Resilience in Tanzanian Youth Living with HIV: A Longitudinal Exploration of Protective Factors and Challenges

by

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

2021

ABSTRACT

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Abstract

Background: Adolescence is a critical risk period for the onset of mental health difficulties. Youth living with HIV (YLWH) face additional challenges navigating relationships due to stigma and disclosure, putting youth more at risk for mental health difficulties. This study explored changes in resilience of youth enrolled in a mental health intervention by examining development of protective factors to address challenges over a six-year period. Methods: YLWH in Moshi, Tanzania were recruited who had enrolled in a mental health intervention, Sauti ya Vijana (SYV) and participated in an in-depth interview (IDI) as a part of a prior needs assessment study, both of which also included demographic, mental health measures, and stigma survey measures. The (IDI) took place in 2014/2015; which was paired with a subsequent IDI in 2020. Both IDIs explored youth experiences with mental health, protective factors, and challenges. Resilience in respondents was defined as positive adaptations made in response to challenges. Results: Five youth completed the IDIs. Three participants were male; mean age of was 23.4 years (SD 0.9 years). PHQ9, SDQ, and UCLA scores decreased an average of 5.8 (SD 5.9), 9.4 (SD 5.7), and 6.0 points (SD 10.0), respectively; Berger stigma scores increased an average of 4.6 points (SD 5.4). Thematic analysis was conducted to determine emergent themes for challenges and protective factors. The primary challenge youth described was stigma; the primary protective factor for resilience and mental health was social support. Conclusions: YLWH face many challenges; however, protective factors improved youth resilience to face these challenges. Youth need consistent support and resources as they transition into adulthood.

Dedication

I would like to dedicate this thesis work first and foremost to the youth who participated in this study. I thank each of you for entrusting me with your thoughts and experiences and for allowing me to engage with the challenges and triumphs you all have experienced throughout your lives. I treasured the opportunity to learn from each of you, and I hope that this work serves to amplify your voices in a way that honors your journeys living with HIV.

I would also like to dedicate this work to my father and mother, who have each challenged me to learn from and serve the world around me with every ounce of knowledge I've been given. Dad, you always told me that I'd get my master's, and though I rolled my eyes, you were right all along. Mom, you have always been my first example of being a strong and independent woman, who never, ever gives up, which I looked to every day in this process. Thank you both for instilling your belief and wisdom in me.

Finally, I dedicate this to my husband and partner, who has walked every step of my master's education with me with tremendous grace and support through long days and late nights. Sin ti a mi lado, este hubiera sido un camino mucho más oscuro. Gracias por tocar mi mano en cada paso, por leer cada página que escribí, y por escuchar cada pensamiento que tenía. Te amo, mi amor.

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1. Introduction

While strides have been made in HIV prevention and treatment, youth living with HIV (YLWH) remain a vulnerable group to horizontal HIV infection and disease progression from perinatal infection. YLWH (15 - 24 years of age) account for 58% of all new HIV infections globally (Asaolu et al., 2016), and an estimated 80% of both perinatally and horizontally infected YLWH live in Sub-Saharan Africa (SSA) (Khalifa et al., 2019; *Youth and HIV — Mainstreaming a Three-Lens Approach to Youth Participation*, n.d.). In addition, young people (10-24 years old) account for 60% of the population living in SSA, and this population continues to grow (*The Youth Bulge and HIV*, n.d.). This “youth bulge” makes preventing horizontal HIV transmission and providing treatment for YLWH increasingly more important to address within the population. While access to testing, monitoring, and antiretroviral therapeutic medicine has significantly improved quality of life and increased life expectancy for perinatally infected youth both globally and in SSA (Slogrove & Sohn, 2018), incidence and mortality rates in YLWH remain elevated above all other age groups (*HIV Statistics - Global and Regional Trends*, n.d.; *Young People, HIV and AIDS*, 2015; Marsh et al., 2019). Adults have seen significant reductions in HIV-infection rates and mortality rates, and child mortality rates (ages 5 to 10) have fallen by more than 50% (Marsh et al., 2019) . However, HIV and AIDS is still one of the top ten causes of death of YLWH in SSA, and HIV-related deaths in youth tripled from 2000 to 2015 (*Active Involvement of Young People Is Key to Ending the AIDS Epidemic by 2030*, n.d.). While mortality rates have recently begun to decline in youth, vulnerability to infection and poor treatment

adherence act as significant challenges to youth as they navigate through adolescence (Khalifa et al., 2019).

Adolescence is a critical risk period for YLWH. Risk of HIV transmission becomes an important concern as youth begin sexual debut and gain more personal autonomy to make decisions about testing, disclosure, and treatment., However, more than 50% of youth do not have a foundational understanding of how HIV is transmitted or even treated (Khalifa et al., 2019; Salvador, n.d.). Additionally, studies have shown that less than 60% of youth know their status within a year of infection (Hall et al., 2012; Khalifa et al., 2019), which delays initiation of antiretroviral treatment (ART) (Agwu & Fairlie, 2013). Another major concern during adolescence is loss to follow-up (LTFU) after diagnosis and/or initiation of ART. YLWH who have initiated ART demonstrate poorer adherence than adults and children, higher levels of virological failure, and increased rates of LTFU (Ammon et al., 2018; Bygrave et al., 2012; Kranzer et al., 2017; Lamb et al., 2014; Nachega et al., 2009a; Slogrove et al., 2017; E. Yang et al., 2018). One study in South Africa found that even though rates of virological suppression was comparable between adults (30 years and older) and adolescents after onset of ART, adolescents in the study were 50% less likely to maintain perfect adherence and more than 70% more likely to experience a viral rebound (Adejumo et al., 2015; Nachega et al., 2009b) . Another study found that approximately 30% of youth and adolescents were lost to follow up, with higher rates associated with older age (>15 years) at initiation of clinical care (Kariminia et al., 2018).With late entry into care, poor ART adherence, and loss to follow up, youth also incur a higher risk of contracting an opportunistic infections, developing viral resistance to ART, and infecting others through sexual transmission (Hudelson & Cluver,

2015; Kim et al., 2017; Slogrove & Sohn, 2018). Adolescence is a stage of life where youth need increased support and care to promote initiation and retention into HIV treatment, but YLWH also face other socioemotional factors that impact ART adherence as well, such as social support and mental health.

Social support and HIV disclosure are two contextual factors that are commonly associated with ART adherence and overall health outcomes in YLWH. Studies have shown that social support, particularly from a caregiver, is associated with improved ART adherence and decreased medication fatigue or refusal in children and adolescents (MacCarthy et al., 2018; Ross et al., 2019). Caregivers play a vital role in managing and guiding youth behavior, and for YLWH, caregivers are often responsible for helping their youth understand their HIV status and manage ART adherence. However, caregivers often choose to not disclose the nature of infection to their child until the youth has already discovered it on their own or learned from another source, like a doctor or relative (Bulali et al., 2018; Ramos et al., 2018b). Two different studies reported that approximately 80% of respondents discovered their status on their own, with an average age of self-discovery of 12 years old (Bulali et al., 2018; Ramos et al., 2018b). Without early disclosure and support from a caregiver, youth must often grapple with the life-long implications their HIV status while being expected to take more autonomy with ART adherence, which can jeopardize proper medication adherence (Chenneville et al., 2017; Dinaj-Koci et al., 2019, p.; Dunn Navarra et al., 2020, p.; MacCarthy et al., 2018). Caregiver disclosure to an HIV-infected child can be affected by other factors as well, such as orphanhood. UNICEF estimates that 10.9 million children have been orphaned (meaning death of either one or both parents) due to HIV/AIDS in SSA alone (*Children,*

HIV and AIDS | Avert, n.d.; *For Every Child, End AIDS*, n.d.), and many of these children live with HIV. Therefore, YLWH who are orphaned are at risk for experiencing revolving caregivers and homes, which can diminish the consistency of the support and guidance they receive as they mature and are given more autonomy with medication adherence and health behaviors. Additionally, orphanhood or having a parent living with HIV increases the risk of poverty, inability to afford education, and homelessness (Lucie Cluver et al., 2013; Woollett et al., 2017), all of which can interrupt youth ability to form trusted peer social support in school and the community. As a result, YLWH are not only faced with a high likelihood of insufficient social support and compounded adverse events that may contribute toward poor ARV adherence (Adejumo et al., 2015; Harrison & Li, 2018).

Mental health is another key factor that impacts health behaviors and health outcomes for YWLH, including ART adherence (T.S. Betancourt et al., 2013). YLWH are at high risk for mental health difficulties due to a variety of factors, including their age group and their HIV status. Adolescence is a pivotal developmental period for biological, psychological, and social changes, during which mental health disorders, such as depression and suicidality, tend to emerge (Catalan et al., 2011; Kessler et al., 2007; Patel et al., 2007). Suicide and depression have become leading causes of mortality and morbidity, respectively, and at least 1 in 5 youth are suffer from a mental health disorder each year (*Adolescent Mental Health*, n.d.; Kessler et al., 2007; Patel et al., 2007). While studies have shown mixed reports of increased mental health disorders in YLWH compared to un-infected peers, there are multiple studies in SSA that have reported elevated mental health difficulties in YLWH in SSA (Theresa S. Betancourt et al., 2013;

Dow et al., 2016a; Kamau et al., 2012; Musisi & Kinyanda, 2009; Okawa et al., 2018; Smith Fawzi et al., 2016). Additionally, a systematic review estimated that one-quarter (25%) of YLWH in Sub-Saharan Africa showed signs of a psychiatric disorder, and between 30% and 50% displayed signs of significant emotional, behavioral or psychological difficulties, with incidence of mental health difficulties increasing with age (*The Prevalence of Mental Health Problems in Sub-Saharan Adolescents Living with HIV: A Systematic Review* | *Global Mental Health* | *Cambridge Core*, n.d.). Meanwhile, global prevalence of mental health disorders in all youth, regardless of HIV status, is estimated closer to 10-20% (*Adolescent Mental Health*, n.d.). YLWH have increased risk of exposure to a number of common determinants of mental health, such as low socioeconomic status, poor quality of home environment, increased stigma, reduced access to social support, and increased experience with violence (*Adolescent Mental Health*, n.d.). In addition, YLWH are at unique risk for mental health difficulties due to lack of social support due caregiver mortality and stigma related to their HIV status.

HIV is a highly stigmatized disease, and many societies have a poor understanding of how HIV is transmitted (*Region Profiles – AIDS 2020*, n.d.; Rueda et al., 2016). A qualitative study in Tanzania reported that 71% of interviewed adolescents considered ongoing or anticipated stigma to be a significant stressor (Ramaiya et al., 2016). Similarly, a Kenyan study found that HIV-related stigma was a leading factor to loss to follow-up (LTFU) of YLWH (Ramos et al., 2018a; Wolf et al., 2014). Stigmatization only increases the likelihood and severity of psychosocial difficulties which can prevent youth from engaging with the healthcare system or taking medication outside of the home for fear it will expose them as HIV positive to peers or the

community (Ph.D et al., 2007; Rueda et al., 2016; Shubber et al., 2016). This intersection of psychosocial factors has been seen in cross-sectional studies of YLWH in SSA, where stigma, lack of caregiver and social support, depression, lack of understanding regarding taking ARVs, and poverty were all determined as distinct barriers to ART adherence (Ammon et al., 2018; Gentz et al., 2018; Kemigisha et al., 2019; West et al., 2019; E. Yang et al., 2018).

Many researchers have worked to address these psychosocial barriers by developing mental health interventions that focus on improving the overall resiliency of youth to respond to the variety of risk factors and barriers YLWH face (Barry et al., 2013; Bhana et al., 2010, 2020a; Dow et al., 2018b; Vreeman et al., 2019). Resilience is defined as the dynamic process of overcoming adversity or risk exposure through positive adaptation, successful coping mechanisms in the face of significant stress or trauma, and avoiding negative trajectories associated with those risks (Fergus & Zimmerman, 2005). Furthermore, resiliency is affected by factors that interact at the individual, interpersonal, and societal levels, and therefore resources and risks are found at each of these levels of the individual's socioecological construct as well (Dulin et al., 2018). As this relates to YLWH, resilience can be defined as an individual's ability to make positive adaptations in the face of HIV-related challenges and risks in their environment through their access to internal and external resources that promote and facilitate positive psychological, social, and physical health outcomes (Dulin et al., 2018; Smith Fawzi et al., 2016). One US pilot program that incorporated a resiliency approach has reported improvements in ART adherence, caregiver support, and mental health in

YLWH through the implementation of a family-based resiliency curriculum, which has since been adapted in South Africa, Argentina, Thailand, and Trinidad (Bhana et al., 2010, 2014; Nestadt et al., 2019; Small et al., 2014). Resiliency frameworks have also been implemented in peer-groups for orphans, showing similar improvements in mental health, as well as future educational and economic attainment (Ssewamala et al., 2016). Many studies that have focused on a resiliency approach have found improvements in youth social support, self-regulation and self-concept, confidence and outlook on life, relationship and communication with caregivers, mental health, and HIV-related health behaviors, such as condom use and ART adherence (Bhana et al., 2016a; Dow et al., 2018b; Funck-Brentano et al., 2016; J. P. Yang et al., 2018). However, systematic review of resiliency studies in HIV-infected youth shows that there remains a significant need for more intervention research regarding YLWH and resiliency, specifically in low resource areas, such as SSA, where the burden of HIV infection is high (Bhana et al., 2020b; Harrison & Li, 2018; Kimera et al., 2019).

Similar to other studies among YLWH across SSA (Kamau et al., 2012; Menon et al., 2007; Musisi & Kinyanda, 2009), a study from Moshi, Tanzania reported that approximately 32% of YLWH reported symptoms of mental health difficulties (Dow et al., 2016a). Findings from the qualitative data led to the development of a pilot mental health and life skills intervention called *Sauti ya Vijana (SYV meaning The Voice of Youth)* (Dow et al., 2016a, 2018b; Ramaiya et al., 2016). Promoting resilience is one of the key aims of the SYV intervention, which focused on factors such as developing social support, promoting youth-caregiver relationships, addressing stigma, and enhancing

self-regulation to support resilience in YLWH (Dow et al., 2018b). Preliminary results 6-months post-intervention showed promising results suggesting SYV increased ART adherence and improved mental health outcomes (Dow et al., 2020). One of the key needs in intervention research with YLWH is to provide more longitudinal data regarding factors influencing ART adherence and health outcomes (Hudelson & Cluver, 2015). The SYV program provides a unique opportunity to follow participants who enrolled in the intervention and provided at least one prior qualitative interview during the original needs assessment.

Intervention studies that provide longitudinal data over time offer valuable insight on the growth and transformation of study participants. The objective of this research project was to combine qualitative and quantitative data from participants who participated in the formative study and later enrolled in the SYV intervention. This six-year longitudinal lens provides a unique opportunity to identify and explore the perceived change of participant's mental health and overall resilience throughout participant enrollment in a mental health intervention. Additionally, the impact of the COVID-19 on youth resiliency and wellbeing, due to the ongoing pandemic around the world was evaluated.

2. Methods

This longitudinal study uses a mixed methods approach to identify and explore the changes and development of factors that impacted SYV participants' mental health, resilience, quality of life and health behaviors over time. In the context of this study, resilience has been defined as an individual's ability to make positive adaptations in the face of barriers or challenges within the individual's context that promote positive health outcomes. Eligible participants were enrolled in the SYV intervention, which is a pilot, stepped-wedge, individually randomized group treatment trial with youth living with HIV (YLWH) (Dow et al., 2018a, 2020). In additional to enrollment, eligible participants also must have completed a prior semi-structured in-depth interview (IDI) in a 2014/2015 needs assessment study (Ramaiya et al., 2016). Eligible youth were invited to participate in a follow-up or prospective IDI, which was structured to address changes in participant's perspectives from key themes explored in the prior or retrospective IDI from the needs assessment study, as well as additional life experiences, SYV participation, and the impact of the COVID-19 pandemic. The retrospective and prospective interviews were thematic analyzed to describe changes in participant resilience over the six-year time period between interviews. Mental health, stigma, and social support measures that had been collected throughout the SYV intervention and the 2014/2015 needs assessment study were used for descriptive analysis in conjunction with the retrospective and prospective interviews to provide a longitudinal view of participants' mental and emotional difficulties and perceived social support over the years between the two interviews analyzed in this study.

2.1 Statement of Reflexivity and Positionality

The primary researcher and author of this study believes it is vital to acknowledge the influences of power and privilege in research practice and publication. This study was developed and funded within an elite university of a high-income country, and the research aims and practices were developed through training at this institution. Furthermore, the primary researcher has no prior experience or background in the local setting, which inherently limits authority and legitimacy of the analysis and discussion by the author. Findings discussed within this paper should be considered under the authority and expertise of local professionals, researchers, and communities including participants.

2.2 Setting

This study with YLWH took place from November 2020 to January 2021 in Moshi, Tanzania. The municipality of Moshi is the capital of the Kilimanjaro region in Northern Tanzania. The Kilimanjaro region has a population of approximately 1.6 million and a total HIV prevalence rate of 3.8% (Ministry of Finance, Ministry of State, 2014; Tanzania Commission for AIDS (TACAIDS), 2018). Approximately 1.7 million people within Tanzania live with HIV (Tanzania Commission for AIDS (TACAIDS), 2018). Youth also make up a significant portion of the national population; more than 60% of the population is younger than 25 years and 19% are between 15 and 24 years (Ministry of Finance, Ministry of State, 2014). Prevalence of HIV among youth (15-24 years) is 1.4%, but prevalence in female is more than double than males (Tanzania Commission for AIDS (TACAIDS), 2018). Perinatal infection rates in Tanzania are approximately 11%,

even though more than 90% of pregnant women are on ARV treatment (UNAIDS, 2017). Incidence of horizontal transmission among Tanzanian youth is 0.07% (28,000 new infections per year) (UNFPA Tanzania, 2019), and approximately 12% of youth reported having their sexual debut before 15 years of age (UNFPA Tanzania, 2019). Of those who are HIV infected, only 41.5% of youth are virally suppressed, but viral suppression is 83.5% for youth on ARV treatment (Tanzania Commission for AIDS (TACAIDS), 2018).

Youth who participated in this study receive adolescent HIV care at Kilimanjaro Christian Medical Center (KCMC). KCMC is located within Moshi, Tanzania, and it is a referral and teaching hospital for the northern zone of Tanzania, which encompasses the Kilimanjaro region. KCMC also has an established adolescent HIV clinic that serves adolescents and youth 12 -24 years old. The clinic provides ARV treatment services and routine medical care, as well as a monthly 'Teen Club' that conducts educational and social activities. Approximately 250 youth attend the Teen Club (Masese et al., 2019), including the participants within the current study. KCMC was also one of two study sites used for the SYV pilot intervention; the other study site was located at Majengo Regional Hospital (Dow et al., 2018a). In the current study, youth were interviewed in a private space at KCMC by a researcher trained in qualitative methods and interview skills. The interviewer was not involved in the SYV pilot intervention to promote transparency in participant responses about their personal experiences. Interviews from the prior needs assessment study took place at KCMC, but with different interviewers.

2.3 Sauti Ya Vijana (SYV)

The SYV intervention consisted of 12 sessions (10 group/ 2 individual) that each lasted about 90 minutes and used evidence-based components of Cognitive Behavioral Therapy (CBT), interpersonal psychotherapy (IPT) and motivational interviewing (MI) (See Figure 1). The intervention was delivered by group leaders (age 23-30 years old) half living with HIV and half with experience in mental health research. The intervention was primarily delivered in a group setting. Participants were recruited in waves (W1-W3), with control groups receiving treatment as usual (TAU). Once the 6-month study visit of Wave 3 was completed, those randomized to TAU were invited to cross over and receive the intervention in subsequent waves (W4-6). The final crossover wave (W6) was completed in March 2020.

Intervention content (Fig. 1): In the first three sessions, participants named their worries, discussed coping strategies, practiced relaxation and breathing exercises, and learned components of CBT (thoughts, feelings, and behaviors and how these components interact). Sessions four through six were dedicated to reflection and processing the experience of learning about their HIV status through narrative derived from CBT and IPT, which included discussion of these difficult memories individually with a group leader, with peers in a group session, and with caregivers to encourage caregiver-youth communication and support. Session seven was all about circles of support based on IPT encouraging youth to name their support networks. Components of IPT and CBT continued in sessions eight and nine as participants considered stigma in their lives and disclosure of their HIV status. These sessions also discussed sexual

reproductive health, condom use, and gender-based violence. Sessions nine and ten addressed making independent choices. Youth were encouraged to consider their values and future goals, acknowledging that with ART adherence they can live long and healthy lives. In a final individual meeting, participants revisited their personal goals set for the next six months and reviewed their support networks as SYV came to an end. A final gathering was used to review of all session content, to celebrate all that was shared and learned, and to distribute certificates of completion. The overall aims of the program were to help participants 1) improve overall participant wellbeing, 2) enhance participant coping skills in response to stressors, 3) promote strong familial relationships, and 4) increase participant anti-retroviral therapy (ART) adherence.

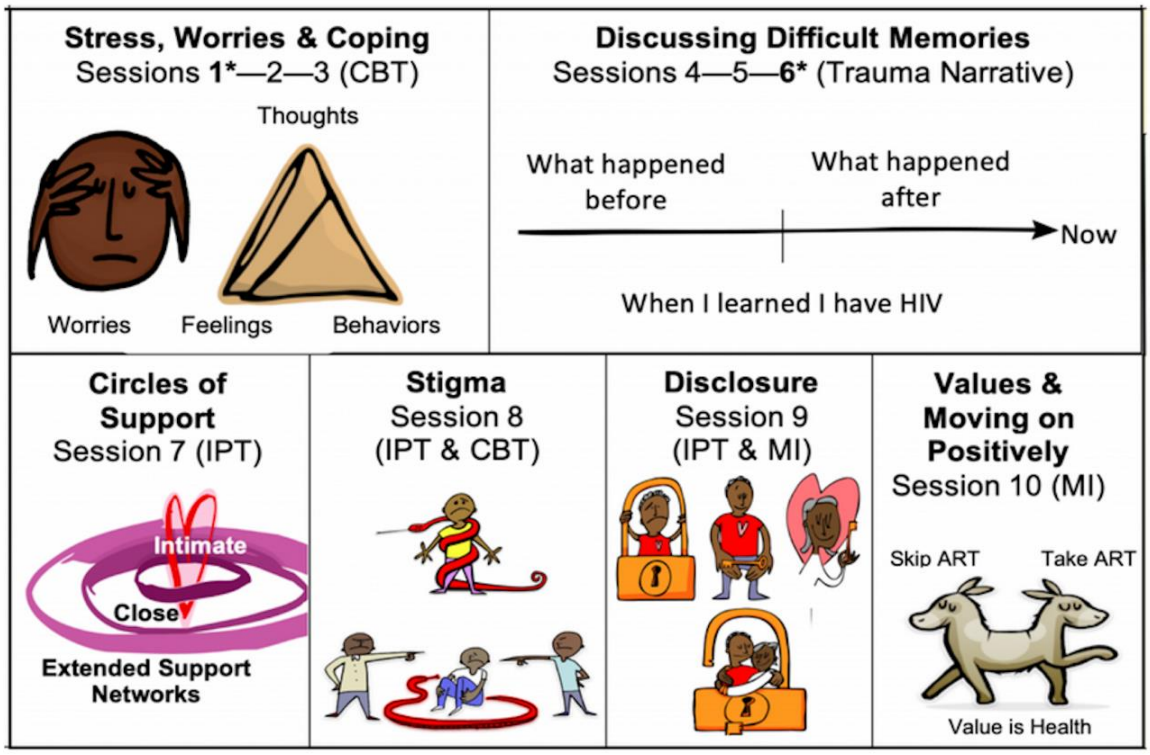

Figure 1: Sauti ya Vijana (SYV) Intervention Content.
Artwork illustrator: Imraan Osman

2.4 Participants

No new participants outside of the pilot trial were recruited to be a part of the study. Enrollment criteria included: 1) enrollment and completion of an IDI during a prior needs assessment study conducted in 2014/2015, (Ramaiya et al., 2016) and 2) the participant must have enrolled in the ongoing pilot SYV intervention study. Criteria for inclusion in these prior studies included being aware of their HIV diagnosis, between 12-24 years of age, and attending the adolescent HIV clinic at Kilimanjaro Christian Medical Center (KCMC). Identified participants made up two categories for comparison: 1) those

who had completed the Sauti ya Vijana (SYV) intervention successfully or 2) individuals who did not complete the SYV intervention successfully or were randomized to the control group and did not crossover to the intervention group during the pilot trial. Original interview responses from the 2014/2015 study were paired with their recent interview from 2020/2021 for applied thematic analysis within individuals and then generalized for all individuals between the 2014/2015 (retrospective) interviews and the 2020/2021 (prospective) interviews.

Eligible participants were identified using their medical record number. The medical record number of participants who provided IDIs from the 2014/2015 study (Ramaiya et al., 2016) were matched to those enrolled in the SYV intervention pilot trial. Matches were confirmed by verifying the participant's name and date of birth. Research staff called all eligible participants using stored contact information from previous involvement in the study or the clinical file at KCMC. All eligible participants were informed of the purpose of the interview and asked to provide written consent to compare responses from an IDI collected in the 2014/2015 study (Ramaiya et al., 2016) with this prospective IDI. All participants were at least 18 years of age at the time of this study. Any youth with significant cognitive impairment or development disability that might inhibit informed consent or understanding of interview questions were excluded.

.

2.5 Data Collection Procedures

2.5.1 In-Depth Interview

The semi-structured IDI guide was developed to create a longitudinal narrative about participants' mental and emotional health, personal and HIV-related challenges, HIV treatment adherence, and coping mechanisms. The retrospective IDI guide was reviewed, and the prospective IDI guide was written to solicit changes in participant perspective on these key themes while exploring additional life experiences since their first interview, the impact of SYV for those that received the intervention, and the impact of the COVID-19 global pandemic. All questions and probes were developed and finalized in English, and wording and intention behind all interview questions were discussed and adjusted with the assistance of a local research assistant. The finalized IDI was translated into Kiswahili by a local research assistant, and then back-translated into English by a different local research assistant to ensure meaning was maintained across translation. All semi-structured IDIs were conducted in Kiswahili, and the audio was digitally recorded on two devices. Two research assistants (not the interviewer) split the interviews and translated the interviews into English.

2.6 Study Visit Measures

Mental health, stigma, and social support measures from previously collected survey data were used in the current study. Survey data was compiled from consenting participants from both the prior 2014/2015 study and throughout enrollment in the SYV program. Other demographic data collected within the SYV intervention and prior needs assessment surveys were also included in analysis and summarized in the results, such

as age, gender and SYV program completion. Harmonized mental health measures across both studies included the Patient Health Questionnaire (PHQ-9), the Strengths and Difficulties Questionnaire (SDQ), the UCLA PTSD exposure and reaction index.

2.6.1 Mental Health Measures

The PHQ-9 is a validated 9 question construct for quantifying severity of depression in individuals. This tool has been previously validated in sub-Saharan Africa with PLWH (Gelaye et al., 2013), such as young adults and adults in Kenya (Mwangi et al., 2020), as well as youth and adolescents (Richardson et al., 2010). Each of the 9 questions are scored on a scale from 0 (not at all) to 3 (nearly everyday), and then scored cumulatively. Level of depression severity is categorized by incremental ranges of the cumulative score: 0-4 (minimal), 5-9 (mild), 10-14 (moderate), 15-19 (moderately severe), and 20-27 (severe) (Kroenke et al., 2001) .

The SDQ is a short behavioral questionnaire for young people containing 25 items that measure emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems and prosocial behavior. The SDQ has been used frequently to assess mental health difficulties in youth throughout sub-Saharan Africa, including YLWH (Casale et al., 2015; Doku, 2010; Hoosen et al., 2018; Menon et al., 2007). Previous validation study has demonstrated satisfactory reliability (Cronbach α: .73) and a test-retest reliability of 0.72 (Goodman, 2001). The cumulative score ranges from 0 to 40, and a score 17 or more is considered to be a sign of potential mental health difficulties in the respondent (Dow et al., 2016b).

The UCLA Posttraumatic Stress Disorder Reaction Index is a survey instrument for trauma assessment in children and adolescents. The survey has been validated around the world (Cronbach α: .90 - .94), including adolescents refugees in Somalia and youth exposed to traumatic events in Kenya (Doric et al., 2019; Ellis et al., 2006; Harder et al., 2012; Mbwayo et al., 2020). The UCLA survey was modified before its use in a former study from a 5-point to a 4-point Likert scale (score range 0-51), due to translation issues into Kiswahili that made distinguishing categories difficult. After adjusting the scoring, a score of 18 or greater was considered to be a sign of potential post-traumatic stress symptoms (Dow et al., 2016a).

2.6.2 Stigma Measure

The Berger HIV stigma scale is a 40-item questionnaire developed to measure perceived stigma with people who are living with HIV (Berger et al., 2001). The Berger scale was modified in the previous study to a 10-item questionnaire using a 1-4 Likert scale for each question, resulting in a total score range of 10 -40 (Dow et al., 2020).

2.6.3 Social Support Measure

The presence of social support was a quantitative measure using a two-part questionnaire. The first measure was a yes/no response to the prompt “If you are feeling sad or bad is there someone in your life you would go to for help?” A positive response indicates the presence of social support. If the respondent selected ‘yes,’ a follow-up question asked the respondent to select from a list of ten types of people (i.e. Mother, Father, Friend) to identify who they would go to for help.

2.7 Qualitative Data Analysis

2.7.1 Qualitative Analysis Methodology

All qualitative analyses were completed in English with the English translations of interviews from each participant using an applied thematic analysis approach, as previously described by Guest et. al (Greg Guest, Kathleen M. MacQueen, Emily E. Namey, 2011). This approach was chosen as the best method to support the exploratory nature of the study because of the non-probabilistic sampling, or method of purposive sample selection based on predetermined criteria. While applied thematic analysis is mostly inductive in nature, which allows for codes to be driven by the text and data, it also seeks to address practical application or contribution to pre-existing knowledge or practice. Structural coding was developed using the thematic topics within the IDI guide and the study aims for describing protective factors and challenges in participants. Participant responses were primarily used for developing thematic codes and emergent themes within the structural codes. Emergent themes were compared longitudinally between the retrospective interviews (Ramaiya et al., 2016) and the prospective interviews conducted in the current study.

2.7.2 Qualitative Analysis Procedure

The analytic procedure was conducted primarily by the first author with regular referral to and discussion with the senior author and a second coder throughout the process. Each interview was read thoroughly several times, with both the retrospective interview and prospective interview from each participant read sequentially to attempt to maintain continuity of experience from participant to participant. The primary author

created document memos describing interview characteristics and themes across the retrospective and prospective interviews, as well as summary memos describing participant characteristics and themes across interview timepoints.

After three prospective interviews had been conducted in Swahili and translated into English, a structural codebook for the prospective and retrospective interviews was formed using the research aims described previously, the prospective IDI guide, and collected memos as a guide for development. The retrospective interviews conducted in the prior 2014/2015 study with the same participants aimed to explore psychosocial problems among YLWH who reported mental health difficulties (Ramaiya et al., 2016). Therefore, both the retrospective and prospective IDIs overlapped in questions regarding social support, relationships, emotional and mental health, health behaviors, experiences living with HIV, and common stressors. Structural coding was then applied to the prospective interviews and to the sections of retrospective interviews where questions and probes overlapped.

After a structural codebook had been developed, two sets of respondent interviews were coded by both the first author and a second coder to assess for inter-rater agreement. The structural codebook was refined and amended until there was at least 80% agreement between coders, where agreement is an overlap of structural codes between coders. Using the finalized codebook, emergent codes were identified and coded by the primary author. Once retrospective and prospective interviews of two participants had been analyzed for emergent codes, the primary author and second coder reviewed the emergent codes of the first two participants and made modifications

to the codebook until both coders agreed on the emergent codes to be used. Then the remaining 6 interviews (3 prospective and 3 retrospective) were coded. After completing coding of all interviews, emergent themes were summarized first within the individual across time, and then across all individuals as memos, which were used to provide a written summary of the findings. The first author summarized findings, which were discussed with a second coder, and then data was revisited or further analyzed if needed. Preliminary findings were also presented to the YCAB in Tanzania for discussion and feedback before the final write up of results.

2.8 Quantitative Analysis

The PHQ-9, SDQ, and UCLA scores from participants were used for descriptive analysis in conjunction with the interviews given to provide a longitudinal view of participants' mental and emotional difficulties and perceived social support over the years between the two interviews analyzed in this study. Descriptive statistics (mean, standard deviation) were calculated for PHQ9, SDQ, and UCLA scores, as well as demographic measures, such as age and gender. All mental health and social support measures were graphed longitudinally by timepoint using R software. Demographic measures and mental health scores were also compared using Fisher's Exact test and Kruskal-Wallace test, respectively, to assess for any differences between respondents and non-respondents in this study.

3. Results

3.1 Respondent Demographics and Quantitative Findings

Fifteen participants met inclusion criteria of whom five youth were available and participated in a prospective interview. There were no differences in demographics and mental health scores between participants who were eligible and participated in the study versus those who did not. However, youth who did not participate in the current study were more likely to have missed study visits during the intervention pilot trial or loss to follow up during the SYV intervention.

The mean age of respondents was 23.4 years (SD 0.9); three (60%) were male (Tbl 1). From the needs assessment study (2014/2015) to the final study visit as part of the SYV intervention pilot trial (2018/2019) all mental health measures decreased (which signifies improvement) but perceived stigma measure increased (which signifies worse stigma). Specifically, the PHQ9, SDQ, and UCLA scores decreased an average of 5.8 (SD 5.9), 9.4 (SD 5.7), and 6.0 points (SD 10.0), from first to last timepoint, respectively. In the first PHQ9 assessment, three of the respondents had a score over 10 points, with moderate to severe depressive symptoms. By the last survey timepoint in 2018/2019, all respondents had PHQ9 scores less than 8 (Fig. 1). Most respondents almost always or always reported they had someone to talk to if they were feeling sad (social support) and had the lowest PHQ9 scores at the end of the study (Fig. 1). Participant (PID) 5 rarely reported social support and had mild depressive symptoms across all timepoint; PID 4 reported social support half of the time and had PHQ9 scores > 10 at those timepoints (Fig. 1). SDQ and UCLA scores showed similar trends to PHQ9 scores; three

respondents scored above the threshold for possible mental health difficulties during the prior needs assessment study (SDQ ≥17, UCLA ≥18), and none scored above either threshold at the last survey timepoint. Berger HIV Stigma scores increased on average of 4.6 points (SD 5.4) from first to last timepoint (Fig. 3).

Table 1: Respondent Demographics. *All demographic information relates to respondent status at time of prospective interview (2020/2021) unless otherwise stated***.**

Respondent ID	*Sex*	*Age*	*Completed SYV*	*Employment Status*	*Orphan Status*	*2014 Household*	*2020 Household*	*PHQ > 10 2013/2014*	*PHQ > 10 2018/2019*
PID 1	Female	23	No	Self-Employed	Single (Dad)	aunt and uncle	female roommate	Yes	No
PID 2	Male	23	No	Student	Single (Mom)	father and stepmother	father and stepmother	No	No
PID 3	Male	23	Yes	Self-Employed	Double	aunt and uncle	male roommate	Yes	No
PID 4	Female	23	Yes	Self-Employed	Double	aunt and uncle	aunt and uncle	Yes	No
PID 5	Male	25	Yes	Self-Employed	Double	aunt and uncle	lives alone	No	No

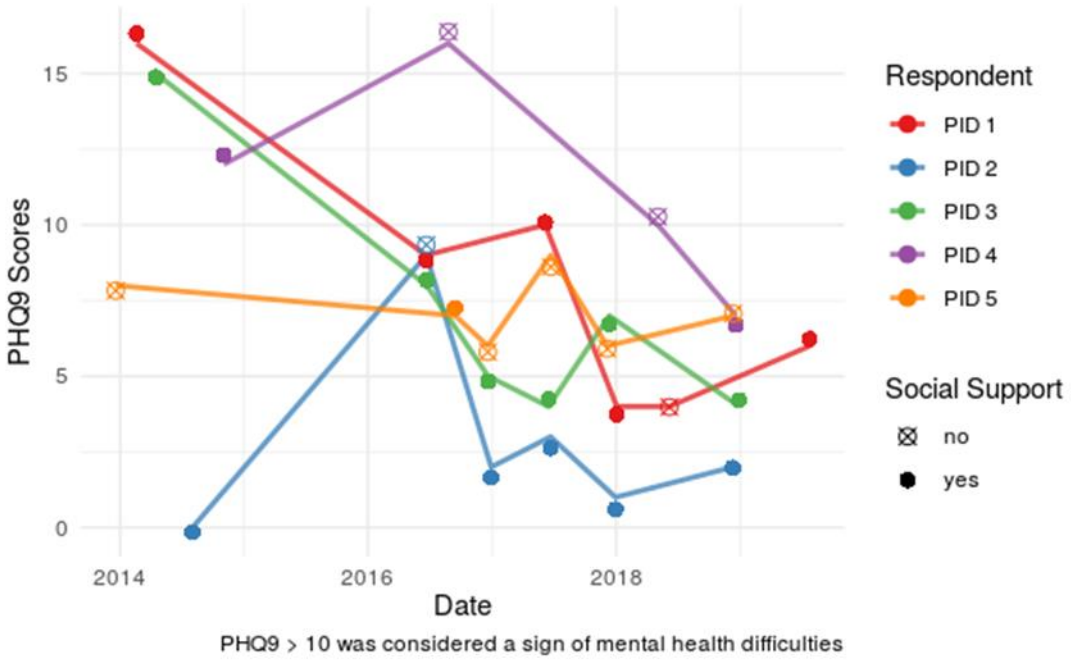

Figure 2: Longitudinal PHQ9 scores and social support responses.
Data was collected at multiple timepoints from 2013/2014 to 2018/2019. PHQ9 scores are represented by the solid line. Social support (yes/no) is represented by symbols at each survey timepoint.

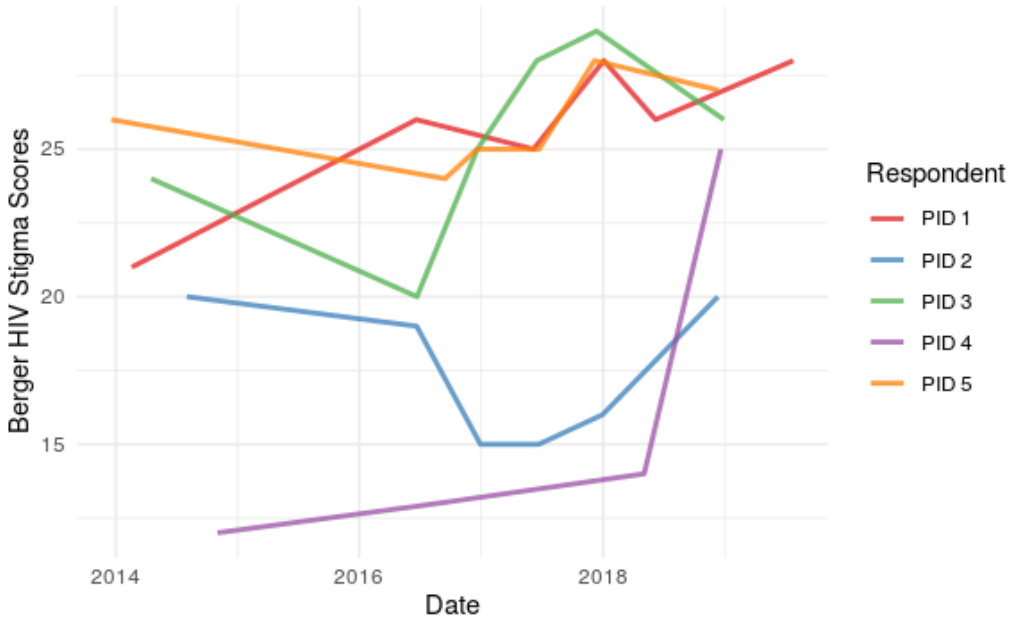

Figure 3: Longitudinal Berger HIV Stigma Scale scores.

3.2 Qualitative Findings

Respondents' retrospective and prospective interviews were analyzed for themes surrounding common challenges and protective factors related to mental health and resilience. Results also describe changes in challenges and protective factors between retrospective and prospective interviews. Common challenges are reported by respondents are discussed first, followed by common protective factors.

3.2.1 Challenges Overview

Youth discussed many challenges they faced due to living with HIV. Stigma was the primary challenge affecting mental health and resilience that emerged from both retrospective and prospective interviews with respondents. Other common challenges that impacted respondents' mental health and resilience included isolation from people

and resources, barriers to productivity, difficulties entering and maintaining romantic relationships, and family planning. Challenges within romantic relationships were more prominent in prospective interviews, but all other challenges were commonly reported by respondents in both sets of interviews. In prospective interviews, respondents also discussed how the COVID-19 pandemic further complicated their ability to navigate some of these barriers, including productivity and stigma. Stigma also impacted other challenges that were mentioned throughout interviews.

3.2.2 Stigma

HIV-related stigma was a common theme for all respondents across interviews. Stigma had significant impact on respondents' mental health, self-concept, and overall wellbeing. Respondents reported experiencing stigma within their families, among friends, and in the community and workplace.

Four of five respondents reported being treated unfairly, ignored, and/or being gossiped about by family to others due to their HIV status. While some respondents in prospective interviews reported decreased familial stigma due to education about HIV, stigma was a common challenge respondents dealt with in family circles, which led some respondents to distance themselves from family once they finished school. Stigma from family impacted youth mental health difficulties, ability to create trusting relationships, and outlook on life. A female respondent discussed that stigma and gossip which had *"started at home"* in her family left her feeling as if *"there was no one I could go to"* and that "*I would better die than continue living in such suffering."* (PID 1) Another respondent discussed the impact HIV had on his self-concept earlier in life, because his

family members abandoned his development and wellbeing due to his status. *"[They thought] that I should be covered with a blanket because I was going to die any moment."* (PID 3) Respondents often pointed to stigma as a source for mental health difficulties, ranging from despair, anger, suicidal thoughts, persistent loneliness, poor self-concept, and fear. As one female respondent stated, *"Now that thing [being HIV positive] was hurting my mind and I was saying why me, why am like this, why and until today when you find me most of the time, I don't like to talk to anyone…and I also get angry…why me, this and this relative is denying me."* (PID 4)

Stigma in the community impacted respondents' abilities to form trusting friendships and affected respondents' self-esteem and confidence. Respondents were cautious about making friendships and discussed difficulties in trusting others due to experienced and anticipated stigma. A male respondent discussed in 2013/2014 how he enjoyed being around peers, *"but there is no way I can tell them my secrets…I don't like to be stigmatized."* (PID 5) In 2020, he discussed the persistence of these problems in social circles, including how gossip made him hesitant to open up to others. *"Even some of my friends, I don't like to follow up their matters. I'm like this because people like to talk about other people's businesses a lot."* (PID 5) Another respondent reflected on how gossip and stigma impacted her self-esteem in social circles, because *"I would worry that people would be pointing fingers…the fact that outsiders had heard about my secret [from others] made my confidence disappear."* (PID 1) Though she reported improvement in her relationships in her prospective interview, she still feared her friends were untrustworthy and said, *"If you tell your friends your secret they cannot keep it."* (PID 1) Fear of stigma among peers also influenced youth decision-making on

adherence to ARV medications. Two respondents admitted that stigma among their peers in the community or at school had previously led to poor ARV adherence for fear of being rejected or stigmatized. As one male respondent said, *"They would be treating you differently, because they know that you have a problem."* (PID 3)

Respondents also discussed their experiences with stigma and discrimination as they have begun to enter the workforce. Four of the five respondents reported being self-employed (one was in school) during the prospective interview, and all four identified workplace stigma and discrimination as a major challenge to accessing and maintaining employment, resulting in stress and anxiety. Multiple respondents reported being required to take health tests during job applications and then being denied employment because of their status. A male respondent discussed being repeatedly denied for jobs, saying that *"There are places where you find that when you apply for a job they have a prerequisite of testing for HIV first…You just have to test because you need the job. Normally I test and when the results come out… sometimes I am told to go back home. But then I know what caused this."* (PID 5) Since respondents were self-employed, they also feared that third party disclosure would drive away current customers or potential clientele. Not only did respondents expect stigma from coworkers and customers if their status were disclosed, and they feared the subsequent stigma could harm both their income and livelihood. As another male respondent said about workplace stigma, *"…What I discovered is that the kind of business that I do does not allow stigma, and if there is stigma, I cannot do my business again."* (11K)

3.2.3 Other Challenges

3.2.3.1 Isolation

Feeling isolated from relationships, opportunities, and resources was a common cause of mental health difficulties in respondents. Respondents reported feeling isolated due to long absences from school, HIV stigma, and orphanhood. All respondents had experienced the death of at least one parent, and only one respondent still lived with a biological parent. Some respondents associated loss of a parent as the reason they lacked resources, and when their caregivers were unable or unwilling to provide for them, they felt they lacked other options. When respondents were asked about common challenges they faced, those who had been orphaned felt that caregivers were neglectful of their needs, because according to one respondent, *"if I need something…no one can support me,"* while a living parent "*[could] support and help me for everything I need different to life, because I have to request what I need. Sometimes it is not enough."* (PID 3) Another female respondent discussed the feeling trapped between a caregiver (aunt) who withheld financial support from her and a mother who was too far away to help her. She discussed her emotional distress and helplessness to attend to her needs, *"When I tell my mother that I want to go someplace and she says she doesn't have money…I asks myself [saying] that I am sick but my mother can't help me."* (PID 1) Some orphaned youth continued to feel isolated and alone as they moved into adulthood. When one female respondent experienced challenges, she said she had *"nobody that I depend on for my problems"* (PID 4), while a male respondent said he couldn't *"rely on relatives too much."* (PID 5) Youth also experienced isolation from peers due to HIV-related health problems that often kept them out of school. One respondent

discussed that one of his biggest stressors was his poor health holding him back while he watched his peers continue their schooling. *"The big problem is this disease I can't attend my studies everyday… I feel sad when I fail my examinations while my fellows passed their examinations."* (PID 3) Some youth also felt isolated from peers in social settings due to the extra burden of having to constantly be monitoring their health or fear of unwanted HIV disclosure. A male respondent discussed how he felt his HIV status restricted his ability to *"enjoy life*" with his friends, because *"you find that your friends want you to come [out]…but you find that it will not be easy for you to swallow your medicine at the right time…"* (PID 5) Another respondent discussed her status as isolating because she feared gossip from others. *"The difficulties that I also have in living with HIV is in the big issue of relationships. There is where we get problems…I am not free to tell anybody [my status]"* (PID 4)

3.2.3.2 Productivity

Another common challenge impacting respondents' mental health was the ability to engage in productive activity, such as school or work. As previously discussed, stigma impacted respondents' ability to access employment, but poor health also limited respondents' capacity to perform certain jobs or from advancing in academic goals. Respondents experienced mental health difficulties due to boredom, feeling trapped or helpless, and stress about financial stability. While in school, multiple respondents identified missing school as a primary source of sadness and stress. A male respondent discussed how his poor health kept him from advancing in school, and now his health makes him feel vulnerable to provide for himself, because *"we who are living with*

opportunistic diseases can be attacked at any time even though you are using the medicine properly." (PID 3) Another respondent said she was similarly affected because *"I stopped going to school because I was sick… until now I am just at home,"* (PID 4) which caused her significant mental distress and boredom. In her prospective interview, the same female respondent reflected on how her absence from school created mental health difficulties as she *"stayed for years not having anything to do…that situation completely ruined me."* (PID 4) As youth aged into young adults, poor health transitioned from impacting school attainment to impacting employment and livelihood. Respondents felt both stress and grief over lost opportunities due to their status. A male respondents said that even though his health no longer inhibits his schooling, he still has struggles with *"thinking/worrying about my condition. Sometimes I think about where I would have been if it had not been for this problem [HIV]."* (PID 2) Health concerns impacted respondents' ability to engage in work, and subsequently their financial ability to pay for health needs. One respondent said that his vulnerable health made it hard to do the limited jobs available to him due to the physical nature of them, *"so there are times where I find myself thinking a lot because I find that I am not moving forward…when I think about life in general that is when I feel really down." (*PID 5) Another respondent discussed how work and health were difficult to balance, because *"without health nothing else is important since if you do not have health you cannot look for money…"* and yet *"you find that the medicine is finished while at the same time I am thinking of paying the rent and so I have to deal with many things at the same time."* (PID 3)

3.2.3.3 Romantic Relationships & Family Planning

While all respondents considered starting a family an important goal, they all reported mental and emotional stress in entering relationships and starting families due to their HIV status. Primary challenges were fear of stigma or lack of trust in partners upon disclosure and concern of transmission to a partner or child. While only two respondents had ever been in a romantic relationship in 2013/2014, by 2020, four of the five had been in at least one romantic relationship and three were in long term relationships. However, all reported ongoing fear of stigma as a challenge to entering any relationship. In the retrospective interview, one male respondent discussed his fears of being rejected by a potential partner *"due to my status"* and doubted he would be able to *"have a family at all in my life."* (PID 5) Even though he's since had positive experiences with disclosure to partners, he still struggled to trust partners due to continuous fear of stigma, because *"as a human being, she is bound to talk."* (PID 5) Another respondent also wrestled to trust a longtime partner who had tricked her into telling him her status. Although she was supportive, she questioned his trustworthiness and said, *"you value and love him, [but] how will he look at you when he goes to publicize you, though you have protected him but you still have fear."* (PID 4) Others trusted their partners, but they feared pursuing marriage for fear of stigma and rejection from their partner's family which *"will hurt you because you have already loved the woman."* (PID 3) Respondents also discussed their fears of infecting their partners or potential children. A male respondent discussed the emotional turmoil of disclosure at the onset of a relationship, because he didn't *"want to destroy [women's] lives, but sometimes feeling can get tricky in situations like [being HIV+]."* (PID 5) Even six years

later he worried, *"I don't want that one day someone will say….'He has destroyed my life.'"* (PID 5) Two other respondents feared transmission to partners. A male respondents worried that "*the medicine they use [will] fail to work"* (PID 3), and a female respondent echoed that even though she takes every precaution to *"protect him, you still fear for this person."* (PID 4) A female respondent feared transmission to a child, which made her reluctant to have children despite encouragement by others. She said she is still afraid to consider children, because she *"think(s) about how the baby is going to come…I don't want the baby to be like myself."* (PID 1)

3.2.3.4 COVID-19

The COVID-19 pandemic was the final topic discussed with respondents. While the impact of COVID-19 varies throughout the world, respondents found that COVID-19 had highest negative impact on mental health due to concerns about financial stability, fear of stigma and vulnerability to infection. None of the respondents had tested positive for COVID-19, and only one respondent knew someone personally who had contracted the disease. However, COVID-19 decreased tourism in Tanzania, which has affected respondents' businesses and income. Respondents experienced significant stress thinking about their ability to pay for the things they need and the pandemic's long-term effects on their future. As a male respondent said, "*There is a lot of challenge [with COVID-19] because…if [tourists] don't come because of this disease it will be a problem for me to get income so I will not be able to reach my future goals that I wish for, I won't be able to get ahead"* (PID 4) Respondents also feared that if they were infected with COVID-19, it would be a death sentence because of their HIV status, especially where

communities didn't take extra precautions to stop transmission. One respondent mentioned the added stress she felt in thoroughly sanitizing her shop multiple times a day, because customers wouldn't wear masks or use sanitizer when they were shopping. Another expressed fear that being HIV positive made him vulnerable, saying, *"They tell you that those who have long time diseases are in a bigger danger of contracting [COVID] and losing their lives… COVID has a tendency of eating up your body immunity and if the immunity is finished they come to the danger of dying."* (PID 3) Even though respondents feared infection, the fear of being stigmatized or exposed as HIV-positive kept some from taking more precautions against contracting COVID-19 than their community members. One respondent said that even though he was afraid of being infected with COVID-19, he avoided wearing a mask in public, because he didn't want to stand out. *"I didn't wear [wear the facemask] for fear that people were going to find me a strange man… the president has announced that there is no corona, and life goes on. Right? In those days even if you had a small fever you started to worry."* (PID 5)

3.2.4 Protective Factors Overview

Protective factors were identified as any characteristic within the respondent or external to the respondent that helped mitigate or avoid the negative impacts from the challenges they faced. All respondents identified several protective factors in both sets of interviews, social support was the most prominent protective factor impacting youth resilience that was mentioned throughout both retrospective and prospective interviews.

Other protective factors discussed by respondents were categorized in the following themes: knowledge acquisition, distraction, spirituality, and avoidance behavior.

3.2.5 Social Support

Social support was a common protective factor for youth when dealing with mental health challenges and stress due to stigma, financial security, health problems, and other daily stressors. Social support expanded from family and other YLWH in clinic in retrospective interviews to included uninfected peers and romantic partners in prospective interviews.

Social support from caregivers was important for youth even as they moved into adulthood, and it influenced their mental health and stressors. One respondent discussed how he was *"totally satisfied*" when it came to meeting his needs because of the consistent support and engagement of his father regarding his healthcare and education. (PID 2) Another male respondent discussed how ongoing support from the cousin and aunt he used to live with were important support systems because they were *"willing to help me at any time."* (PID 3) He described how a cousin mentored him in caring well for his health, and other family members provided valuable support that helped him realize his business goals. He said, *"When my relatives saw that I was trying [to start a small business] they asked me what I wanted to do in life…later I told them there was a place…they came to inspect the place and thought that what I wanted to do could work out for me and so I decided to open."* (PID 3) Caregivers and family also offered mental health support for youth as they grappled with their HIV status. A female respondent discussed how an aunt's encouragement helped her process through family

and community stigma and her mental health difficulties, *"to get me back to my good state, she made a big effort until I reached a certain point where I understood [why I was HIV+]."* (PID 4)

Youth also sought social support in friends, community members, and other social circles despite their hesitation to disclose and fear of stigma. Youth who had a positive disclosure experience with a friend, partner or other community member also tended to describe the individual(s) as a vital piece of their support system. One respondent discussed the importance of neighbors, extended family, and teachers in her life who supported her through significant mental health difficulties and a suicide attempt due to ongoing stigma at home. Because of their support, she said, *"…I started to form friendships with people…They started encouraging me, telling me that I shouldn't worry about my aunt [caregiver] because she was not a wise person."* (PID 1) As respondents moved out of caregivers' homes, some found valuable social support in roommates, who could help them with health or general friendship and advice. One respondent discussed how he decided to tell his roommate about his HIV status *"because I had built faith in him,"* over time, and that today the social support his roommate provides has only deepened and helped him *"in a big way."* (PID 3) Romantic partners also provided social support to some respondents. Some respondents reported positive reactions from partners after disclosure of their HIV, and some partners responded to the disclosure by providing additional support through family planning fears, stigma, and supporting positive health behavior. One respondent identified her fiancé as a helpful support system in managing her health after she disclosed to him, and said that *"even if there*

was a time I forgot to swallow the medicine he would call me on the phone to remind me about it." (PID 1)

Finally, the teen clinic was an important source of social support for most respondents. Respondents valued the camaraderie of other youth who were also HIV-positive and depended on other YLWH for advice, mentorship, and solidarity with the challenges they faced. Respondents reported friendships at the teen clinic as an important source of social support for overcoming stigma, improving health behaviors, and managing mental health difficulties. One respondent discussed how the presence of other youth within the teen clinic helped her feel more confident as someone living with HIV. *"On the first day I went to the clinic I didn't feel bad about it because I met my fellow patients, and in my heart, I was thinking, "so I am not alone but we are many?" From that point I started making friends even though I am not a chatty person."* (PID 1) She pointed to those same friends as the support she needed to deal with stigma in her environment. The clinic was also a place that gave respondents a distinct feeling of belonging and community. A male respondent said, *"I think that Saturdays are the best since when I come here there are people who already have their families, but they come on Saturdays not to take their medicine but to mix with other friends which gives them joy."* (PID 3) Social support was also an important factor for youth as they transitioned to the adult clinic. Those who found the transition easy cited the continuance of social support, such as one female respondent, *"Some of the members of my group had moved into that clinic and so I had many friends there. You would also meet elder women who would say, "don't worry my daughter, you'll be fine. God is there and is going to help us…"* (PID 1) In comparison, those who found the transition difficult also

cited lack of social support as the reason, like one male respondent who said, *"I want to ask them to allow me to go back to [teen clinic] because I'm suffering… I find [teen club] more profitable because we know each other, and we are accustomed to each other's company."* (PID 5)

3.2.6 Other Protective Factors

3.2.6.1 Knowledge Acquisition

Knowledge acquisition was another protective factor that respondents discussed more in prospective interviews than retrospective interviews. In the retrospective interviews only two respondents mentioned knowledge, gained understanding or education as a way of dealing with obstacles or challenges, but in the prospective interviews all five respondents referenced knowledge acquisition as an important factor in handling difficulties, especially HIV-related stigma and mental health challenges. One male respondent who reported facing no current challenges in his life, spoke at length about the power of knowledge, saying he views living with HIV as *"an ordinary thing in life because it is something I've been educated about…the challenges come to those people who have not been trained about the virus."* (PID 2) Another discussed how learning about stigma and HIV has helped him identify when "*someone is starting to show some signs of stigma….find ways to avoid it and then later on if I have an opportunity I educate them"* (PID 3) without it impacting his mental health like it used to. Knowledge about how to live with HIV also helped give respondents confidence, such as one female respondent who said the knowledge she had now built her *"confidence in front of people, it has built big trust in me…[so] I will also be free to do anything."* (PID 4)

Respondents also reported that increasing understanding and educating themselves and others about the COVID-19 virus was a helpful way to reduce fear and stress. As one male respondent reported, *"What helped me was listening to the education that was being distributed about the pandemic and helping other people to understand what was involved and the precautions to take, the dangers involved etc."* (PID 2)

For those who attended, the SYV program was often described as an invaluable source of education and learning that helped participants learn how to deal with stigma, increase their confidence among others, manage their mental health, improve ARV adherence, and understand how to protect themselves from poor health outcomes. One respondent discussed that when she used the coping skills she learned for mental health and depression "*it's something that I tried and found its true it helps…lessen thoughts."* (PID 4) Another respondent discussed the impact of the knowledge she received from the program as a being equipped with tools and skills that allowed her to take control of her life.

> *"Before joining the program, I wasn't as confident as I am today. In those days if someone said that I was going to die soon I would believe them. And in those days even when I wanted to swallow the medicine I was frightened about it, even I didn't like the container. But now I have decided to say that I am a winner. I will try hard to survive so that I can accomplish my goals. Therefore, I can say that the training helped us so much in building us up."* (PID 1)

3.2.6.2 Spirituality

Spirituality, which is defined here as a belief or reliance on a divine power for help or support, was a protective factor that emerged in prospective interviews for most respondents. In the retrospective interviews, no respondents mentioned spirituality, but

in the prospective interviews, four of the five mentioned “God” as an important resource for overcoming challenges. Prayer and belief in divine characteristics, such as sovereignty, compassion, and healing power, were two common ways respondents used their spirituality to persevere through and mitigate the impact of mental health challenges they faced. One respondent said that the most important thing in her life was God, because *“he is the one who guides me in all my ways and who sustains me.”* (PID 1) Another female respondent credited God as the one who *“bestowed me with strength”* to face challenges and *“will help me…if I fail.”* (PID 4) God’s power and sovereignty were also seen as a motive for accepting their situations in life, as one male respondent said, *“[Being HIV+] is my gift from God and so God has given me this blessing …otherwise you would offend God and we were taught in religion that if we offend God it is a sin.”* (PID 3) Another male respondent gave a similar reason, saying that he had to persevere through the challenges he faced, or he would be *“blaspheming God.”* (PID 5) Respondents also trusted in God’s power to answer prayers for the challenges that caused them stress and anxiety, such as money, jobs, providing future spouses, and healing from sickness. As one respondent said, *“I always believe my faith lead me...so if it was written…God will bring me a husband.”* (PID 1) Belief in God’s power was also used an important source of comfort when experiencing fear or anxiety, including fear related to the COVID-19 pandemic, such as one male respondent, *“I depend on [God] whenever it [fear of COVID-19] happens [and] I run to him.”* (PID 3)

3.2.6.3 Distraction

In the retrospective interviews, distraction was the primary protective factor respondents used to deal with challenges and the difficulties that burdened them. Respondents used a variety of distraction tactics to deal with stressors, such as being with friends, listening to music, watching television, sleeping, using drugs, exercising, and engaging in work/chores. However, respondents in retrospective interviews were more likely to see distraction as their primary resource. One respondent discussed that when deep thoughts and stress wouldn't let up, *"there is nothing I can do until it finishes, maybe if I am in a group of friends then they can cheer me up."* (PID 5) In the prospective interviews, distraction was replaced by social support and application knowledge as protective factors, but respondents still found distraction as an effective method when dealing with stress, challenges, or mental health difficulties. In prospective interviews, a female respondent stated, *"I mingle with people talking a few stories or if I am very angry I go to sleep…those are the things that made me lessen depression."* (PID 4) Even though respondents reported that not all peers could be trusted with "secrets," having friends and social circles were helpful resources for respondents to help distract them from the problems or challenges that consumed them. *"Being with friends making stories and playing*" helped one respondent *"forget [sad feelings] I am thinking."* (PID 2) Another respondent discussed how distraction tactics helped "*keep me busy"* so that *"you don't allow [depression] to enter your mind. When you find that such thoughts are clouding your mind you call a friend, and you ask them to accompany you to town so that you can do some shopping and then you find that the thoughts disappear."* (PID 1)

3.2.6.4 Avoidance Behavior

Avoidance behavior was another common coping strategy some respondents relied upon to mitigate negative impact of challenges, especially when trying to avoid stigma and its impact on mental health. Avoidance behavior employed by respondents included creative methods for hiding ARV medication in public, retreating from stigmatizing family, and avoiding friends and community members to minimize potential stigma. In the retrospective interviews, only one respondent discussed creative tactics for hiding ARVs as a way of dealing with stigma and exposure of his status at home. *"I usually put [the drugs] in my mouth then I go to the dinner room…so people will think I am just thirsty."* (PID 5) In the prospective interviews, three respondents reported avoidance behavior as a coping strategy for avoiding detection of their ARVs and associated stigma. One of them stated, *"Nowadays I have discovered a way of swallowing my medicine even when I'm in the presence of other people. And no one can know about it."* (PID 1) Another respondent *"put my medicine in an envelope since the container makes a certain sound,"* (PID 5) which he says has freed him to take his medications with him outside of the home. Respondents discussed learning and sharing these tactics with other teens at the clinic to help hide their status and avoid public stigma. Some respondents considered avoidance through social isolation as a way to find freedom from stigma or peace from the stigma they experienced around them. Two respondents in particular discussed that living and being alone has been a preferred method for avoiding stigma among family and the community. When discussing coping with stigma, one male respondent said, *"I just go about my business that brought me to this world and I don't follow up on other people's businesses. Maybe it is because I am*

alone without any relatives. I don't want to meddle into other people's businesses. Even some of my friends, I don't like to follow up their matters. I'm like this because people like to talk about other people's businesses a lot." (PID 5) Another respondent echoed that she used avoidance tactics to hide from family stigma *which "caused me depression"* but that *"when I am alone I am extremely happy…I just lock myself inside and do my work is my happiness."* (PID 4) However, it is important to note that the two respondents who primarily relied on avoidance to deal with stigma also reported feeling lack of support with other challenges they faced. Other respondents who did not rely on avoidance behavior as a protective factor reported stronger social support and positive experiences of disclosure.

4. Discussion

Youth in this study were followed using in-depth interviews and structured surveys over a period of six years (17/18 years of age to 23/24 years of age) during a critical developmental period of late adolescence. This stage of adolescence is characterized by major life changes, including transition from caregiver to peer support, increased exploration into romantic relationships, and entrance into the workforce to establish economic independence (Wood et al., 2018). These common characteristics of late adolescence were evident in respondents across their interviews. In retrospective interviews, all respondents were living with and primarily relied on caregivers for support, few had entered romantic relationships, and most were in school. In prospective interviews, most respondents had moved out of their caregivers' homes, had developed important friendships, were working, and had been engaged in at least one romantic relationship; three reported being in long-term relationships. Mental health difficulties and disorders tend to emerge throughout adolescence and into young adulthood (Gore et al., 2011). At the time of the retrospective interview, three respondents had a PHQ9 score (≥10) suggesting moderate or severe depressive symptoms, but by the final time point in 2018, nearly all participants had reduced PHQ9 scores and all were ≤10. Youth discussed two major themes in their in-depth interviews that impacted their mental health and resilience over this developmental period, which were stigma and social support.

4.1 Stigma Impact on Mental Health

Respondents reported stigma to be an ongoing and evolving challenge throughout their retrospective and prospective interviews. Stigma had distinct impacts on youth mental health and wellbeing, and stigma was reported by youth as an impetus for suicidal ideation and attempts, long-term emotional struggles with anger, and ongoing anxiety/fear of disclosure or exposure, which encouraged avoidance behavior. Youth who reported these mental and emotional difficulties due to stigma in retrospective interviews mostly had high PHQ9 scores (≥10) suggestive of moderate to severe depressive symptoms. Despite PHQ9 scores dropping < 10 in later follow-up, respondents' HIV stigma scores remained constant or increased to the low to mid 20s. The exception was a female participant who had a PHQ9 score of 16 between 2014 to 2016, while her HIV Berger stigma scale scores were low (12-13). However, over time her Berger stigma score rose to 25 even though her PHQ9 score dropped to 7. Her interviews provided important contextualization to the trajectory of her stigma and PHQ9 scores. In her retrospective interview, she reported that she recently left her orphanage and school to live with extended family members whom she hardly knew, which caused her significant emotional distress. In her prospective interview, she reported experiencing consistent rejection and stigma from caregivers and family in the years following her arrival until she moved out on her own to escape the stigma between interviews. Her increase in stigma scores paralleled her experience, as she explained the stigma from her family had "ruined" her in the prospective interview.

4.1.2 Stigma and Family

Stigma from caregivers and family members had a powerful impact on respondents' mental health and their access and willingness to seek social support. When respondents were younger and lived at home, family and caregivers were their primary source of social support. However, all but one respondent reported experiencing stigma directly from family, such as isolating the respondent and using derogatory language, and indirectly through disclosing the respondent's status to community members, who then stigmatized the respondent. As one respondent described (PID 1), her caregiver's disclosure of her status to others led to pervasive stigma and isolation from peers in the community, which then made her feel so isolated that she attempted suicide. Other respondents reported feeling anxious/depressed and lonely due to verbal beratement or neglect by caregivers. As respondents aged and moved out from caregiver homes, youth who had not been able to establish positive relationships with at least some family members by the time of the prospective interviews reported ongoing family/caregiver stigma causing them to feel alone and lacking anyone to "depend on" as young adults. While literature on the relationship between caregiver HIV-stigma and mental health of YLWH is limited, the impact of caregiver-child relationship on youth emotional and social development is well understood, and several studies have demonstrated the negative psychological impacts caregiver stigma has on children (L. Cluver & Gardner, 2007; Messer et al., 2010; Morantz et al., 2013). One qualitative study with YLWH in Uganda also discussed how caregiver stigma led to internal stigma, such as feeling worthless and self-isolating from social engagement with peers (Kimera et al., 2020).

4.1.3 Stigma and Peer Support

Stigma caused youth to be reluctant in seeking social support among peers, especially in retrospective interviews. In retrospective interviews, respondents commonly considered peers as “untrustworthy” with their HIV status and prone to gossip, causing hesitancy to disclose to anyone beyond family who already knew their status. While stigma kept youth from disclosing to and trusting peers, youth would often turn to peers for distraction or help when they were in emotional distress, but most youth were adamant that deeper relationships were not possible with friends due to stigma. However, the teen clinic for YLWH was a valuable context to build peer support for all respondents across time without being concerned with stigma and disclosure. In prospective interviews, youth viewed peer support in the clinic as helpful in giving them confidence to disclose their status to romantic partners and other peers despite fear of stigma. However, all respondents still referenced stigma as a major barrier and concern in their social circles, as well as fear that stigma could ruin ongoing romantic relationships or social networks. Despite HIV stigma scores for all respondents remaining relatively stable or increased into the 20s, they described stigma as an ongoing challenge in their relationships. Studies have shown that the stigma and mental health difficulties decrease with expanded social support, but youth need ongoing support navigating anticipated stigma with safe disclosure in order to develop trusting peer and romantic relationships that can improve resilience (Barker et al., 2019; Fang et al., 2019; S. Lee et al., 2015; Lockwood et al., 2019; Parcesepe et al., 2018).

4.1.3 Stigma and Employment

Workplace stigma and employment discrimination became a primary challenge affecting youth mental health in prospective interviews. The economic and psychological impact from societal HIV stigma has been commonly reported in various studies across the world (Derose et al., 2017; Dos Santos et al., 2014; Messersmith et al., 2013; Tan et al., 2013; Zhang et al., 2016). Youth in this study echoed those impacts in their own employment histories in prospective interviews. Four respondents had finished school and were working, but all four were self-employed. Youth commonly reported institutional stigma and discrimination as a reason for having to pursue self-employment. Youth also reported that one of their primary stressors was managing self-employment, which included lack of access to affordable healthcare, inconsistent work and financial strain, and fear that stigma would deter business clientele. Respondents reported feeling down, stressed, and anxious not only because stigma limited the jobs available to them, but also because potential stigma could impact their self-employment as well. Access to employment and stable income is an important factor for maintaining good quality of life and mental health, and other studies have demonstrated the connection between stable employment, mental health, and physical health outcomes for PLWH (Conyers et al., 2017; Dray-Spira et al., 2005; Maulsby et al., 2020; Rueda et al., 2015, 2016; Serrano, 2015; Tsai et al., 2017). While youth demonstrated resilience in their drive and resourcefulness to build their own business to produce income, both enacted and anticipated stigma caused youth to stress and worry about the sustainability of their income long term.

4.1.4 Stigma and Clinic Education

Respondents felt that stigma education in the clinic setting was an important protective factor that helped them address and engage with stigma. In retrospective interviews, youth reported distraction and avoidance as primary protective factors from stigma, but in prospective interviews, education and knowledge was the most cited protective factor for stigma other than social support. Although not all respondents participated in the SYV program, the program uniquely included lessons on understanding and addressing stigma and four dedicated sessions to unpacking the experience of learning about their HIV diagnosis and proposed steps to successful purposeful disclosure (Dow et al., 2016b). Youth reported that these lessons and skills helped dispel false assumptions grounded in stigma from others (i.e. HIV transmission through sharing food), improved their confidence to take responsibility for their health, and improved their outlook on life. While stigma scores did not decrease after participation for participants in the intervention, youth commented that coping skills from clinic trainings were effective tools in managing their mental health difficulties, reducing internal stigma, and avoiding stigma in different social circles, which is reflected in the decline of respondents' PHQ9 scores. Other studies have shown positive impacts of stigma reduction approaches using educational resources and coping strategies to improve youth mental health (Bos et al., 2008; Denison et al., 2020; French et al., 2015; Li et al., 2018; Stangl et al., 2013; Uys et al., 2009). However, stigma is an intrapersonal, interpersonal, and societal problem that requires multi-pronged approaches that support youth in making positive adaptations that rely less on avoidant coping strategies and

isolation as a way to manage stigma (Boyes et al., 2019; Kimera et al., 2020; Pantelic, Sprague, et al., 2019; Pantelic, Steinert, et al., 2019).

4.1.5 Stigma and Avoidant Behavior

While some youth found relief from stigma through disclosure and social support, others reported finding relief from stigma through secrecy and avoiding activities that might invite disclosure. Stigma and fear of disclosure were often the lynchpin factors in whether respondents pursued proactive coping strategies, like social support, or avoidant coping strategies. In retrospective interviews, youth commonly reported isolating and avoidance from others as an effective away to avoid stigma until their emotional distress subsided. Especially for youth experiencing stigma from caregivers, youth felt “there was no one to go to,” without being forced to disclose, which could invite more stigma. Disclosure is a high-risk activity for stigmatized identities, such as PLWH, and while disclosure has been associated with improved mental health, perceived social support, and self-esteem (Gabbidon et al., 2020; S.-J. Lee et al., 2007; Smith et al., 2008; Vyavaharkar et al., 2011), it can result in increased mental health difficulties, increased stigma, and poorer quality of life (Maman et al., 2014; Mugo et al., 2021; Thoth et al., 2014). In prospective interviews, some youth discussed a shift to increased reliance on social support due to positive experiences with disclosure, including increased trust and reliance on their peers and partners, as well as more confidence to disclose again in another trusting relationship. However, other respondents had negative experiences with disclosure, such as one who had a sexual partner tell his status to others (PID 5) and another whose romantic partner tricked her into disclosing her status

(PID 4). These respondents continued to prefer avoidant behavior to avoid stigma as young adults. While avoidant coping may decrease exposure to stigma, it has also been associated with increased depression and poorer emotional functioning in YLWH (Bennett et al., 2016; Orban et al., 2010; Schibalski et al., 2017). This association was evident among youth who reported ongoing reliance on avoidance behavior, as they also reported emotional regulation difficulties such as rage and rumination, loneliness, and sadness in prospective interviews even though their PHQ9 scores had decreased over time.

4.2 Social Support Impact on Mental Health

Social support was an important protective factor in mitigating mental health difficulties and improving resilience in youth over time. While social support data did not clearly trend with longitudinal PHQ9 data or other mental health measures, social support data were consistent with the respondent narratives given in retrospective and prospective interviews. Three respondents reported having social support in more than 80% of the surveys given over the six-year period, and these respondents tended to report broader and deeper social support networks in prospective interviews. The two respondents (PID 4 & 5) who had two or more data points designating no social support tended to report preference for avoidance behavior and smaller social support networks in prospective interviews. As previously discussed, youth social support broadened as they moved from prioritizing relationships with caregivers to cultivating more peer and romantic relationships and seeking social support from other YLWH in the HIV adolescent clinic. Caregiver and family relationships clearly remained important sources

of social support, but the emphasis shifted to building stronger relationships with peers and romantic partners.

4.2.1 Social Support and Family

In retrospective interviews, youth were between 17 and 18 years old, in school, and depended on caregivers to meet their needs. All participants were orphans and three were double orphans with no living biologic parent. While respondents lived with caregivers, only one lived with a biologic parent. YLWH reported that they primarily looked to caregivers and extended family to support them with their challenges. Caregiver and family social support has been closely connected with youth mental health (Dessauvagie et al., 2020), and studies have shown improved resilience in youth who develop strong bonds with caregivers and family (Bhana et al., 2014; Nestadt et al., 2019). Only one respondent (PID 2) reported consistent support from his caregiver (biological father) over time, and he also had consistently lower PHQ9 scores. In prospective interviews, the respondent described his father's support as the reason he did not experience stress and the reason he had everything he needed. The other four respondents struggled with mental health difficulties due to lack of social support from caregivers and family. In retrospective interviews, youth reported that they experienced despair, grief, suicidal ideation, and hopelessness in the absence of family social support due to parental death or absence, caregiver neglect, or familial stigma. However, those who were able to find non-stigmatizing family members to provide reported this as an important resource. A trusting and supportive relationship to any trusted adult, including extended family members, has been associated with improved

wellbeing and psychosocial development in children (Barenbaum & Smith, 2016), and youth also discussed the importance of having the social support of an older family member in their lives. Even though most youth were living independently during the prospective interview, youth who had found supportive family members still considered them 'the most important people' in their lives and relied on these family members for advice and help with their mental health, financial struggles, and health behaviors (i.e., ARV adherence). One respondent (PID 4) discussed how important an aunt was who helped her process her emotional distress from family stigma. Another participant (PID 3) credited supportive family members for helping him start his own business. Respondents who developed and/or maintained positive relationships with family members over time also tended to have more positive peer relationships in prospective interviews than respondents who were isolated from family members.

4.2.2 Social Support and Peers

Youth experienced increased social support among peers and romantic partners as they aged from adolescence into young adulthood. In retrospective interviews, respondents reported peers as "untrustworthy" with secrets, and respondents primarily relied on peers for distraction from mental health difficulties and other challenges, rather than social support. However, in prospective interviews youth reported peers, roommates, and romantic partners as important resources for social support for challenges in their lives. All respondents valued peer social support, primarily within the teen clinic setting. Youth described the social support they received from peers and staff in the clinic as important for improving their self-confidence, sense of belonging, and

belief in their ability to thrive while living with HIV. Additionally, youth valued the teen clinic for exchanging advice and ideas with other peers about dealing with HIV challenges. Maintaining peer social support in the adult clinic was also crucial to youth as they began to transition into adult care, which underlines the importance they placed on social support with other YLWH. Other studies have also found that clinic-based social support with other YLWH of similar age is important for continuing care and a protective factor for youth mental health as they transition to adulthood (Kung et al., 2016; Pinzón-Iregui et al., 2017; Yi et al., 2017). However, development of social support from peers outside of the clinic setting involved HIV status disclosure, which was a substantial challenge for youth due to stigma, as previously discussed. Nevertheless, youth reported increased disclosure to peers and romantic partners in prospective interviews, many of whom became trusted resources for social support as young adults. Those who had positive experiences with disclosure described increased trust and intimacy in the relationship, increased perceived social support, and increased confidence and freedom from fear of stigma. Other studies have described the numerous benefits of social support on mental health of YLWH, and as youth age from adolescence to adulthood, developing social support outside of caregiver and family relationships is important for maintaining resilience to combat challenges to mental health, such as stigma (Dessauvagie et al., 2020; Mellins & Malee, 2013; Neuman et al., 2013; Parcesepe et al., 2018; Smith et al., 2008; West et al., 2019). However, interventions for YLWH rarely include a focus on stigma and more research is urgently needed to better understand and support YLWH to combat stigma and safely disclose to form social support systems for themselves as they enter adulthood and form more peer

and romantic relationships (Dow et al., 2020; Evangeli et al., 2020; Evangeli & Foster, 2014).

4.3 Implications on Youth Resilience

As previously stated in the aims of this study, resilience was defined as an individual's ability to make positive adaptations despite the presence of challenges within the individual's context that promote positive health outcomes. Stigma was a major challenge that put respondents at risk for mental health difficulties across time, and stigma also accentuated other reported challenges such as isolation, employment, and romantic relationships. While resilience research with YLWH is limited, one study found stigma to be significantly correlated with resilience in young men who have sex with men (MSM) (Hussen et al., 2018), and another study reported strong correlations between disclosure, stigma and depression with YLWH in SSA (Mugo et al., 2021). A third study on resilience with YLWH in South Africa also cited stigma as a vulnerability factor affecting youth resilience and mental health outcomes (Bhana et al., 2016b). Youth responses in the current study echoed these findings. Youth connected stigma to their mental health difficulties, including suicidal ideation and emotional dysregulation. Youth also consistently pointed to stigma as a barrier to accessing and pursuing social support as a positive adaptation, which made youth more likely to resort to avoidant coping and isolation, which have been cited by other studies to hamper resilience (Garrido-hernansaiz et al., 2017; Livingston & Boyd, 2010).

Youth demonstrated resilience through developing and relying on social support networks despite experiencing stigma. As youth aged, their social support expanded from family and other YLWH to other peers, roommates, and romantic partners, which required youth to navigate disclosure. Social support is an important protective factor for resilience for YLWH, and studies have underlined the importance of helping youth navigate disclosure within safe relationships as vital for developing social support and resilience for youth (Evangeli & Foster, 2014; Vyavaharkar et al., 2011). Youth narratives in this study drew clear connections between social support and improved mental health during a developmental period when mental health difficulties usually increase. Participant PHQ9 scores all reduced during the study follow up and most youth answered they had someone to talk to if they were feeling sad (social support). While qualitative interviews were not time matched with PHQ9 and social support quantitative data, respondents described the importance of social support for their mental health.

Most respondents pursued social support among family and peers despite experiences with stigma, and they considered these relationships as facilitators for decreased reliance on avoidance behavior and improved overall confidence and trust in their social support. Youth also developed resilience through the social support and education they received within the teen clinic, and youth considered their relationships with other YLWH as an important protective factor for both mental health and health behaviors. Other studies have also cited the value of HIV+ communities, which help promote resilience and help promote collective agency and empowerment (Perez-Brumer et al., 2017). Improvement in youth resilience was evident through the

development of protective factors and subsequent impacts on mental health and other challenges. However, youth challenges, such as employment and stigma, continued to evolve as they transitioned from adolescents to young adults, which requires ongoing support to ensure continued resilience through each stage of life for PLWH (Greifinger & Dick, 2011; Harrison & Li, 2018).

4.4 Contributions and Future Directions

This study contributes to ongoing research for improving mental health and resilience in YLWH. It provides a longitudinal view of changes throughout adolescence using both qualitative and quantitative data. Very few studies with YLWH provide qualitative data highlighting the experiences of YLWH over a six-year timeframe while youth transition through the critical developmental period of adolescence to young adulthood. Qualitative data provided insight and context into the interplay between protective factors and challenges that impact mental health changes described in the quantitative measures over time. Finally, youth insights also clarify the contextual needs and concerns they have within a low-resource context, which helps to inform future directions such as evidence-based interventions that can help youth address stigma and disclosure in order to help youth develop trusting relationships and the social support needed to improve mental health outcomes for YLWH (Dessauvagie et al., 2020; Idele et al., 2014).

4.5 Strengths and Limitations

This study has several strengths in design and context of the project. Study participants were familiar with qualitative data collection due to prior participation in a broader study and willing to speak at length on mental health and other sensitive topics. Interview guides also underwent thorough English to Kiswahili translation and back-translation with local study staff and the authors of this study to ensure that the meaning of terms in mental health topics were well understood within the local context. The longitudinal design and mixed methods approach provided rich qualitative and quantitative data over six years of follow-up that allowed evaluation of processes of change and long-term outcomes. As a mixed-methods study, the qualitative data helped to contextualize the quantitative data and further inform the changes seen in the quantitative data.

The study had several limitations. The ethical process to approve the amendment to evaluate participant data longitudinally and with an additional in-depth interview was delayed due to impacts of COVID19. This limited the window of time to recruitment participants for the in-depth interview. Two-thirds of study participants identified were unable or unavailable to participate, which led to low recruitment numbers for this study. Respondents were only recruited from one clinic site within Tanzania, limiting the generalizability and validity of the study. During interviews, youth may have been vulnerable to desirability bias by under or overreporting on sensitive topics or their own behavior even though an independent interviewer was used from study or clinic staff. Recall bias was a potential limitation, as youth were asked to recall information from several years in the past, and memories may have deviated from the

actual experience. Additionally, qualitative analysis is inherently a subjective process, and findings are therefore limited by the interpretation and perspective of the study author. The author was unable to travel to Tanzania due to COVID19 restrictions, thus did not experience the cultural context in which the study took place. Additionally, qualitative data was collected in Kiswahili but analyzed in English, which can result in the loss of meaning in participant responses and limit the interpretation and application of findings in the local context. Finally, quantitative data and qualitative data were collected at differing time points of the study. The first quantitative survey was administered before the first qualitative interview and the final qualitative interview was approximately 6-12 months after the final quantitative survey was administered. This time discordance may limit the interpretation of the quantitative mental health measures to qualitative data regarding respondent mental health difficulties, stigma, and social support. This study is descriptive and explorative in nature and therefore cannot draw conclusions about causation and associations among data.

5. Conclusion

This study aimed to explore youth perspectives on factors that promoted resilience over a 6-year period using a mixed methods study design. The findings of the study showed that although mental health scores improved throughout enrollment, youth continued to be impacted by stigma in vital areas of their lives, such as relationships and the workplace. Stigma also remained a powerful barrier to accessing social support and promoted avoidance behavior. Youth reported social support was a valuable protective factor for resilience both in their social circles and within the clinic setting. These findings clearly highlight the importance of continuing to develop and improve mental health programs that address stigma, disclosure, and social support to equip youth with critical skills to make positive adaptations in the face of ongoing challenges, as well as providing them consistent levels of support as they transition to adulthood.

Appendix A

In-depth Interview Guide 2020/2021

READ ALOUD: Hello. Thank you for taking your time to participate with us in this study. Your participation is really important to us. The purpose of this interview is to talk with you about your experience in the past and your experience now as you have HIV, your experience with the SYV program and also your experience of living through world's pandemic of COVID 19. Your opinion as this study participant are very important because we are trying to modify the SYV and HIV services. I ask you to speak the truth and openly about your experience. Please feel free to speak as you feel. If I bring up a topic or an experience that you don't like to discuss, please tell me that you want to skip the question and to continue with another topic, there is no problem. This conversation will take 60 minutes and will be recorded with a tape recorder so as to make sure that we have understood everything that you have shared with us today. The information that you will share with us will be kept confidential. Please do not mention people's names if there is a memory you want to share with us so as to protect their information also. Do you have any question before we start?	
1. Please tell me a little bit about yourself (name, age, where you come from)	Are you studying/ are you working? Where? Where do you live? Whom do you live with, with your family?
2. What are the most	Who are the most important people in your life? Who

important things in your life?	do you rely on for big and small problems in your life? - Do you feel like you have the support you need for most things in your life? Why?
Personal challenges/growth Thank you for telling me about yourself, now I would like to ask you some questions about challenges or the struggle you have gone through. You can skip any question if you don't want to answer.	
3. What are some of the major challenges that you have ever gone through?	For how long have you gone through this challenges/struggle? (look at the challenge/struggle for more than four years that have passed) What helped you at that time? What did not help you at that time? Do you think that you have changed because of those challenges? How? Have those challenges been solved or are they are still there? Is it different with how you overcame the challenges in the past? How?
4. How do you feel about your future life?	What are your goals or dreams for now? Can you say that you have reached any goals or fighting to reach any goals?

	What obstacles do you think that you should overcome in order to reach those goals?
HIV challenges/growth I would like to ask some questions about living with HIV and the challenge that you are facing. You can skip any question that you do not want to answer. Is it ok for me to continue?	
5. Can you tell me a little bit about how you felt when you found out you were HIV positive?	How was your experience when you first started going to clinic?/ How did you feel? How do you feel about living with HIV now? How do you feel about going to clinic/how is your experience? Is it different from when you started to attend clinic? How?
6. What are the major challenges that you are facing by being HIV positive for now?	(Probe about stigma and disclosure): Have you disclosed your status to anyone? How did that go? Do you feel comfortable disclosing? why or why not?
7. Have you ever transferred to the adult clinic?	If yes, how was it? Any challenges? If no why? Do you wish anything could be different about the clinic? Are you still taking ARV? Is there anything difficult about taking ARV medications? Do you experience any symptoms from the ARV

	medications you are on? Do you find it difficult to take the ARV medications because or work or school?
Romantic/Sexual Relationships and Family Planning	
8. I would like to ask about sexual relations. Are you in a relationship or have you ever been in a sexual relationship recently?	Did you tell your sexual partner that you are HIV positive? Why did tell him/her or why didn't you tell him/her. Have you ever been scared to be in a sexual relationship because you are HIV positive/ why were you scared or why were you not scared? Are you (still in) or in another relationship now? Why or why not?
9. If it is ok I would like to speak with you about unwanted sex. Meaning being force to have sex without wanting to. Have you ever done unexpected sex in the last five years?	How did you overcome this situation? Do you think you can say no to that kind of situation? How do you feel about the use of condom? What about partners/your sexual partner? Was there a time that you wanted to use condom, but your partner did not want to use it? What happened?
10. Do you feel like there are any barriers to you starting a family?	Do you feel like you are able to overcome or deal with those barriers? Why or why not? Do you wish that something could be different to

	make things easier?
Mental health challenges/growth I would like to ask you some questions about mental health, including depression/sadness and stress. You can skip any question that you do not want to answer. Is it ok for me to continue?	
11. Have you ever got stress/depression/sadness in the past?	At what period and at what time did you get stress/depression or sadness? Was there anything that made you to get stress or depression/sadness? Have you ever done anything that helped to reduce stress or depression/sadness what did you do?
12. If you were to experience stress/depression/sadness today, what would you to help reduce it?	Would you do anything differently from the past?
13. Have you experienced any suicidal thoughts in the past year?	If yes, how often did you have them? What helped these thoughts go away? Did you have a plan?
Questions about COVID 19	
14. World's pandemics can have stressful moments. Do you think COVID-19 has	If yes, how? Have you done anything that has helped you reduce stress, fear or depression/sadness? What did you

stressed, depressed/made you sad or made you have any fear?	do?
15. Has COVID-19 caused any challenges in your life?	How (at work, school, family ,your health) How did you overcome these challenges? What helped you? What did not help you? If you were infected with Corona where do you think you could go? What could you do? Can you tell me an experience of anyone you know that got COVID-19? Do you know anyone who has died due to COVID-19? Has COVID-19 affected how you feel about your future life? How?
16. Do you think being HIV positive has affected how you think about COVID-19?	What are the things that makes you fear or you think of? How is COVID-19 transmitted and what are its symptoms? How many times in a day have you hear about COVID-19(in a radio, reading newspapers or conversation with friends?) How has your behavior changed since COVID-19 appeared (wearing masks, washing your hands,

	touching other people's hands?) How is COVID-19 different to people who are HIV positive? Has it affected how you take your ARV frequently or attending to clinics? • What has become your biggest fear that surrounds you in the COVID-19 pandemic?
SYV program Thank you. I would like to ask you about SYV training that you might have participated one of the sessions in the group at KCMC. You can skip any question that you do not want to answer. Is it ok for me to continue?	
17. Did you participate in the group sessions of SYV that took place at KCMC?	*If you did not participate*: why didn't you participate? [probe for specific reason – different between motivation and ability] Would you like to participate in the sessions about mental health and life skills? *If you did participate*: why did you decide to participate in the group sessions? How long did you participate? How did you see the program? Did you like it/ what didn't you like? What things did you learn that helped you the most? Do you feel different now that before you started the

	SYV group sessions? How? What things do you remember the most about SYV? During this period are you using anything that you had learn at SYV? If yes what is it? Is there assistance that you would want or need with keeping your mental health or skills after the SYV program? Would you want to participate in something like SYV in the future?
Conclusion	
18. If there is one thing that you were able to change in your life today, what could it be? Why?	
19. If there is one thing that you were able to change in order to get your HIV services easily what could it be/ why?	
20. Is there anything that I have not asked you and you would like to share with me?	
Thank you for participating in this interview and sharing with me your experience. We value your opinions and your willingness of sharing with us.	

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