Evaluating the Long-Term Outcomes of a Mental Health Intervention in Tanzanian Youth Living with HIV

by

Laura Mkumba

Duke Global Health Institute
Duke University

Date: _____

Approved:

_____
Dorothy Dow, Advisor

_____
Kearsley Stewart

_____
Joseph Egger

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

2020

ABSTRACT

Evaluating the Long-Term Effects of a Mental Health Intervention in Tanzanian Youth Living with HIV

by

Laura Mkumba

Duke Global Health Institute
Duke University

Date: _____

Approved:

_____
Dorothy Dow, Advisor

_____
Kearsley Stewart

_____
Joseph Egger

An abstract of a thesis submitted in partial
fulfillment of the requirements for the degree
of Master of Science in the Duke Global Health Institute
in the Graduate School of Duke University

2020

Abstract

Six percent of the world's population of youth living with HIV (YLWH) reside in Tanzania. Despite scale up of antiretroviral therapy (ART), poor ART adherence contributes to AIDS related morbidity and mortality in YLWH. Reasons for poor adherence include mental health challenges, HIV-related stigma, and lack of psychosocial support. *Sauti Ya Vijana (SYV)*, a group-based, lay counselor delivered, 10-session mental health intervention for Tanzanian youth living with HIV was developed. The objective of this study was to describe the mental health outcomes of SYV in youth living with HIV.

This mixed-methods study enrolled 128 YLWH, aged 12-24, in Moshi, Tanzania to receive either the SYV intervention or treatment as usual. Youth in both arms completed structured questionnaires assessing their demographics, mental health and stigma symptoms, and self-reported ART adherence, at baseline, 6 months, 12 months, and 18 months study timepoints. A mixed effects linear regression model was used to analyze the change in stigma and mental health measures from baseline to the three follow-up timepoints. A subset of 10 youth who were randomized to the intervention arm completed semi-structured in-depth interviews at least one year after the intervention. Interviews were conducted in Kiswahili, and interview guide topics included participant description of history of depression symptoms, current challenges,

recollection of specific SYV topics, and their experience during and after the SYV intervention. Interviews were transcribed and translated to English. Inductive thematic analysis using NVivo was used to analyze interview transcripts and identify common themes.

One hundred and five youth were randomized; 58 to the intervention arm and 47 to the treatment as usual arm. Average age of participants at baseline was 17.8 years and 49% of enrolled participants were male. Majority of the youth (86%) randomized to the intervention arm attended at least 8 out of 10 SYV sessions. The study was not powered to statistically detect treatment efficacy, but youth enrolled in both study groups showed improvement in their mental health and internal stigma measures at all follow-up timepoints in comparison to baseline. Ten youth, 18-25 years of age, were interviewed. Seven of the ten participants were male, and 60% were responders. All participants attended at least eight of the 10 intervention sessions and all baseline, 6 months, and 18-month follow-up appointments. Participants all reported experiencing intermittent symptoms of depression such as feelings of sadness. Current challenges included difficult interpersonal relationships and taking ART on time. The most memorable SYV lessons were coping skills such as breathing exercises. Participants described how SYV helped them have “more confidence”, accept themselves, and incorporate positive coping skills such as relaxation (deep breathing) when they felt stressed.

The findings provide evidence that providing a 10-session group based mental health intervention can have a long-term impact on the psychosocial outcomes of YLWH and can improve resilience in this population. Implementation of the SYV intervention into the routine HIV clinical care has promise to improve overall well-being of YLWH.

Dedication

I dedicate this thesis to Joyce, Hafia, and Herry without whom the rhythm of my heartbeat is off. Thank you for your love, support, encouragement, and prayers during this journey. This thesis would truly not be possible without you.

Contents

Abstract iv

List of Tables xi

List of Figures xii

Acknowledgements xiii

1. Introduction 1

1.1 Global Burden of Adolescents Living with HIV 1

1.2 Mental Health and Stigma in Adolescents Living with HIV 1

1.3 Current Research of ALWH in Sub-Saharan Africa 2

1.4 Study Objectives and Aims 3

2. Methods 4

2.1 Setting 4

2.2 Participants 5

2.3 Procedures 5

2.3.1 Measures 9

2.3.1.1 Depression 10

2.3.1.2 Emotional and behavioral symptoms 10

2.3.1.3 Post-Traumatic Stress 10

2.3.1.4 HIV Stigma 11

2.3.2 In-Depth Interviews 11

2.4 Analysis 12

3. Results 15
3.1 Quantitative Results 15
3.1.1 Baseline Demographics 15
3.1.2 Follow-up and Attrition 16
3.1.3 Stigma and Mental Health Outcomes 17
3.1.3.1 Stigma 19
3.1.3.2 Depression 21
3.1.3.3 Strengths and Difficulties Scores 22
3.2 Qualitative Results 25
3.2.1 Description of Interview Participants 25
3.2.2 History of Depression 26
3.2.1.1 Triggers of Symptoms of Depression 26
3.2.1.2 History of Suicidality 27
3.2.1.3 Coping Mechanisms 28
3.2.3 Challenges Living with HIV 29
3.2.3.1 Experiences with Stigma 29
3.2.3.2 ART adherence 30
3.2.4 Experience with SYV Intervention 31
3.2.4.1 Lessons from SYV Intervention 31
3.2.5 Resilience After SYV 33
4. Discussion 35
4.1 Implications for Policy 39

4.2 Implications for Future Research 41

4.3 Strengths and Limitations 42

5. Conclusions 44

Appendix A: Cartoon Images Used During SYV Sessions 45

Appendix B: SYV Questionnaire 48

Appendix C: Semi-Structured Interview Guide 73

Appendix D: Codebook 78

References 79

List of Tables

Table 1: Components of SYV Sessions 8

Table 2: Baseline Demographics of Participants by Intervention Group 15

Table 3: Stigma and Mental Health Outcomes Between Intervention and Control from Baseline to 18 Months Based on Mixed Effects Linear Regression Model 18

Table 4: Demographics and PHQ-9 Scores of Interview Participants 25

List of Figures

Figure 1: SYV Study Design 7

Figure 2: Flow Diagram of Participants Included at Each Follow-up 17

Figure 3: Total Stigma Scores Across Study Timepoints 19

Figure 4: Internal Stigma Across Study Timepoints 20

Figure 5: External Stigma Across Study Timepoints 21

Figure 6: PHQ-9 Scores Across Study Timepoints 22

Figure 7: SDQ Scores Across Study Timepoints 23

Figure 8: PTSD- Reaction Index Scores Across Study Timepoints 24

Acknowledgements

First, I would like to thank my mentor and advisor, Dr. Dorothy Dow, for her guidance and support throughout the development and execution of this thesis. Second, I would like to thank the members of my thesis committee, Professor Kearsley Stewart and Dr. Joseph Egger. Third, thank you to Fortunata Nasuwa and the Sauti Ya Vijana group leaders for all their efforts during the SYV intervention and interviewing participants. Last but not least, I would like to express my gratitude to my chosen family, Kamry Goodwin, Yadurshini Raveendran, Jacob Stocks, and the Friendos 2.0: The Re-Up Collective, whose laughter, joy, support, and encouragement gave me strength throughout this journey.

1. Introduction

1.1 Global Burden of Adolescents Living with HIV

In 2019, there were 1.6 million adolescents (ages 10-19) living with HIV (ALWH) globally. The majority of these adolescents (89%) reside in Sub-Saharan Africa and over half primarily live in just five countries: South Africa, Nigeria, Kenya, Mozambique, and Tanzania (UNICEF, 2019). An estimated 93,000 ALWH live in Tanzania accounting for about 6% of all ALWH globally. Over the past two decades, there have been improvements in antiretroviral (ART) potency and coverage in the region that have resulted in a decrease in AIDS related deaths for people living with HIV (PLHIV). However, the rate of decline in AIDS related deaths has been the slowest in youth (ages 15-24), and AIDS-related deaths remain one of the leading causes of death of youth in Tanzania. YLWH are less likely than adults living with HIV to be adherent to ART and clinical care (MacPherson et al., 2015; Nachega et al., 2009). There are multiple factors that affect young people's adherence to ART including, poor availability and accessibility of youth-friendly clinical services, lack of psychosocial support, stigma, and mental health challenges (Hudelson & Cluver, 2015; Kemigisha. 2019).

1.2 Mental Health and Stigma in Adolescents Living with HIV

Adolescence is a period of rapid physical, emotional, and behavioral transition that may result in challenges for young people. In ALWH, these challenges may be compounded with physical and social implications of living with HIV such as

opportunistic infections, stunting, stigma, and losing one or more parents due to HIV (Vreeman et al., 2017; Lowenthal et al., 2014). Data from previous studies showed that individual, family, and community level stigma were the primary socio-cultural factors that hindered ART adherence in people living with HIV in Tanzania (PLHIV) (Kahema & Kahema, 2018). As a result of this stigma, many ALWH may have less social support and this is exacerbated in adolescents who may have lost family and friends due to HIV related causes. ALWH have reported poor familial connections, a lack of social support from peers, isolation, stigma, and abuse; all of which are the determinants of poor psychosocial and mental health well-being (Casale et al., 2019; Petersen I et al., 2010; Ramaiya et al., 2016). A study found that 32% of adolescents enrolled in two Moshi hospitals reported mental health difficulties, such as trauma and depression (Dow et al., 2018). Mental health difficulties were also reported in other ALWH in the region and in other resource limited settings (Benton et al., 2019; Vreeman et al., 2017)

1.3 Current Research of ALWH in Sub-Saharan Africa

There have been randomized controlled trials in the last few years to address ART adherence in PLHIV (Bhana et al., 2014; Mavhu et al., 2013; Mbuagbaw et al., 2012; Nestadt et al., 2019). While there have been a few interventions targeted towards ALWH, a small number of these interventions have addressed mental health outcomes and the impact they may have on ART adherence of adolescents in resource limited settings (Bhana et al., 2014; Willis et al., 2019). Given the high numbers of deaths due to

HIV in adolescents and the unique mental health challenges of this population, there is an urgent need for culturally appropriate and developmentally tailored interventions that address mental health gaps and focus on integrating mental health services into the clinical care of ALWH.

1.4 Study Objectives and Aims

Tanzania signed on to be a 90-90-90 target country. This goal aims to have 90% of people living with HIV to be aware of their status, 90% of those who are aware of their status to be on ART, and 90% of those who are on ART to be virally suppressed. While Tanzania has made significant strides to meet these targets, current challenges of ALWH mean that this group may not be on track for these targets. While there are ongoing efforts to conduct interventions to address psychosocial challenges of ALHIV, such interventions are relatively recent and data describing longitudinal outcomes of youth who complete such interventions are lacking.

The objective of this study was to evaluate the long-term outcomes of the Sauti ya Vijana (SYV) intervention in youth living with HIV. The aims for this study were two-fold. The first study aim was to describe the mental health challenges of YLWH at the 18- month study visit, at least one year after receiving the Sauti Ya Vijana Intervention. Second, the study aimed to evaluate the change in mental health outcomes of in YLWH enrolled in the study at 6 months, 12 months, and 18 months.

2. Methods

This mixed methods study was conducted as part of the *Sauti Ya Vijana* (SYV) intervention, a site and gender stratified individually randomized stepped wedge group delivered trial developed to address the psychosocial needs of YLWH in Moshi, Tanzania. Quantitative data were collected between May 2015 and July 2019 through interview-assisted structured questionnaires with 128 YLWH. Qualitative data were collected from August through September 2019 through in-depth interviews with a subset of 10 YLWH who completed the intervention. The study was approved by Duke University Health System Institutional Review Board, the Kilimanjaro Christian Medical Center (KCMC) Research Ethics, and the Tanzania National Institute for Medical Research.

2.1 Setting

The study enrolled participants from two adolescent HIV clinics, KCMC and Mawenzi Regional Hospital Care and Treatment Center, in Moshi, Tanzania. Both hospitals host a monthly Saturday clinic for youth, age 11-24 years old, where youth receive HIV medical care and support from their peers. The intervention was conducted at a neutral research space at the Kilimanjaro Christian Research Institute satellite building in the Majengo neighborhood. All follow up interviews and sample collection were performed at KCMC to be near the biotechnology laboratory that analyzed HIV RNA.

2.2 Participants

128 youth were enrolled at KCMC and Mawenzi between 2015 and 2017. Individuals were eligible to participate if they were between 12-24 years of age, aware of their HIV diagnosis, receiving ART, and attended the youth HIV clinic called "Teen Club" at one of the two study sites. Youth who lived in orphanages or had cognitive disabilities that precluded their ability to consent or meaningfully participate in the intervention were excluded from the intervention.

Participants were recruited by a member of the study team during their Teen Club visit. A letter explaining the study was sent home with the youth to their parent or guardian. Youth also provided a phone number for the study team to contact their guardian about the study. Youth over 18 years of age provided written informed consent. Youth under the age of 18 provided assent while their parent or guardian provided written informed consent.

2.3 Procedures

Study visits occurred approximately every six months from baseline. During the study visit, youth completed a structured baseline questionnaire that was repeated at three follow-up time points: 6-months, 12-months, and 18-months. The questionnaire was administered orally in Kiswahili (Appendix B)

Study participants were grouped into groups of 18-20 participants based on gender (males and females in separate groups), age, and site. Once a group of males and

females with similar age was realized they were individually randomized by coin flip in the presence of the PI and group leaders to receive either the intervention (SYV) or treatment as usual (TAU), which consisted of routine clinical care and adherence counseling. The intervention was delivered across three randomized waves of two groups (one male and one female). Figure 1 displays the stepped-wedge study design of SYV.

Year		2016		2017				2018			2019
Wave 1		**Entry/Baseline**		**6 Mon**		**12 Mon**		**18 Mon**			
	Male SYV	x	Intervention	x		X		X			
	Female SYV	x		x		X		X			
	Male TAU	x		x		X			Intervention	X	x
	Female TAU	x		x		X				x	
Wave 2		**Entry**		**Baseline**		**6 Mon**		**12 Mon**		**18 Mon**	
	Male SYV			X	Intervention	X		X		X	
	Female SYV			X		X		X		X	
	Female TAU			X		X		X	Intervention	X	x
Wave 3		**Entry**				**Baseline**		**6 Mon**		**12 Mon**	**18 Mon**
	Male SYV	X				X	Intervention	X		X	X
	Female SYV	X				X		X		X	X
	Male TAU	X				X		X	Intervention	X	X
	Female TAU	X				X		X		X	X

Figure 1: SYV Study Design

Wave 1 is shaded yellow, Wave 2 is shaded in blue, and Wave 3 is shaded in green. First cross over group is shaded in pink.

The TAU group did not necessarily know others in their TAU group and never formally met as a study group. The intervention group met weekly for 10 weeks as part of the intervention and completed the same six-month follow-up study visits as the TAU group.

The SYV intervention was developed based on principles of cognitive behavioral therapy to address the psychosocial needs of YLWH. The intervention was delivered in group of 8 – 11 youth by trained young adult group leaders. The intervention included 10 sessions, with two individual sessions with counselors, and two sessions held jointly with parents or caregivers. Youth met three Saturdays a month over the span of four months. The goals of the SYV intervention were to help youth identify and cope with stressful events, foster strong familial relationships, and cultivate a safe and healthy living environment. Details of the session topics can be found in Table 1 and examples of cartoon diagrams used during SYV sessions can be found in Appendix A.

Table 1: Components of SYV Sessions

Session	Key Components
Youth Group 1 (Held jointly with caregivers)	**Introduction to SYV:** Group leaders describe SYV and how it will benefit the youth. Youth sign confidentiality agreements and later describe their stress and worries
Caregivers only	Describe what will happen in youth groups and discuss how caregivers can support youth in SYV
Youth Group 2	**Worries, stress, and coping:** Review worries and stresses and discuss coping strategies used by youth
Youth Group 3	**Thoughts, feelings, and behavior:** Youth learn about thoughts, feelings, and behavior using the cognitive behavioral triangle and how they affect each other

Youth Group 4	**Talking about memories:** youth prepare for the trauma narrative of "How I found out I have HIV"
Individual 4.1	**Finding out about having HIV infection:** Youth share memory with group leader and prepare to share with the group
Youth Group 5	**Sharing difficult memories with others:** Share the narrative with the group and emphasize the benefits of sharing. Youth were reminded that sharing is an individual choice.
Youth Group 6 (Held with caregivers)	**Sharing memories with caregivers:** Practice with group leaders and share memories with caregivers
Caregivers only	**Prepare for youth sharing:** Discuss the importance of youth being able to share their memories
Youth Group 7	**Circles of support:** Identify trusted support persons to increase social and emotional support
Youth Group 8	**Stigma:** Discuss identifying and coping with internal and external stigma; review how to discuss HIV transmission to cope with stigma
Youth Group 9	**Disclosure:** Discuss disclosure with household persons and sexual partners and practice disclosure in role play
Youth Group 10	**Values and moving on positively:** Identify values and how youth see themselves in six months; youth describe what they value in life and how to consider their values when making choices
Individual 10.1	**Planning for moving on positively:** Plan for group ending; identify support system outside of the group; individual exit interview
Final Celebration	**Review accomplishments:** praise youth for hard work and enjoy a party celebrating the end of SYV

2.3.1 Measures

The structured survey included questions addressing demographics, schooling, home life, hobbies, substance use, sexual history, HIV disclosure, stigma, mental health, and adherence to antiretroviral therapy (ART). The structured questionnaire was translated to Kiswahili and then back translated to English. Two focus groups were

conducted to make sure the translated questionnaire was understandable. The following constructs were used in this study.

2.3.1.1 Depression

The Patient Health Questionnaire (PHQ-9) was used to measure depression symptoms. This is a standardized depression screening tool that has been used and validated in several sub-Saharan African countries (Cholera, 2015; Gelaye,2013). The PHQ-9 is a nine-item instrument; items are summed, with total scores ranging from 0 – 27.

2.3.1.2 Emotional and behavioral symptoms

The Strengths and Difficulties Questionnaire (SDQ) was used to measure emotional and behavioral symptoms. This tool has been used to evaluate mental health challenges in youth in several sub-Saharan African countries (Goodman, 2001). This is a 25-item instrument; items are summed, with total scores ranging from 0 – 40.

2.3.1.3 Post-Traumatic Stress

The UCLA Post Traumatic Stress Disorder Reaction Index was used to assess post-traumatic stress disorder symptoms in the youth (Steinberg, 2013). This study used a modified 4-point scale for the youth. The reaction index is a 22-item scale; items are summed with total scores ranging from 0 – 51.

2.3.1.4 HIV Stigma

Internal and External Stigma were measured using a modified 10-question, 4 item, Berger HIV stigma scale (Berger, 2001). The total stigma scores ranged from 10-40, with internal stigma scores ranging from 4-16 and external stigma scores ranging from 6-24.

2.3.2 In-Depth Interviews

Youth were eligible to complete an IDI if they were at least 18 years of age, had attended at least eight of the ten SYV group sessions, had completed an 18-month follow-up survey, and showed change of at least half a standard deviation (~2 points) in their PHQ-9 scores from baseline to 18 months. In order to get a variety of experiences, participants were categorized as "responders" (PHQ-9 score decreased by two or more points from baseline) or "non-responders" (PHQ-9 score increased by three or more points from baseline). Twenty-two youth were identified and contacted for potential in-depth interviews. Due to migration and inability to establish communication, 10 youth were interviewed; six "responders" and four "non-responders". In-depth interviews were conducted in Kiswahili using a semi-structured interview guide. The interview guide topics included participants' history of depression symptoms (defined as losing interest in things they usually enjoyed or feeling hopeless), current challenges, recollection of specific SYV topics, and their experience during and after the SYV intervention. Interviews were conducted by a qualitative researcher in Kiswahili in a

private room at KCMC and lasted approximately 60 minutes. To reduce bias, the qualitative researcher was a member of the study team that was not present for the intervention and did not administer the quantitative questionnaires during the follow-up visits. Participants received compensation to cover the cost of transportation to and from the interview as well as a meal voucher (~$2 equivalent).

2.4 Analysis

While the overall study design was stepped wedge, the data were analyzed as a parallel study design. Quantitative analysis used an intent-to-treat analysis approach, and youth were analyzed according to their randomization assignment at baseline regardless of whether they attended any SYV sessions. Descriptive statistics included demographic characteristics and mean mental health measures by treatment group at the baseline study timepoint. A mixed effects linear regression model was fitted to trial data to compare the change in mental health measures from baseline to six months, twelve months, and eighteen months. Because youth were stratified by site and gender, the model included fixed effects of these terms. Furthermore, fixed effects of intervention wave and SYV group were included in the model to account for clustering by site and intervention group to provide within and between group differences. To account for multiple measures for each participant, the model included a random intercept by participant ID. The random intercept was fitted with random slope to induce a within-individual correlation matrix that accounts for study timepoints. Lastly,

the model included a time and study group interaction term of to observe the intervention effect or change of mental health measures over time and compare the differences in changes between the intervention group and the TAU group. All randomized participants were included in the quantitative analysis even if they were missing follow-up visits. Stata 16 was used to complete the quantitative analysis (Stata Corp, College Station, TX).

Two trained research assistants fluent in Swahili and English transcribed and simultaneously translated the in-depth interviews to English. Analysis followed a three-step process. First, a member of the study team (LM) listened to the audio recordings and wrote narrative memos summarizing each participant's interview. After transcription, the same study member reviewed the English transcripts and edited the memos as needed to ensure they were comprehensive. Second, interview transcripts and memos were uploaded to a qualitative analysis software, NVivo 12, and coded using an integrated inductive and deductive thematic analysis approach (Guest et al., 2012). Transcripts were coded using structural codes developed from the topics of the interview guide. Then, each structural code was reviewed independently and coded for emergent themes. A second person coded 2 transcripts independently, and the transcripts were uploaded to NVivo to assess consistency in coding. After discussion and agreement on common themes, a final codebook was developed and applied to the remaining transcripts (Appendix 2). Queries were conducted in NVivo to look at cross

tabulations of themes across codes. After querying, analytic memos were written to summarize themes and enriched with quotes from participants.

3. Results

3.1 Quantitative Results

3.1.1 Baseline Demographics

One hundred and twenty-eight youth were enrolled into the SYV intervention. 105 youth were included in the final analysis of the data; 21 youth were excluded because they were never randomized due to failure to establish contact after enrollment. Fifty-eight youth were randomized to the intervention arm and 47 youth were randomized to the control arm. Baseline demographics of youth by treatment group are reported in Table 2. The mean age of all participants at baseline was 17.8 years (SD 2.35). Overall, 49% of all participants were male.

Table 2: Baseline Demographics of Participants by Intervention Group

Variable	*Intervention (N=58) N (%)*	*Control (N=47) N (%)*
Age		
Mean (SD)	17.38 (2.30)	18.32 (2.33)
Median (IQR)	16 (17,18)	17 (18,20)
Sex		
Male	30 (51.72)	20 (42.55)
Female	28 (48.28)	27 (57.45)
Site		
KCMC	31 (53.45)	28 (59.57)
Mawenzi	27 (46.55)	19 (40.43)
Primary Caregiver		
Mom or Dad	30 (51.72)	20 (42.55)
Aunt/Uncle	11 (18.97)	18 (38.30)
Grandmother/Grandfather	13 (22.41)	2 (4.26)

Sibling	2 (3.45)	3 (6.38)
Other	2 (3.45)	4 (8.51)
Enrolled in School		
Yes	37 (74.0)	43 (74.14)
No	13 (26.0)	15 (25.86)
Socioeconomic Status (proxy)		
Electricity	40 (68.97)	37 (78.72)
Indoor plumbing	38 (65.52)	29 (63.04)
Owns a cellphone	35 (60.34)	30 (63.83)

3.1.2 Follow-up and Attrition

A majority of youth (86%) randomized to the intervention group attended at least eight out of ten SYV sessions. Fifty-five youth in the intervention group (94%) and 39 youth in the TAU group (82%) completed the 6-month follow-up visit. Fifty-two participants in the intervention group (89%) and 37 participants in the control group (65%) completed the 12-month follow-up visits. At the 18-month follow-up visit, 49 participants in the intervention group (84%) and 29 participants (61%) completed the visit. Figure 2 contains a flowchart of the number of participants analyzed at each follow-up timepoint.

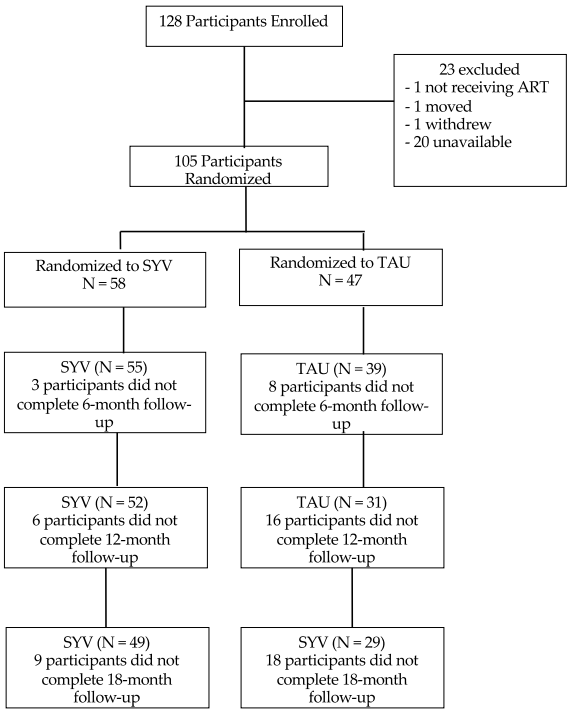


Figure 2: Flow Diagram of Participants Included at Each Follow-up

3.1.3 Stigma and Mental Health Outcomes

Table 3 shows the mean of the stigma and mental health measures at baseline and the change from baseline to 6 months, 12 months, and 18 months for both study groups.

Table 3: Stigma and Mental Health Outcomes Between Intervention and Control from Baseline to 18 Months Based on Mixed Effects Linear Regression Model

	Baseline [a]		6 Months			12 Months			18 Months		
	SYV (N=58)	Control (N= 47)	SYV [b] (N=55)	Control [c] (N=39)	Effect [d]	SYV [b] (N=52)	Control [c] (N=31)	Effect [d]	SYV [b] (N=49)	Control [c] (N=29)	Effect [d]
Total Stigma	22.00 (20.75, 23.25)	23.62 (22.25, 25.01)	0.60 (-0.51, 1.71)	-2.25 (-3.55, -0.95)	2.85 (1.14, 4.56)	0.26 (-0.88, 1.39)	-2.36 (-3.76, -0.97)	2.62 (0.81, 4.42)	0.28 (-0.87, 1.43)	-0.88 (-2.33, 0.58)	1.15 (-0.70, 3.00)
Internal Stigma	7.80 (7.31, 8.28)	8.26 (7.73, 8.79)	-0.24 (-0.79, 0.31)	-1.06 (-1.69, -0.42)	0.81 (-0.03, 1.65)	-0.09 (-0.65, 0.47)	-1.25 (-1.93, -0.57)	1.16 (0.28, 2.04)	-0.02 (-0.58, 0.55)	-0.67 (-1.38, -0.04)	0.66 (-0.25, 1.56)
External Stigma	14.31 (13.25, 15.37)	15.36 (14.19, 16.54)	0.69 (-1.18, 1.56)	-1.26 (-2.29, -0.24)	1.95 (0.61, 3.30)	0.19 (-0.70, 1.08)	-1.18 (-2.29, -0.07)	1.37 (-0.05, 2.79)	0.17 (-0.74, 1.08)	-0.30 (-1.45, 0.86)	0.47 (-1.00, 1.93)
PHQ-9	5.10 (4.21, 5.99)	6.59 (5.60, 7.58)	-0.92 (-1.88, -0.04)	-1.07 (-2.19, 0.05)	0.15 (-1.32, 1.63)	-0.52 (-1.51, 0.48)	-2.52 (-3.75, -1.28)	2.00 (0.42, 3.59)	-0.80 (-1.85, 0.24)	-2.10 (-3.41, -0.78)	1.29 (-0.39, 2.97)
SDQ	7.97 (6.93, 9.01)	8.06 (6.91, 9.22)	-0.45 (-1.46, 0.55)	0.10 (-1.07, 1.28)	-0.56 (-2.11,0.99)	-1.24 (-2.31, -0.17)	-0.71 (-2.04, 0.61)	-0.53 (-2.22, 1.17)	-1.05 (-2.20, 0.11)	-1.39 (-2.84, -0.07)	0.34 (-1.51, 2.20)
UCLA PTSD-RI	9.09 (7.16, 11.02)	11.19 (9.04, 13.33)	0.20 (-1.60, 2.00)	-1.00 (-3.11, 1.10)	1.20 (-1.57, 3.97)	-0.29 (-2.14, 1.57)	-3.26 (-5.58, -0.95)	2.98 (0.01, 5.94)	-0.88 (-2.81, 1.06)	-4.60 (-7.04, -2.15)	3.72 (0.60, 6.84)

a. Adjusted mean scores at baseline (95% confidence interval)
b. Change in score in the intervention group from baseline (95% confidence interval)
c. Change in scores in the control group from baseline (95% confidence interval)
d. Difference in change at each time point between intervention and control group (treatment effect)

3.1.3.1 Stigma

The control group had higher total stigma scores, 23.62 (95% CI = 22.25 – 25.01), at baseline in comparison to the youth in the SYV group, 22.00 (95% CI = 20.75, 23.25). In comparison to baseline, the stigma scores decreased in the control group at all follow-up timepoints. The intervention group saw an increase in the HIV stigma scores at all follow-up visits in comparison to baseline. Figure 3 depicts a graph of the average change in total stigma scores based on the mixed effects linear regression model.

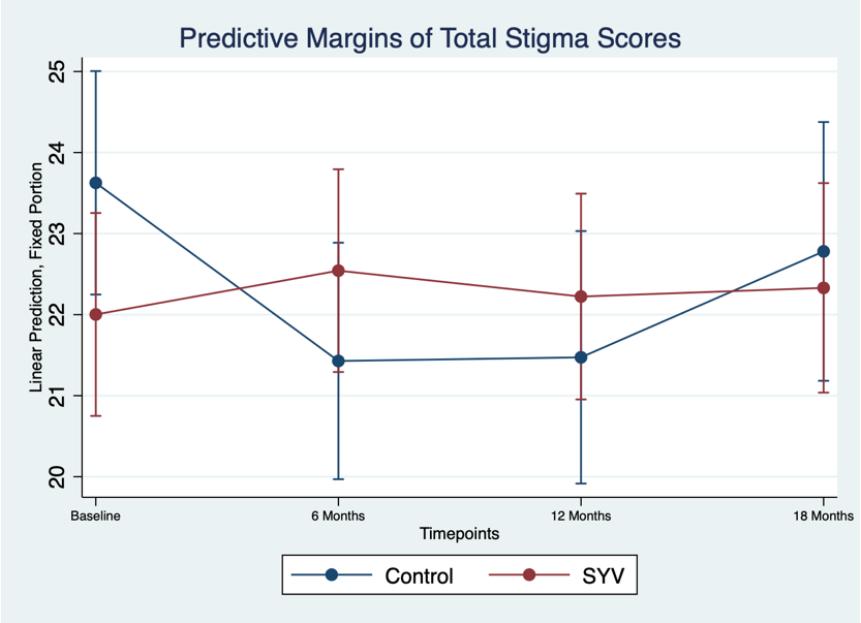


Figure 3: Total Stigma Scores Across Study Timepoints

At baseline the TAU group had higher internal stigma scores, 8.26 (95% CI = 7.73, 8.79) and external stigma scores, 15.36 (95% CI = 14.19, 16.54), compared to the SYV intervention group, internal stigma 7.80 (95% CI = 7.31, 8.28) and external stigma 14.31

(95% CI = 13.25, 15.37) . The TAU group saw an average decrease in both external stigma score at all follow-up timepoints. The intervention had an average increase of external stigma scores at 6 months, 12, and 18 months in comparison to scores at baseline. Figure 4 and 5 depict the average marginal estimates of internal and external stigma scores for both study groups based on the linear mixed effects models for both outcomes.

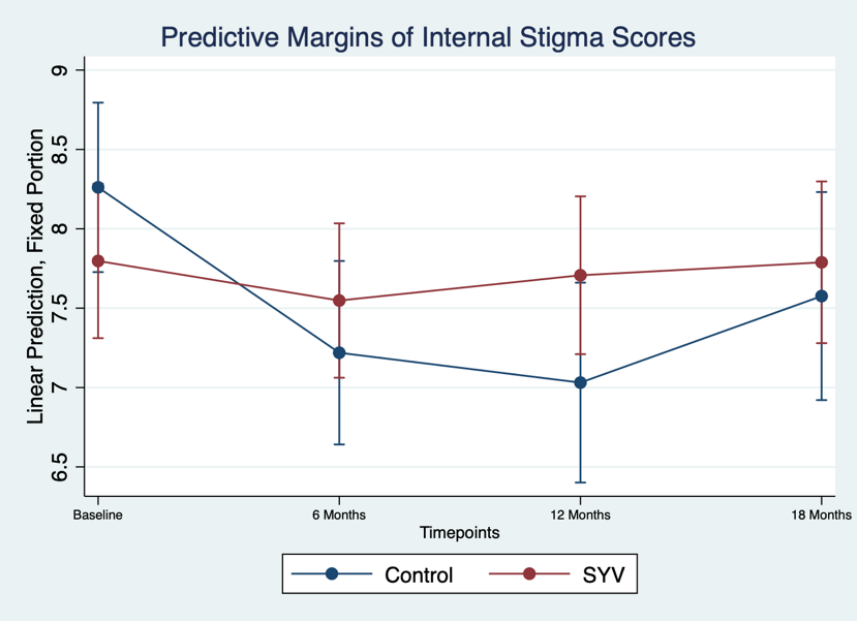


Figure 4: Internal Stigma Across Study Timepoints

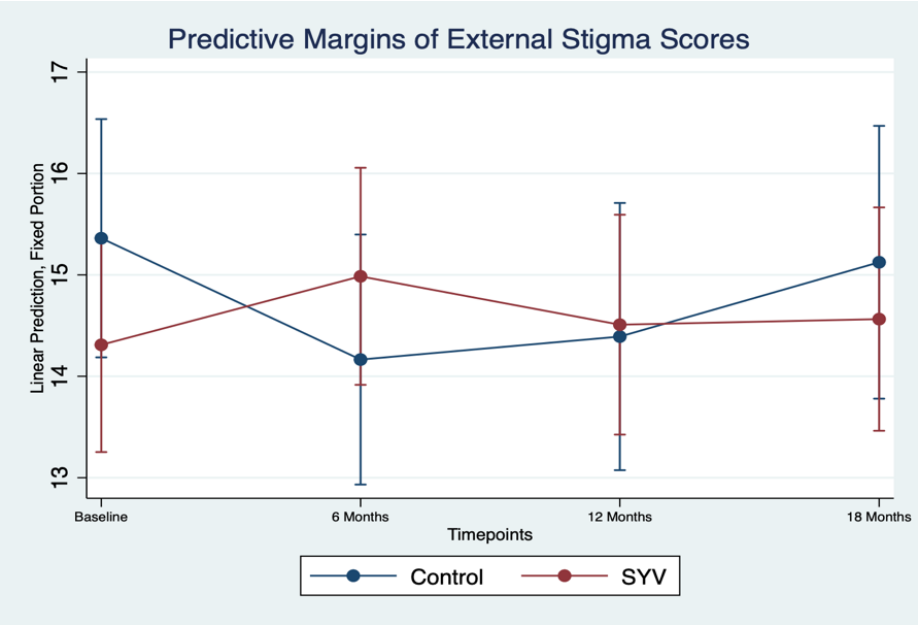


Figure 5: External Stigma Across Study Timepoints

3.1.3.2 Depression

The average PHQ-9 scores of the TAU group were higher at baseline, 6.59 (95% CI= 5.60, 7.58) in comparison to the scores in the SYV group, 5.10 (95% CI= 4.21, 5.99). Youth in the SYV group had an average decrease in their PHQ-9 scores at six months in comparison to baseline. However, the averages of the scores increased at 12 and 18 months but remained below the averages at baseline. Overall youth in the control group had higher PHQ9 scores at baseline in comparison to the youth in the intervention group. In comparison to baseline, the average PHQ9 scores of the control group decreased at all post-intervention follow-up timepoints. Figure 4 depicts the predictive margins of PHQ-9 scores for both study groups across study timepoints based on the linear mixed effects model.

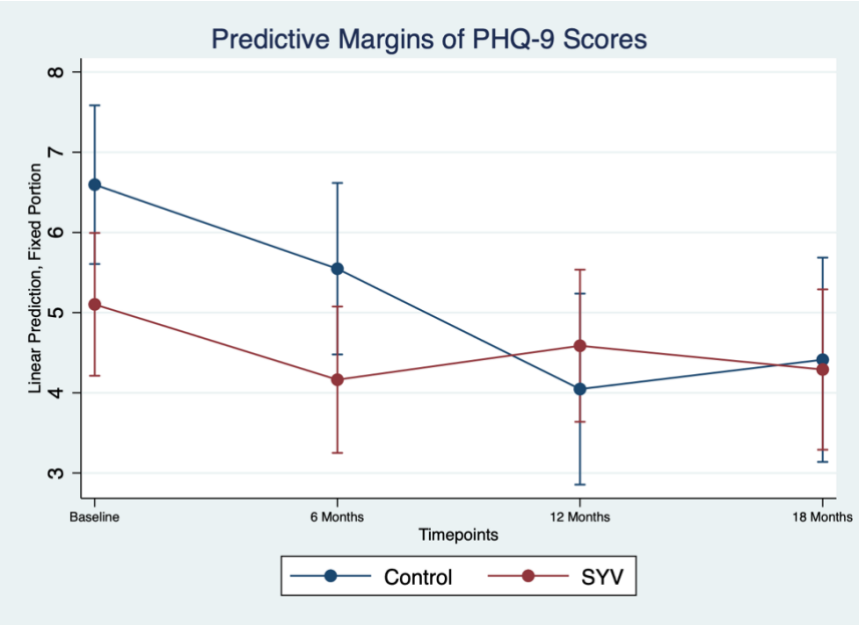


Figure 6: PHQ-9 Scores Across Study Timepoints

3.1.3.3 Strengths and Difficulties Scores

Baseline SDQ scores were slightly higher in the control group, 8.06 (95% CI= 6.91, 9.22), than in the intervention group, 7.97 (95% CI = 6.93, 9.01). In comparison to baseline, both study groups had an average decrease of SDQ scores at all post-intervention follow-up timepoints, except at the 6 month visit where the control group had a slight increase. Figure 5 depicts the predictive margin scores of SDQ of both study groups across the timepoints based on the linear mixed effects model.

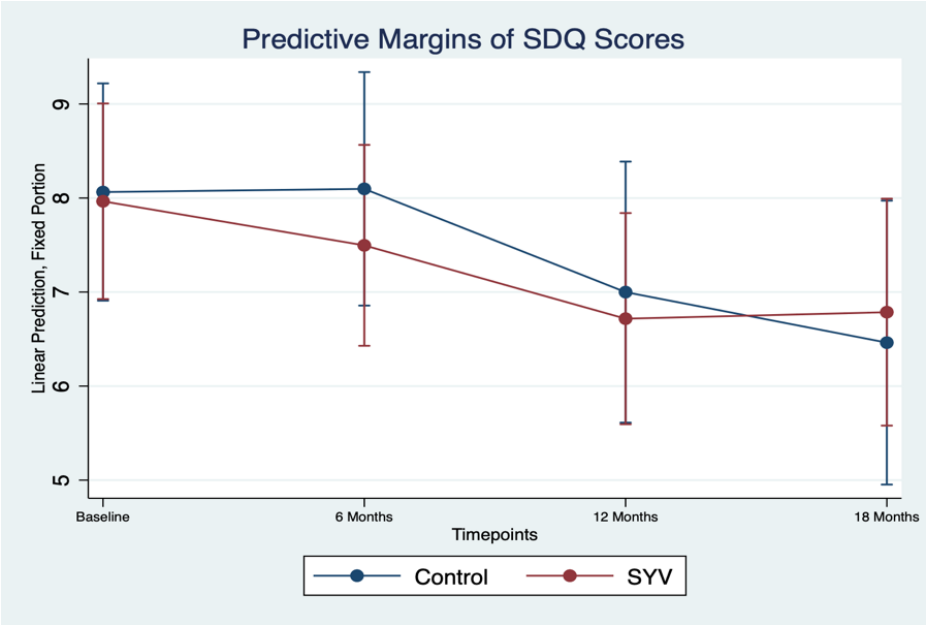


Figure 7: SDQ Scores Across Study Timepoints

3.1.2.4 PTSD Reaction Index

At baseline, the average PTSD reaction index score for the control group, 11.19 (95% CI = 9.04, 13.33), was higher than PTSD-RI scores for the intervention group, 9.09 (95% CI = 7.16, 11.02). The SYV group had average increase of PTSD-RI scores at 6 months, but the scores at 12 and 18 months decreased in comparison to baseline. The control group had an average decrease in PTSD-RI scores at all follow-up timepoints. Figure 6 depicts the predictive margins of PTSD-RI scores for both treatment groups based on the linear mixed effects model.

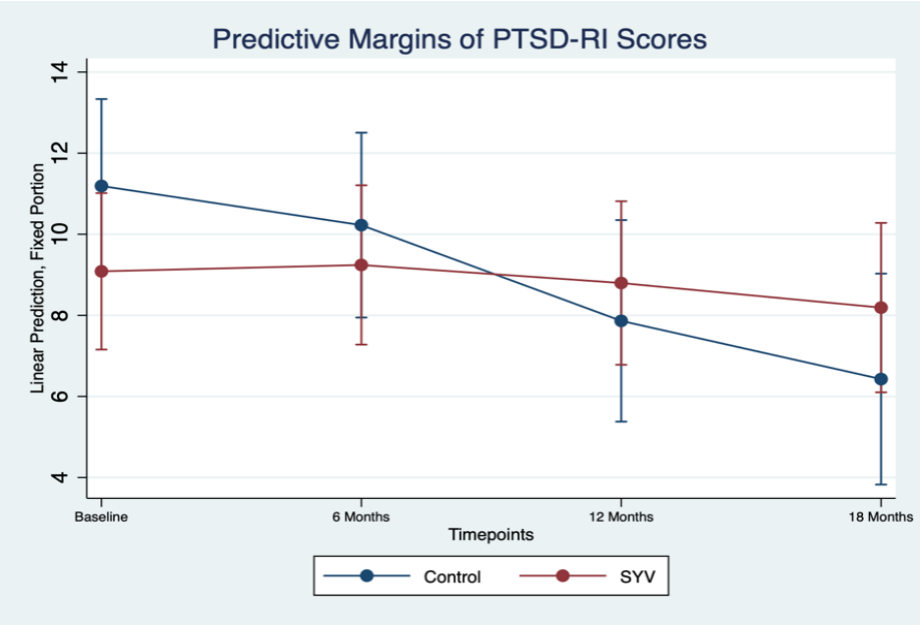


Figure 8: PTSD- Reaction Index Scores Across Study Timepoints

3.2 Qualitative Results

3.2.1 Description of Interview Participants

10 YLWH completed an in-depth interview. The average participant was 21.6 years old. Seven (70%) participants were male, and six (60%) of participants were "responders." Table 4 includes the demographic information of participants who completed in-depth interviews.

Table 4: Demographics and PHQ-9 Scores of Interview Participants

PID	Baseline PHQ-9 Scores	6 Months PHQ-9 Scores	18 Months PHQ-9 Scores	Sex	Age	Intervention Wave	Intervention Response
003K	7	10	13	Male	24	1	Non-responder
010K	4	2	0	Male	18	3	Responder
014K	4	5	7	Male	20	3	Non-responder
018K	10	12	8	Male	23	1	Responder
018M	8	2	2	Female	18	3	Responder
028K	6	1	0	Male	25	1	Responder
047M	9	2	4	Male	19	2	Responder
052M	2	4	6	Female	22	3	Non-responder
053K	9	11	14	Female	18	2	Non-responder
066K	14	1	2	Male	21	3	Responder

3.2.2 History of Depression

All participants reported experiencing intermittent symptoms of depression in the past, but these symptoms were not present at the time of the interview. Symptoms of depression were defined as losing interest in activities or things they usually enjoyed or feeling helpless.

3.2.1.1 Triggers of Symptoms of Depression

Five participants identified challenging interpersonal relationships in their home life as triggers of depressive episodes. These difficult relationships manifested in recurring arguments with other family members that were often centered around the participant's HIV status.

> *"That has happened to a person like me, at first when I was living with my brother sometimes, he blabbed (ropoka) on my condition [HIV] when he was drunk. So that made me lose peace because I wondered why am I this way [living with HIV] and why is he doing that? I did not like it."* – Male, 25 years old, Responder

> *"I used to have depression when I was in form three in secondary school. I was staying with my aunt, but I discovered that my aunt didn't love me. When I started form one, she used to separate all the dishes that I was using. I was given my own room. And I wasn't used to this situation and I suffered inwardly."* – Female, 18 years old, Non-responder

All participants lost one or both of their parents at a young age due to HIV related causes. Two participants identified the event of their parent(s) death or thinking of the event as triggers of depression.

> *It was that of the death of my mother, I had depression and later on I advised myself, I just had to keep quiet and not share with someone. I just kept quiet like that and bear*

> *with it without telling someone. It's until now I have forgotten, but I have not forgotten a lot just a little. It's like I have put it aside* – Male, 19 years old, Responder

Fear of disclosure emerged as another trigger of depressive symptoms. Participants reported being worried about people finding out their HIV-positive status and in turn being stigmatized. These worries and fears resulted in them in losing hope about forming relationships with others. One participant identified being in a serodiscordant relationship as a trigger of his symptoms of depression as the fear of losing his partner after disclosing his status was a constant worry in his life.

> *"On depression, there is one matter that is troubling me. I have a girlfriend that I love but she is not HIV positive like me. So how to tell her is what is difficult. It is what is giving me thoughts and stress of what will happen if she comes to know"* – Male, 23 years old, Non-responder

Youth also reported financial challenges as one of their triggers of depression. Half of the youth reported being concerned with gaining and sustaining employment, earning enough money to cover living expenses, and achieving their life goals.

> *"Apart from school challenges of studying, with life challenges, there is being queried for rent and not having money. Sometimes, even at school, you have books to buy and if you check with mum [for money] she does not have it. You find university examination is approaching or maybe there is a test, so a lot of challenges happen"* – Male, 20 years old, Non-responder

3.2.1.2 History of Suicidality

Four participants also endorsed suicidal ideation in the past that were triggered by difficult relationships and lack of support at home. Of the youth who endorsed these ideations, only one participant reported acting on his suicidal ideations in the past by

overdosing on his medication. This youth did not seek medical attention and reported that his ideations were not present at the time of the interview.

> *"I mean, at the beginning I thought that it would be better if I died because, on my father's side, they do not want me. Whom am I going to live with now that my grandmother didn't want me?"* – Female, 22 years old, Non-responder

> *"When my father came, he started to ask me while scolding me. I left and it led me wanting to kill myself (suicide). I remember on that day I drank these same drugs [ART], like seven pills.* – Male, 21 years old, Responder

3.2.1.3 Coping Mechanisms

Participants had different methods of coping with mental health distress and symptoms of depression. Coping methods included listening to music, walking away from the stressful or triggering situation, and seeking support from others.

> *"For example, if I have depression I listen to the radio, and that is when my thoughts end. If I don't do that, I will be a person that is not happy all the time. So, it makes me listen to the radio and music, and I feel well."* – Male, 25 years old, Responder

Peer social support was a coping mechanism endorsed by all participants. For participants with difficult relationships at home, the peer support helps them escape their problems at home and helps them access psychosocial support that they would otherwise not get at home.

> *"I normally like to leave. When a challenge has happened at home, I don't stay, I go to exchange ideas/thoughts with my friend and forget the event. Because if I stay there, I know it will completely overwhelm me and will not be able to tolerate so I leave there."* – Male, 21 years old, Responder

All the participants endorsed using skills they learned in SYV to help them cope with symptoms of depression or stressful events. Some skills that they used were mindful breathing and "soldier" or muscle contraction and relaxation.

> *"For me because at the Sauti ya Vijana project we were taught to tighten like this (showing the interviewer) to reduce depression, to breath in. So I made an effort to use that and it helped me reduce depression"* – Male, 25 years old, Responder

3.2.3 Challenges Living with HIV

3.2.3.1 Experiences with Stigma

Participants were split when reporting experiences of external or enacted stigma (stigmatizing attitudes or behavior from other people) and internal stigma (stigmatizing attitudes within themselves). When asked to describe stigma that they have experienced, half of the youth stated that they had never experienced external or internal stigma.

> *"Personally, I have never been stigmatized by a person because I have never explained to someone about my real condition or my health condition…Yes, and also I have never stigmatized myself because at home people care about me. They love me so I have not stigmatized me as me"* – Female, 18 years old, Responder

For youth who did report experiences with external or enacted stigma, almost all of the experiences occurred in their homes or in their community where relatives and neighbors had stigmatizing attitudes towards the youth.

> *"The first challenge was stigma, which really tortured me in that time when they segregated me from the others and the family to the point of separating my plates and cups and sleeping arrangements."* – Female, 18 years old, Non-responder

On the other hand, all the youth endorsed experiencing anticipated stigma or believing other people will stigmatize them. As a result, participants reported avoiding

situations, like disclosing their status or being around people they did not trust, where stigma or social isolation is a potential outcome.

> *"Personally, I have never been through stigma. I am afraid of it that is why I escape it. When I just suspect there is a sign that it will be present, I escape"* – Male, 23 years old, Non-responder

3.2.3.2 ART adherence

Participants also cited ART adherence as a challenge of living with HIV. Youth were worried about missing their ART dosing time but also reported general discomfort about taking their medication in front of others. Youth who reported challenges with ART adherence also reported fear of unintended disclosure of their status.

> *"Other challenges are the normal ones maybe just taking drugs and things like that… Sometimes you are with friends or at home with friends and so it becomes a problem in taking drugs, so challenges like those."* – Male, 24 years old, Non-responder

Peer support helped with challenges related to medication adherence and having another person who understood their situation. Youth reported using coded text messages to remind themselves and their peers to take their ART.

> *"I like to swallow them at 10 p.m. My friend told me that whenever I was swallowing the medicine, I should send him an SMS. There was a boy who used to go together with him [his friend] to Mawenzi, and there they had started a system where they were sending each other SMS. One of them sent me a time saying '10 PM' and it was written in such a way that if someone touched your phone, they wouldn't know what it meant"* – Male, 18 years old, Responder

3.2.4 Experience with SYV Intervention

All participants reported having a positive experience with the SYV intervention. Participants described SYV as an "education program" where they received training on coping with depression and stress, taking antiretroviral therapy properly, and general education about HIV. Participants reported "feeling free" during the lessons and enjoying having additional interaction with other YLWH.

> *"I first remember my fellows, all those that we were with there. There were others that were very funny. There were people who were enjoyable for real. But also, it was a very free area for a person to explain himself on his history like the way I am explaining here on my depression. You explain, and people encourage you. You see that this situation is not just happening to me is normal to everyone"* – Male, 23 years old, Non-Responder

All participants reported that they would advise other youth to participate in the intervention because of the lessons they learned. They stated that the lessons would help other youth to "not give up" and take their ART properly.

> *"I thought that way because a lot of youth right now are easy to give up…You find others give up and their friends advise them badly. And you find their friends did not go to Sauti Ya Vijana to learn. That is why he has that thought of advising him badly, 'you should stop taking drugs', like that. But if we all know or we all have that knowledge, or we all have that training, we can encourage our fellows well and they can stop that thing of giving up and not taking drugs."* – Female, 18 years old, Responder

3.2.4.1 Lessons from SYV Intervention

Participants were asked to describe specific lessons from the SYV intervention: coping with depression, the cognitive behavioral triangle, sharing difficult memories with others, and circles of support. All participants remembered the lesson on coping

with depression and were able to describe most of the coping skills they learned in the lesson. Participants also identified this lesson as the most useful lesson from SYV, and a lesson that they have incorporated into their lives.

> *"The training that we have been given is that when you have depression you are supposed to sit on a chair straighten your legs, your back should lean on the chair then you massage yourself slowly or someone massage you and depression goes away"* – Male, 19 years old, Responder

Three participants were able to remember and correctly describe the lesson on the cognitive behavioral triangle (thoughts, feelings, and behavior). Most of the participants reported that this was a difficult lesson to understand and thus have not incorporated the lesson or skill or used the skill since the intervention.

> *"In general, I have never used the triangle, meaning I still have not been able to use it. I did not quote that one very much; I did not take it as much as the others like that of stomach tightening."* – Male, 21 years old, Responder.

All participants were able to remember the lesson on sharing difficult memories with other people. While they all described sharing difficult memories in the SYV intervention, none reported sharing a difficult memory with someone outside of the intervention. The most cited reason for not sharing with others is lack of trust in the confidence of others and fear of being stigmatized after sharing their difficult memories.

Six participants could recall and describe the lesson on circles of support. These participants also identified the same people who were in the circles of support as people they turn to for support to cope with mental health distress.

3.2.5 Resilience After SYV

Participants described resilience as one the main long-term effects of SYV. In addition to incorporating coping skills they learned in SYV, participants reported that their ability to deal with challenges increased after participating in SYV. Specifically, participants were able to identify and choose healthier coping mechanisms for dealing with life challenges and mental health distress.

> *"In the past, believed that when you have a lot of thoughts [depression], it helped when you drank alcohol. But I did not know that when you drink alcohol it just helps for a short time and you also get health effects. Now I have completely stopped to touch alcohol."* – Male, 23 years old, Responder

Participants also reported having more "confidence" in speaking publicly and interacting with other people

> *"My ability was different because of courage. It has increased my courage to talk to a person like customers. When a customer talked on something, I had fear, meaning I am afraid to talk a lot to him. I could not talk in a business way, so in talking, by staying in Sauti ya Vijana, it gave me courage like in business; to talk to customers."* – Male, 21 years old, Responder

Other participants reported that SYV helped them accept themselves and their diagnosis. Because they interacted with other YLWH, participants saw that they were not alone.

> *"It's that situation [SYV] that has made me accept myself. You know when you are told that you have that problem [HIV] you give up. But after going to that seminar, made me see that I am like other people. For example, I accept myself as me. So, for example, when I find someone talking about that problem [HIV], I don't think much about it and leave them to talk. But for me to lose happiness; it does not make me lose any happiness"* – Male, 25 years old, Responder

Participants also reported using the skills they learned in SYV to help other people in their lives deal with mental health difficulties. Youth shared the lessons they learned in SYV with peers who were not a part of the intervention.

> *"Has changed in great extent, I know how I can advise my fellow so that he moves from self-stigmatizing and be in normal condition…Because of Sauti Ya Vijana I normally deal with my challenges and even my relatives and friends challenges…Mostly those friends that I am with in Mawenzi, when he comes to explain to you his problem you can advise him and understands you."* – Female, 18 years old, Responder

4. Discussion

The goal of this study was to evaluate the long-term change in mental health outcomes in YLWH enrolled in the SYV study. The SYV intervention is one of the first interventions to incorporate a mental health curriculum to improve mental health outcomes of YLWH in Tanzania. At least one year after the intervention, youth could remember specific lessons from the SYV curriculum and reported incorporating at least one of the coping skills taught in SYV into their current lives. Additionally, youth in the in-depth interviews stated that the intervention had an effect in their ability to cope with life challenges and symptoms of depression.

On average, youth enrolled in both study groups saw decrease in their PHQ-9, SDQ, and PTSD-RI scores at all follow-up timepoints in comparison to baseline; however, the mean baseline scores were not, on average, in a symptomatic range (≥10). Youth randomized to the TAU had slightly higher PHQ-9 scores at baseline (6.59) compared to intervention group (5.1) and subsequently had a one- or two-point greater decrease in their PHQ-9 scores at 6 and 12 months in comparison to the intervention group. A possible reason for the TAU group's decrease in their PHQ-9 scores could be contamination with the control group. The youth were recruited from two HIV youth clinics where youth typically interact with each other during Teen Club. Because youth were individually randomized by site, it is possible that the youth in the intervention group shared the lessons they learned in the intervention with the youth in the control

group. As a result, this contamination may have exaggerated the decrease in mental health measures at post-baseline timepoints. Another possibility is being asked the mental health questionnaires at multiple time points may desensitize youth as the mean scores were below 5, i.e., asymptomatic in later follow-up visits.

In qualitative interviews, youth reported experiencing mental health difficulties such as depression. For many of the youth, the challenges of living with HIV, such as fear of disclosure, and difficult interpersonal relationships emerged as the main triggers of symptoms of depression. Living with a stigmatized chronic condition, it is not surprising that some youth reported lack of psychosocial support in their homes. Peer social support, specifically support from other YLWH, was a protective factor and a coping mechanism for these youth. These results are consistent with results from other studies have demonstrated the importance of community and peer support in the mental health outcomes of YLWH (Casale et al., 2019; Petersen I et al., 2010; Tapera et al., 2019; Willis et al., 2019).

The average total HIV stigma scores for the TAU group were slightly higher at baseline (23.62) in comparison to the in the intervention group (22.00). Similarly, mean internal and external stigma scores at baseline were higher in the TAU group in comparison to the intervention group. The internal stigma scores of both study groups decreased at 6 months in comparison to baseline; however, external stigma scores of youth in the intervention group increased (got worse) at 6 months in comparison to the

control group. The SYV curriculum included lessons on identifying internal and external stigma This increase in the external HIV Stigma scores in the intervention group could be due to youth being more aware of stigma and thus being able to report more instances of enacted stigma after exposure having received the intervention. Furthermore, the intervention focused on improving youths' ability to cope with internal stigma and did not have a community component aimed at reducing external stigma other than teaching youth how to educate others about HIV and dispel myths.

During in-depth interviews youth were asked to describe a time they experienced stigma, youth did not report experiences of internal stigma and only half of the youth reported experiencing external stigma. All youth reported anticipated stigma or beliefs of being stigmatized in the future. However, for many of the youth who denied having experienced stigma, they would describe instances of stigma during other parts of the interview. The qualitative work suggests that perhaps the way in which questions on the stigma scale are asked does not reveal the complexities of how YLWH experience or realize stigma. Perhaps by endorsing experience of stigma, youth may feel that they are "othering" themselves or confirming their status in an outgroup. Though the Berger Stigma Scale used in this study has been used and validated in many SSA countries, researchers suggest that the current psychological frameworks used to evaluate internalized stigma are outdated and need to be updated to include more social and cultural contexts (Pantelic, Sprague, and Stangl, 2019). Additionally, these updated

frameworks need to consider the role of anticipated stigma in HIV stigma mechanism and health outcomes in YLWH as these could improve the precision of these tools (Earnshaw et al., 2013; Earnshaw & Chaudoir, 2009). Though internal stigma went down in both groups, researchers are suggesting that it may not be as precise and may need to be re-evaluated for this population.

This study used an intent to treat analysis, and the models did not take into account attendance rate to sessions or treatment compliance for the intervention group nor exclude participants who missed study follow-up visits. To examine this effect further, a future analysis will include a complier average causal effect to evaluate noncompliance in the intervention group and examine its effect on the treatment effect. Additionally, because of the stepped wedge design of the study, seven youth in the TAU group received the intervention in between the 12- and 18-month follow-up study visits (Figure 1). While these seven participants are only 7% of the overall sample size, it is possible that the early cross over of these youth may play a role in the improvements noted in the TAU group, especially at later timepoints.

The SYV study was not powered for treatment efficacy but rather feasibility and acceptability. As a result, we did not observe a statically significant treatment effect between the intervention and TAU groups. However, taken together, the qualitative and quantitative measures demonstrate that the SYV intervention was feasible and acceptable for YLWH in Tanzania and offers promise to reduce symptoms of mental

health difficulties and improve adherence and at least one-year after receiving the intervention, youth reported incorporating components of the intervention into their lives and changes in their abilities to cope with challenges after receiving the intervention. Other randomized control interventions have shown an effect of on mental health outcomes in this population ((Bhana et al., 2014; Mavhu et al., 2013; Tapera et al., 2019)

4.1 Implications for Policy

In 2008, a mental health legislation was passed to integrate mental health services to primary care, but the number of trained mental health professionals remains low (Mbatia & Jenkins, 2010). Despite increasing volumes of data highlighting the mental health difficulties of YLWH, country-wide policies that address mental health outcomes in adolescents have not been adopted or implemented. Furthermore, comprehensive clinical care for ALWH does not currently integrate mental health services or psychosocial support. The results from this study provide further evidence of the need to incorporate psychosocial support into the clinical care of YLWH. Providing 10 group sessions and two individual sessions with youth has the ability to improve the mental health outcomes and more importantly has the ability to improve resilience in ALWH. Furthermore, providing peer support has been shown to be improve treatment retention and psychosocial wellbeing in other intervention among ALWH in SSA (Willis et al, 2019).

Additionally, the results demonstrated that youth's response to the intervention was not associated with their reported symptoms at the time of the in-depth interviews. The "responder" and "non-responder" categorization was based on the hypothesis that youth who did not see an improvement in their PHQ-9 scores at 18 months may not remember certain SYV lessons as clearly or may not have had a positive experience with the intervention. However, the qualitative responses to history of symptoms of depression, experience with the intervention, and their recall of specific SYV lessons did not align with categories of intervention response. Responders and non-responders all reported having intermittent symptoms of depression in the past, all were able to recall the lessons on coping with stress and depression, and all reported having positive experiences with the intervention. These findings suggest that, while SYV helped youth learn how to cope with stressors and symptoms of depression, many of the triggers of mental health difficulties in YLWH are based on systemic issues such as inability to find employment or financial hardship that could not have been addressed during the intervention. While current evidence on the role of economic empowerment is sparse, a study in Uganda found asset ownership in AIDs-orphaned youth to be positively affected with mental health functioning (Ssewamala et al., 2009). Future research should take into account how to address coping with mental health distress given these external systemic factors that may trigger mental health difficulties in YLWH.

4.2 Implications for Future Research

While this intervention was acceptable and feasible, future research should scale up the results to other parts of Tanzania to make the results more generalizable for YLWH. The results from this intervention also highlight the need for implementing community targeted interventions that would improve stigmatizing attitudes towards people living with HIV. For adolescent specific interventions, using schools as intervention sites has proven useful in Ethiopia, Nigeria, and Tanzania where attitudes towards PLHIV improved after the intervention (Fawole et al., 1999; Klepp et al., 1997; Kuhn et al., 1994).

Resilience emerged as a long-term outcome of the SYV intervention among the youth who received the intervention. Youth reported accepting themselves and their HIV status and increased ability to cope with challenges and mental health difficulties as the major ways that SYV helped them. Studies in other countries and in populations of older PLWH have had similar findings in improving resilience (Hussen et al., 2018; Pennar et al., 2018; Whiteley et al., 2018). However, SYV is among the first mental health interventions to address resilience in YLWH in Sub-Saharan Africa. Additional research is needed to build evidence on effective methods of improving resilience in this population. Furthermore, there is a current need to develop and validate tools to measure resilience for ALWH in SSA and specifically Tanzania (Govender et al., 2017).

4.3 Strengths and Limitations

This study had several strengths and limitations. One the strengths of this study was the longitudinal follow-up design. The study design was dynamic and provided useful information on group and individual changes over time. In addition, the regular contact with study personnel provided youth with additional forms of social interaction and support and may play a role in improving psychosocial outcomes for both study groups (Caruana et al., 2015; Piliavin & Siegl, 2007; Walders-Abramson et al., 2016). Another strength of the study was the incorporation of in-depth interviews that make this a mixed methods design. The mixed methods design provided additional context to the feasibility and acceptability of the intervention as youth were able to qualitatively describe their personal change after the intervention that may not have been captured by the quantitative measures. The qualitative results also provided additional insight into the complexities of addressing and measuring stigma and mental health outcomes in this population that have implications for future research and policies. The qualitative measures complemented the quantitative results and provided additional insight into next steps for research.

These results should be interpreted in light of some limitations. First, the study relied on self-report for all the variables. Because the quantitative and qualitative data were collected at KCMC, there was a possibility of desirability bias. Second, while the scales have been validated in several sub-Saharan African countries, these are Western

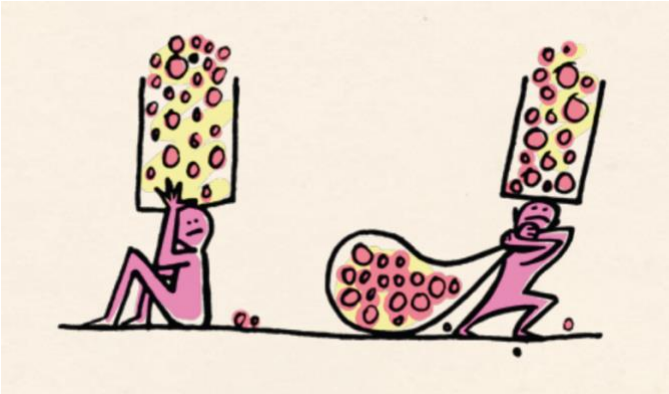
constructs that have not been fully validated for use in YLWH in Tanzania. Concepts such as depression are challenging to translate into Kiswahili and may have been used interchangeably with "stress." For example, the Swahili term for depression is "Msongo wa Mawazo" which directly translates to "many thoughts" in Swahili. It is possible that youth may conflate having many thoughts and worries with symptoms of depression. Similarly, stigma may have many different meanings based on our study findings evidenced by the non-endorsement of external stigma that contradicted the quantitative stigma scores. Third, due to challenges with establishing communication with youth, the original eligibility criteria for interviews had to be modified and the final sample did not represent the gender makeup and site distribution of the overall intervention group. However, despite these imbalances, saturation was reached during the in-depth interviews. Fourth, the quantitative and qualitative measures were collected at different timepoints. In addition, PHQ-9 questionnaires could not be administered at the time of the in-depth interviews. As a result, the reported symptoms of depressions in the qualitative interviews could not be corroborated with their quantitative scores at the time of the interview.

5. Conclusions

This study aimed to describe the long-term change in mental health outcomes of YLWH enrolled in the SYV intervention. SYV is one of the first mental health interventions for YLWH in this region, and it demonstrated improvements in resilience and ART adherence. A 10-session intervention was acceptable and feasible, and youth randomized to the intervention reported having a positive experience and a change in their abilities to cope with mental health distress at least one year after the intervention. However, the qualitative findings highlighted the need to reevaluate how stigma and depression are measured in this population, and how to better develop contextualized tools with more precision. While some youth reported not having experienced stigma when directly asked, the fact that they would later describe stigmatizing experiences without using the word stigma shows that youth may be conceptualizing stigma differently than researchers. Given the high mortality and morbidity due to HIV in Tanzanian YLWH, further research is necessary towards designing and implementing effective evidence-based interventions that are scalable to address mental health challenges in this population.

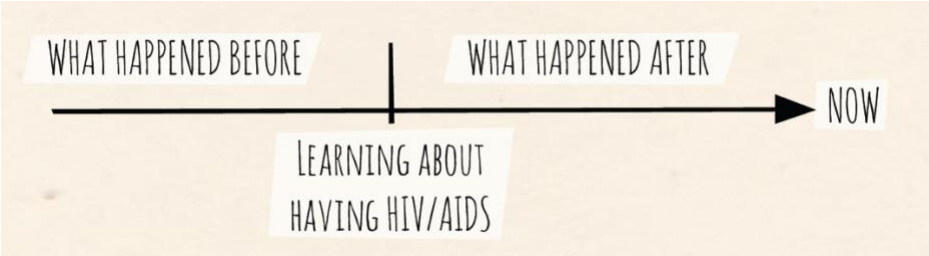
Appendix A: Cartoon Images Used During SYV Sessions

Youth Group 1 and Youth Group 2 – Worries, Stress, and Coping



Youth Group 3 – Cognitive Behavioral Triangle: Thoughts, Feelings, and Behavior

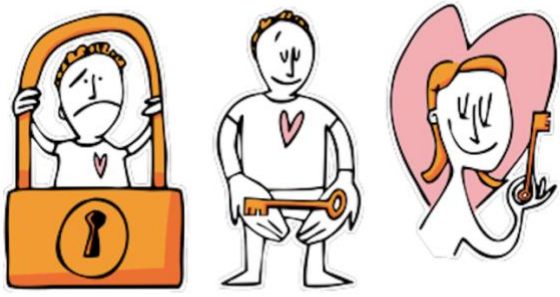
Youth Group 4-6 – Timeline and Sharing Difficult Memories with Others



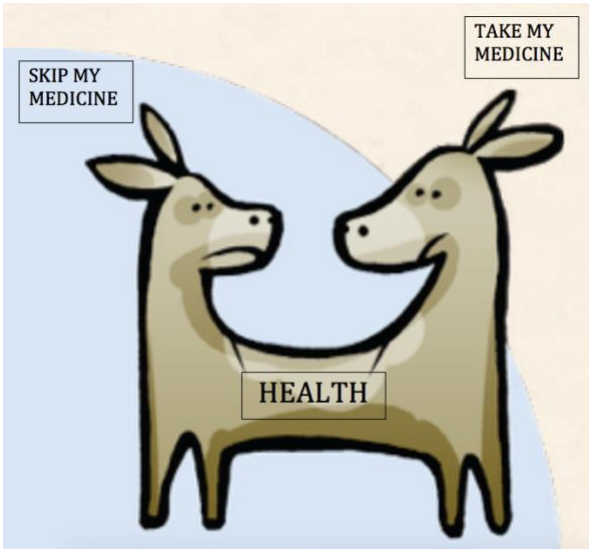
Youth Group 7 – Circles of Support

Youth Group 8 – Stigma

Youth Group 9 – Disclosure



Youth Group 10 – Values and Moving on Positively



Appendix B: SYV Questionnaire

Teen Club Survey Interview
Mental Health

Study ID: ____ ____ ____ ____ ____ ____ **Date:** ____ / ____ / _____
(dd) (mm) (yyyy)

Interviewer: _____ **Data entry initials:** ___ ___

Please welcome, introduce yourself and describe your role:

I would like to ask you some questions about yourself. These questions will be about your medical and personal background, your emotions and social life, and the stressful things that have happened to you.

There are no right answers to these questions and there is no benefit to answering any certain way. Please try to answer the questions as honestly as you can. We are in a private place where no one will hear your answers, and I am not allowed to share your answers with anyone except the research team. As you can see, your name is not on this form, only a study number that is confidential.

We are gathering this information to help us identify ways to improve your overall health and the Teen Club experience. If you don't understand a question, please tell me. You are not obligated to answer every question and can skip a question if it makes you feel uncomfortable. Do you have any questions before we begin?

1. DEMOGRAPHICS

1. Interviewer, please begin by circling the patient's gender.	1. Male 2. Female
2. How old are you?	_____ years old
b. What is your birth date? *(if known: ex 15/07/1999)*	____ / ____ / _____ dd mm YYYY
3. Where do you live?	_____ (Village, District)
4. What is your tribe?	1. Chaga 2. Meru 3. Maasai 4. Pare 5. Sukuma 6. Other, please specify _____
5. Who is your primary caregiver?	Response: _____
6. Are you a member of Teen Club (Saturday Clinic)?	1. Yes 2. No
a. (If yes), for how many years?	Write the number _____ or the year _____
7. Are you currently enrolled in school?	1. Yes 2. No

8. What is the highest level of education you have completed?	Response: _____
9. What work do you want to do when you grow up?	1. Doctor 2. Lawyer 3. Teacher 4. Nurse 5. Engineer 6. Acountant 7. Police 8. Tourism 9. Electrician/Plumber 10. IT/Computers 11. Other _____
10. In the future, would you like to marry?	1. Yes 2. No 3. I am already
a. (If already), when did you get married?	Age _____ or Year _____
11. In the future, do you want to have children?	1. Yes 2. No 3. I do already
a. (If answer is I already have children), how	Number of Children ____

many children do you have?	
b. (If answer is I already have children), how old are they?	_____ Age _____ Age of a second child
12. Do you think you will be able to achieve your life goals?	1. Yes 2. No 3. I don't know
13. Are you currently working for money outside of the home?	1. Yes 2. No
a. If yes, what is your job?	1. Housegirl/Houseboy 2. Farmer 3. Taxi/Boda Boda/Dalla Dalla driver 4. Carpenter 5. Shopkeeper 6. Seller of market produce 6. Porter 7. Other, please specify - _____
14. How many people live with you in your household? (this includes adults and children)	Number: _____
15. Who lives in your household?	1. Mother (biologic) 2. Father (biologic)

(please circle all that apply) (If he/she lives with your mother skip to question 17; If he/she lives with mom and dad skip to question 18)	3. Sibling(s) 4. Aunt(s) 5. Uncle(s) 6. Cousin(s) 7. Grandmother 8. Grandfather 9. Others, please specify _____
16. If not living with **biologic mother**, ask: Is your mother still alive?	1. Yes 2. No 3. Unsure
a. If No, *when* did she die?	Year _____ or <u>Patient's Age</u> at death _____
b. If No, do you know *how* she died?	1. Accidental/Traumatic Death: _____ 2. HIV/AIDS 3. Cancer, other illness not defined 4. Uncertain 5. Other, please specify: _____
17. If not living with **biologic father**, ask: Is your father still alive?	1. Yes 2. No 3. Unsure

a. If No, *when* did he die?	1. Year _____ or 2. **Patient's Age** at death _____ or 3. I am unsure
b. If No, do you know *how* he died?	1. Accidental/Traumatic Death: _____ 2. HIV/AIDS 3. Cancer, other illness not defined 4. Uncertain 5. Other, please specify: _____
18. When did you first find out you were HIV positive? (Year or Age)	Please fill in Year _____ or Age of patient _____
19. How did you first learn you were HIV positive? (You can read the answers)	1. I overheard people talking about my HIV 2. I figured it out on my own (ex. Taking medication) 3. I was purposefully told
20. *Who* first told you that you were HIV positive? *(You can read the answers)*	1. Family (please specify who) _____ 2. Health care provider 3. Friend 4. Teacher 5. Self
21. Is anyone else in your household HIV positive?	1. Yes specify who: _____

(If yes, please specify who)	2. No 3. Unsure
22. Does anyone else in your household take HIV medication? (If yes, please specify who)	1. Yes specify who: _____ 2. No 3. Unsure

EDUCATION: I would now like to ask you some questions about HIV transmission. Please answer Yes or No	Yes 1	No 2	Don't know 3
23. Can a person reduce the risk of getting HIV by using a condom every time they have sex?	1	2	3
24. Can a healthy-looking person have HIV?	1	2	3
25. Can a person get HIV from mosquito bites?	1	2	3
26. Can a person get HIV by sharing food with someone who is infected?	1	2	3
27. During school, did you formally discuss HIV as part of your educational curriculum?	1	2	3

STIGMA: I'd like to ask about your feelings regarding HIV. I am going to read you some statements. Please think about each statement, then tell me how much you agree with it. You can Strongly Disagree,	Strongly Disagree 1	Disagree 2	Agree 3	Strongly Agree 4

Disagree, Agree, or Strongly Agree.				
Questions 28 to 31 are about how you feel				
28. I feel I am not as good a person as others because I have HIV.	1	2	3	4
29. Other people's attitudes about HIV make me feel worse about myself.	1	2	3	4
30. Having HIV makes me feel unclean.	1	2	3	4
31. I feel guilty because I have HIV.	1	2	3	4
Questions 32-37 are about your perception of how other people feel				
32. People I know believe that someone with HIV is dirty.	1	2	3	4
33. People I know would treat someone with HIV as an outcast.	1	2	3	4
34. People I know would be uncomfortable around someone with HIV.	1	2	3	4
35. People I know would reject someone with HIV.	1	2	3	4

36. People I know would not want someone with HIV around their children.	1	2	3	4
37. People I know think that a person with HIV is disgusting.	1	2	3	4

ADHERENCE: Now I'd like to ask some questions about how you take your HIV medication.

38. Some people find it hard to remember to take every dose of their medication. How do you remember to take your medication? *(Please circle all that apply)*	1. Alarm to remind self 2. A calendar to verify dose was taken 3. Association with activities of daily living *(ex brushing teeth or daily morning chai)* 4. Reminded by caregiver 5. Other: _____
39. Have you missed any medication doses in the past 2 weeks?	1. Yes 2. No
40. Do you know the name(s) of the HIV medication do you take?	1. Yes please specify _____ 2. No 3. Unsure
41. Do you take Septrin?	1. Yes 2. No 3. Unsure
42. Many people have trouble	Response: _____

remembering to take their medication. Please think about the last time you missed your medication. What was the reason?	_____
43. What are common difficulties you have in taking every dose of your medication? (Interviewer please first listen to responses and circle all those that apply).	1. Too busy 2. Forgot 3. Couldn't get medications refilled 4. Felt too sick 5. Feeling well and no longer need medicine 6. Am not sure what medication I should be taking 7. Moved and/or lost my medication 8. No where to keep medications without people finding out and I am embarrased 9. Don't feel the medicine is working 10. No problems. Its easy. No difficulties
44. Many people miss their medication. Think about the past week (7 days). On average, how often did you miss a dose of medication?	1. Once a day 2. More than once a week, but not every day 3. Once a week 4. I don't miss my medicine
PERSONAL: Now I'd like to ask you some questions about what you do in your free time	
45. What do you enjoy doing when you are	Please fill in response: _____

not at school or work?	
46. In the past 6 months, have you consumed any alcoholic beverages?	1. Yes 2. No
a. If yes, ask: What types of alcohol have you consumed in the last 6 months? *Circle all that apply.*	1. Beer *(ex. Kilimanjaro, Safari, Serengeti, etc.)* 2. Liquor *(ex. Kinyagi, Vodka)* 3. Wine 4. Home brew *(ex. pombe made in the village)* 5. Other, please specify _____
b. If yes to alcohol use, ask: How often have you drunk alcohol in the last 6 months?	1. Daily 2. Most days 3. Weekly 4. Several times a month
47. In the past 6 months, have you smoked tobacco, sniffed glue, or used other drugs?	1. Yes 2. No
a. If Yes, ask: *Which* drugs have you used in the past 6 months? *Circle all that apply*	1. Tobacco Cigarettes 2. Marijuana 3. Sniff glue 4. Cocaine 5. Heroin 6. Other, please specify _____

b. If Yes to drug use, ask: *How often* do you use these drugs?	1. Daily 2. Most days 3. Weekly 4. Several times a month
SEXUAL: Now I would like to ask you about your sexual history. I know this may be uncomfortable to talk about and I appreciate your talking with me about this. Please remember your answers are confidential.	
48. Have you ever had sexual intercourse?	1. Yes 2. No
49. If Yes, how old were you the first time you had sexual intercourse?	Age _____ or Year _____
50. If Yes, How many people have you had sexual intercourse with in your lifetime?	Number of different partners _____
51. The last time you had sex did you or your partner use a condom?	1. Yes 2. No

PHQ-9: Now I'd like to ask you some questions about your recent mood and energy over the last 2 weeks.	Not at all 0	One day or a few days 1	More than half the days 2	Nearly every day 3

52. In the past two weeks, how often have you been bothered by little interest or pleasure in doing things?	0	1	2	3
53. In the past two weeks, how often have you been bothered by feeling down, depressed, or hopeless?	0	1	2	3
54. In the past two weeks, how often have you been bothered by trouble falling or staying asleep, or sleeping too much?	0	1	2	3
55. In the past two weeks, how often have you been bothered by feeling tired or having little energy?	0	1	2	3
56. In the past two weeks, how often have you been bothered by poor appetite or over eating?	0	1	2	3
57. In the past two weeks, how often have you been bothered by feeling bad about yourself, or that you are a failure, or that you have let yourself or your family down?	0	1	2	3
58. In the past two weeks, how often have you been bothered by trouble concentrating on things,	0	1	2	3

such as what you are doing?				
59. In the past two weeks, how often have you been bothered by a. moving or speaking so slowly that other people could have noticed Or b. the opposite, being so fidgety or restless that you have been moving around a lot more than usual?	0 0	1 1	2 2	3 3
60. In the past two weeks, how often have you been bothered by thoughts that you would be better off dead or hurting yourself in some way?	0	1	2	3
61. How difficult have these problems you mentioned made it for you to do your work, take care of things at home, or get along with other people?	0	1	2	3
Score Sheet for PHQ-9	_____			
62. Has a health care provider ever asked you about these types of mental health problems such as feeling depressed or overwhelmed?	1. Yes 2. No			

63. If Yes, how often?	1. Frequently (example, nearly every clinic visit) 2. Sometimes (example, every 3 months or so) 3. Rarely (example, once in the last six months)
64. If you are feeling sad or bad is there someone in your life you would go to for help?	1. Yes 2. No
65. If yes, *who?* *(Please circle all who are mentioned)* *…any one else?* _____ *specify:* _____ ___	1. Mother (biologic) 2. Father (biologic) 3. Sister 4. Brother 5. Aunt 6. Uncle 7. Grandmother 8. Grandfather 9. Friend 10. Teacher 11. Doctor

SDQ: Now I am going to read some statements. Please tell me how "true" they are of you, or how much they describe you.	**Never True of me 0**	**Sometimes True of me 1**	**Usually True of me 2**
66. I try to be nice to other people. I care about their feelings.	0	1	2

67. I am restless. I cannot stay still for long.	0	1	2
68. I get headaches, stomachaches, or sickness.	0	1	2
69. I share with others, for example toys.	0	1	2
70. I get very angry and lose my temper.	0	1	2
71. I would rather be alone than with others my age.	0	1	2
72. I do what adults tell me to do.	0	1	2
73. I worry a lot.	0	1	2
74. I am helpful if someone is hurt, upset, or feeling ill.	0	1	2
75. I am constantly moving around, squirming, feel restless.	0	1	2
76. I have one good friend or more.	0	1	2
77. I fight a lot	0	1	2
78. I am unhappy, depressed, tearful.	0	1	2
79. Other people my age like me.	0	1	2
80. I am easily distracted. I find it difficult to concentrate.	0	1	2
81. I am nervous in new situations. I easily lose confidence.	0	1	2

82. I am kind to younger children.	0	1	2
83. I have been accused of lying or cheating.	0	1	2
84. Other children or young people pick on me or bully me.	0	1	2
85. I offer to help others (adults, other children.)	0	1	2
86. I think before doing things.	0	1	2
87. I take things that are not mine from school, home, or elsewhere.	0	1	2
88. I get along better with adults than with people my own age.	0	1	2
89. I am afraid of many things. I am easily scared.	0	1	2
90. I finish the work I am doing. My attention is good.	0	1	2

SDQ Score _____

*Note total score should not include the prosocial questions (Questions)

Trauma Exposure Screener (Adapted from UCLA PTSD): Now I'm going to ask you about some difficult things that many people have experienced and may have happened to you.

"Please tell me if any of these things have happened to you, how many times, and how long ago."	Yes, one time 1	More than	Never Happened 3	Don't Know 4	When did this happen?

		one time 2			a) < 1 yr ago b) ≥ 1 yr ago c) Both
91. Been in a big disaster, such as a fire or flood	1	2	3	4	a b c
92. Been in a bad accident, like a car or dalla dalla accident	1	2	3	4	a b c
93. Been in a place where war, conflict, fighting, or riots were going on	1	2	3	4	a b c
94. Been hit, kicked, or beaten (by adult or **other children)** so badly that I was really scared. If has happened please specify who did this to you:_____ _____	1	2	3	4	a b c
95. Saw a family member or someone in the	1	2	3	4	a b c

place where I am living get hit, kicked, or beaten so that I was really scared. *to whom*_____ _					
96. Saw a family member or someone in the place where I am living shot at or killed	1	2	3	4	a b c
97. Saw someone in my town shot at or killed.	1	2	3	4	a b c
98. Someone touched my private sexual parts when I did not want them to	1	2	3	4	a b c
99. I was raped or sexually molested	1	2	3	4	a b c
100. Saw a family member or someone in the place where I am living raped or sexually molested.	1	2	3	4	a b c
101. Saw a family member or someone in the place where I am living die a violent death or be seriously injured	1	2	3	4	a b c
102. Saw a family member or someone in the place where I am living die from illness	1	2	3	4	a b c

103. Have a brother or sister or fellow orphan in the place where I am living die	1	2	3	4	a b c
104. Had a painful or scary medical treatment when I was sick or hurt	1	2	3	4	a b c
105. Saw someone hurt or killed during a war, conflict, fighting or riots	1	2	3	4	a b c
106. Was forced to move or run from home or in the place where I am living due to a war, conflict, fighting or riots.	1	2	3	4	a b c
107. Was forced to move from home or in the place where I am living because there was no adult at home to stay with	1	2	3	4	a b c
108. Other really bad or scary things that happened? Please describe: _____	1	2	3	4	a b c
UCLA symptoms: We just talked about a lot of scary or upsetting events. Of those that happened, which of these has affected you the most and continues to affect you? (If necessary, remind patient of the items endorsed)					

Patient Response:

_____

Please fill in the number relating to that question above _____

Let's talk about how *this* experience (*Please restate from above)* still affects you. Please tell me how often in the PAST MONTH you have had each of these feelings.	**None**, does not happen to me 0	**Little**, happens a little 1	**Much**, it happens much of the time 2	**Most**, it happens most of the time 3
109. I watch out for danger or things I am afraid of	0	1	2	3
110. If something reminds me of what happened, I get very upset, afraid or sad.	0	1	2	3
111. I have upsetting thoughts, pictures, or sounds about what happened come into my mind when I do not want them to.	0	1	2	3
112. I feel grouchy, angry, or mad.	0	1	2	3
113. I have bad dreams or dreams about what happened or other bad dreams.	0	1	2	3
114. I feel like I am back at the time when the bad thing happened, living through it again.	0	1	2	3
115. I feel like staying by myself & not being with my friends.	0	1	2	3

116. I feel alone inside and not close to other people.	0	1	2	3
117. I try not to talk about, think about, or have feelings about what happened.	0	1	2	3
118. I have trouble feeling happiness or love.	0	1	2	3
119. I have trouble feeling sadness or anger.	0	1	2	3
120. I feel jumpy or startle easily like when I hear a loud noise or when something surprises me.	0	1	2	3
121. I have trouble going to sleep at night.	0	1	2	3
122. I have trouble staying asleep at night.	0	1	2	3
123. I think part of what happened is my fault.	0	1	2	3
124. I have trouble paying attention or thinking clearly.	0	1	2	3
125. I try to stay away from people or places that make me remember what happened.	0	1	2	3
126. When someone reminds me of what happened, I have strong feelings in my body, like my heart beats fast, I have headaches, or stomach aches.	0	1	2	3

127. I think I will not live a long life.	0	1	2	3
128. I have arguments or physical fights.	0	1	2	3
129. I feel pessimistic or negative about my future.	0	1	2	3
130. I am afraid that the bad thing will happen again.	0	1	2	3
Trauma Score _____				
I have finished asking all of my questions. Do you have any other comments or questions? Is there something you think I should know about that I haven't asked about? _____ **Thank you very much for your participation and honesty. Please come with me to the break room.**				

Information collected from the patient's chart:

131. From the patient's chart, how was the patient infected with HIV?	1. Perinatally Infected 2. Sexually infected 3. Unknown
132. From the patient's chart, when was the patient first diagnosed with HIV?	____ / ____ / _____ dd mm YYYY
133. From the patient's chart, when did he/she first start ARV treatment?	____ / ____ / _____ dd mm YYYY

134. From the patient's chart, what is the patient's current HIV regimen?	1. Triamune: Stavudine, Lamivudine, Nevirapine (D4T, 3TC, NVP) 2. Duovir: Zidovudine, Lamivudine, Nevirapine (D4T, 3TC, NVP) 3. Combivir + Efavirenz: (AZT, 3TC, EFV) 4. Abacavir, 3TC (or AZT), Aluvia 5. Other, please specify _____ _____
135. From the patient's chart, find the blue card and the column labeled "ARV Adhere status." Over the past year please read how many times "P" has been written or how many times the patient has skipped filling meds over the last year	1. 0 times 2. 1 time 3. 2 times 4. > 2 times
136. When was the most recent CD4?	_____ -- _____-- _____ Day Month Year
137. What is the CD4+ absolute number?	_____
138. What is the CD4+ percentage (if available)	_____
139. Has the patient received a viral load (HIV RNA) test?	_____ -- _____ -- _____ Day Month Year

140. What was the result?	1. Not Detected (write in 1) 2. Detected <40 copies/mL (write in 20) 3. _____copies/mL (write the number)
141. Do you feel this client tried their level best to answer the questions honestly?	1. Yes 2. No
142. Do you feel this client listened carefully and understood the questions?	1. Yes 2. No
143. Do you feel this client has mental health difficulties?	1. Yes 2. No

Data verified for completeness by: Initials __ __

Confirmation of correct patient 1. Yes 2. No

PHQ 9 Score _____ SDQ 9 Score _____ Trauma Score _____

Need to schedule indepth interview? 1. Yes 2. No

Reason:

_____

If Yes: Day __ __ Month __ __ Year 2015 Time: __ __ : __ __

Signature _____ Initials ___ ____

Appendix C: Semi-Structured Interview Guide

READ ALOUD:

Hello. Thank you for taking the time to participate in our research project. Your participation is very important to us. The purpose of this interview is to talk with you about your experiences with Teen Club and Sauti Ya Vijana.

Your opinions as a youth in Teen Club who has completed the Sauti Ya Vijana program are very important to us as we try to understand the experiences of all who have completed the intervention. I encourage you to speak honestly and openly with me about your experiences. Please feel free to speak about as much as you are comfortable with. If I bring up a subject or experience that is too difficult to speak about, just let me know you prefer not to discuss it, and we will move on to a new topic.

This conversation will last about 60-90 minutes and will be audio recorded so that we can make sure that we understand everything you share with us today. The information that you share will be kept confidential. Do you have any questions before we begin?

Introduction

I am going to start by asking some general questions about you and your home

1. Please tell me about yourself
    a. *How old are you?*
    b. *Where are you from?*
    c. *Do you have any siblings? If so, how many siblings do you have?*
    d. *What grade are you in? If you have already completed school, what was the highest grade you completed?*
    e. *If you are employed, what is your current employment?*
    f. *What do you like to do for fun?*

I am going to ask some questions about your home life

2. Please describe your home life
    a. *Who do you live with?*
    b. *How many people live in your home?*
    c. *If you have a problem, who at home would you go to for help?*
        i. *Why would you go to this person?*

Depression

1. During the SYV project, your responses to some of the follow-up questions at KCMC suggested you had symptoms of depression, please tell me more about that
    a. Can you tell me about a time when you lost interest in doing things you usually liked or felt hopeless?
        i. Can you tell me more about that? (What made it better?)
        ii. Do these feelings come and go or are they always present?
        iii. How do you usually cope with these feelings?
    b. Have you ever been bothered by thoughts that you would be better off dead or hurting yourself in some way?

        i. If they respond yes:
            1. Did you act on those thoughts?
                a. If yes:
                    i. How? What did you do?
                    ii. Do you feel that way now?
                b. If no they did not act on those thoughts: what prevented you from acting on those thoughts?

Challenges

Now I am going to ask you about the challenges that you face in your life and how you deal with them.

1. Please tell me about some challenges that you have faced
2. How do you usually deal with these challenges?
    a. *Are there any activities you do to help you deal with the challenges?*

What about HIV-related challenges?

3. Please tell me about your experience living with HIV
    a. Do you remember when you were diagnosed with HIV?
    b. Do you remember how you found out your HIV status?
        i. How did you feel when you found out about your HIV status?
    c. Who is aware of your HIV status?
        1. Please tell me of a time you purposefully disclosed your status to someone
            a. How did it go

2. *If you have not disclosed to anyone, why haven't you disclosed your status to others?*

d. *Please tell me about the stigma you have experienced*
   i. *Please describe a situation where you felt stigmatized*
   ii. *How did you deal with this situation where you felt stigmatized?*
   iii. *How does experiencing stigma make you feel?*

e. *Please tell me about your worries living with HIV*
   i. *How do you usually deal with these worries?*

<u>Experience with the SYV Intervention</u>

Now I am going to ask you about your experience specifically with Sauti Ya Vijana

1. May you describe the SYV program to me?
2. How did you come to know about SYV?
   a. *What was your motivation to participate?*
   b. *Please describe any problems you had with registering for SYV*
      i. *how did you overcome these problems?*
   c. *In SYV you received money for transport- would you still have participated if you didn't receive the money for transportation?*
3. Please tell me about your experience in SYV?
   a. *What did you like about the program? Ask them to elaborate*
   b. *What didn't you like about the program? Ask them to elaborate*
   c. *Please describe your most memorable moment in SYV?*
4. Is there anything that you would change about the SYV program?
   a. *If yes, what would you change?*
      i. *Why?*
5. If you could give feedback to the SYV leaders, what would it be?
6. What advice would you give another youth who wants to participate in the SYV program?

<u>Lessons from SYV Intervention</u>

Now I am going to ask you some questions about what you learned from SYV

1. May you tell me what you learned from SYV?
   a. *What was the most useful skill or lesson you learned from SYV?*
      i. *Why?*
   b. *What was the least useful skill or lesson you learned from SYV?*
      i. *Why?*

The next set of questions will ask you about specific SYV lessons

2. In SYV you learned about skills to help you when you are feeling stressed, may you tell me about some of the skills that you learned from this lesson?
    a. *May you describe a time when you were stressed, and you used what you learned in SYV to help you cope?*
    b. *How did it go?*
3. In SYV, you learned about the thoughts, feelings, and behaviors triangle, may you describe this lesson to me?
    a. *May you tell me of a time after SYV where the triangle helped you think about your feelings?*
    b. *How did it go?*
4. In SYV, you learned about sharing difficult memories with other people
    a. Have you shared any difficult memories with other people since participating in SYV?
        i. *If yes, think about the most recent time you shared a difficult memory with someone else, how did it go?*
    b. Have you shared any difficult memories with your caregiver since participating in SYV?
        i. *If yes, think about the most recent time you shared a difficult memory with a caregiver, how did it go?*
    c. How did SYV prepare you for sharing these memories?
5. In SYV you learned about circles of support, may you describe the circles of support in your life?
    a. *Who is in your circle of support?*
    b. *Why are these people in your circles of support?*
    c. *How do the people in your circles of support impact your life?*
6. Immediately after SYV ended, how did your ability to cope with challenges change?
    a. How is this ability different than before you participated in SYV?
7. Now it's been over a year since SYV ended, how would you describe the effect SYV has had in your life?
    a. How is your life going?
    b. If you have been facing some challenges, how has what you have learned in SYV helped you through the challenges?
8. Are there any other challenges that SYV helped you through?

<u>Teen Club Lessons</u>

Now I am going to ask you about your experience in Teen Club

1. When did you start coming to Teen Club?
2. Did you attend Teen Club when there was a peer leader teaching the lesson?

If no, skip to question 9

3. How is being taught by a peer leader different than being taught by an older adult?
    a. How do you feel you learn when peer leaders teach versus when older adults teach?
4. What do you like about the Teen Club lessons that are taught by a peer leader?
    a. What was your favorite lesson?
        i. Why?
    b. What was your least favorite lesson?
        i. Why?
5. What is your most memorable lesson you've been taught in Teen Club?
    a. Why?
6. Are there topics you want to hear more about that were not covered in the lessons?
7. How comfortable are you asking the peer leaders questions?
8. Can you describe a time when you or a friend asked a peer leader a question while they were teaching?
    a. To what extent did they answer your questions
9. What is your opinion of having peer leaders teach?
    a. What do you like about it?
    b. What do you NOT like about it?

<u>Conclusion</u>

1. Is there anything that I did not ask you that you would like to share with me?

Thank you for participating in the interview and sharing your experiences with me.

Appendix D: Codebook

Code Name	Description
1. Explanation of the interview	This is for the beginning section of the transcript where the interviewer is explaining the interview and purposes of the interview to the participant. Using this to exclude the text in this section when running queries.
2. Introduction	This is a general code to capture the introduction section of the interview. Using this to exclude this section when running the query later
3. Depression	This is for the section of the interview where the participant answers questions about depression
Coping	This code describes how youth cope with depressive thought, suicidal ideation, and life challenges
History of Suicidal Ideation	This code is used for an instance where a participant endorses experiencing suicidal ideation
Triggers	This code refers to triggers of depression symptom, suicidal ideation
4. Challenges	This is for the section of the interview where the participant talks about the challenges they face in their life. This will also include HIV-related challenges.
Support Systems	This code is for participants' identification of support systems as it relates to challenges
5. Experience with SYV	This section is for the section of the interview where the participants talks about the experience with SYV
Coping skills from SYV	
6. SYV Lessons	This node is for the section of the interview where the participant discusses specific SYV lessons
Resilience	This code is for discussion of resilience in youth after completing SYV (examples include self-confidence, ability to cope with stressors, forming healthy relationships)
7. Teen Club	This is for the section of the interview where the participant talks about Teen Club
8. Conclusion	This is for the section of the concluding section of the interview. This will be omitted when running queries later

References

Ashaba, S., Cooper-Vincen, C. E., Vorechovska, D., Rukundo, G. Z., Maling, S., Akena, D., & Tsai, A. C. (n.d.). Community beliefs, HIV stigma, and depression among adolescents living with HIV in rural Uganda. *Ajar-African Journal of Aids Research*. https://doi.org/10.2989/16085906.2019.1637912

Benton, T. D., Kee Ng, W. Y., Leung, D., Canetti, A., & Karnik, N. (2019). Depression among Youth Living with HIV/AIDS. *Child and Adolescent Psychiatric Clinics of North America*, *28*(3), 447–459. https://doi.org/10.1016/j.chc.2019.02.014

Berger, B. E., Ferrans, C. E., & Lashley, F. R. (2001). Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. *Research in Nursing & Health*, *24*(6), 518–529. https://doi.org/10.1002/nur.10011

Bhana, A., Mellins, C. A., Petersen, I., Alicea, S., Myeza, N., Holst, H., Abrams, E., John, S., Chhagan, M., Nestadt, D. F., Leu, C.-S., & McKay, M. (2014). The VUKA family program: Piloting a family-based psychosocial intervention to promote health and mental health among HIV infected early adolescents in South Africa. *AIDS Care*, *26*(1), 1–11. https://doi.org/10.1080/09540121.2013.806770

Brown, L. K., Kennard, B. D., Emslie, G. J., Mayes, T. L., Whiteley, L. B., Bethel, J., Xu, J., Thornton, S., Tanney, M. R., Hawkins, L. A., Garvie, P. A., Subramaniam, G. A., Worrell, C. J., & Stoff, L. W. (2016). Effective Treatment of Depressive Disorders in Medical Clinics for Adolescents and Young Adults living with HIV: A controlled trial. *Journal of Acquired Immune Deficiency Syndromes (1999)*, *71*(1), 38–46. https://doi.org/10.1097/QAI.0000000000000803

Caruana, E. J., Roman, M., Hernández-Sánchez, J., & Solli, P. (2015). Longitudinal studies. *Journal of Thoracic Disease*, *7*(11), E537–E540. https://doi.org/10.3978/j.issn.2072-1439.2015.10.63

Casale, M., Boyes, M., Pantelic, M., Toska, E., & Cluver, L. (2019). Suicidal thoughts and behaviour among South African adolescents living with HIV: Can social support buffer the impact of stigma? *Journal of Affective Disorders*, *245*, 82–90. https://doi.org/10.1016/j.jad.2018.10.102

Casale, M., Carlqvist, A., & Cluver, L. (2019). Recent Interventions to Improve Retention in HIV Care and Adherence to Antiretroviral Treatment Among Adolescents and

Youth: A Systematic Review. *AIDS Patient Care and STDs*, *33*(6), 237–252. https://doi.org/10.1089/apc.2018.0320

Chenneville, T., Gabbidon, K., Lynn, C., & Rodriguez, C. (2018). Psychological factors related to resilience and vulnerability among youth with HIV in an integrated care setting. *AIDS Care*, *30*(sup4), 5–11. https://doi.org/10.1080/09540121.2018.1488032

Children and AIDS. (n.d.). Retrieved February 23, 2020, from https://www.unicef.org/tanzania/what-we-do/hiv-aids

Cholera, R., Gaynes, B. N., Pence, B. W., Bassett, J., Qangule, N., Macphail, C., Bernhardt, S., Pettifor, A., & Miller, W. C. (2014). Validity of the Patient Health Questionnaire-9 to screen for depression in a high-HIV burden primary healthcare clinic in Johannesburg, South Africa. *Journal of Affective Disorders*, *167*, 160–166. PubMed. https://doi.org/10.1016/j.jad.2014.06.003

Cluver, L. D., Orkin, F. M., Campeau, L., Toska, E., Webb, D., Carlqvist, A., & Sherr, L. (2019). Improving lives by accelerating progress towards the UN Sustainable Development Goals for adolescents living with HIV: A prospective cohort study. *The Lancet Child & Adolescent Health*, *3*(4), 245–254. https://doi.org/10.1016/S2352-4642(19)30033-1

Depression among Youth Living with HIV/AIDS- ClinicalKey. (n.d.). Retrieved June 18, 2019, from https://www-clinicalkey-com.proxy.lib.duke.edu/#!/content/playContent/1-s2.0-S1056499319300355

Dow, D. E., Mmbaga, B. T., Turner, E. L., Gallis, J. A., Tabb, Z. J., Cunningham, C. K., & O'Donnell, K. E. (2018). Building resilience: A mental health intervention for Tanzanian youth living with HIV. *AIDS Care*, *30*(sup4), 12–20. https://doi.org/10.1080/09540121.2018.1527008

Earnshaw, V. A., & Chaudoir, S. R. (2009). From Conceptualizing to Measuring HIV Stigma: A Review of HIV Stigma Mechanism Measures. *AIDS and Behavior*, *13*(6), 1160–1177. https://doi.org/10.1007/s10461-009-9593-3

Earnshaw, V. A., Smith, L. R., Chaudoir, S. R., Amico, K. R., & Copenhaver, M. M. (2013). HIV Stigma Mechanisms and Well-Being among PLWH: A Test of the HIV Stigma Framework. *AIDS and Behavior*, *17*(5), 1785–1795. https://doi.org/10.1007/s10461-013-0437-9

Freeman M, Nkomo N, Kafaar Z, & Kelly K. (2007). Factors associated with prevalence of mental disorder in people living with HIV/AIDS in South Africa. *AIDS Care*, *19*(10), 1201–1209.

Gelaye, B., Williams, M. A., Lemma, S., Deyessa, N., Bahretibeb, Y., Shibre, T., Wondimagegn, D., Lemenhe, A., Fann, J. R., Vander Stoep, A., & Andrew Zhou, X.-H. (2013). Validity of the Patient Health Questionnaire-9 for depression screening and diagnosis in East Africa. *Psychiatry Research*, *210*(2), 653–661. PubMed. https://doi.org/10.1016/j.psychres.2013.07.015

Goodman, R. (2001). Psychometric Properties of the Strengths and Difficulties Questionnaire. *Journal of the American Academy of Child & Adolescent Psychiatry*, *40*(11), 1337–1345. https://doi.org/10.1097/00004583-200111000-00015

Govender, K., Cowden, R. G., Oppong Asante, K., George, G., & Reardon, C. (2017). Validation of the child and youth resilience measure among South African adolescents. *PloS One*, *12*(10), e0185815. https://doi.org/10.1371/journal.pone.0185815

Guest, G., MacQueen, K., & Namey, E. (2012). *Applied Thematic Analysis*. SAGE Publications, Inc. https://doi.org/10.4135/9781483384436

Hudelson, C., & Cluver, L. (2015). Factors associated with adherence to antiretroviral therapy among adolescents living with HIV/AIDS in low- and middle-income countries: A systematic review. *AIDS Care*, *27*(7), 805–816. https://doi.org/10.1080/09540121.2015.1011073

Hussen, S. A., Jones, M., Moore, S., Hood, J., Smith, J. C., Camacho-Gonzalez, A., Del Rio, C., & Harper, G. W. (2018). Brothers Building Brothers by Breaking Barriers: Development of a resilience-building social capital intervention for young black gay and bisexual men living with HIV. *AIDS Care*, *30*(sup4), 51–58. https://doi.org/10.1080/09540121.2018.1527007

Kahema, S. E., & Kahema, S. E. (2018). Factors Influencing Adherence to Antiretroviral Therapy among HIV Infected Patients in Nyamagana-Mwanza, Northern Tanzania: A Cross Sectional Study. https://doi.org/10.23937/iamm-2017/1710002

Kamau, J. W., Kuria, W., Mathai, M., Atwoli, L., & Kangethe, R. (2012). Psychiatric morbidity among HIV-infected children and adolescents in a resource-poor Kenyan

urban community. *AIDS Care*, *24*(7), 836–842. https://doi.org/10.1080/09540121.2011.644234

Kemigisha, E., Zanoni, B., Bruce, K., Menjivar, R., Kadengye, D., Atwine, D., & Rukundo, G. Z. (2019). Prevalence of depressive symptoms and associated factors among adolescents living with HIV/AIDS in South Western Uganda. *AIDS Care*, *31*(10), 1297–1303. https://doi.org/10.1080/09540121.2019.1566511

Kim, S.-H., Gerver, S. M., Fidler, S., & Ward, H. (2014). Adherence to antiretroviral therapy in adolescents living with HIV: Systematic review and meta-analysis. *AIDS (London, England)*, *28*(13), 1945–1956. https://doi.org/10.1097/QAD.0000000000000316

Kumakech, E., Cantor-Graae, E., Maling, S., & Bajunirwe, F. (2009). Peer-group support intervention improves the psychosocial well-being of AIDS orphans: Cluster randomized trial. *Social Science & Medicine*, *68*(6), 1038–1043. https://doi.org/10.1016/j.socscimed.2008.10.033

Lamb, M. R., Fayorsey, R., Nuwagaba-Biribonwoha, H., Viola, V., Mutabazi, V., Alwar, T., Casalini, C., & Elul, B. (2014). High attrition before and after ART initiation among youth (15–24 years of age) enrolled in HIV care. *AIDS (London, England)*, *28*(4), 559–568. https://doi.org/10.1097/QAD.0000000000000054

Liu, F. F., & Adrian, M. C. (2019). Is Treatment Working? Detecting Real Change in the Treatment of Child and Adolescent Depression. *Journal of the American Academy of Child & Adolescent Psychiatry*. https://doi.org/10.1016/j.jaac.2019.02.011

Lockwood, N. M., Lypen, K., Shalabi, F., Kumar, M., Ngugi, E., & Harper, G. W. (2019). 'Know that You are not Alone.' Influences of Social Support on Youth Newly Diagnosed with HIV in Kibera, Kenya: A Qualitative Study Informing Intervention Development. *International Journal of Environmental Research and Public Health*, *16*(5). https://doi.org/10.3390/ijerph16050775

Lowenthal, E. D., Bakeera-Kitaka, S., Marukutira, T., Chapman, J., Goldrath, K., & Ferrand, R. A. (2014). Perinatally acquired HIV infection in adolescents from sub-Saharan Africa: A review of emerging challenges. *The Lancet Infectious Diseases*, *14*(7), 627–639. https://doi.org/10.1016/S1473-3099(13)70363-3

MacPherson, P., Munthali, C., Ferguson, J., Armstrong, A., Kranzer, K., Ferrand, R. A., & Ross, D. A. (2015). Service delivery interventions to improve adolescents' linkage,

retention and adherence to antiretroviral therapy and HIV care. *Tropical Medicine & International Health*, *20*(8), 1015–1032. https://doi.org/10.1111/tmi.12517

Marwick KFM, & Kaaya SF. (2010). Prevalence of depression and anxiety disorders in HIV-positive outpatients in rural Tanzania. *AIDS Care*, *22*(4), 415–419. https://doi.org/10.1080/09540120903253981

Mavhu, W., Berwick, J., Chirawu, P., Makamba, M., Copas, A., Dirawo, J., Willis, N., Araya, R., Abas, M. A., Corbett, E. L., Mungofa, S., Laver, S. M., & Cowan, F. M. (2013). Enhancing Psychosocial Support for HIV Positive Adolescents in Harare, Zimbabwe. *PLOS ONE*, *8*(7), e70254. https://doi.org/10.1371/journal.pone.0070254

Mbatia, J., & Jenkins, R. (2010). Development of a mental health policy and system in Tanzania: An integrated approach to achieve equity. *Psychiatric Services (Washington, D.C.)*, *61*(10), 1028–1031. https://doi.org/10.1176/ps.2010.61.10.1028

Mbuagbaw, L., Ye, C., & Thabane, L. (2012). Motivational interviewing for improving outcomes in youth living with HIV. *Cochrane Database of Systematic Reviews*, *9*. https://doi.org/10.1002/14651858.CD009748.pub2

Musiimenta, A., Atukunda, E. C., Tumuhimbise, W., & Haberer, J. E. (2018). Resilience after withdrawing a technology-based medication adherence support intervention from people living with HIV in rural Uganda. *AIDS Care*, *30*(sup5), S89–S96. https://doi.org/10.1080/09540121.2018.1510107

Nachega, J. B., Hislop, M., Nguyen, H., Dowdy, D. W., Chaisson, R. E., Regensberg, L., Cotton, M., & Maartens, G. (2009). Antiretroviral therapy adherence, virologic and immunologic outcomes in adolescents compared with adults in southern Africa. *Journal of Acquired Immune Deficiency Syndromes (1999)*, *51*(1), 65–71. https://doi.org/10.1097/QAI.0b013e318199072e

Nestadt, D. F., Saisaengjan, C., McKay, M. M., Bunupuradah, T., Pardo, G., Lakhonpon, S., Gopalan, P., Leu, C.-S., Petdachai, W., Kosalaraksa, P., Srirompotong, U., Ananworanich, J., & Mellins, C. A. (2019). CHAMP+ Thailand: Pilot Randomized Control Trial of a Family-Based Psychosocial Intervention for Perinatally HIV-Infected Early Adolescents. *AIDS Patient Care and STDs*, *33*(5), 227–236. https://doi.org/10.1089/apc.2019.0021

Pantelic, M., Sprague, L., & Stangl, A. L. (2019). It's not "all in your head": Critical knowledge gaps on internalized HIV stigma and a call for integrating social and

structural conceptualizations. *BMC Infectious Diseases*, *19*(1), 210. https://doi.org/10.1186/s12879-019-3704-1

Pennar, A., Naar, S., Woods, S., Nichols, S., Outlaw, A., & Ellis, D. (2018). Promoting resilience through neurocognitive functioning in youth living with HIV. *AIDS Care*, *30*(sup4), 59–64. https://doi.org/10.1080/09540121.2019.1576851

Petersen I, Bhana A, Myeza N, Alicea S, John S, Holst H, McKay M, & Mellins C. (2010). Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: A qualitative investigation. *AIDS Care*, *22*(8), 970–978. https://doi.org/10.1080/09540121003623693

Piliavin, J. A., & Siegl, E. (2007). Health Benefits of Volunteering in the Wisconsin Longitudinal Study. *Journal of Health and Social Behavior*, *48*(4), 450–464. https://doi.org/10.1177/002214650704800408

Ramaiya, M. K., Sullivan, K. A., O' Donnell, K., Cunningham, C. K., Shayo, A. M., Mmbaga, B. T., & Dow, D. E. (2016). A Qualitative Exploration of the Mental Health and Psychosocial Contexts of HIV-Positive Adolescents in Tanzania. *PLoS ONE*, *11*(11), e0165936. Academic OneFile.

Sikkema, K. J., Dennis, A. C., Watt, M. H., Choi, K. W., Yemeke, T. T., & Joska, J. A. (2015). Improving mental health among people living with HIV: A review of intervention trials in low- and middle-income countries. *Global Mental Health*, *2*. https://doi.org/10.1017/gmh.2015.17

Ssewamala, F. M., Han, C.-K., & Neilands, T. B. (2009). Asset Ownership and Health and Mental Health Functioning Among AIDS-Orphaned Adolescents: Findings From a Randomized Clinical Trial in Rural Uganda. *Social Science & Medicine (1982)*, *69*(2), 191. https://doi.org/10.1016/j.socscimed.2009.05.019

Steinberg, A. M., Brymer, M. J., Kim, S., Briggs, E. C., Ippen, C. G., Ostrowski, S. A., Gully, K. J., & Pynoos, R. S. (2013). Psychometric properties of the UCLA PTSD reaction index: Part I. *Journal of Traumatic Stress*, *26*(1), 1–9. https://doi.org/10.1002/jts.21780

Tapera, T., Willis, N., Madzeke, K., Napei, T., Mawodzeke, M., Chamoko, S., Mutsinze, A., Zvirawa, T., Dupwa, B., Mangombe, A., Chimwaza, A., Makoni, T. M., Mandewo, W., Senkoro, M., Owiti, P., Tripathy, J. P., & Kumar, A. M. V. (2019). Effects of a Peer-Led Intervention on HIV Care Continuum Outcomes Among

Contacts of Children, Adolescents, and Young Adults Living With HIV in Zimbabwe. *Global Health: Science and Practice*, *7*(4), 575–584. https://doi.org/10.9745/GHSP-D-19-00210

Thomas, B. E., Rehman, F., Suryanarayanan, D., Josephine, K., Dilip, M., Dorairaj, V. S., & Swaminathan, D. S. (2005). How stigmatizing is Stigma in the life of people living with HIV: A study on HIV positive individuals from Chennai, South India. *AIDS Care*, *17*(7), 795–801. https://doi.org/10.1080/09540120500099936

Toska, E., Cluver, L., Orkin, M., Bains, A., Sherr, L., Berezin, M., & Gulaid, L. (2019). Screening and supporting through schools: Educational experiences and needs of adolescents living with HIV in a South African cohort. *BMC Public Health*, *19*(1). Academic OneFile. http://link.galegroup.com/apps/doc/A581442899/AONE?u=duke_perkins&sid=AONE&xid=aeeca964

UNICEF. (2016). *Adolescent deaths from AIDS tripled since 2000*. UNICEF. https://www.unicef.org/media/media_86384.html

UNICEF. (2019). *Adolescent HIV prevention*. UNICEF DATA. https://data.unicef.org/topic/hivaids/adolescents-young-people/

Vreeman, R. C., McCoy, B. M., & Lee, S. (2017). Mental health challenges among adolescents living with HIV. *Journal of the International AIDS Society*, *20*(S3), 21497. https://doi.org/10.7448/IAS.20.4.21497

Walders-Abramson, N., Anderson, B., Larkin, M. E., Chang, N., Venditti, E., Bzdick, S., Tryggestad, J. B., Tan, K., Geffner, M. E., & Hirst, K. (2016). Benefits and barriers to participating in longitudinal research of youth-onset type 2 diabetes: Results from the TODAY retention survey. *Clinical Trials (London, England)*, *13*(2), 240–243. https://doi.org/10.1177/1740774515613949

Whiteley, L., Brown, L. K., Mena, L., Craker, L., & Arnold, T. (2018). Enhancing health among youth living with HIV using an iPhone game. *AIDS Care*, *30*(sup4), 21–33. https://doi.org/10.1080/09540121.2018.1503224

Willis, N., Milanzi, A., Mawodzeke, M., Dziwa, C., Armstrong, A., Yekeye, I., Mtshali, P., & James, V. (2019). Effectiveness of community adolescent treatment supporters (CATS) interventions in improving linkage and retention in care, adherence to ART and psychosocial well-being: A randomised trial among adolescents living with

HIV in rural Zimbabwe. *BMC Public Health, 19*(1). Academic OneFile. http://link.galegroup.com/apps/doc/A581430303/AONE?u=duke_perkins&sid=AONE&xid=a7d2652f

World Health Organization, & World Health Organization (Eds.). (2018). *Mental health atlas 2017*. World Health Organization.