youth, not more than three feet away. Please also make sure your cell phone is off.

Thank you so much for joining us today for your first of two interviews. During today's interview and your interview in the future, we hope to talk about Teen Club and what you think you've learned during Teen Club lessons. Our conversation today will last between 45 minutes to an hour. In order to learn about your experience in Teen Club lessons we'll be talking about your peer educator and what you think about the different lessons that you've been taught so far. The information we gain from you will be helpful in understanding the importance of peer-led education in young people living with HIV.

I have a recorder here and I have turned it on. You don't need to pay any attention to it, it will stay here during the interview. The recorder will help me capture all that you share with me today. What we discuss will remain confidential and only the study team will listen to your recording. We ask that you try not to use names during the interview in order to protect your privacy and the privacy of others. Before we begin, is it okay with you if I record this interview?

ESTABLISHING RAPPORT/EXPLORING SELF PERCEPTIONS

Tell me a little about yourself.

PROBES:

What is important to you in your life?

Why is it important to you?

What motivates you to take your medicine every day and to be adherent?

How do you describe yourself as a peer group leader?

Relationships

Describe any changes (if any) to your relationships since becoming a peer group leader?

Probes: relationship with caregiver, friends

Specifically with other PGL

How do you think knowing your friend's HIV status (or them knowing yours) impacts how open you are around them?

How supportive or unsupportive are your current friends?

Probe: How would it change if they knew your HIV status

How aware are your friends in your role as a peer group leader?

Probes: have they noticed any changes/made comments

How aware is your family in your role as a peer group leader?

Probes: have they noticed any changes/made comments

Being a Peer Leader

What do you think makes you a good leader?

What do you think you've learned about yourself after leading Teen Club education sessions?

How has your opinion on peer group leaders changed?

How do you feel the youth see peer group leaders?

Probes: compared to nurses or social workers providing education

If you could go back and give yourself advice before you started leading what would you change?

What is your favorite aspect of being a peer leader? Least favorite?

How has training helped/hurt you in your life?

After leading a couple of lessons what are you going to change about your teaching method moving forward?

How comfortable are the youth in asking you questions and engaging in discussion?

How is using peer group leaders to teach different than before (when nurses taught)?

Describe how you deal with youth who are disruptive during Teen Club.

Probes: youth that make jokes, ask questions they know the answers to

How close do you follow the lesson plan while teaching?

Have there been any times you had to change anything through the course of the lesson?

Please describe the situation.

How receptive are the youth while you're teaching?

Probes: eye contact, asking questions

What do you think of the previous structure for the lessons compared to now?
What do you like about the new structure?
What do you not like about it?
What suggestions do you have to make this teaching model better?

Stress and Coping

How well do you cope in stressful situations?
How often do you feel overwhelmed by stress?
What do you try to do in order to reduce stress?
How often do you feel overwhelmed with your treatment or HIV status?
When something bad happens how do you cope with that negative event?
How has teaching changed the way you cope with stress if any?

Disclosure and Stigma

Now I want to talk about living with HIV.
Who have you disclosed your status to? Has this changed since beginning PGL training?
Have you had any bad experiences telling anyone? Describe the situation.
How supportive is your immediate family?
caretakers, siblings, etc.
Why do you think you haven't disclosed your status to others?
Probes: why they haven't disclosed to (friends, other family)
How do you think people will treat you if they become aware of your status?
Describe a time you felt you were treated differently because of your status.
Do you think having HIV limits you?
Probes: career, relationships
Why do you think people treat those who have HIV differently?
Probes: lack of education, religious beliefs (divine justice), cultural beliefs
What would you like to tell them about HIV to get them to change their minds?
How important is education about HIV to you?
What do you think needs to happen to reduce the stigma around HIV in your community?
What has this experience of teaching peers taught you about educating others about HIV?
Probes: Do they feel comfortable going into their community to teach?
Do you feel you have any change in HIV related stigma?
Probes: from the community, from yourself (internal stigma)
If one of the youth came to you asking for advice on how to disclose their status to someone, what would you tell them?

Resilience

Now we will begin with statements. Please rate each statement on a scale from 0-4 (Connor-Davidson Resilience Scale 25) with 0 being not true at all and 4 being very true nearly all the time. Please use this illustration to help rate each statement.
I am able to deal with change
I have at least one close and secure relationship that helps me when I am stressed.
When there are no clear solutions to my problems, sometimes fate or God can help.
I can deal with whatever comes my way

Past successes give me confidence in dealing with new challenges and difficulties
I try to see the humorous side of things when I am faced with problems
Having to cope with stress can make me stronger.
I tend to bounce back after being sick, injury, or other hardships
Good or bad, I believe that most things happen for a reason.
I give my best effort no matter what the outcome may be.
I believe I can achieve my goals, even if there are obstacles.
Even when things look hopeless, I don't give up.
During times of stress/crisis, I know where to turn for help.
Under pressure, I stay focused and think clearly.
I prefer to take the lead in solving problems rather than letting others make all the decisions.
I am not easily discouraged by failure
I think of myself as a strong person when dealing with life's challenges and difficulties
I can make unpopular or difficult decisions that affect other people, if it is necessary.
I am able to handle unpleasant or painful feelings like sadness, fear, and anger.
In dealing with life's problems, sometimes you have to act on a hunch without knowing why.
I have a strong sense of purpose in life.
I feel in control of my life
I like challenges
I work to attain my goals no matter what roadblocks I encounter along the way.
I take pride in my achievements.

CLOSING OF INTERVIEW

What else haven't I asked you that you think I should know?

I would like to thank you for sharing your experiences with me today. Is there anything else before we conclude the interview?

If I have any other questions would you be willing to discuss it with me?

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